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NICU Nurses' Perceptions of Obstacles and Supportive Behaviors in End-of-Life Care

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ABSTRACT

NICU Nurses' Perceptions of Obstacles and Supportive Behaviors in End-of-Life Care

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Background: Losing an infant is difficult for parents to face. To improve EOL care for dying neonates and their families, NICU nurses need to overcome obstacles and implement supportive behaviors. Understanding the size of obstacles and supportive behaviors will better enable NICU nurses to provide quality EOL care.

Objectives: To determine the largest obstacles and supportive behaviors in NICU EOL care.

Methods: A descriptive quantitative study of a random national sample of 1058 NICU nurses who were members of NANN (National Association of Neonatal Nurses). The *National Survey of NICU Nurses' Perceptions of End-of-Life Care* questionnaire was mailed twice yielding 234 usable questionnaires for a response rate of 26%.

Results: Three themes emerged in the top rated obstacles: (a) obstacles related to families, (b) obstacles regarding language and communication, and (c) obstacles concerning ethical dilemmas. The lowest rated obstacles were nurses believing that life-saving measures/treatments were prematurely discontinued and unit visiting hours being too liberal. The top eight supportive behaviors included helping families cope with the infant's death and those involving helpful physician behaviors. Lowest rated supportive behaviors were those related to the nurses' own family death experience and behaviors promoting nurse convenience.

Conclusions: Obstacles and supportive behaviors for NICU EOL care have been identified. Issues regarding families, communication, and ethical dilemmas need to be addressed. Efforts should be made to more quickly align the plan of care with the projected outcome to limit both infant suffering and nurse distress from inappropriate use of life-extending measures.

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NICU Nurses' Perceptions of Obstacles and

Supportive Behaviors in End-of-Life Care

Neonatal end-of-life (EOL) care supports a peaceful, dignified death for the infant and the provision of loving support to the family.[1] Neonatal Intensive Care Unit (NICU) nurses play a vital role in the administration of EOL care. With infant mortality rates of almost 24,000 deaths per year in the United States,[2] NICU nurses often care for dying infants and their families.

Background and Significance

NICU nurses who care for dying infants and their families are faced with unique EOL care obstacles. Wright, Prasun, and Hilgenberg[3] identified major obstacles including an inability for the NICU nurse to express opinions regarding the plan of care and the lack of EOL nursing education. Martin[4] cited conflict among members of the care team along with deficits in EOL education as obstacles to appropriate transition of palliative care. Additionally, Martin[4] reported that the fear of overmedicating patients was an obstacle to adequate symptom management at the EOL. Inadequate staffing, an unconducive environment, too much technology, and unmet parental expectations have also been identified as common EOL care obstacles.[3,5] Individually or collectively, these obstacles can prevent NICU nurses from providing optimal EOL care to dying neonates.

Losing an infant is one of the most difficult challenges a parent may face. Grief can be especially intense as it is accompanied by a number of secondary losses such as the experience of raising a child and a lifetime of hopes and dreams.[6] As the leading causes of infant mortality are babies born with congenital malformations and preterm birth,[2] parental grief may also be complicated by feelings of failure and guilt.[7] Regardless of the cause, the death of an infant can

produce profound feelings of sadness and loss for the families that factor into EOL care in the NICU.

NICU nurses need to identify and then overcome obstacles that inhibit EOL care while also learning to identify and incorporate supportive behaviors into their EOL care practices. A study on EOL obstacles and supportive behaviors in the pediatric population was previously completed;[8] however, research addressing both common obstacles and supportive behaviors in the NICU is limited. The purpose of this study was to determine the size of obstacles and supportive behaviors in providing EOL care to neonates as a next step to better educating and enabling NICU nurses to provide this vital care.

Research Questions

The research questions for this study were as follows:

1. What are the sizes of listed obstacles in providing EOL care to neonates as perceived by NICU nurses?
2. What are the sizes of listed supportive behaviors in providing EOL care to neonates as perceived by NICU nurses?

