

NURSE-PERCEIVED INFANT WELL-BEING

Nurse-perceived infant well-being and associations with survival

Purpose and Background/Significance

Background: More than 500,000 US infants are admitted to the neonatal intensive care unit (NICU) each year, with many experiencing discomfort as a result of medical intervention. This study explored associations between COMFORT-B Scale scores and nurse perceptions of infant discomfort, as well as between nurses' perceptions of suffering and QOL (quality of life) and expectations for survival.

Theoretical Framework: Fortney & Steward's (2014) Framework for a Good Neonatal Death that highlights accurate symptom assessment as an important component of the neonatal palliative and end-of-life experience was used to guide this study.

Methods: In this exploratory descriptive study, infant participants were recruited from a Level IV NICU in the Midwest. Nurses caring for enrolled infants completed the Nurse Perceptions of Infant Well-Being questionnaire regarding their perceptions of the infant symptom experience and expectations for survival. Weekly behavioral observations of infants were obtained before and after standard delivery of care to obtain a COMFORT-B score. Using Pearson's r , nurse survey data was compared to the total COMFORT-B score and associations between nurses' perceptions of the symptom experience and expectations for survival were explored.

Results: 237 nurses who cared for 83 infants completed 593 surveys over a period of 28 months. Bivariate correlations indicated that the COMFORT-B score was not significantly correlated with nurse perceptions of infant discomfort. But, nurse-perceived infant suffering was significantly correlated with nurse-reported expectations for survival during hospitalization, within the next 6 months, and within the next year ($r=-.296, -.323, -.349, p<0.001$). Further,

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nurse-perceived infant QOL was also significantly correlated with nurse-reported nurse expectations for survival ($r=.560, .629, .647, p<0.001$).

Discussion: Even though associations between COMFORT-B scores and nurse perceptions of infant discomfort were not significant, they are discrepant. It is unclear whether the COMFORT-B scale performs better than the perceptions of the bedside nurse. Further, nurse perceptions of infant suffering or poor QOL is related to expectations for infant survival, which may affect decision-making, recommendations for care, and care delivery. Future research should focus on the development of improved assessment of the infant symptom experience in the NICU, as well as the effect of nurse expectations for infant survival on care delivery.

Introduction

In the United States, over 500,000 infants are admitted to a neonatal intensive care unit (NICU) each year due to varying conditions, including prematurity, congenital anomalies, and genetic abnormalities (Bettegowda, Lackritz, & Petrini, 2014). The length of stay for these infants can range from days to months, depending on care the infant requires (Seaton, Barker, Jenkins, Draper, Abrams, & Manktelow, 2015). Improvements in technology, including mechanical ventilation, have extended the lives of infants who would have previously died and have raised important questions about the provision of palliative care for infants (Philip, 2005), and increased the need (Fontana, Farrell, Gauvin, Lacroix, & Janvier, 2013). Despite this need for palliative care, there have been barriers to utilization, such as differences of opinion regarding the right time to begin palliative care as well as looking for “clear” signs from the infant that palliative care is needed (Marc-Aurele & English, 2017). This can be difficult to assess in infants who cannot speak and must rely on others to interpret the signs and symptoms they are expressing (Marc-Aurele & English, 2017; Selekman & Malloy, 1995). Recently, pediatric palliative care has received more attention due to findings that indicate that the early introduction of palliative care can improve QOL, reduce costs, and potentially improve patient survival (Temel & Greer, 2010; Morrison & Dietrich, 2011). Another important aspect of palliative care is symptom management, but challenges remain as there is no universally accepted pain scale and assessments rely on varying methods and scales (Quill & Abernethy, 2013; Witt, Coynor, Edwards, & Bradshaw, 2016). Further, assessment tools that measure symptoms other than pain are also limited.

Having an understanding of the symptoms that infants in the NICU experience, and that parents find distressing to witness, is vital to developing tools and evidence-based standards that

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can be used to improve symptom assessment and management throughout an infant's illness trajectory.

