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Medical record documentation and symptom management at the end-of-life in the NICU

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Abstract

Purpose—In neonates, the course of illness is often unpredictable and symptom assessment is difficult. This is even truer at the end-of-life (EOL). Time to death can take minutes to days, and ongoing management of the infant is needed during the time between discontinuation of life-sustaining treatment and death to ensure the infant remains free of pain and suffering. The symptoms experienced by neonates as they die, as well as best ways to treat those symptoms, are understudied. The purpose of this study was to examine symptoms exhibited by neonates at the EOL and the treatments utilized to manage those symptoms as documented in the medical record during the last 24 hours of life.

Subjects—The sample included 20 neonates who died at a large children's hospital

Design—This was an exploratory, descriptive study.

Methods—Descriptive data, such as diagnosis, on-going therapy at time of treatment withdrawal or withholding, pharmacologic and non-pharmacologic interventions associated with treatment withdrawal, time of treatment withdrawal and death, age at time of death, signs and symptoms exhibited during EOL care, and pain scores, was abstracted from the infant's medical record.

Main Outcome Measures—Inadequate documentation in the medical record resulted in missing data that made it not possible to fully explore aspects of symptom management during the last 24 hours of life, however some important results were found.

Principal Results—Importantly, this study showed a difference in the way neonates approach the EOL period. Other findings were that most infants in the study received pain medication even though pain scores were infrequently documented and drug dosages varied across infants. Finally, documentation of non-pharmacologic interventions utilized at the EOL was also lacking.

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Keywords

neonatal; end-of-life; symptom identification; symptom management

Despite a recent increase in the attention given to end-of-life (EOL) care in the neonatal intensive care unit (NICU), the literature continues to focus on the parents of neonates who have died and the clinicians who treat them regarding their attitudes and experiences with issues such as decision-making roles, communication, creating memories, bereavement support and coping.¹⁻⁵ The experiences of dying neonates themselves remain scant. It is well recognized that neonates should receive adequate EOL care, but specific information about what neonates do and experience at the EOL is missing. How an infant approaches the EOL trajectory as well as the recognition and management of the symptoms being exhibited may be paramount to a positive EOL experience for neonates and, ultimately, for their parents and the health care team.

For a small percentage of neonates in the neonatal intensive care unit (NICU), death becomes an inevitable outcome. The majority of their deaths result from withholding or withdrawing life-support.^{6,7} Parents make the decision to have life-sustaining therapies discontinued with the hope of ending pain and suffering for their infant.⁸ To ensure this, ongoing management of manifested symptoms is required during the time between the discontinuation of life-sustaining treatment and death to ensure that the infant remains free of pain and suffering as they die. This is a difficult time period to manage as time to death can be hard to predict and death can take minutes to days to occur.^{8,9} And, parents begin to question their decision the longer it takes for their infant to die.⁸

Because there is little empirical evidence to guide EOL care in the NICU, available neonatal palliative care protocols are based on best clinical practices. Little direction for symptom management is offered by these protocols because of wide variations in the current delivery of EOL care to neonates,^{8,10} resulting in less than ideal management of symptoms that neonates may exhibit during the dying process.¹¹ Parents report being distressed by the physical signs (e.g. unpleasant noises, color changes, gasping) their infant exhibits while dying, especially when symptoms they are not expecting develop.⁵ This leads them to believe their infant is suffering.^{8,12} Symptom management is especially important to parents at the EOL. (Note: While it can be debated whether a neonate exhibits signs or symptoms, for the purposes of this paper, we are using symptoms.)

Pain and symptom management of neonates in the NICU is difficult in general, outside of the EOL. Although there are many pain assessment tools available for use, no specific measure has been set as the “gold standard” and many questions and controversies remain over how pain responses are exhibited in neonates.¹³ Because of the preverbal status of infants, communication of symptoms is through both physiologic indicators and behavioral cues, which must then be accurately interpreted by others. Many factors impact the recognition of symptoms, including the effectiveness of the physiologic indicators and behavioral cues exhibited by the infant; the capacity of the caregiver to interpret those indicators and/or cues correctly; and the caregiver’s knowledge of normal neurodevelopment and pathophysiology, as well as their experience and intuition.^{14,15}

Further, some infants might exhibit few obvious cues and one physiologic indicator may indicate any number of symptoms the infant might be experiencing.¹³ For example, changes in heart rate from crying can be evidence of pain, agitation, a soiled diaper, hunger or a physical need to be held.

