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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.

Research Methodology/Design—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.

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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.

Keywords

qualitative; infant; symptoms; end-of-life care; neonatal intensive care unit

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 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, Sanders, Brownell, & Moss, 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 & Steward, 2014) guided this exploratory study. This theoretical framework (figure 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, with 1-uncomfortable, 2-slightly uncomfortable, 3-neutral, 4-comfortable, and 5-very comfortable.

Semi-Structured Interviews

The interviews were conducted within two weeks of the infant’s death. As part of the interview process, nurses were asked to complete a survey that gathered demographic information. The semi-structured interview consisted of 11 questions designed to obtain information related to the infant’s entry into EOL care, the signs and symptoms observed, treatment strategies used and educational needs of the nurse. Probes were used to obtain additional information (Liamputtong & Ezzy, 2005). All interviews were audio-recorded and then transcribed verbatim. Printed versions of the transcripts were used to facilitate analysis of the interview data.

Interview data were analyzed using the Framework Approach (Ritchie, Spencer, & O’Connor, 2003), which is a type of content analysis. The Framework approach involves three comprehensive steps designed to enhance rigour. These include data management, descriptive accounts, and explanatory accounts. During data management, two investigators independently became familiar with the data by reading the transcripts through multiple times to identify initial categories or themes that resulted in the development of a coding

matrix. One of the investigators, who was not a part of the interview process, served as an unbiased reviewer of the data. Data were then assigned to the themes in the coding matrix. During the descriptive accounts step, coded data were synthesized further resulting in a refinement of the initial themes. Similar themes were brought together to form a coding index. The coding index was used as a means of organizing the entire data set and was revised throughout data analysis as new insights emerged from the data. The broader themes were examined for associations between the themes resulting in development of more abstract concepts. Both authors repeatedly discussed and refined the themes to assure consistency and accuracy of the data. In the final step, associations between concepts were identified that were reflective of the interview data and prevented misinterpretation of the data (Smith & Firth, 2011). To confirm the findings, the results of the analyses were compared with the theoretical framework, as well as existing relevant literature. An example of how the initial themes and categories were continually refined until final themes emerged and a core concept was reached is included in figure 2.

Results

Fourteen staff nurses, who cared for 20 infants who died during the study period, agreed to participate in face-to-face interviews. Nurse participants had an average of 6.5 years of nursing experience (SD 4.6) and 6.1 years of NICU experience (SD 4.5). Years of service in the NICU ranged from 0.5–15 years. All nurses were female and white, non-Hispanic, between 20 and 45 years of age. Baccalaureate preparation was achieved by 87% of the nurses, while 13% held Associate's degrees. In response to their comfort level with EOL care, 73% of the nurses reported being comfortable or very comfortable.

Nurse participants were asked to describe the infant for whom they provided EOL care, the situation surrounding the infant's death, their observations of symptoms the infant experienced at the EOL, therapies used to treat pain and other symptoms exhibited by the infant, and their comfort level in relaying EOL care information to parents. Three core concepts, or themes, emerged from content analyses of the transcripts: uncertainty, discomfort, and chaos. These themes support the constructs of the theory that are included within the nurse domain.

Uncertainty

Several characteristics of the EOL process were identified by the nurse participants that led to perceptions of uncertainty in providing EOL care. These included infant prognosis, time of transition from curative to EOL care, symptom recognition and treatment, time to death following withdrawal of life-sustaining treatment, and lack of knowledge related to the religious/cultural customs of the various infants and their families.

Nurses reported that when infants were admitted to the NICU it was not immediately clear that EOL care might be needed. One nurse stated:

“We weren't really sure what his prognosis was going to be.” (Nurse 2)

The focus of care for the infants was always on survival, especially during the initial period following admission to the NICU. It was often difficult for the NICU staff to make the

decision to discontinue further therapies, making the time to initiate EOL care for an infant uncertain. This uncertainty is demonstrated by the following statement:

“I don’t know who mentioned ECMO first, the fellow or the attending. I remember thinking, ‘Are you kidding me?’ because we don’t normally use it for that purpose in the NICU. Sometimes I wonder if we are grasping at straws. Did they really think they were going to save this child’s life? I mean he was in complete DIC.”
(Nurse 1)

Another nurse stated:

“Nothing the team could do helped her. At the end they were pushing in blood product after blood product and it was coming out as fast and she had swelled so much, she was twice her normal size.” (Nurse 8)

In terms of symptom recognition, a few nurse participants recalled some symptoms infants had experienced at EOL, such as pain, gasping, grimacing, and color changes. Nurses were not always certain that infants were exhibiting symptoms in the same way they were being interpreted, such as in cases where the infant was obtunded and offering few cues into symptoms being experienced. Often the perception was that the infant was not in pain. Nurses expressed uncertainty in knowing if the infant for whom they were caring was actually experiencing pain or any other symptoms. Statements by three nurses reflected the uncertainty:

“She would desat all the time. I don’t know if it was from pain or issues with not being able to breathe.” (Nurse 7)

“I don’t know that he was necessarily in pain.” (Nurse 5)

“He never really acted in my mind like he was in pain, but who knows. Even if he had been in pain, I don’t even know if he could have shown it.” (Nurse 1)

Nurses reported that EOL trajectory for infants is hard to predict. This unpredictability made it difficult to explain to parents what might happen once treatment is withdrawn and the infant begins to actively die. One nurse reported:

“I told the parents I didn’t think it would happen immediately; that we should have time to take him from the bedside to the parent room.” (Nurse 14)

Another nurse stated:

“The physician told the parents it might take a couple of days. I told the family I thought it would only take a couple of hours.”

Last is the uncertainty in providing culturally competent EOL care for various populations. Nurses knew that there were special considerations that should be made, but had little direction in what needed to be done. One nurse recalled:

“The baby was Muslim and the chaplain was never called. I knew they had special funeral customs from past experiences. I called the chaplain and he said he didn’t know the family’s wishes.” (Nurse 10)

Discomfort

Of all the events surrounding the death of the infant discussed by the nurse participants, the most overwhelming theme that arose was the discomfort nurses felt with various components of the neonatal EOL care process. Factors that clearly contributed to nurse discomfort in providing EOL care included a lack of: formal EOL care education, opportunity to deliver EOL care, resources to help with the provision of EOL care, familiarity with the infant, and the specific EOL plan for the infant. In addition, inconsistency between providers in EOL care delivery, talking with families about EOL care, taking on the role of advocate for the infant, and ethical dilemmas related perceived use or misuse of advanced technology and medications also contributed to discomfort among nurse participants.

Nurses reported a lack of formal education in relation to EOL care during their nursing education. Some content was included during orientation classes. Nurses also reported that a lack of opportunity to provide EOL care resulted in feeling uncomfortable when placed in an EOL situation. As one nurse said:

“It would be beneficial if they had a class we could take. In orientation you don’t always get the experience of caring for a dying baby and by the time it comes around for you to do it on your own, you don’t remember.” (Nurse 13)

and

“I think we do have a good program, but our unit is so large, you don’t get a dying baby very often and the circumstances are always different, the comfort level with it (EOL care) is not very high.” (Nurse 2)

Nurses acknowledged a lack of availability of EOL care resources from which to draw upon when providing EOL care to an infant. They agreed that the availability of these resources would make them more comfortable with the EOL process. As one nurse said:

“There could be something written out...more than just the bereavement checklist, such as things that are good or not good to say to families.” (Nurse 11)

Nurse participants reported discomfort with knowing what to say to families, as well as their role as an advocate for the infant and the family at the EOL. One nurse who experienced discomfort in talking with families, stated:

“I am always at a loss with things to say to the families. I don’t want to say the wrong thing. So, when in doubt, I just shut my mouth. Because what do you say, “Sorry for your loss?” (Nurse 1)

While another nurse struggled with her role as an advocate:

“There were several times throughout the day when I just wanted to go over to them (parents) and give them permission to ask the team to stop. I don’t know what they would have said. I also didn’t know what was going to happen in the end. Maybe something would have worked out, who knows. I wasn’t the doctor so I kept silent. I was just supportive.” (Nurse 8)

Nurses are also concerned about the various ethical dilemmas that arise from the use of technology and medications. One nurse was very troubled by having to give certain medications at the EOL:

“Sometimes I feel what we do is euthanasia...It’s hard with the gasping; you don’t want to see that because it seems like they are suffering, but it is hard for me when they order a large bolus of something, to give it.” (Nurse 2)

Another major concern for nurses was the inconsistency they witnessed in the provision of EOL care between patients and between providers. In one nurse’s account, she relayed that an EOL care plan had been determined earlier in a conference with the family but a new provider coming on duty did not agree to carry out the established plan. This caused considerable distress for the nurse:

“Care was not withdrawn; it was changed. I had a lot of anxiety because I felt we were opening the door to a whole host of symptoms or manifestations of discomfort based on the fact we weren’t doing anything to prevent that. I had no idea what to tell mom (about the plan being changed). Had the palliative care team been involved, we could have called them and maybe they could have stepped in to do something.” (Nurse 5)

However, nurses valued a medical team that communicates well and is involved.

“The doctor explained to the parents what the baby might do and what our response would be. He really prepared the parents well for what might happen” (Nurse 6)

Familiarity of the nurse with the infant and the family was key to the nurse’s comfort with the EOL care situation. Those nurses who had experience caring for the infant and family were better prepared to dialogue with parents about the infant’s condition and prognosis, as well as answer questions in order to provide good, comprehensive EOL care. Not having that familiarity led to discomfort:

“I didn’t know the baby and I didn’t know the family. It was not a very good thing. I was very detached.” (Nurse 11).

