

# Perceptions of Neonatal Palliative Care: Similarities and Differences between Medical and Nursing Staff in a Level IV Neonatal Intensive Care Unit

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## Abstract

**Background:** A significant number of newborns are affected by life-limiting or life-threatening conditions. Despite this prevalence, there are inconsistencies in attitudes toward, and delivery of, neonatal palliative care. Implementing neonatal palliative care practice requires a multidisciplinary, collaborative effort.

**Objective:** To examine institutional and individual barriers to and facilitators of neonatal palliative care from both medical and nursing perspectives.

**Design/Setting/Subjects:** A prospective cross-sectional study design was used to collect data using the Neonatal Palliative Care Attitude Scale (NiPCAS) survey from medical providers and nurses in a 64-bed level IV neonatal intensive care unit in the United States. The response rate was 67%.

**Measurements:** The NiPCAS survey included 26 attitudinal questions on a Likert scale. The instrument included three subscales: organization, resources, and clinician, in addition to other questions.

**Results:** Six facilitators to neonatal palliative care were identified: (1) support of palliative care by the health care team, (2) support of palliative care by medical and nursing practice, (3) agreement that palliative care is as important as curative care, (4) parental involvement in decision making, (5) recognition of the importance of palliative care education, and (6) prioritizing pain relief. Three barriers to neonatal palliative care were highlighted: (1) a physical environment that is not conducive to providing palliative care, (2) technological obligations and parental demands, and (3) the societal belief that babies should not die. In addition, there were differences between medical and nursing staffs' attitudes on several topics.

**Conclusions:** Several facilitators and barriers of neonatal palliative care were identified. There were similarities and differences in perceptions of neonatal palliative care between medical and nursing staff. Future work should be done to strengthen facilitators and to mitigate barriers.

**Keywords:** attitudes toward palliative care; barriers to palliative care; facilitators of palliative care; neonatal intensive care unit; neonatal palliative care

## Introduction

A SIGNIFICANT NUMBER of newborns are affected by life-limiting or life-threatening conditions.<sup>1</sup> More children die in the first year of life than in all other years combined and 34% of all pediatric deaths occur in the neonatal period. Many of the mortalities are due to prematurity or congenital malformations.<sup>2</sup> One study found that 18% of all infants admitted to a level III neonatal intensive care unit (NICU) over a five-year period had a life-limiting or life-threatening

condition.<sup>3</sup> Given the high incidence of serious disease, the American Academy of Pediatrics has recommended initiation of pediatric palliative care at diagnosis and integration throughout the illness course to relieve suffering, improve quality of life, and facilitate informed decision making.<sup>4</sup>

Despite these recommendations, there are inconsistencies in attitudes toward, and delivery of, neonatal palliative care.<sup>5–7</sup> Cortezzo et al. found that end-of-life practice was inconsistent between providers in the NICU.<sup>5</sup> Haug et al. found that nearly half of NICUs in the United States did not

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have neonatal palliative care guidelines.<sup>6</sup> At institutions where neonatal palliative care standards existed, Twamley et al. found that there was a discordance between perceived high palliative care knowledge, awareness, and support, and low actual utilization of palliative care services.<sup>7</sup>

To examine institutional and individual barriers to and facilitators of palliative care, Kain et al. developed the Neonatal Palliative Care Attitude Scale (NiPCAS) survey.<sup>8</sup> In that study, Kain et al. identified five facilitators to neonatal palliative care as perceived by neonatal nurses: support for a neonatal palliative model of care by the health care team; the ability to express values, opinions, and beliefs; the availability of counseling support for caregivers; the presence of clinical guidelines to support practice; and the support of parents by the health care team.<sup>8</sup> Kain et al. also identified three barriers to neonatal palliative care: inadequate staffing; a physical environment that was not conducive to palliative care practice; and technological imperatives and parental demands.<sup>8</sup> The NiPCAS survey was subsequently administered to neonatal nurses in the United States,<sup>9</sup> Taiwan,<sup>10</sup> and Iran<sup>11</sup> with similar findings to the original study.