It becomes even more difficult at the EOL to observe, assess and interpret symptoms appropriately. Infants may be obtunded and unable to mount physiologic responses to pain and other symptoms. And once EOL decisions have been made, clinicians often begin to turn their attention toward other activities, such as assisting the parents to cope with the impending loss and preparing equipment and medications. Further, nurses may step back to allow the family private time with their infant thus removing them from direct line of site of the infant. Parent report of infant symptoms may be important during this time.

Discrepancies between parent report and nursing assessment have been reported in the literature,^{16,17} that can cause difficulties with communication and relationships between families and clinicians during a very critical time in the dying process. Advances in knowledge regarding the recognition and management of symptoms may alleviate infant suffering, as well as emotional distress experienced by parents and clinicians at the EOL.

Theoretical Framework

A framework to evaluate the quality of neonatal death, guided the project and is fully describe elsewhere.¹⁸ This model was adapted from Emanuel and Emanuel's Framework for a Good Death, which examines the overall experience and quality of care at the EOL for those individuals who are able, or were once able, to interact with their environment and make decisions about their EOL care.¹⁹ Their model depicts both fixed and modifiable characteristics of the individual and highlights those care-system and larger social network interventions supportive to patients and families at EOL, but it is not directly applicable to infants in the NICU. For example, infants do not participate in decision-making surrounding their death. Rather, the parents must serve as proxies to make decisions for them. Further, the infant's preverbal status makes the assessment of pain and discomfort challenging. Behavioral and physiologic cues exhibited by the dying infant, such as grimacing, furrowed brow, retractions or other any cue that indicates discomfort must be recognized and interpreted correctly by a parent or health care professional who then acts on that cue to provide adequate treatment.¹⁴ This is a crucial component to the evaluation of quality of death experience for an infant that is not included in Emanuel and Emanuel's framework.

The adapted model, shown in Figure 1, proposes several factors in various domains that may have an effect on the dying experience of neonates in the NICU. The model describes three domains: infant, parent, and nurse. Each domain interacts with the others within the context of the larger NICU environment. The underlying assumption is that the interactions between these domains will impact, either positively or negatively, the neonatal death experience. Because so little is known about the infant's experience at the end of life, more information is needed regarding those variables that may have an impact on the infant domain; specifically those modifiable infant characteristics, such as manifested symptoms, that may be changed through appropriate intervention. Future testing of the model is incumbent upon learning more about infant experiences, which are largely understudied. Therefore, the

purpose of this study was to examine symptoms exhibited by neonates at the EOL and the treatments utilized to manage those symptoms as documented in the medical record.

Methods

This was an exploratory study that employed the use of data abstracted from the medical record. Human subjects' approval was obtained from the hospital institutional review board.

Sample

A convenience sample of 20 neonates whose deaths occurred between August 2007 and October 2010 in a single large Mid-Western NICU was utilized for the project. Infants who died in the NICU as a result of withdrawing or withholding of life-sustaining treatment were eligible for the study. The objective of the study was to identify from medical records all documented symptoms as well as the medical management of those symptoms during the dying process. Infants were excluded if the death was a result of cardiopulmonary resuscitation or a sudden or unexpected death as observation of the infant may have been hindered, thereby impacting accuracy and frequency of documentation in the medical record.

Data Collection

Medical Record Abstraction—EOL symptoms and medical interventions were abstracted from the medical record for the 24-hour period prior to the death as soon as it was made available from the medical records department, usually within 2–4 weeks following the death. Abstracted data included demographics, prenatal history, diagnoses, on-going therapy at time of treatment withdrawal or withholding, pharmacologic and non-pharmacologic interventions associated with treatment withdrawal, time of treatment withdrawal and death, age at time of death, signs and symptoms exhibited during EOL care, pain scale ratings, and parental presence during the EOL process. Inter rater reliability checks were completed by a second researcher to ensure information was being correctly located in the medical record. Descriptive statistics are used to present the medical record data.