“I knew from the checklist exactly what to do and what would be happening, but I didn’t feel like I was adequately able to support the mom not knowing her.” (Nurse 9)

A nurse who was familiar with the infant and family had a different response:

“I was her primary nurse. I was very familiar with the infant and her family. There was a plan and I was very comfortable with what we needed to do.” (Nurse 6)

Finally, nurses also reported a natural discomfort that comes from just being in an EOL care situation:

“No matter what, there is always some level of discomfort, but you just do the best you can.” (Nurse 4)

Chaos

Nurse participants described the milieu of the NICU as chaotic. Factors contributing to the perceived chaotic environment include many providers caring for one infant, the presence of 'extra' staff wanting to observe EOL care, having many tasks to complete that need to be performed quickly, as well as the uncertainty and magnitude of the situation, especially if the infant's death was not expected.

Having 'extra' staff at the bedside can lead to nurses perceiving that the situation is chaotic:

"I remember at one point looking up and seeing six respiratory therapists and I am pretty sure we didn't need six...all these people were gawking and this poor dad was just standing there. I think we could have handled that better." (Nurse 1)

Nurses are focused on getting tasks done and reported not being able to talk much to the parents or observe the baby during this time. Parents often witness this chaos. One nurse stated:

"Your adrenalin is going and you are all about task-oriented things; trying to do whatever it you need to do." (Nurse 2)

and

"I came in and got report and then was immediately hanging lines. I didn't get to talk to the parents until like an hour or so later. I knew they had been updated; I could hear the physicians talking to them." (Nurse 12)

One nurse was relieved that the parents of her infant had left the unit:

"I felt that we were doing a lot of scrambling. We couldn't find the (memory) boxes and then there were only like two boxes left in the back. We were scrambling trying to get things done. I mean it was probably good that mom and dad weren't there. I think it would have made it a lot harder for them to see us scrambling around." (Nurse 3)

Often, the critical nature of the infant's condition combined with ambiguity about the best treatment option lead to varied opinions and confusion surrounding the infant's care. A nurse recalled:

"Many times during the night I had two different opinions about what to do. I mean at one time I had bicarb in one hand and epi in the other and two different people telling me to give two different meds. It was confusing." (Nurse 1)

Discussion

For the majority of high-risk infants, the initial emphasis of care upon admission to the NICU is on survival. Life-sustaining interventions are initiated and the infant's response is monitored. Unfortunately, at some point during the disease trajectory it becomes clear that further intervention is futile and death is inevitable. For these infants, the focus must shift from curative to supportive EOL care. However, uncertainty surrounds determining that point in time when this shift in care goals should occur.

As the nurses in the study described, the environment surrounding this specific group of infants can be chaotic since numerous members of the NICU staff are present and multiple interventions are often being attempted with the goal of achieving physiologic stability. In addition, nurses were not always in agreement with the medical plan, believing instead that further intervention may be futile and actually cause the infant more distress. This contributed to the nurses' frustration and discomfort with the EOL process. These findings are supported by Yam and colleagues (2001) who reported the dilemma nurses confront when asked to perform invasive procedures that they believe are inappropriate based on their perceptions of the infant's failing medical condition. Researchers have demonstrated that nurses and physicians do not always agree on the likelihood of the survival of critically ill neonates (Meadow, et al., 2012). Their findings highlight the difficulties in determining the point of time when life-sustaining treatment has become futile (Meadow, et al., 2012). The perspectives of nurses and physicians originate from repeated exposure to the various nuances of caring for critically ill infants.

An interesting finding is the incongruence between the nurses' self-rating of their comfort level with EOL care and the amount of discomfort surrounding participation in EOL care. The majority of nurses in the study rated themselves as comfortable or very comfortable providing EOL care and yet discomfort with the entire EOL process was a clear theme throughout most of the interviews. Contributing to their discomfort was a lack of formal education related to EOL care during their nursing education as well as orientation. Nurses have reported that a lack of education is a barrier to the provision of adequate EOL care (Catlin, 2011) and that structured educational opportunities would increase their comfort level with all aspects of EOL care (Chan et al., 2008). In January 2016, the American Association of Colleges of Nursing released their competencies and recommendations for palliative and EOL care education for undergraduate nursing students, which included the content areas and courses where the competencies could be taught and even incorporated into existing curricula (AACN, 2016). Clearly, there is a need for formal education both in academic institutions and NICUs that could provide a foundation for nurses that would improve symptom assessment and management skills, as well communication with families.

