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Parent Perceptions of Infant Symptoms at End-of-Life in the NICU

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Abstract

Despite significant technological advances, not all infants admitted to the neonatal intensive care unit (NICU) survive. Limited research has focused on symptoms infants experience as they approach end-of-life (EOL). The purpose of this study was to examine concordance in infant symptom identification between medical record and parental report. The Framework for a Good Neonatal Death was used to guide this study. This framework includes factors including symptom identification and parents perceptions, that may result in an improved experience at EOL. 433 parents (248 mothers, 185 fathers) of infants who died in the NICU between 2009 and 2014 were invited to participate. Following informed consent, parents of 40 infants [40 mothers (M age = 33 years), 27 fathers (M age = 37 years)] reported on the presence of symptoms during the last week of their infant's life. Medical record reviews were also completed for each infant. Parent survey and chart data were compared for six symptoms for which there was overlapping data: pain, agitation, respiratory distress, feeding intolerance, seizures, and lethargy. Parents identified several symptoms (Mother $M = 2.8$, Father $M = 2.6$, range = 1-5) with pain, agitation, and respiratory distress most commonly endorsed. Within the 27 parental dyads, mothers reported agitation significantly more than fathers, while fathers reported seizures significantly more than mothers. Both parents reported seizures more often than documented in the medical record. Parents reported frequencies similar to the chart for the presence of pain, agitation, respiratory distress, feeding intolerance, and lethargy. Parents demonstrate awareness of the infant's well-being at EOL which closely matches medical staff documentation, however perceptions may differ between parents. Parent perceptions of infant symptom burden likely play an important role in decision-making regarding treatment. Future research is needed to further understand parents' views of symptoms and potential suffering as it relates to EOL care.

Chapter 1: Statement of the Problem

Introduction and Background of the Problem

Over 24,000 infants die each year in the United States before the age of one. Over 16,000 die each year in the neonatal intensive care unit (NICU) (Heron et al., 2010). Technological advances have increased survival rates in the NICU by focusing on stabilization and survival to ensure that every effort is made to preserve life. Unfortunately, some infants are unable to overcome their illness. The majority of infants in the NICU die following withdrawal of life sustaining treatment for congenital anomalies or birth defects, complications from pregnancy or delivery, or prematurity. Parents are concerned that when life-sustaining treatment is withdrawn their infant will suffer (Armentrout, 2009). Thus, assessment and management of symptoms are critically important during the dying process (Coughlin et al., 2007). However, infants may experience numerous symptoms at the end-of-life that are difficult to assess and manage. Neonatal palliative care is defined as an “active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, death, and beyond” (Together for Short Lives, 2013). Parent perception of their infant’s symptoms is an important component to the palliative care process as it can dictate end-of-life decisions, views of infant suffering, and may even result in prolonged and complicated grief for some parents.

Purpose of the Study

The purpose of this study was to examine concordance in infant symptom identification between medical record and parental report. Understanding parent perceptions of their infant’s symptoms in comparison to medical report may help improve family experiences in the NICU and foster a more positive neonatal death experience.

Significance of the Study

Pain is most often the symptom that parents associate with suffering (Cortezzo, Sanders, Brownell, & Moss, 2015). Many studies have been done that have advanced medical assessment and management of neonatal pain (Franck & Allen, 2005) but limited research has been done in regard to the assessment and management of symptoms other than pain that infants may experience in the NICU or how parents feel about what they observe their infants' pain or symptom experience to be. Pain is recognized as a subjective experience with the pain being whatever the patient describes. With the subjectivity comes a difficulty in measuring pain in patients who cannot describe or verbalize the pain they are experiencing (Anand, 2007). Other symptoms, such as respiratory distress, feeding difficulty, and swelling, may be more objectively seen and described. No matter whether it is a more subjective or objective assessment of what the baby is experiencing, the parents are key observers to their infants' care experience. Research is needed to better understand what parents observe about their infant's symptoms and suffering and how their observations can be used by health care professionals to improve symptom recognition and management. This becomes even more critical during the dying process as symptom assessment and management are crucial to ensure that the infant receives appropriate care to mitigate suffering, and that parents are satisfied that their infant's symptoms were addressed and controlled to allow for the best end-of-life care experience as possible.