Jones et al. conducted a survey of pediatric critical care physicians and nurses and found that physicians were less comfortable with the practical and medical aspects of palliative care, such as facilitating communication or providing maximal pain relief, than nurses; however, there was no difference between groups in comfort for the psychosocial aspects of palliative care.<sup>12</sup> Wool conducted a survey of physicians and nurses in perinatal palliative care and found that nurses expressed more obstacles at the system level, such as gaining interdisciplinary support; however, both groups reported a lack of societal support for palliative care.<sup>13</sup>

Implementing neonatal palliative care practice requires a multidisciplinary, collaborative effort. This is the first study to utilize NiPCAS to compare palliative care perceptions of both medical providers and nurses.

## Materials and Methods

A prospective cross-sectional study design was used to collect data from the NiPCAS survey. Institutional Review Board approval was not sought because the study was conducted as a quality improvement measure for neonatal palliative care delivery in our institution. Furthermore, the survey did not collect personal information from participants. Participation in the survey was voluntary and anonymous, thus completing the questionnaire-indicated consent. Potential study participants included all medical (attending physicians, neonatology fellows, nurse practitioners, and physician assistants) and nursing (registered nurses) staff working in a 64-bed level IV NICU in the United States. Two hundred nine participants were invited to complete the survey. The survey was distributed electronically; the online version of the survey was hosted and stored on Survey Monkey®. The survey was open for a one-month period in 2017.

The NiPCAS survey included 26 attitudinal questions on a Likert scale. As in the original analysis,<sup>8</sup> the response scale was coded as follows: strongly disagree = 1, somewhat disagree = 2, unsure (neutral) = 3, somewhat agree = 4, and strongly agree = 5. Eight questions were worded negatively, thus those responses were coded in reverse. This nomenclature allowed more “positive” responses to have a higher

mean score than more “negative” responses. Also as in the original instrument,<sup>8</sup> the “unsure” response was placed on the far right to dissuade participants from routinely selecting that option.

The content of the NiPCAS survey was independently evaluated by our institution’s neonatal palliative care committee, in addition to face and content validity testing previously performed by the survey’s authors.<sup>8</sup> Kain et al. had used exploratory factor analysis to identify subscales of the instrument: organization, resources, and clinician.<sup>8</sup> In that research, there were acceptable Cronbach alpha scores of 0.73, 0.65, and 0.63 respectively, which demonstrated reliability.<sup>8</sup> Because of the smaller sample size in this study, the same subscales were used as previously validated by Kain et al.

Statistical analysis was performed using SAS 9.4 software (Cary, NC). Differences in means were estimated using the Wilcoxon Rank Sum test.

## Results

Of the 209 neonatal medical and nursing staff surveyed for this study, 139 completed the questionnaire, resulting in a response rate of 67%. The majority of respondents (64%) were nurses. Nearly half of respondents had >10 years’ experience in their current role. Table 1 demonstrates the demographic characteristics of respondents.

The majority of survey respondents indicated they had experience with neonatal palliative care. In our survey population, medical staff, compared with nursing staff, reported more experience taking care of dying neonates (*p* value 0.03). Nearly all respondents (total mean score  $4.90 \pm 0.49$ ) agreed that palliative care was necessary in neonatal nursing and medical education; but less than half of all respondents had received education in the subject (total mean score  $2.85 \pm 1.40$ ). Table 2 describes responses to all questions.

### Organization subscale

The organization subscale measured the effect of the institutional setting on barriers and facilitators to providing palliative care.<sup>8</sup> There was overall agreement with items in this subscale by both medical and nursing respondents (medical mean score  $4.09 \pm 0.59$ , nursing mean score  $3.94 \pm 0.76$ , and *p* value 0.39). Individual questions in this subscale addressed parental involvement in decision making, support of palliative

TABLE 1. DEMOGRAPHIC CHARACTERISTICS (*n* = 139)

Variable	Frequency, % (n)
Current role	
Attending physician	12 (16)
Neonatology fellow	6 (9)
Nurse practitioner or physician assistant	18 (25)
Nurse	64 (89)
Years in current role	
<1 year	7 (10)
1–4 years	21 (29)
5–10 years	23 (32)
>10 years	49 (68)

