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NICU Nurses' Suggestions for Improving Obstacles in End-of-Life Care

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ABSTRACT

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Obstacles in End-of-Life Care

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Background: Approximately 25,000 pediatric deaths occur in hospitals in the United States each year with over 50% of these deaths occurring in Newborn Intensive Care Units (NICU). NICU nurses are frequently involved in end-of-life (EOL) care and face unique obstacles.

Objective: The objective of this study was to obtain NICU nurses' suggestions for improving obstacles in EOL care in NICUs.

Methods: Suggestions were obtained through mailed survey research in qualitative study design. Returned surveys yielded 121 nurse respondents who gave a total of 138 suggestions.

Results: A total of 10 cohesive themes were identified: (1) environmental design issues, (2) improved communication between healthcare teams, (3) ending futile care earlier, (4) realistic and honest physician communications to families, (5) providing a "good death," (6) improved nurse staffing, (7) need for EOL education, (8) earlier entry into hospice/palliative care, (9) availability of ancillary staff, and (10) allowing parents more time to prepare for death.

Conclusions: Despite the variety of obstacles encountered in providing EOL care to dying infants and their families, NICU nurses can use self-assessment tools to identify obstacles to EOL care and collaborate with key members of the healthcare team to alleviate these obstacles.

Keywords: End-of-Life, NICU, obstacles, helps, perceptions, NICU nurses

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NICU Nurses' Suggestions for Improving Obstacles in End-of-Life Care

Approximately 25,000 pediatric deaths occur in hospitals in the United States each year with over 50% of these deaths occurring in Newborn Intensive Care Units (NICU).[1] NICU nurses' exposure to death has been described as ongoing and unremitting[2] meaning NICU nurses are consistently responsible for providing end-of-life (EOL) care to patients and families. NICU nurses face unique obstacles to providing EOL care.

Background

NICU nurses care for some of the most challenging patients, especially those born prematurely.[1] Death rates for admitted patients are notoriously high in NICUs.[1] A 2015 study reporting death rates found mortality rate for infants admitted to NICUs in the United States ranged between 16-34%.[3] In 2005, there were a reported 28,000 infants in the United States who died.[4] Of those infant deaths, almost 19,000 occurred during the neonatal period (less than 28 days old).[4] Others have reported that 50,000 children die yearly with around 66% of these deaths occurring in the neonatal period.[5] These high numbers demonstrate that NICU nurses care for dying infants on a daily basis. EOL care obstacles are common for the nurse caring for dying infants and their families.

Research has been published on obstacles to EOL care in hospital settings including adult ICU[6,7], emergency room[8,9], oncology[10,11], pediatric ICU[12], and NICU.[1,2,4,5] Two articles were found specifically looking at NICU nurses' perceptions of EOL care obstacles. In 2011, Kain interviewed 24 registered NICU nurses for the purpose of determining nurses' opinions regarding identified EOL care obstacles. Using an interpretive research framework, focus groups were conducted in Australia at three NICU's. These NICU nurses reported the primary barriers to incorporating palliative care practices in NICUs were: (1) inadequate staffing to care for dying

babies; (2) environmental factors that were unconducive to EOL care such as lack of rooms, small spaces, and loud environment; (3) technological advances leading to futile care; and, (4) parental expectations being unrealistically high about long-term outcomes. Completed in the same year, Wright, Prasun, and Hilgenburg, reported on barriers and facilitators to providing high quality EOL care in the NICU.[4] Using the Neonatal Palliative Care Attitude Scale Questionnaire, 50 NICU nurses were sampled.[4] The five most reported obstacles were: (1) nurses inability to express opinions, values, and beliefs, regarding palliative care; (2) negative physical environment issues; (3) technological life support used in futile cases; (4) parental demands to continue life extending care; and, (5) lack of EOL care education for nurses.[4] These researchers concluded that obstacles in NICU EOL care and further research is warranted.[4]

While both articles identified common obstacles to providing EOL care in NICUs, no other studies were found specifically look at NICU nurses' suggestions for improving EOL care. Specific research looking at NICU nurses' perceptions on EOL care is limited.