Results

Demographic Data for Infants

Infant demographic data are displayed in Table 1. Forty-five percent of infants had gestational ages between 29 0/7 and 33 6/7 weeks. Only 10% of the sample was comprised of infants considered to be extremely low birth weight, weighing less than 1000 grams. The majority of infants in the sample were 1–4 weeks of age.

Medical Record Data

The last 24 hours of life of each infant's medical record was reviewed. Ninety-five percent of infants underwent some type of life-sustaining therapy. Only one infant had life-sustaining care completely withheld while a second infant had care withheld after an initial palliation surgery. Analysis of circumstances surrounding the infant's death demonstrated

infants entered the EOL care trajectory in one of two ways: emergently or planned (see Table 2). Infants who entered EOL care emergently had life-sustaining therapy withdrawn while physiologically failing so that parents could hold their infant free of all medical equipment. Infants whose entry into EOL care was planned were physiologically stable while receiving life-sustaining therapy. These infants were transitioned into EOL care for reasons of declining quality of life or poor neurological prognosis. Withdrawal of therapy occurred at a predetermined time based on discussions with the parents.

Various therapies, such as ventilator adjustments, were used to maintain the stability of infant vital signs following periods of oxygen desaturation or bradycardia until the time of treatment withdrawal. Exceptions were made in those cases where the infant was physiologically failing on the ventilator despite medical intervention and the decision was made to stop ongoing therapies. Following treatment withdrawal, vital signs were no longer documented as the infants progressed toward EOL. Thus, a record of change in vital signs was not available for analyses.

Time to death was within one hour of treatment withdrawal for 70% of infants, with 40% of those deaths occurring within 30 minutes. The longest time period between treatment withdrawal and time of death was just over 20 hours. The remaining 25% of infants died between 1 and 3 hours of treatment withdrawal.

In every case, there were missing data or a lack of documentation related to the EOL care process. There were inconsistencies in the amount of detail provided in progress notes or death summaries about what transpired during the infant's last hours of life. Some physicians gave detailed accounts of what the infant experienced and how and why the infant was treated with a particular medication, while others only provided a summary of the pronouncement of death.

Given the objective of the study was to identify manifested symptoms, there was a lack of symptom documentation following entry into EOL care. This included the inconsistent documentation of pain scores. Table 3 illustrates when pain scores were obtained in this sample of neonates. No pain scores for any infant were documented after treatment withdrawal.

The majority of infants in this study received pain medication throughout the EOL care process. Of the 20 cases, only three infants did not receive some type of medication for pain or sedation before withdrawal, at withdrawal or after withdrawal of life-sustaining treatment. Reasons included parental religious preferences, diagnosis of anencephaly, and change in EOL care plan. Eighty-five percent of infants received medication prior to treatment withdrawal; 55% received medication at withdrawal of treatment and 60% received medication after withdrawal. Most infants already had continuous intravenous medication for pain and sedation related to their condition, infusing at the time of treatment withdrawal and death. Medications utilized for pain were Fentanyl and Morphine, while Versed and Ativan were given for sedation. Most medication was given intravenously. However, one infant received oral Morphine, and five infants received aerosolized Fentanyl.

Variability in prescribed drug dosage amounts between patients was noted. For example in those patients given morphine by IV injection and not on continuous infusion, ordered dosages ranged from 0.05 – 0.4mg/kg. Infants with continuous morphine infusions had ordered rates ranging from 0.15 – 0.4 mg/kg/hr.

The use of non-pharmacological techniques, such as swaddling, non-nutritive sucking, noise and light reduction, nesting, kangaroo care and minimal stimulation is crucial in the management of infant pain and discomfort.^{21,22} Again, very limited documentation was found regarding the use of these important strategies to minimize symptom burden at the EOL.