Several symptoms have been identified as important to understand when an infant is undergoing palliative care, including nausea or vomiting, bowel movements, disordered sleep, pain, and shortness of breath (Marc-Aurele & English, 2017). Parents also report that they are particularly distressed by the symptoms of respiratory distress, pain, agitation/irritability, skin swelling and breakdown, fatigue, and feeding intolerance that they witness in their infants (Shultz, et al, 2017). Despite the importance of these symptoms to infant and parent comfort, it remains challenging to directly assess them in infants. For example, shortness of breath cannot be verbally expressed by infants, so the healthcare team must look at other factors, like work of breathing or oxygen saturation levels to conclude if an infant may be experiencing shortness of breath (Marc-Aurele & English, 2017). Further, an infant who is crying could be in pain, need a diaper change, want to be held, or is hungry. The inability to verbally communicate with an infant makes symptom assessment difficult and leaves providers to rely primarily on subjective measures to assess pain, infant comfort, and other symptoms (Marc-Aurele & English, 2017; Boyle, Bradshaw, & Blake, 2018; Witt, Coynor, Edwards, & Bradshaw, 2016). Boyle et al (2018) states that "pain assessment is an important part of care in the NICU and can help to achieve appropriate and timely pain management" (p. 63). However, due to lack of ability to report their own comfort, a limited repertoire of behavior, and no clear separation from pain and anxiety, obtaining a good understanding of an infant's symptoms becomes increasingly difficult (Boyle, Bradshaw, & Blake, 2018; Marc-Aurele & English, 2017).

The assessment of pain and discomfort is perhaps the most widely studied. In one report the use of pain assessment tools across units varied from 40% to 60%, but more than 80% of

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ventilated infants in the study received sedatives or analgesics, suggesting that subjective evaluations played a part in the therapy the infants received (Boyle, Bradshaw, & Blake, 2017). Further evidence of subjectivity in symptom assessment was found in another study of nurses who reported often using their own instincts to assess pain and comfort of infants (Cong, Delaney, & Vasquez, 2013). Subjective assessments could ultimately affect continuity of care between patients as well as prescribed therapies because individual healthcare providers may interpret infant symptoms differently (Boyle, Bradshaw, & Blake, 2017). Nurses have reported that they use pain tools frequently but have concerns about the accuracy of those tools (Cong, Delaney, & Vasquez, 2013). Further, results showed that a majority of the nurses surveyed agreed that they have the responsibility to advocate for the treatment of pain, but less than half thought that they were able to do so (Cong, Delaney, & Vasquez, 2013).

Pain scores are generally recorded for an infant with each general care episode as well as before and after procedures that might be considered painful. Several tools are used in the NICU for the assessment of pain and/or discomfort that may be chosen according to the infant's gestational age or status or according to the NICU's preference. For example, the Neonatal Pain, Agitation, and Sedation scale (N-PASS) scale assesses pain/agitation and sedation levels in infants from 23 weeks' gestation to term and was designed to be used for all infants in the NICU (Hummel, 2017). The N-PASS scale rates sedation from -2 to 0, -2 being the most sedated and 0 being the least sedated, for 5 different assessment criteria (crying/irritability, behavior state, facial expression, extremities tone, and vital signs) (Hummel, 2017). Pain/agitation is rated from 0 to 2, 0 being the least amount of pain/agitation and 2 being the most, in the same 5 assessment criteria (Hummel, 2017). The Face, Legs, Activity, Cry, and Consolability (FLACC) scale rates 5 behaviors (face, legs, activity, consolability, and cry), leading to a total score out of 10 (Crellin,

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Harrison, Santamaria, Huque, & Babl, 2018). Although it was originally designed to assess postoperative pain, it is now one of the most common pain scales used in infants who are greater than 2 months (Crellin, Harrison, Santamaria, Huque, & Babl, 2018). CRIES scale is another tool that is used to evaluate infants, with the minimum score being 0 and the maximum score being 10 (Spence, Gillies, Harrison, Johnston, & Nagy, 2005). The CRIES scale was originally created for use in postoperative infants (Spence, Gillies, Harrison, Johnston, & Nagy, 2005). The Newborn Individual Development Care and Assessment Program (NIDCAP) is a weekly systematic behavioral observation of premature infants that leads to a care plan that details care of the infant and appropriate stimuli to capitalize on the strengths of the infant (Wallin & Eriksson, 2009). This scale requires considerable training of the observer to be able to be utilized in the clinical setting.