Significance

The purpose of this study was to obtain NICU nurses suggestions for improving EOL care for dying infants. Categorizing themes from nurses' suggestions may help identify areas where improvement is most needed and would be most beneficial to provide compassionate, dignified, EOL care to dying infants and their families in the NICU.

Research Question

The research question for this study was: *"If you had the ability to change just one aspect of the end-of-life care given to dying infants, what would it be?"*

Methods

Design

A cross-sectional qualitative study design was used looking at NICU nurses' suggestions for improving EOL care for dying NICU patients and their families. Nurses suggestions were obtained through mailed survey research.

Sample

After institutional review board approval, a geographically-dispersed sample of 1,058 NICU nurses was acquired from the National Association of Neonatal Nurses (NANN). NICU nurses who were members of NANN, read English, and had cared for at least one dying newborn were eligible to participate in the study. Return of the questionnaire was considered consent to participate.

Instrument

The *National Survey of NICU Nurses' Perceptions of End-of-Life Care* questionnaire used for the study was modified from four similar questionnaires with adult ICU nurses[6,7] emergency room nurses[8,9] oncology nurses[10,11], and pediatric ICU nurses.[12] Input from experts was used to further revise the questionnaire. The final instrument contained 68 items. Fifty-one were Likert-type, 4 were open-ended, and 13 were demographic items. The questionnaire was pretested by 24 NICU nurses for content and clarity and took about 30 minutes to complete.

Procedure

After purchasing the mailing list of potential subjects from NANN, the initial mailing consisted of a cover letter explaining the purpose of the study, the questionnaire, along with a self-addressed stamped return envelope. Non-respondents were sent one additional mailing a few months after the initial mailing.

Data Analysis

The data were entered into a Microsoft Excel™ (2016) file and suggestions were categorized (based on theme) by individual members of the research team. The team included researchers with expertise in critical care nursing, qualitative research, EOL care, NICU nursing, and a graduate student with five years of fulltime NICU nurse experience. Each suggestion was evaluated until all researchers agreed on categorization of the response.

Results

Demographics

Of the 1,058 questionnaires originally mailed, 15 came back undeliverable and 142 were returned with subjects stating that they were ineligible to participate, leaving 901 as the useable total sample. Of these, 234 subjects completed and returned the questionnaire, giving a final response rate for the larger study of 26%. Of the 234 who returned the questionnaire, a total of 121 (51.7%) subjects provided a response to the open-ended question for this report, which resulted in 138 total suggestions.

Demographic data were obtained. Of the subjects reporting gender, 118 (97.5%) were female and 3 (2.5%) were male. Subjects reported a mean of 21.7 (SD=12.1) years as an RN and a mean of 18.7 (SD=10.5) years of NICU experience. Nurses' age in years ranged from 29-70 (M=50.4, SD=11.3). Nurses reporting having earned a bachelor degree or higher included more than 80% or respondents. Remaining demographic data are presented in Table 1.

Themes

After analyzing and categorizing responses, a total of 10 cohesive themes were identified with a few additional miscellaneous items (n=9, 6.5%). The top six obstacle themes comprised: (1) environmental issues, (2) improved communication between healthcare teams, (3) ending futile care earlier, (4) realistic and honest physician communications to families (5) providing a

"good death," and, (6) improved nurse staffing. Nurses' suggestions for these top six obstacles follow.

Environmental issues. NICU nurses caring for dying infants and their families desired to have the physical environment changed to provide better EOL care (n=27, 19.6%). Change suggestions included improving privacy, adding to limited space, and the need for special family areas.

Privacy. A common theme related to environmental issues focused on improving privacy for the infant and family. One nurse suggested,

> I wish every patient and family had access to a private room. Unfortunately, our sicker babies are in a large open pod. EOL care can become a side show for other parents and staff sometimes. It can be very morbid.