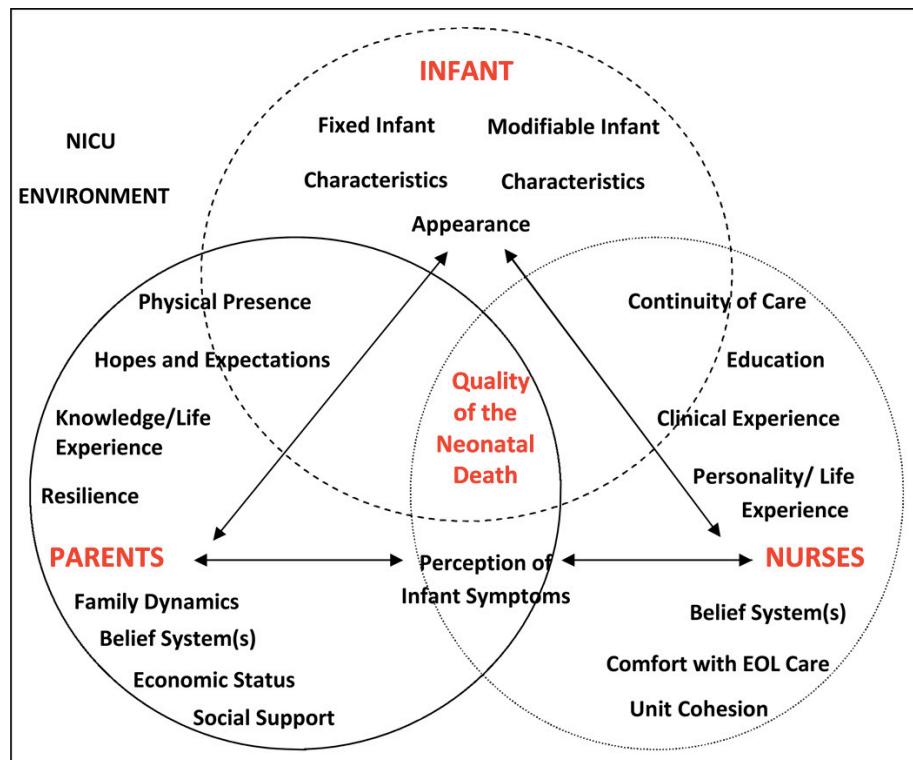
Conceptual Frame of Reference

A framework to evaluate the quality of neonatal death was used to guide the project (Fortney & Steward, 2014). This framework was adapted from Emanuel and Emanuel's Framework for a Good Death in which the EOL experiences of adult patients who have been able to interact with their environment and make their own decisions for their care are evaluated

(Emanuel & Emanuel, 1998). Because an infant requires others to assess their symptoms, manage their care, and make decisions on their behalf, a new framework was needed that would account for these differences in the care of non-verbal, infant patients.

The neonatal framework proposes several factors in infant, parent, and nurse domains that may have an effect on the dying experience of neonates in the NICU. These domains interact with each other within the larger NICU environment to have either a positive or negative effect on the death experience of the infant. Within the infant domain, manifested symptoms are considered modifiable infant characteristics that may be changed through appropriate intervention. However, in order for symptoms to be appropriately managed they must be observed and interpreted correctly by those who are caring for the infant and this can lead to disagreement about the infant's symptoms or how to treat them and increase parental stress (Gale, et al.,)

Figure 1. Framework for a Good Neonatal Death



Research Questions

The questions asked in this study were:

- 1) What was the concordance between parental observations of symptoms in their dying infant as compared to symptoms documented in the medical chart?
- 2) What were the differences between what mother and father observed?

Chapter II: Review of the Literature

Limited research has examined multiple perspectives of infant symptoms at the end-of-life. Even fewer studies have focused on parent perceptions of their infant's symptoms at the end-of-life (Maxwell, Malavolta & Fraga, 2013). However, research that has been done shows the importance of collaboration between healthcare providers and parents, effects of nurses preparing parents for the infant's death, and how parents view their infants suffering on parental perception of the end- of-life experience for their infant (Epstein, 2010).

Parents whose infants had died following removal of life-sustaining treatment were asked to rate their infants level of pain. The study findings showed that parents did believe that their infant experienced some amount of pain while dying (Hellmann, Williams, Ives-Baine, & Shah, 2013). However, the parents were satisfied with how well the neonatal healthcare team responded to their infant's pain. This is important because it helps parents believe that they made the best decision for their infant.