Further, a lack of documentation of pain scores as an infant approaches the end of life (EOL) has also been reported. This could be related to a variety of factors, such as that the infant was too ill to show signs of pain or that the nurse was focused on other tasks like completing orders, moving equipment, or preparing parents and not assessing the infant as frequently. In order to ensure that infants are not experiencing pain or discomfort, knowledge of effective pain strategies and in-depth observation and assessment skills are needed (Fortney & Steward, 2015).

While the previously discussed scales have proven to have some utility in the clinical setting, they were not developed for research purposes. Further, the electronic medical record was also developed for use in the clinical setting, and while much information is recorded about the infant, issues with missing data can be problematic. The lack of a gold standard assessment tool that measures all aspects of the infant symptom experience for infants underscores the need to find or develop a reliable, universal tool that can be used both clinically, as well as for

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research purposes. The use of an objective behavioral observation as an assessment tool may provide additional information about the infant symptom experience in the NICU. Further, nurses not only think about an infant's current symptoms, they often consider the outlook of survival for infants in the NICU. Park and Oh (2019) looked at nurse's attitudes of death and discovered that there is an important connection between how nurses perceive death and how EOL care is performed. Further, Noh and colleagues found that nurse attitudes towards palliative care reflects the nurses' motivations, emotions, and perceptions of care to meet the needs of adult patients and their families (Noh, Han, Ahn, & Kim, 1997). In another study on the accuracy of physician and nurse predictions of survival of adult patients in intensive care units, nurses were more accurate about their predictions of in-hospital death, while physicians achieved more accuracy in predicting death within the next 6 months (Detsky, Harhay, Bayard, Delman, Buehler, Kent, Ciufftelli, Cooney, Gabler, Ratcliffe, Mikkelsen, & Halpern, 2017). And, predictions of future survival may influence clinician decision-making for palliative and EOL care (Cook, Rucker, Marshall, Sjøkvist, Dodek, Griffith, Freitag, Varon, Bradley, Levy, Finfer, Hamielec, McMullin, Weaver, Walter, & Guyatt, 2003). Aside from these sources, the research about nurse perceptions of the infant symptom experience and their predictions for infant survival is limited, as is information about how these factors might affect the delivery of palliative and EOL care across the illness trajectory.

Currently, infant comfort relies on traditional pain scores and nurse perceptions and subjective data from the medical team. The purpose of this study was to explore the relationship between the infant COMFORT-B scores and the nurse perception of infant distress to determine if there was a correlation between how nurses felt that the infants were doing and the COMFORT-B score that the infants received. In addition, the relationship between nurse

perceptions of infant suffering and QOL, as well as their expectations for infant survival was explored.

Methods

Research Design

This exploratory descriptive study examined the association between nurses' perceptions of infant suffering, QOL, and expectations for survival during hospitalization, within the next 6 months, and within the next year. It also explored the connection between nurses' perceptions of infant distress and behavioral COMFORT-B scores recorded by trained research nurse observers.

Sample and Setting

The sample for this study included infants and nurses from a 114-bed, Level IV NICU in the Midwest. An infant was eligible for this study if they: a) were admitted to the NICU with or developed during hospitalization any of these potentially life-limiting conditions: congenital heart defect, multiple congenital anomalies, life-limiting genetic syndrome, surgical necrotizing enterocolitis, hypoxic ischemic encephalopathy Sarnat Stage ≥ 2 requiring mechanical ventilation, with multiple organ system involvement and/or seizures, congenital diaphragmatic hernia, multiple organ failure with sepsis, and extreme prematurity ≤ 27 weeks gestation requiring $>30\%$ FiO₂ with significant comorbidity; or b) were consulted by palliative care; and c) are ≥ 23 weeks gestation at birth; and d) had a English speaking parent ≥ 18 years. Exclusion criteria included: a diagnosis of neonatal abstinence syndrome or positive drug screen. Infants with these criteria often exhibit signs that complicate the understanding of infant symptoms. Nurses qualified for the study if they cared for an infant with any of the previous criteria. Nurses from both day and night shift participated in the study. One to twelve nurses were

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involved for each patient related to changing daily assignments and the use of primary care nursing. Nurses in the study reported being quite a bit familiar or very much familiar ($n=170$, 71.2%) with the infants for whom they were caring.