Another NICU nurse wrote, *"[I would suggest] private rooms for infant and family to be together and grieve/cry in private. We have curtains around the bedside – NOT PRIVATE!"*

Limited space. An example of the limited space contained in NICUs was shared by this nurse,

> Our NICU is a large, one room NICU and there is no space except two back private rooms with curtains. This is the room the dying infant would be in. The family is still aware of the activity in the NICU. We [can] move them to a unit close by with private (adult) rooms, but this is not optimal.

Special areas for families. Several nurses suggested special areas be designed for families at the EOL. One nurse requested, "*To have a special area for family to do things with their infant they will never get to do again– a walk outside, or a bath."* Another nurse included, *"Having a garden for parents to take their child to be with them when they die."*

Improved communication between health care teams. Providing consistent information to families and other team members was the second largest suggestion made by NICU nurses (n=18, 13.0%). One nurse suggested that, *"The interdisciplinary team (attending MD, surgeon, specialty services, etc.) would all be on the same page and deliver a consistent message to the family."* Another nurse wrote,

> Our NICU has four teams. Many teams don't always share the same diagnosis and/or treatment the other physician presented to the family. This [lack of consistency] causes serious conflict among the family. When physicians don't present a united front, it causes conflict with staff as well as families.

Another nurse noted the need for physicians to agree and accept responsibility for care. She stated,

> Having the team of physicians in agreement about care and willing to accept responsibility for [that] care. We have a team of physicians and often the one on night duty will do anything to keep a baby alive so he doesn't have to deal with the death on his shift and can leave it for the attending physician [to handle in the morning].

Ending futile care earlier. Many nurses (n=15; 10.8%) recognized the common futility of care and wanted that futile care to stop earlier. One nurse said, *"We prolong suffering too long. Make a decision earlier and faster."* Other nurses described their desire to stop care sooner to decrease the infant's pain. One nurse shared, *"When you are all aware the infant is near death, don't keep poking for an IV. Sometimes enough is enough. Think of the pain the infant is experiencing."* Another nurse described his/her experience this way, *"I would not allow parents the choice to keep dying infants alive when death is certain. I find it inhumane and unethical to keep infants alive when their tissue is splitting open from edema."*

Realistic and honest physician communications. Other nurses suggested that physicians have more realistic and honest communications with families and not give families false hope (n=14; 10.1%). A poignant example from one nurse said,

> I would change the physicians' approaches to the parents when discussing EOL. The [doctors] always seem to chicken out when the parents are sitting in front of them. Most, unfortunately, don't want to be the 'bad guy.' So the patient lingers on because parents will hold onto any hope you give them. But if [doctors] would have been straightforward with parents [earlier], I think most parents would be able to reach that difficult 'withdraw' decision sooner, as a result, the patient would suffer that much less.

Providing a good death. Nurses desired providing a good death for infants including having the child die unattached to technology, being held, and out of pain (n=14; 10.1%). One nurse shared,

> I recently had to watch a baby die in its bed attached to vent and drips while his heart slowly stopped. I would like all babies to leave this world cradled in someone's loving arms. No baby should die untouched [while] attached to machines.

Improved nurse staffing. Nurses suggested that dying infants be afforded the attention from one nurse rather than having the nurse care for two patients (n=13, 9.4%). *"Having the dying infant be my only patient,"* wrote one nurse while another echoed with, *"Always being there for the family, hence having only one baby until it passes."*

Remaining themes. The remaining themes included: (7) need for EOL education (n=9, 6.5%), (8) earlier entry into hospice/palliative care (n=9, 6.5%), (9) availability of ancillary staff (n=7, 5.1%) and, (10) allowing parents more time to prepare for death (n=3, 2.2%).

EOL education. Most suggestions regarding improved EOL education centered around NICU nurses be taught appropriate things to say to families. One nurse said, "*Increased*

education about what to say, what words or phrases to avoid, and words or phrases to use to convey genuine compassion."