Discussion

The objective of this study was to gain more detailed information about the symptoms exhibited by neonates at the EOL and the management strategies used to treat these symptoms. Unfortunately, the lack of documentation in the medical record during the last 24 hours of life further hinders our understanding of symptoms at the EOL. While the objective of this study may not have been fully realized, important information was gained from the findings. Importantly, this study showed a difference in the way neonates approach the EOL trajectory. Infants entered EOL care via two distinct pathways; emergent and planned. Verhagen and colleagues (2010) similarly categorized these pathways as stable and unstable based upon physiology and interventions delivered to the infant.⁷

Of concern is the lack of documentation of pain scores. These findings are contradictory to those of Garten et al. who demonstrated that 75% of NICU nurses surveyed believe that regular pain assessment should be performed throughout the dying process.²³ Furthermore, NICU nurses strongly believe that providing pain relief should be a priority during the dying process.²⁴ Lack of documentation may have partly been a function of the flurry of activities surrounding the infant's entry into EOL care. Or, nurses may not be consistently at the bedside and in a position to observe subtle changes at the EOL as they may be carrying out other duties or have stepped back to allow the family private time with their infant. An important consideration requiring further study is whether the pain scales currently available are appropriate for EOL management. It is possible that an infant could be given a low pain score because they are too ill to mount a response to pain and yet be in pain. This could lead to an infant being under-treated for pain. In either scenario, the infant is left without proper assessment of pain and suffering and the health care team is unable to intervene appropriately to provide relief. A lack of valid instruments to aid in symptom identification at the EOL makes it difficult for clinicians to know with any certainty if an infant is having pain or suffering from any other symptoms as they die.

In this study, almost every infant received medication for pain and sedation, however these medications were not specifically prescribed for treatment or management of EOL sequelae but were already in use in the management of the infant's illness. Across infants, the number of doses and dosage amounts varied. Findings from this study demonstrate that dying infants often received pain medications at doses slightly out of the usual range.²⁰ These findings are congruent with those of other researchers who found that infants received higher doses of

pain medications following withdrawal of life-sustaining therapies.^{25,26} In the current study, the rationale for the use of increased doses is unknown due to the lack of documentation. Janvier et al. and Verhagen et al. also reported a lack of documentation in the medical record explaining the rationale for the increased doses.^{25, 26} One can hypothesize that the increased doses were in response to maintaining the same level of comfort the infant was receiving prior to treatment withdrawal²⁷ since symptoms may have increased following treatment withdrawal.²⁶ The lack of information regarding the symptoms neonates experience at EOL make it difficult to then treat those symptoms appropriately.

Further, the lack of documentation surrounding the use of non-pharmacologic interventions in the treatment of pain and other symptoms at the EOL is yet another concerning finding as these are well-established nursing practices for providing comfort. It is possible that the lack of documentation of these interventions is a function of the electronic medical record that is organized for charting by exception and may not be an accurate reflection of all of the care nurses provide at the EOL.

Once it became evident that the neonate would not survive and life-supporting mechanisms were discontinued, so did documentation. This finding is consistent with Abe, et al who found a lack of clarity and consistency in the medical records of infants who died after ventilator withdrawal.⁶ Attention begins to turn away from the infant, and re-focuses on the family who will survive. It is natural to assist the family at this devastating time, however support and attention should continue to be maintained for the infant to ensure maximum comfort throughout the dying process.

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. Because of inconsistencies and lack of documentation in the electronic medical record following withdrawal of treatment until the time of death it was not feasible to collect the data of interest. Other studies have also reported many problems inherent in the documentation of patient information that was not collected exclusively for the purpose of research, such as missing data.^{28–31} The ideal sample for the project would have been neonates actively experiencing the dying process. However, direct observation of the dying neonate by a researcher would disrupt the dignity and privacy of the EOL experience for the family and neonate and is ill-advised until there is sufficient systematic research to identify relevant variables to observe.