Procedures

IRB approval was obtained for the study. At enrollment, informed consent was obtained from the parents of the infants who were enrolled as part of a larger study. Formal consent was not obtained from nurses because of the collection of limited personal information. Nurses verbally agreed to participate in the study at the time of survey completion. The infants were assessed weekly starting at baseline until the patient was discharged or for a maximum of 12 weeks. Three trained research nurse observers assessed seven different aspects of infant behavior including: alertness, calmness/agitation, respiratory response, crying, physical movement, muscle tone, and facial tension. The scores for each of these categories were then summed to obtain a total score. Inter-rater reliability was assessed between the trained research nurse observers at the study start and then again when enrollment reached 25, 50 and 75 participants. At the same time as the behavioral observation, the nurse was asked to complete a survey to the best of their ability based on their observations of the infant's symptoms and their experiences with the patient over the previous week. The survey took approximately 5 minutes to complete and nurses were compensated with a \$3 coffee card for each weekly assessment they completed. Nurses may have completed several surveys throughout the course of the study.

Measures

The Nurse Perceptions of Infant Well-Being survey was completed weekly by the nurse who was caring for the infant at the same time that the behavioral observation was completed. The survey was developed by the research team utilizing the literature and expert opinion as a validated survey to collect data on infant symptoms, suffering, QOL, and expectations for

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survival is not available. Nurses reported on their perceptions of the infant's current level of suffering and expectations for infant survival (to hospital discharge, within the next 6 months, and within the next year) via a five-point Likert Scale. The answer choices included 0=Not at all; 1=A little bit; 2=Somewhat; 3=Quite a bit; and 4=Very much. The nurses were also asked to rate the infant's QOL on a five-point Likert scale. The answer choices included 0=Very poor; 1=Poor; 2=Good; 3=Very good; and 4=Excellent. Only limited demographic information was collected from nurses: gender, age, years of experience, and shift worked.

The COMFORT-Behavior (COMFORT-B) Scale is valid for use in postoperative patients from 0-3 years old (van Dijk, M. et al., 2000). The COMFORT-B scale assesses alertness, calmness/agitation, respiratory response, crying, physical movement, muscle tone, and facial tension. Each component is rated on scale of 1-5. The COMFORT-B scale has been used reliably in the NICU and provides a total distress score, which ranges from 0-40, with a higher score indicating a higher level of distress (Wielenga, De Vos, de Leeuw, & De Haan, 2004).

Analysis

Pearson's correlations examined association between nurse perceptions of infant suffering and QOL and COMFORT-B scale scores, as well as between nurses' perceptions of the infant experience and their expectations for infant survival. (IBM SPSS Version 24.0) was used in all analyses.

Results

Participants

This exploratory descriptive study included 237 nurses who completed 593 surveys about 79 infants over the study period. All infant enrolled in the study were diagnosed with a life-

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threatening or life-limiting illness while in the NICU. Infant's had varying diagnoses and ranged in gestational age. Infant demographics are displayed in Table 1. Nurses who participated in the study ranged from 21-68 years of age and had worked an average of 13.3 years as a registered nurse. The majority of participating nurses worked day shift (n=216, 91%).

The variables analyzed included total COMFORT-B scores, nurses' perceptions of the infant symptom experience, suffering, and QOL, as well as nurses' expectations for infant survival.

Nurse perception of infant suffering and expectations for survival

Associations between nurse perception of infant suffering and expectations for survival were evaluated using a Pearson correlation. As a result of using this model, it was found that nurses' perceptions of infant suffering were significantly associated with nurses' expectations for infant survival ($r=-.296, -.323, -.349, p<0.001$). The correlation was negative, which means that as nurses' perceptions of infant suffering increased, their expectations for the infants' survival during the hospital stay, within the next 6 months, and within the next year decreased.