Earlier hospice/palliative care. Nurses wished to include hospice or palliative care earlier. "[My suggestion would be to] *bring in palliative care earlier to give parents an option. Hospice should not be a scary thing, but should be embraced so more of these babies do not suffer and parents do not feel guilty."*

More ancillary staff. A few nurses wanted 24 hours staff availability in the form of social work, chaplain, or secretarial support. One nurse asked for, "*Having access to resources 24 hours a day."*

More time for parents to prepare. While many nurses expressed frustration at continuing care they deemed as futile, a few nurses wanted more time for parents to prepare for the death of their child. Two nurses expressed the need for more time, "*More time for parents to "accept" the infant's death," and, "Time for parents to prepare and accept the decision BEFORE the infant dies."*

Discussion

Advances in neonatal care have positively impacted the survivability of infants who previously would have died.[13] NICU nurses play an essential role in how death occurs and are keenly aware of obstacles impeding a peaceful death experience.[14] Impeding obstacles can be include *external factors* such as limited space and privacy, lack of education or lack of staff, hospice/palliative care policies not being used; or, *human factors* such as the need for honest communication between physicians and families, recognizing futile care earlier, providing a good death, and allowing parents time to prepare for death.

External factors

NICU nurses' priorities of care are patients and families. External factors such as limited space and privacy, lack of education or staff, and hospice/palliative care policies not being used all greatly impact EOL experiences, but are not easily remedied during the EOL process.

Many NICUs are designed with large rooms with multiple beds in each room to allow nurses to watch multiple infants at once. Lack of privacy can affect the family's grieving process if they feel on display to other families in the NICU. EOL displays can also be traumatic to other families who become acutely aware of the impending death of a neighboring infant while worrying about the health of their own newborn. In a focus group study of 24 nurses published in 2011, nurses described the lack of private rooms as a barrier to providing EOL care and that relocation to a private room was not often feasible.[15]

Nurses from a focus group study published in 2011 reported that lack of staffing precluded their ability to provide adequate EOL care.[15] The time-intensive nature of providing EOL care requires adequate staffing, but is not always available which can lead to substandard EOL care provided.

In a quantitative study of 50 NICU nurses examining barriers to EOL care in the NICU, nurses all expressed the need for EOL care education, but less than half reported that they had ever received EOL care education.[4] A 2003 report released by the Institute of Medicine recommended that physicians, nurses, and other healthcare members should receive EOL care education to be able to provide adequate and appropriate EOL care to dying infants and children.[16]

The American Academy of Pediatrics released an official statement about palliative care for children of all ages in 2000. Members of the AAP stated that palliative care programs are essential for providing EOL care to support the dying infant, the family, and health care team.[17]

Although this data has been long published about the need for palliative care programs, our responses did not confirm that palliative care was either available or was being used in NICUs.

Human Factors

Nurses are at the bedside more than physicians, parents, or other types of staff, and often recognize futile cases earlier than other staff members or parents. Many nurses recommended recognizing futility earlier and stopping care sooner. In a 2013 article reviewing ethical principles in the NICU, researches stated the ethical principle of nonmaleficence, or do no harm, is violated when infants with a poor prognosis are kept alive by technology and/or other means that cause suffering and pain which supports nurses suggestion to recognize futility early.[18]

Physicians are responsible for communicating each patient's prognosis to parents and family members. Nurses requested physicians be more open and honest in their communication of each patient's prognosis. Lack of direct physician communication could be related to reports from two articles published in 2013 and 2006 where both discussed that most medical schools do not train provide education about EOL care communication.[19,20]

Wanting to provide a good death for a terminally ill infant is a natural response for nurses giving EOL care. If a good death is provided, infants will experience less pain, and families will receive emotional support. In a 2016 article, researchers asked nurses how they provided a good death for dying infants. Nurses stated they would collect keepsakes for family members to remember their dying infant, allow parents to hold their infant, and remove as much technology as possible prior to death.