Limitations

There were several limitations to this study. The generalizability of the sample is limited due to the small sample size from one Mid-western NICU. Further, not all eligible staff nurses wanted to be interviewed for the study, so it is possible there could be points of view that have yet to be uncovered. Restrictions placed by the institutional review board and the unit that prohibited incentivizing or interviewing nurses on the unit or during their scheduled shift made it difficult, at times, for nurses to participate. Further, the nurses also had a working relationship with the investigator conducting the interviews which may have contributed to their willingness to participate in the study. Another limitation was the use of semi-structured questions, such that while allowing us to keep the interview goal-directed, it may have inadvertently precluded the discovery of important views held by participating nurses. However, we are confident that the themes that emerged are congruent with the theoretical framework and the available supporting literature. To more effectively address the qualitative rigour concepts of confirmability, member checking could have been utilized.

Finally, little research has been done to examine the perceptions of nurses who are for infants at the EOL in the NICU and few models are available to guide research in this area.

Recommendations for Future Research

Continued research is necessary if we are to ensure improved EOL experiences for infants and their parents in the NICU. Parents must be included in any new research efforts on symptom identification at the EOL in the neonatal population. Parents have a vantage point that rarely belongs to another group or individual. They are present for the final moments of their infant's life, fully taking in all the infant has to show us. Research is also needed to examine the effect of educational strategies on comfort with EOL care. This topic may benefit from a more grounded approach and should be replicated in another NICU to obtain a more heterogeneous view.

Conclusion

There is no doubt that infants die in the NICU despite our best efforts. The EOL experience for the infant must be well managed to ensure their maximum comfort and to not add to the emotional burden parents encounter. Symptom recognition and management, as well as enhanced palliative and EOL care education, are key components that will offer nurses the necessary level of comfort needed to provide outstanding palliative and EOL care to infants and their families; to ensure timely and accurate assessment and management of symptoms exhibited by infants, and to ease the emotional burden felt by parents who must make decisions based on the observations of the infant's symptoms that they make. It is crucial that research with this unique population of infants and parents continue so that our management of the infant EOL experience will ultimately be based upon strong evidence that will guide our practice.

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Implications for Clinical Practice

1. 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.
2. 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.
3. 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.

Figure 1.

Framework to evaluate the quality of a neonatal death

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Transcript # 9	Description	Preliminary Thoughts	Initial Categories
Infant			
"chronic patient"	Initial problem	Babies present with varying problems	Treat appropriately, not always immediately clear that EOL care is needed
"organs were no longer functioning"	Escalation of problem	Entry into EOL care - when is this evident?	Timing of entry into EOL care
"absolutely not a candidate for dialysis"	Limits to care	System protocols in place to determine eligibility	Limiting care
"on continuous morphine; pretty much no reaction to anything"	Pain/sedation	Drugs we use for pain and comfort and appropriate use at the EOL	Appropriate medication use at EOL
"when we did remove the ventilator, he had what we thought was gasping..."	Infant response	How infants respond; subjective observations by staff	Recognition/treatment of signs
"fentanyl aerosols...gave it to him when we saw something"	Pain/sedation	Drugs we use for pain and comfort and appropriate use at the EOL	Appropriate medication use at EOL
"infant was placed in nurse's arms and support was withdrawn"	Nurses role in EOL care	Nurses may or may not understand their role in EOL care; personal intuition takes over during times of uncertainty	Personal intuition/experience as a guide

Figure 2.
An example of the coding matrix

Table 1

An example of the coding matrix

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Table 2

An example of the coding index

Initial Themes	Initial Categories
<i>Infant</i>	
Uncertainty	<ul style="list-style-type: none"> • EOL care need not immediately evident vs certain need • Different times of Entry into EOL; acute vs planned • Recognition and treatment of signs/symptoms • EOL trajectory
Focus on Survival	<ul style="list-style-type: none"> • Appropriate use of technology • All possible interventions utilized • Nurses are task-oriented vs observant
Infant Comfort	<ul style="list-style-type: none"> • Appropriate use of medications • Infant appearance • Limiting care • Palliative care • Withholding care

Table 3

Defining the core concept of uncertainty

Initial Themes	Initial Categories	Refined Categories	Final Themes	Core Concept
Uncertainty	<ul style="list-style-type: none"> • Need not evident vs certain need • Entry into EOL; acute vs planned • Recognition of signs/symptoms • Treatment of signs/symptoms • Unknown EOL trajectory 	Care varies greatly between patients Still so much that is unknown	Best practice unknown	UNCERTAINTY
Focus on Survival	<ul style="list-style-type: none"> • Appropriate use of technology • All possible interventions utilized • Nurses are task-oriented vs observant 	EOL care after all interventions are exhausted	Transition to EOL care is uncertain	
Infant Comfort	<ul style="list-style-type: none"> • Appropriate use of medications • Infant appearance • Limiting care • Palliative care • Withholding care 	Goal is for infant to not suffer	Don't know if suffering	