Nurse perception of infant QOL and expectations for survival

Associations between nurse perception of infant QOL and expectations for survival were also evaluated using Pearson correlations. As a result of this model, it was found that nurses' perceptions of infant QOL was significantly correlated with nurses' expectations for the infants' survival ($r=.560, .629, .647, p<0.001$). The correlation was positive, so as nurses' perceptions of infants' QOL improved, their expectations for infants' survival also improved. Conversely, if nurses perceived that QOL was poor, their expectations for infants' survival decreased.

Nurse perception of infant QOL, expectations for survival, and COMFORT-B scale total score

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Associations between nurses' perceptions of infants' QOL, suffering, and the COMFORT-B total score were also evaluated using Pearson correlations. No significant correlations were found between nurses' perceptions of infant QOL, suffering, and the COMFORT-B scale total score.

Table 1

Infant Demographics (n=78)

Variable	<i>n</i>	%
Infant Sex		
Females	32	38
Males	46	61
Gestational Age		
≤ 28 weeks (extremely preterm)	17	21.8
29-38 weeks (pre-term)	49	62.8
39-40 weeks (full-term)	11	14.1
≥ 40 weeks (post-term)	1	1.3
Race ^a		
White	51	67.1
Black/African American	19	25
Other	6	7.9
Primary Diagnosis at Admission		
Prematurity	30	39
Congenital Anomalies/CHD	16	20.8
Respiratory	15	19.5
Other ^b	16	20.7

Note. CHD = congenital heart disease.

^aMissing data for 2 infants; mothers' race and ethnicity used to define infants' race and ethnicity.

^bOther diagnoses include hypoxic ischemic encephalopathy (HIE), congenital diaphragmatic hernia (CDH), and

Discussion

The purpose of this study was to understand associations between the COMFORT-B scores and nurse perceptions of infant discomfort and associations between nurse perceived infant suffering and QOL and expectations for survival during hospitalization, within the next 6 months, and within the next year. Our study discovered that there is an association between nurse-perceived infant suffering and expectations for survival during hospitalization, within the

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next 6 months, and within the next year. The inverse relationship that was uncovered by this study between these two variables indicates that as nurse-perceived infant suffering increases, the outlook of survival decreases and vice versa. In addition, our study discovered that there is an association between nurse-perceived infant QOL and estimated survival during hospitalization, within the next 6 months, and within the next year. This positive relationship indicated that lower QOL perceived by the nurse led to shorter expectations for survival.

Both of the findings related to the infant symptoms experience and expectations for survival are important for palliative care. As previously discussed, nurse perceptions may have an effect on how they advocate for care on behalf of the infant (Park & Oh, 2019). In the future, it will be important to explore the relationship between nurses' perceptions of the infant symptom experience, expectations for survival, and palliative care delivery to discover if expectations for survival could impact care that infants receive in the NICU. In addition, it will be important to explore actual death and expected death within hospitalization, within the next 6 months, and within the next year to explore if nurses' perceptions regarding infant symptoms and expectations for survival are accurate.

In our study, no association was found between the COMFORT-B scores and nurses' perception of infant suffering and QOL. According to Boyle, E., Bradshaw, J., & Blake, K. (2018), nurses often rely on their perceptions to determine discomfort in infants. For example, if an infant receives a low COMFORT-B score, it does not necessarily mean that the nurse perceptions align with that objective score. In this case, the nurse may perceive that the infant is actually experiencing more distress than indicated by the COMFORT-B Scale. In the future, it will be important to determine if an assessment scale is the most accurate and efficient to use in the NICU, or if nurse's perceptions could be relied upon in the NICU. If nurse perceptions are

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more reliable than other methods, it will be important to find a way to standardize that data for collection in the future.

Conclusion

Even though associations between COMFORT- B scores and nurse perceptions of infant discomfort were not significant, they are discrepant. It is unclear whether the COMFORT-B scale performs better than the perceptions of the bedside nurse in determining infant discomfort. Further, nurse perceptions of infant suffering or poor QOL is related to expectations for infant survival, which may affect decision-making, recommendations for care, and care delivery. Future research should focus on the development of improved assessment of the infant symptom experience in the NICU, as well as the effect of nurse expectations for infant survival on palliative and EOL care delivery.

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