Implications for NICU Nurses

Though the physical environment in which EOL care is provided can be the most difficult to manipulate, nurses can modify the existing environment by moving infants out of a room or to a more private corner of a room so a dying infant and his/her family can have privacy. When

new units are being built, NICU nurses should be on planning committees and provide input on the new unit design to facilitate privacy and adequate space to provide appropriate EOL care. Nurses can also advocate for dying infants by coordinating with interdisciplinary team members so a clear uniform prognosis and care options can be communicated to families of dying infants.

In a 2014 study, researchers created a self-assessment tool to evaluate healthcare workers' perceptions of EOL care.[21] The self-assessment had four sections: (1) individual opinions on EOL care, (2) opinions about current EOL care practices in the individual's work setting, (3) how well the healthcare team provides EOL care, and (4) the neonatologists' role in EOL care.[21] The questions in these sections asked: (1) if individuals felt they had received EOL care education, (2) if family's questions were answered, (3) if dying babies were comfortable during EOL care, (3) if pain management was provided, (4) if team communication occurred to clarify plan of care, and (5) if the neonatologist provided respectful honest communication about the baby's prognosis and other similar questions.[21] Nurses can access this self-assessment tool to evaluate their unit's current EOL care practices to identify common issues.

Once nurses identify issues, coordination with appropriate healthcare team members to create and implement solutions to the obstacles identified in EOL care can be completed. The National Association of Neonatal Nurses (NANN) and the American Academy of Pediatrics' (AAP) state that respectful, compassionate, and competent EOL care should be provided dying newborns and their families.[17,22] As NICU nurses assess their unit's current EOL care practices, identify obstacles, and help implement solutions, compliance with and advocating for NANN and AAP standards will create better EOL care experiences for many dying babies and their families.

Limitations

Responses were only collected from members of NANN. NICU nurses from other professional organizations or those not part of a professional organization may have different suggestions to improve EOL care.

Conclusion

NICU nurses face a variety of obstacles in providing EOL care to dying infants and their families. While these obstacles vary in size and frequency for each unit, NICU nurses can be key in assessing, identifying, and working to create solutions to these obstacles to provide competent, respectful, and compassionate EOL care to dying infants and their families.

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Table 1. *Demographics*

Table 1. Demographics of Nurses. *n* = 121				
Sex	*n*	%		
Male	3	2.5		
Female	118	97.5		
Age (y)	*M*		*SD*	Range
	50.4		11.3	29-70
Years as RN	21.7		12.1	3-45
Years in NICU	18.7		10.5	1-42
Hours worked/week	34.8		10.5	0-72
Number of beds in unit	45.8		23.6	6-120
Dying patients cared for:	*n*	%		
>30	35	(28.9)		
21 – 30	16	(13.2)		
11 – 20	25	(20.7)		
5-10	32	(26.4)		
<5	13	(10.7)		
Highest degree:	*n*	%		
Diploma	10	(8.3)		
Associate	11	(9.1)		
Bachelor	51	(42.2)		
Master	42	(34.7)		
Doctoral	7	(5.8)		
Ever certified as CCRN	*n*	%		
Yes	35	(28.9)		
No	84	(69.4)		
Currently CCRN	*n*	%		
Yes	25	(20.7)		
No	89	(73.6)		
Years as CCRN	*M*		*SD*	Range
	10.3		9.4	1-27
Position Held at Facility:	*n*	%		
Direct care/bedside nurse	75	(62)		
Neonatal Nurse Practitioner	25	(20.7)		
Department Manager/ Educator	14	(11.6)		
Clinical Nurse Specialist	7	(5.8)		
	n	%		
Facility type:	59	(48.8)		
Community, non-profit	35	(28.9)		
University Medical Center	14	(11.6)		
Community, profit	8	(6.6)		
County hospital	3	(2.5)		
State	1	(0.8)		
Military hospital				