Methods

Design

This was a descriptive quantitative study of a random national sample of NICU nurses who were members of the National Association of Neonatal Nurses (NANN) regarding nurses' perceptions of the size of selected obstacles and supportive behaviors in caring for dying neonates.

Sample

After institutional review board approval, a mailing list of the entire membership of NANN's association was purchased. From this list, a random, geographically dispersed sample of 1058 NANN members were chosen. Nurses who read English and who had cared for dying neonates were considered eligible. Consent to participate was assumed upon completion and return of the questionnaire.

Instrument

The *National Survey of NICU Nurses' Perceptions of End-of-Life Care* questionnaire was adapted from four similar surveys with critical care nurses,[9] emergency nurses,[10] oncology nurses,[11] and pediatric nurses.[8] Information from experts was used to further revise questionnaire items. The questionnaire was pretested by 24 NICU nurses.

Procedure

Questionnaires were mailed with a cover letter explaining the purpose of the study and included a self-addressed, stamped return envelope. One additional mailing to non-respondents was completed.

Data Analysis

SPSS 20 (SPSS® Inc., Chicago, Illinois) was used for data analysis. Frequencies, measures of central tendency, dispersion, and reliability statistics were calculated. Both obstacle and supportive behavior items were ranked from highest to lowest mean scores. Cronbach's alpha scores were calculated to determine internal consistency estimates of reliability for the size of the obstacle items and of the supportive behavior items. Cronbach's alpha for the obstacle items was .94 and for supportive behaviors was .83.

Results

Demographics

Of the 1058 questionnaires initially mailed, 15 came back undeliverable and 142 were returned with subjects stating that they were ineligible to participate, leaving the useable total mailed at 901. Of these 234 respondents completed the questionnaires for a response rate of 26%. Demographic data is presented on Table 1.

Obstacles

Thirty-three obstacles with regard to EOL care in the NICU were rated on a scale from 0 (not an obstacle) to 5 (extremely large obstacle). The overall mean scores of the obstacles ranged from a high of 3.87 to a low of 1.17 (see Table 2). In the top ten most highly rated obstacles, three themes emerged: (a) obstacles related to families, (b) obstacles regarding language and communication, and (c) obstacles concerning ethical dilemmas.

Family related obstacles. Five of the top ten obstacles related to issues with families in the NICU. The highest rated obstacle was families not being ready to acknowledge their infant had an incurable condition ($M = 3.87$, $SD = 1.02$). Similarly, parental discomfort in withdrawing ventilation ($M = 3.45$, $SD = 1.12$) had the third highest mean score. Conflict among family members was also a notable obstacle in that family members having disagreements about whether to continue or stop aggressive treatment ($M = 3.25$, $SD = 1.27$) and one parent being ready to "let go" before the other parent ($M = 3.24$, $SD = 1.11$) were rated eighth and ninth respectively. In addition, the last obstacle relating to family (ranked tenth overall) was the nurse having to deal with angry family members ($M = 3.23$, $SD = 1.11$).

Language and communication obstacles. The second highest rated obstacle was language barriers where the family speaks another language than English ($M = 3.67$, $SD = 1.24$).

Additionally, communication problems between medical staff and families also hindered appropriate care of the dying infant. For example, family members not understanding what "life-saving measures" really meant (i.e., multiple needle sticks causing pain and bruising; the infant crying during treatment) (M = 3.35, SD = 1.14) was rated fifth overall. The seventh ranked obstacle, physicians not initiating a discussion with the family on forgoing life sustaining treatments (M = 3.29, SD = 1.53), was also related to problems with communication.

Ethical dilemma obstacles. Ethical dilemmas regarding continuing aggressive treatments for dying infants were also highly rated. Instigating or continuing painful treatments or procedures with no hope of recovery (M = 3.40, SD = 1.38) was rated fourth overall. The nurse feeling that life-saving measures were morally wrong (M = 3.30, SD = 1.44) rated sixth. Congruently, the second to the lowest rated item was the nurse's belief that life-saving measures or treatment were stopped too soon (M = 1.84, SD = 1.43).