TABLE 2. DISTRIBUTION OF RESPONSES AND MEAN VALUES FOR ALL QUESTIONS

<i>NiPCAS item</i>	<i>Medical (n = 50)</i>				<i>Nursing (n = 89)</i>			
	<i>Strongly/ somewhat disagree, % (n)</i>	<i>Strongly/ somewhat agree, % (n)</i>	<i>Unsure, % (n)</i>	<i>Did not answer, % (n)</i>	<i>Strongly/ somewhat disagree, % (n)</i>	<i>Strongly/ somewhat agree, % (n)</i>	<i>Unsure, % (n)</i>	<i>Did not answer, % (n)</i>
1. In my unit, when a diagnosis with a likely poor outcome is made, parents are informed of palliative care options Mean (SD)	22 (11)	70 (35)	6 (3)	2 (1)	18 (16)	63 (56)	13 (12)	6 (5)
2. The medical staff support palliative care for dying babies in my unit Mean (SD)	4 (2)	3.69 (1.04) 92 (46)	4 (2)	0 (0)	11 (10)	82 (73) 3.68 (1.11)	5 (4)	2 (2)
3. In my unit the team expresses its opinions, values, and beliefs about providing care to dying babies Mean (SD)	8 (4)	4.34 (0.89) 78 (39)	12 (6)	2 (1)	15 (13)	66 (59) 4.15 (0.99)	13 (12)	6 (5)
4. In my unit, parents are involved in decisions about their dying baby Mean (SD)	2 (1)	3.98 (0.99) 96 (48)	2 (1)	0 (0)	6 (5)	78 (69) 3.82 (1.08)	13 (12)	3 (3)
5. There is enough assistance from peers to provide the needs of dying babies requiring palliative care and their families Mean (SD)	44 (22)	4.72 (0.61) 50 (25)	6 (3)	0 (0)	14 (12)	75 (67) 4.36 (0.93)	10 (9)	1 (1)
6. All members of the health care team in my unit agree with and support palliative care when it is implemented for a dying baby Mean (SD)	24 (12)	3.12 (1.27) 60 (30)	14 (7)	2 (1)	18 (16)	63 (56) 3.99 (1.04)	12 (11)	7 (6)
7. The physical environment of my unit is ideal for providing palliative care to dying babies Mean (SD)	88 (44)	3.65 (1.15) 10 (5)	2 (1)	0 (0)	82 (73)	3.76 (1.16) 15 (13)	2 (2)	1 (1)
8. There are policies/guidelines to assist in the delivery of palliative care in my unit Mean (SD)	48 (24)	1.70 (0.93) 28 (14)	24 (12)	0 (0)	12 (11)	56 (50) 1.93 (1.07)	26 (23)	6 (5)
9. When a baby dies in my unit, counseling is available if I need it Mean (SD)	22 (11)	2.76 (1.15) 48 (24)	28 (14)	2 (1)	18 (16)	3.73 (1.03) 61 (54)	12 (11)	9 (8)
		3.31 (1.06)				3.78 (1.19)		

(continued)

TABLE 2. (CONTINUED)