Clinical Implications

Several clinical implications arise from this study. First and foremost, every neonatal intensive unit should have an established protocol to guide the provision of palliative and EOL care to neonates based on the most recent literature available. While further research is needed, great strides have been made in the recommendations that are available to guide clinicians and these can be utilized in the creation of standardized protocols.²²

Ensuring that infants do not suffer at the end of life requires detailed observation and assessment skills, as well as knowledge of strategies most effective in providing relief from

pain and discomfort at the EOL. Documentation of all interventions provided at the EOL should be recorded in the medical record not only for communication purposes between clinicians caring for the infant but also to begin to establish evidence-based methods of documentation.²⁵ Many non-pharmacologic interventions have become standard of care in the NICU, which are then not documented when charting is by exception. It begs the question whether the medical record should be modified to allow capture of these crucial interventions at EOL. The development of a brief checklist to be completed by the bedside nurse immediately following the infant's death may help to improve documentation of important information surrounding EOL care.

Recommendations for Future Research

Specific information about what the infant does and experiences at the EOL is lacking. Continued research is necessary if we are to ensure the best EOL care for infants and their parents in the NICU and several recommendations can be offered. Future research should examine the unique aspects of entry into EOL care, emergent versus planned, in order to develop expanded EOL care protocols that are individualized based on the infant's pathway into the EOL trajectory. The characteristics of each group appear to be different and should be considered separately. This will require clearly defined inclusion/exclusion criteria.

It will also be very important to include parent perceptions of symptom burden and infant suffering in any new research efforts on symptom identification at the EOL as they have a vantage point that rarely belongs to another group or individual. They are present for the final moments of their infant's life at the time when many clinicians step back to offer privacy and may be able to offer an invaluable perspective in determining best EOL care practices. It should be noted that before stepping back to offer privacy, clinicians must prepare parents as well as possible for what they may see their infant experience.

Finally, and maybe most importantly, is that multi-method, prospective research involving adequate numbers of dying neonates and their families should be undertaken in order to truly understand the EOL experience in this population of patients. A prospective approach may yield detailed information that could be useful in the development of valid measures to assess and manage symptoms that infants experience at EOL or in determining the most effective drugs and drug dosages necessary for adequate pain and symptom relief in neonates at the EOL. These, we believe, are crucial steps to advancing the science around neonatal EOL care.

Conclusion

Unfortunately infants die in the NICU despite the best efforts of the medical team. What is considered to be optimal EOL care varies according to each family's individual perspective. Symptom recognition and treatment of those symptoms is a key component and more detailed information is needed in order to improve care for neonates at the EOL. It is important that research with this unique population of infants and parents occurs so that our management of EOL does not continue to be based solely upon clinical experience but rather on strong scientific evidence to guide practice.

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Figure 1.

Potential Factors Affecting the Neonatal Death Experience.

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Table 1

Infant Demographic Data.

Characteristic	n=20	%
Male Sex	9	45
Race		
White, non-Hispanic	11	55
Black, African American	7	35
Birth Weight		
< 1000 grams	2	10
> 1000 grams	18	90
Gestational Age		
< 29 weeks	2	10
29 ^{0/7} –33 ^{6/7} weeks	9	45
34 weeks and above	9	45
Age at Death		
1 week	7	35
2–4 weeks	8	40
1–8 months	5	25

Table 2

Differences in Emergent and Planned Entry to EOL Trajectory.

Emergent Entry	Planned Entry
Characteristics	
Physiologically failing on vent	Poor neurologic prognosis/quality of life
Chaotic environment	More controlled environment
Focus on survival	Focus on comfort care
Attempts made to achieve stability	Plan for treatment withdrawal formulated
Infant may be obtunded	Infant may exhibit symptoms
Infant died quickly	Time to death variable
Examples of Diagnoses	
Intestinal perforation, NEC totalis	Holoprosencephaly
Sepsis, septic shock	Hypoxic Ischemic Encephalopathy
Respiratory Failure	Hepato-Renal failure
Congenital diaphragmatic hernia	CHARGE Syndrome
Persistent metabolic acidosis, persistent hypotension	Chromosomal abnormalities, multiple congenital anomalies
Prematurity	Ruptured omphalocele

Table 3

Timing of Pain Scores.

Last Documented Pain Score	n	%
>8 hours prior to withdrawal	5	25
2–8 hours prior to withdrawal	5	25
1–2 hours prior to withdrawal	4	20
Within hour prior to withdrawal	5	25
At withdrawal	1	15
After withdrawal until death	0	0