Lowest rated obstacles. The lowest rated obstacle was unit visiting hours being too liberal (M = 1.17, SD = 1.58). Similarly, family and friends continually calling the nurse wanting an update on the patient's condition rather than calling the designated family member for information (M = 2.08, SD = 1.48) was rated in the bottom five.

Supportive Behaviors

Eighteen supportive behaviors were rated on a scale from 0 (not a help) to 5 (extremely large help). The overall mean scores of the supportive behaviors ranged from a high of 4.64 to a low of 2.96 (see Table 3). The top eight most highly rated supportive behaviors included behaviors involving helping families cope with the death and those involving helpful physician behaviors.

Family supportive behaviors. Six of the top eight highest rated supportive behaviors related to caring for the family in the period of time immediately preceding, during, and directly following the death of an infant. The highest rated supportive behavior was allowing family members adequate time to be alone with the infant after death ($M = 4.64$, $SD = .66$). Second was allowing parents to hold the infant while life support was being discontinued ($M = 4.62$, $SD = .61$). Other highly rated family-centered supportive behaviors included having family members accept that the infant was dying ($M = 4.54$, $SD = .70$), having a unit designed so that the family had a place to go to grieve in private ($M = 4.50$, $SD = .88$), providing a peaceful and dignified bedside scene for family members once the infant had died ($M = 4.47$, $SD = .87$), and having a unit schedule that allows for continuity of care for the dying infant by the same nurses ($M = 4.45$, $SD = .67$).

Physician supportive behaviors. The other two highest rated supportive behaviors related to physicians. Physicians being compassionate, but very clear about prognosis ($M = 4.60$, $SD = .58$) had the third highest overall supportive behavior mean score. Having all the physicians involved in the infant's care agree about the direction the care should go ($M = 4.48$, $SD = .70$) was rated sixth.

Lowest supportive behaviors. The supportive behaviors most directly concerned with the individual nurse were ranked in the bottom five as least helpful. The lowest rated supportive behavior was the nurse having had their own previous experience with the death of a family member ($M = 2.96$, $SD = 1.35$). Having a support person outside of the work setting who would listen to the nurse after the patient's death ($M = 3.61$, $SD = 1.29$) had the second lowest mean score. Though still in the bottom five, support from coworkers was rated slightly higher than support from outside the work setting. Having a coworker tell you, "You did all you could do

for that infant," or some other words of support after the child died (M = 3.99, SD = 1.09) was ranked in the bottom five.

Discussion

This highly experienced group of NICU nurses provided a wealth of information regarding perceptions of neonatal EOL care. Family behavior emerged as the prominent theme in both obstacles and supportive behaviors sections. The grief and anger experienced by families in the event of an infant death were highly rated behaviors. Other themes included issues concerning communication, ethical dilemmas, education, and patient-centered care.

Family Grief and Anger

Bereaved parents' grief contributed to a number of the top ranked obstacles found in this study. Factors such as inadequate prenatal care and unexpected pre-term labor quickly changed the expected outcome of having a healthy infant. Without time to adjust, it may be difficult for parents to accept the reality of an incurable condition. Therefore, it was not a surprise parents experienced denial.

Denial is often the first stage of grief.[12] The denial stage may be more prominent in the NICU setting than other areas of healthcare because families in the NICU do not witness a sudden change in the function and ability of their child as a result of unexpected trauma, neither do they watch their child slowly deteriorate from an extended illness as is common in other age groups.[13] Denial in families in the NICU may contribute to other highly rated obstacles such as instigating or continuing painful treatments or procedures with no hope of recovery, family members having disagreements about whether to continue or stop aggressive treatment, and one parent being ready to "let go" before the other parent.

Anger, another phase of grief,[12] can also be an obstacle during EOL care in the NICU. Dyer[7] noted that anger was one of the common intense emotions experienced in erratic waves by parents in the NICU. Unfortunately, grieving family members' anger may be directed towards medical staff. In the case where family members were angry, Thomas[14] recommended nurses avoid defensive stances and instead respond with reassurance, taking the initiative to restore the patient-nurse relationship, and remaining alert for signs of anger escalating to violence. By employing highly ranked supportive behaviors, NICU nurses can assist families in working through grief and provide better overall EOL care.