<i>NiPCAS item</i>	<i>Medical (n = 50)</i>				<i>Nursing (n = 89)</i>			
	<i>Strongly/ somewhat disagree, % (n)</i>	<i>Strongly/ somewhat agree, % (n)</i>	<i>Unsure, % (n)</i>	<i>Did not answer, % (n)</i>	<i>Strongly/ somewhat disagree, % (n)</i>	<i>Strongly/ somewhat agree, % (n)</i>	<i>Unsure, % (n)</i>	<i>Did not answer, % (n)</i>
10. When a baby dies in my unit, I have sufficient time to spend with the family Mean (SD)	46 (23)	44 (22)	10 (5)	0 (0)	10 (9)	55 (49)	29 (26)	6 (5)
11. I have had the experience of providing palliative care to dying babies and their families Mean (SD)	4 (2)	92 (46)	4 (2)	0 (0)	22 (20)	70 (62)	6 (5)	2 (2)
12. My previous experiences of providing palliative care to dying babies have been rewarding Mean (SD)	8 (4)	72 (36)	20 (10)	0 (0)	4.5 (4)	61 (54)	30 (27)	4.5 (4)
13. I am often exposed to death in the neonatal environment Mean (SD)	10 (5)	88 (44)	2 (1)	0 (0)	31 (28)	54 (48)	10 (9)	5 (4)
14. I have received in-service education that assists me to support and communicate with parents of dying babies Mean (SD)	64 (32)	28 (14)	6 (3)	2 (1)	41 (37)	46 (41)	7 (6)	6 (5)
15. Palliative care is against the values of neonatal nursing and neonatology practice <sup>a</sup> Mean (SD)	98 (49)	0 (0)	0 (0)	2 (1)	90 (80)	1 (1)	1 (1)	8 (7)
16. My personal attitudes about death affects my willingness to deliver palliative care <sup>a</sup> Mean (SD)	72 (36)	22 (11)	4 (2)	2 (1)	67 (60)	15 (13)	10 (9)	8 (7)
17. I feel a sense of personal failure when a baby dies <sup>a</sup> Mean (SD)	44 (22)	40 (20)	16 (8)	0 (0)	53 (47)	24 (21)	21 (19)	2 (2)
18. Curative care is more important than palliative care in the neonatal unit <sup>a</sup> Mean (SD)	64 (32)	26 (13)	8 (4)	2 (1)	68 (61)	18 (16)	6 (5)	8 (7)
19. In my unit, the staff go beyond what they feel comfortable with in using technological life support <sup>a</sup> Mean (SD)	28 (14)	50 (25)	24 (12)	2 (1)	7 (6)	65 (58)	21 (19)	7 (6)
		2.73 (1.25)				2.13 (0.91)		

(continued)

TABLE 2. (CONTINUED)

<i>NiPCAS item</i>	<i>Medical (n = 50)</i>				<i>Nursing (n = 89)</i>				<i>p</i>
	<i>Strongly/</i> <i>somewhat</i> <i>disagree, % (n)</i>	<i>Strongly/</i> <i>somewhat</i> <i>agree, % (n)</i>	<i>Unsure,</i> <i>% (n)</i>	<i>Did not</i> <i>answer,</i> <i>% (n)</i>	<i>Strongly/</i> <i>somewhat</i> <i>disagree, % (n)</i>	<i>Strongly/</i> <i>somewhat</i> <i>agree, % (n)</i>	<i>Unsure,</i> <i>% (n)</i>	<i>Did not</i> <i>answer,</i> <i>% (n)</i>	
20. In my unit, staff are asked by parents to continue life-extending care beyond what they feel is right <sup>a</sup> Mean (SD)	10 (5)	74 (37)	14 (7)	2 (1)	12 (11)	61 (54)	21 (19)	6 (50)	
21. Palliative care is necessary in neonatal nursing and medical education Mean (SD)	0 (0)	100 (50)	0 (0)	0 (0)	2 (2)	92 (82)	1 (1)	5 (4)	0.8
22. When babies are dying in my unit, providing pain relief is a priority for me Mean (SD)	0 (0)	4.98 (0.14)	0 (0)	0 (0)	0 (0)	4.86 (0.60)	4.5 (4)	4.5 (4)	0.2
23. Palliative care is as important as curative care in the neonatal environment Mean (SD)	8 (4)	4.94 (0.24)	0 (0)	0 (0)	0 (0)	4.79 (0.51)	1 (1)	1 (1)	0.07
24. There is support for neonatal palliative care in society Mean (SD)	16 (8)	4.54 (1.05)	14 (7)	0 (0)	28 (25)	4.94 (0.28)	18 (16)	1 (1)	<0.001*
25. Caring for dying babies is traumatic for me <sup>a</sup> Mean (SD)	56 (28)	3.66 (0.96)	8 (4)	2 (1)	33 (30)	3.45 (1.17)	16 (14)	7 (6)	0.36
26. There is a belief in society that babies should not die, under any circumstances <sup>a</sup> Mean (SD)	42 (21)	3.33 (1.28)	6 (3)	2 (1)	36 (32)	2.90 (1.32)	11 (10)	8 (7)	0.08
		2.96 (1.26)				2.88 (1.30)			0.72

\**p* value <0.05.<sup>a</sup>Responses were coded in reverse.