There are times when parents and neonatal caregivers do not agree on how well the infant's symptoms are managed during the end-of-life. In a survey of neonatal healthcare providers and parents, the majority of healthcare providers (>85%) believed infant symptoms were well-managed, while only 57% of parents believed their infants were comfortable (Cortezzo, Sanders, Brownell, & Moss, 2015). These findings show the important need for further study on how infant symptoms during the dying process are assessed and managed, as well as observed by parents at the end-of-life.

Healthcare professionals are trained to care and cure their patient. When patients cannot be cured, end-of-life discussions are often difficult as the quality of the patient's life is assessed, and the potential success of further treatment is evaluated. Collaboration between parents and

healthcare providers is essential for appropriate decisions to be made in the best interest of the infant and family. Furthermore, discussion between nurses and physicians is also essential so that any miscommunication that could be potentially harmful during this most stressful time is avoided. The initiation of end-of-life discussion is often different between the two professions, but the obligations are essentially the same. Nurses' often focus on initiating care-giving activities such as talking to parents, encouraging parental involvement, preparing parents for what they may observe and hear, and spending time with the family as dying occurs. Alternatively, physicians focus on these obligations during decision-making when time of death is imminent (Epstein, 2010). While it is important to note that there is agreement in obligation to the family, the timing of initiation of conversation can have the most impact on parents in their decision-making and bereavement process (Epstein, 2010)

Healthcare professionals have a major role in preparing parents for the end of their infant's life. It is essential that effective communication with parents is achieved so that appropriate decisions can be made in the best interest of the infant. Educating parents on quality of life, opioid use, and infant symptoms and suffering can lead to a better experience in the neonatal intensive care unit. This can be difficult as there are conflicting views on the use of opioids in infants related to religious or ethical objections, or the principle of double-effect where giving the medication might cause respiratory distress and possibly an earlier death than might have otherwise occurred. Further, infants are often under medicated, leading to discomfort for the infant and complicated parent bereavement related to their perceptions of their infant's suffering (Martin, 2013).

Few research studies have been conducted on how parents view their infant's pain. Studies that have been done are focused on engaging parents in meaningful dialogue about their

involvement in care and helping parents understand misconceptions about their infant's well being. Parents feel that medical interventions are a major source of pain for their infant and they need information on medical interventions and care as they are occurring (Franck & Allen, 2005). They are often worried about their perceived lack of parental role with their infant, which can have negative emotional effects on parents. Understanding how parents perceive their infant's symptom experiences may be very helpful in developing interventions to help families better cope with the symptoms the infant is experiencing throughout their NICU experience.

Chapter III: Methodology

This is a descriptive, cross-sectional, retrospective study that included chart review and parental report instruments. This work is part of a larger pilot study where a total of 434 bereaved parents (249 mothers, 185 fathers) of infants who died after admittance to the NICU during a five-year period were mailed an invitation to participate in the study. Parents mailed back a response card to indicate an interest in enrolling in the study. Infants were admitted to a Level IV NICU at a large Midwestern children's hospital between 2009 and 2014, where almost 900 patients are admitted annually and the survival rate is approximately 96%. The NICU is, however, a regional referral center for the sickest patients and inevitably there are some infants who do not survive; around 50 infants per year.

Infant Characteristics

243 infants were studied in the medical chart review. The mean age at death was 35 days (SD = 53). 77% of infants (n = 186) survived more than 1 week. 66% (n = 160) received a prenatal diagnosis. 74% of the infants were born premature (<37 weeks gestation) and 49% of them were extremely premature (< 27 weeks gestation). The most common diagnosis at birth were related to respiratory distress syndrome (38%), multiple congenital anomalies (29%), and prematurity (19%). Other diagnoses were included in the last 14% and included neurologic, genetic, and cardiac disorders as well as sepsis and necrotizing enterocolitis. In comparison, diagnoses at death included cardiorespiratory failure (35%), congenital anomalies (13%), and congenital heart defects (13%). The last 40% were in result of other conditions like genetic conditions, necrotizing enterocolitis, sepsis, intraventricular hemorrhage.