The actual death of an infant can be especially poignant as most of the highest rated supportive behaviors in this study relate to caring for the family during EOL. The course and conditions immediately surrounding the infant's death can be significant for the family in coping with the loss as they have the rest of their lives to reflect back on the death of their child.[15]

Similar to the most supportive behaviors as ranked by Pediatric Nurses,[8] top rated behaviors identified in this study included allowing family to hold the infant while life support was being discontinued and providing a peaceful, dignified bedside scene for family members once the infant had died. To better support the families of dying neonates, NICU nurses need to be aware of best care practices and implement them at the bedside throughout the period immediately preceding, during, and directly following the death of an infant.

Communication

Obstacles relating to communication are common in neonatal EOL care literature.[3,4] In 2011, an estimated 21 percent of the population spoke a language other than English in their home with over 300 primary languages spoken across the U.S.[16] The assortment of primary languages across the U.S. contributes to impaired communication between healthcare providers

and families of infants in a NICU. Certainly language barriers exist in all aspects of healthcare; however, it can be especially challenging to navigate the delicate topic of EOL care for an infant with a family who does not speak English. In a similar study in the pediatric population, dealing with a language barrier was ranked as the greatest obstacle not only in size, but in frequency and magnitude as well.[8] These findings suggest a profound need for better means to bridge the divide between providers and families with limited English proficiency.

Even within the same language, effective communication can be a challenge at times. Ward[17] found a distinct difference between providers and families in perceptions of the quality of communication in the NICU. Providers reported feeling they thoroughly explain neonates' condition and treatment needs while parents reported a lack of appropriate communication from providers. Rosenthal and Nolan[18] agreed with Ward[17] that it is important for providers and families to maintain open lines of communication and for providers to develop a therapeutic relationship based on trust to better enable families to participate in EOL decisions in the NICU. Behaviors that promote better communication include starting patient education early, prior to the birth if possible;[19] having families present during physician rounds;[20] holding regular conferences such as palliative care conferences;[21] and repeating critical information multiple times to ensure parents have absorbed the facts and understand the implications.[22] Incorporating practices that promote good communication is essential to providing adequate EOL care in the NICU.

Effective communication between physicians and families in the NICU is especially important. Just as NICU nurses across the nation identified clear yet compassionate physician communication as a large supportive behavior, Miguel-Verges and colleagues[23] found that parents meeting with a neonatologist in the event of congenital anomaly also highly valued

caring, knowledgeable providers and consistency between providers. Parents identified physicians as one of the main sources of support and reported increased anxiety and decreased trust when providers gave conflicting information.[23] As families look to physicians for direction and support it is important physicians be readily available and provide a united and caring front.

Ethical Dilemmas

Inadequate communication can contribute to the ethical issues which are all too common in the NICU.[24] NICU nurses felt that life-extending measures were used too liberally. Nurses' distress from continuing treatment they felt was inappropriate or morally wrong was consistent with the results of other studies.[25,26] Although the literature indicated that parents should be involved in decisions made regarding EOL care in the NICU,[27] researchers have consistently found discrepancies between the ethical standpoints and priorities of families and healthcare providers.[19] Kopelman[24] points out that often a family's priority has been to keep the infant alive regardless of the circumstances, while providers believed aggressive interventions would only use medical resources to prolong suffering. While better communication is a good place to start in bridging the gap,[17] it is unclear how to best balance the emotional needs of the families with those of the providers.

Education

Deficits in EOL education have been previously cited as a major obstacle to quality EOL care in the NICU.[3,4] It is unclear why in this study education deficits were only rated as a medium sized obstacle while previous studies identify inadequate education as a large obstacle. However, recent improvements in EOL education may account for the discrepancy. Another explanation could be related to sample acquisition. This study was completed using a randomized national sample while other sources utilized convenience samples[3] or were based on

case studies.[4] Despite the moderate ranking of lack of nursing education regarding quality EOL care, education-based interventions may help to address some of the more highly ranked items such as impaired communication and inadequate parental support in the NICU.[18]

Patient-centered Care

Florence Nightingale strongly promoted patient-centered care and advocacy as a basis for nursing care.[28] Gooding and associates[29] support Nightingale's position citing many benefits to implementing family-centered care in the NICU including improved family psychological well-being, better communication, and increased parent and staff satisfaction. NICU nurses confirmed the prevalence of these core values as trends within both the obstacles and supportive behaviors indicated that, despite the sometimes taxing nature of EOL care, NICU nurses were willing to set aside personal convenience and self-centered behaviors to focus on the needs of the patient and family.

Limitations

The results of this study may not fully represent all NICU nurses. The opinions of nurses who are not members of a professional organization may differ from those in this study. In addition, our response rate was 26%, and a higher response rate could have altered the results.

Conclusion/Implications

Obstacles and supportive behaviors for NICU EOL care have been identified. Issues regarding families, communication, and ethical dilemmas need to be addressed. Efforts should be made to more quickly align the plan of care with the projected outcome to limit both infant suffering and nurse distress from inappropriate use of life-extending measures.

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Table 1

Demographics

Table 1 **Demographics of Nurses. 391 returned, 157 not eligible/not deliverable = 234 usable (26% response rate).**			
Characteristics			
Sex Male Female	 7 (3%) 234 (97%)		
	M	SD	Range
Age	48.2	11.2	24-67
Years as RN	22.9	12	1-45
Years in NICU	19.3	10.9	1-42
Hours worked/week	34	10.5	0-72
Number of beds in unit	46	24	6-120
Dying patients cared for: >30 21 – 30 11 – 20 5 – 10 <5	 26.4% 12.1% 20.3% 24.7% 16.5%		
Highest degree: Diploma Associate Bachelor, Nursing Bachelor, Other Master, Nursing Master, Other Doctoral, PhD Other	 5.2% 8.2% 39.2% 7.8% 30.3% 2.2% 3.9% 3.4%		
Ever CCRN No Yes	 72.6% 27.4%		
Years as CCRN	10.3	9.5	1-36

Currently CCRN No Yes	 77.1% 22.9%		
Position Held at Facility : Direct care/Bedside/Staff nurse Clinical Nurse Specialist Department Manager/Educator Other		 59.3% 5.6% 9.9% 25%	
Hospital type: Non-profit, Community For-profit, Community University Medical Center State Hospital County Hospital Military Hospital Other		 48.3% 12.2% 29.1% 0.9% 4.3% 0.4% 4.8%	

Table 2

Averages for Obstacle Size Reported by NICU Nurses With Regard to End-of-Life Care

Obstacle	M	SD	n[a]
1. Families not ready to acknowledge their infant has an incurable condition.	3.87	1.02	232
2. Language barriers: The family speaks a language other than English.	3.67	1.24	232
3. Parental discomfort in withdrawing ventilation.	3.45	1.12	231
4. Instigating or continuing painful treatments or procedures when there is no hope of recovery.	3.40	1.38	226
5. Family members not understanding what "life-saving measures" really mean (i.e., multiple needle sticks cause pain and bruising; the infant may cry during treatment)	3.35	1.14	228
6. The nurse feeling that the life-saving measures they are asked to perform are morally wrong because they are cruel to the infant.	3.30	1.44	232
7. Physicians not initiating a discussion with family on forgoing life sustaining treatments.	3.29	1.53	227
8. Family members having disagreements about whether to continue or stop aggressive treatment.	3.25	1.25	232
9. One parent is ready to "let go" before the other parent is ready.	3.24	1.11	231
10. The nurse having to deal with angry family members.	3.23	1.11	228
11. The nurse not knowing what to say to the grieving family.	3.13	1.17	227
12. Parental lack of trust in a medical system which has failed to heal their infant.	3.08	1.26	229