Parent Characteristics

40 mothers and 27 fathers were included in the survey portion of the study. The mothers were an average of 33 years old ($SD = 6$) and the fathers were an average of 37 years old ($SD = 10$). 88% of the women were white and 95% were non-Hispanic. Similarly, 85% of the men were white and 96% were non-Hispanic. Most of the participants were married. 80% of the mothers were married white 89% of the fathers were married. Of our participant, 13% of the annual income was less than \$25,000. Alternatively, 25% of the annual family income was more than \$100,000. Finally, the average time since the infant's death for both mother and father was 3 years, with the range being from 3 months to 5 years. Participants were more likely to have fewer documented symptoms in the medical chart than non-participants. However, there were no other significant differences between participants and non-participants.

Table 1. Participant Characteristics

Mothers (n = 40)	Fathers (n = 27)
<ul style="list-style-type: none"> • $M_{age} = 33$ years (6) • 88% white, 95% non-Hispanic • 80% married • Average of 3 years since death Range: 3 months to 5 years 	<ul style="list-style-type: none"> • $M_{age} = 37$ years (10) • 85% white, 96% non-Hispanic • 89% married • Average of 3 years since death Range: 3 months to 5 years
Infants (n = 40)	
Age at death (days)	35 (53), 1-453
Prenatal diagnosis	66%
Prematurity (<37 weeks)	74%
Diagnoses at Death	
Cardiorespiratory Failure	35%
Congenital anomalies	13%
Congenital Heart Defect	13%
Other conditions (e.g. genetic conditions, necrotizing enterocolitis, sepsis, intraventricular hemorrhage)	40%

Data Collection Procedures and Instruments

Measures used in the study collected the following data: 1) socio-demographic; 2) parent report of infant symptoms; and 3) infant information and pain scores from the electronic medical record.

Socio-demographic data included: gender, marital status, education level, age, annual household income, number of other children, race and ethnic status. Data on parent's experiences with previous deaths, religious practices, and spirituality were also collected.

The NICU Symptom Assessment: Parent Report is a 30-item assessment tool that assesses symptoms parents observed in their infant during the last week of life. Parent survey and chart data were compared for six symptoms for which there were overlapping data: pain, agitation, respiratory distress, feeding intolerance, seizures, and lethargy.

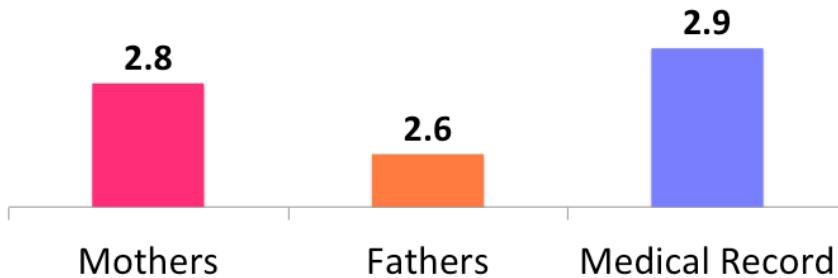
The medical chart abstraction included: date of infant birth, date of admission to the ICU, date of infant death, location at time of death, gestational age, primary diagnosis at birth, primary diagnosis at death, secondary diagnoses, total number of comorbid conditions at death, symptoms documented in the last week of life. Symptoms abstracted from the medical chart review included: pain, agitation, respiratory difficulty, lethargy, abdominal distention, feeding intolerance, seizures, unstable vital signs (increased heart rate, respiratory rate, blood pressure, decreased oxygen saturation).

Chapter IV: Results

The investigator observed six overlapping symptoms from parental report and medical chart review. These symptoms included pain, agitation, respiratory distress, feeding intolerance, seizures, and lethargy. Data analysis included paired sample t-tests and the McNemar Test.