Table 2 (Continued)

Obstacle	M	SD	n[a]
13. The nurse's workload being too heavy to adequately care for the dying infant and grieving family.	2.95	1.67	227
14. Dealing with anxious family members.	2.94	1.15	231
15. Poor design of units which do not allow for either privacy of dying patients or grieving family members.	2.86	1.79	232
16. The discontinuity of care of the dying infant from lack of communication between interdisciplinary team members.	2.80	1.57	225
17. Lack of nursing education regarding quality end-of-life care.	2.79	1.38	227
18. Physicians who are overly optimistic to the family about the infant surviving.	2.763	1.44	232
19. Nurse's opinion regarding the direction of their patient's care not valued.	2.762	1.41	227
20. Dealing with the cultural differences that families employ in grieving for their dying infant.	2.75	1.23	233
21. Continuing life saving measures in an infant with poor prognosis due to real or imagined threat of future legal action by the family.	2.70	1.59	227
22. The infant having pain that is difficult to assess.	2.65	1.37	231
23. The nurse having to deal with distraught family members.	2.64	1.24	233
24. Insufficient education of physicians about pain management in palliative care.	2.56	1.47	227

Table 2 (Continued)

Obstacle	M	SD	n[a]
25. Physician not ready to make referrals to hospice because physicians are not ready to accept the infant is dying.	2.56	1.65	221
26. The lack of "standards of care" for dying infants.	2.52	1.63	231
27. The infant cannot communicate EOL care wishes.	2.24	1.89	224
28. Fear that the grieving process for the nurse will be greater if allowing themselves to become 'attached' to the infant and family.	2.16	1.27	227
29. Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information.	2.08	1.48	226
30. The nurse knowing about the infant's poor prognosis before the family knows the prognosis.	2.07	1.56	232
31. No available support person for the family such as a social worker or religious leader.	1.90	1.48	231
32. Nurses believe that life-saving measures or treatments are stopped too soon.	1.84	1.43	227
33. Unit visiting hours are too liberal.	1.17	1.58	229

[a]Reflects the number of respondents rating this item.

Table 3

Averages for Supportive Behavior Size Reported by NICU Nurses With Regard to End-of-Life Care

Help	M	SD	n[a]
1. Allowing family members adequate time to be alone with the infant after he/she dies.	4.64	.66	229
2. Allowing parents to hold the infant while life support is being discontinued.	4.62	.61	229
3. Physicians who are compassionate, but very clear about prognosis.	4.60	.58	229
4. Having family members accept that the infant is dying.	4.54	.70	229
5. A unit designed so that the family has a place to go to grieve in private.	4.50	.88	229
6. Having the physicians involved in the infant's care agree about the direction the care should go.	4.48	.70	227
7. Providing a peaceful, dignified bedside scene for family members once the infant has died.	4.47	.87	229
8. Having a unit schedule that allows for continuity of care for the dying infant by the same nurses.	4.45	.67	229
9. Having the code status of the infant clearly described in the chart.	4.42	.92	228
10. Physician meets with the family after the infant's death to offer support and validate that all possible care was given.	4.41	.71	226
11. Understanding/supporting individual family's religious beliefs.	4.35	.71	229
12. Having enough time to prepare the family for the expected death of the infant.	4.18	.83	227

Table 3 (Continued)

Help	M	SD	n[a]
13. Having a Bereavement Specialist available to obtain memorabilia for the family.	4.13	1.11	229
14. Having a coworker tell you, "You did all you could do for that infant," or some other words of support after the child has died.	3.99	1.11	229
15. Having one family member be the designated contact person for all other family members regarding patient information.	3.86	1.13	228
16. Bereavement debriefing sessions to discuss how to remember/honor the infant.	3.67	1.13	228
17. Having a support person outside of the work setting who will listen to you, the nurse, after the death of your patient.	3.61	1.29	229
18. The nurse having had their own previous experience with the death of a family member.	2.96	1.35	228

[a]Reflects the number of respondents rating this item.