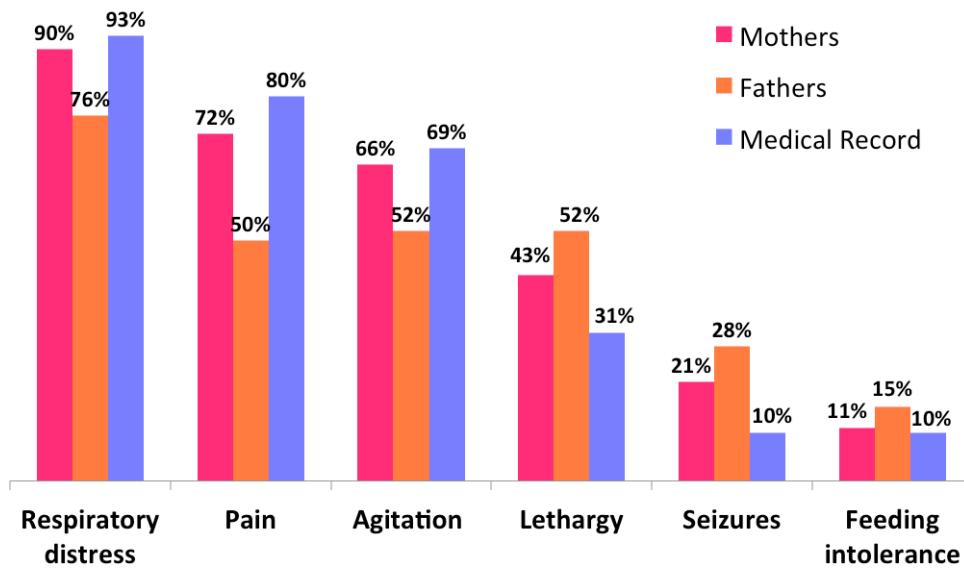
Within the 26 parental dyads, paired sample t-tests indicated that fathers ($M = 2.62, SD = 1.53$) reported significantly more symptoms than mothers ($M = 2.58, SD = 1.25$) in the last week of life [$t(25) = -0.14, p < 0.01, d = 0.03$]. However, neither mother nor father report differed from the number of symptoms documented in the medical record (See Figure 2).

Figure 2. Average Number of Infant Symptoms in Last Week of Life



Generally, mother and father reports were similar to one another and to medical chart documentation (see Figure 3). Parents identified several symptoms, with respiratory distress, pain, and agitation most commonly endorsed. Trends indicated that mothers reported respiratory distress more frequently than fathers ($p = 0.13, n = 25$). Comparison between the medical record and parental report of symptoms demonstrated that fathers reported seizures more often than documented in the medical record ($p = 0.06, n = 25$). In contrast, the medical record documented pain more than fathers ($p = 0.07, n = 24$).

Figure 3. Parent Perceptions of Symptoms During Last Week of Life



Chapter V: Conclusions and Recommendations

Conclusions

In general, parents demonstrate awareness of the infant's well-being at end-of-life which closely matches medical staff documentation. The results concluded that parents are instrumental observers of infant suffering. Parents demonstrated that they were vigilant during their infant's stay and attuned to the surroundings. While pain is noted as the most distressing symptom to parents, in this study respiratory distress was most frequently endorsed amongst parents. Signs of respiratory distress, such as gasping, have been perceived by family members as an indication of patient suffering (Daubin et al., 2014). Early work shows that there is often missing data in the medical record as the end-of-life approaches. Charting can be skewed as time to death can range from hours to days (Fortney & Steward, 2015). Symptoms in this study were noted throughout the week, however data was not collected exactly when the symptoms occurred while the child was actively dying. Parents were asked to reflect on they symptoms and suffering they perceived their infant endured during the last week of life. Although there was concordance between parents and medical record documentation, there is still further research that needs to be done in discovering parental perception of their infant's suffering.

Limitations

Limitations include small sample size, potential for response bias, retrospective reporting, cross-sectional design, and measurement limitations. Parents who chose to enroll in the study and complete survey packets were very satisfied with the care that their infant received at the end-of-life. It is possible that the perspective of those parents who were not satisfied with their infant's care were not captured. Measurement limitation included different sample sizes. 243 infants were studied in the chart review while 40 mothers and 27 fathers participated in the

parental report. Furthermore, the infants and parent participants were treated at one large Midwestern children's hospital, limiting the population. Finally, the chart review was limiting in that multiple research assistants were simultaneously collecting data.

Implications of this Study

This study has important implications for communication and collaboration with parents in order to improve care at the end-of-life. Parental perceptions and medical chart concordance found in this study show the importance in asking parents about their infant's symptoms and suffering. Nurses are important members of the healthcare team who have direct patient interaction and play an important role in communication with parents and other inter-disciplinary members of the team who are involved with the patient. Considering that parent reports closely match nurse symptom reports, nurses should utilize parents as vital observers of infant well being.

Recommendations

Further research is needed to more fully understand parents' views of symptom management and potential suffering as they relate to end-of-life care and parents' concerns related. Studying the pharmacological interventions used to treat the symptoms infants experience most often at the end-of-life, as well as parent perceptions toward these interventions might help healthcare professions further understand how to create a better end-of-life experience for infants and their parents.

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