NiPCAS, Neonatal Palliative Care Attitude Scale; SD, standard deviation.

TABLE 3. ORGANIZATION SUBSCALE COMPARISON

<i>NiPCAS item</i>	<i>Medical mean score (SD)</i>	<i>Nursing mean score (SD)</i>	<i>All respondents mean score (SD)</i>	<i>p</i>
In my unit, when a diagnosis with a likely poor outcome is made, parents are informed of palliative care options	3.69 (1.04)	3.68 (1.11)	3.68 (1.08)	0.99
The medical staff support palliative care for dying babies in my unit	4.34 (0.89)	4.15 (0.99)	4.22 (0.96)	0.3
In my unit the team expresses its opinions, values, and beliefs about providing care to dying babies	3.98 (0.99)	3.82 (1.08)	3.88 (1.04)	0.45
In my unit, parents are involved in decisions about their dying baby	4.72 (0.61)	4.36 (0.93)	4.49 (0.84)	0.026*
All members of the health care team in my unit agree with and support palliative care when it is implemented for a dying baby	3.65 (1.15)	3.76 (1.16)	3.72 (1.15)	0.57
Average organization subscale	4.09 (0.59)	3.94 (0.76)	3.99 (0.70)	0.39

\**p* value <0.05.

care by staff, and ability of team members to express opinions. Refer to Table 3 for more information.

### Resources subscale

The resources subscale included a variety of resource-related issues.<sup>8</sup> The items in this subscale addressed staffing, the physical environment of the unit, policies and guidelines, availability of counseling, and accommodating the time to spend with families. The mean scores in this subscale were lower than the previous subscale, indicating disagreement with this theme. The mean score for all questions in this subscale was lower in the medical group than the nursing group (medical mean score  $2.77 \pm 0.80$ , nursing mean score  $3.39 \pm 0.67$ , and *p* value <0.001), indicating more disagreement from medical than nursing respondents. Refer to Table 4 for more information.

### Clinician subscale

The clinician subscale measured moral-related issues, including parental demands and technological imperatives.<sup>8</sup> The majority of all respondents agreed that staff are asked by parents to continue life-extending care beyond what they feel is right and that staff go beyond what they feel comfortable

with in using technological life support (total mean score  $2.25 \pm 0.92$ ). Refer to Table 5 for more information.

### Discussion

#### Facilitators to neonatal palliative care

The findings from this research highlight six facilitators to neonatal palliative care: (1) support of palliative care by the health care team, (2) support of palliative care by medical and nursing practice, (3) agreement that palliative care is as important as curative care, (4) parental involvement in decision making, (5) recognition of the importance of palliative care education, and (6) prioritizing pain relief. Facilitators were designated as those survey elements that had an overwhelmingly positive responses by participants (mean score  $\geq 4$ ).

There was a strong level of agreement among both medical and nursing respondents that the health care team supports neonatal palliative care (total mean score  $4.22 \pm 0.96$ ) and that palliative care is supported by medical and nursing practice (total mean score  $4.89 \pm 0.46$ ).

While both groups agreed that palliative care is as important as curative care, nurses' level of agreement (mean score  $4.94 \pm 0.28$ ) was significantly higher than medical staffs' level of agreement (mean score  $4.54 \pm 1.05$ ) (*p* value

TABLE 4. RESOURCES SUBSCALE COMPARISON

<i>NiPCAS item</i>	<i>Medical mean score (SD)</i>	<i>Nursing mean score (SD)</i>	<i>All respondents mean score (SD)</i>	<i>p</i>
There is enough assistance from peers to provide the needs of dying babies requiring palliative care and their families	3.12 (1.27)	3.99 (1.04)	3.67 (1.20)	<0.001*
The physical environment of my unit is ideal for providing palliative care to dying babies	1.70 (0.93)	1.93 (1.07)	1.85 (1.02)	0.19
There are policies/guidelines to assist in the delivery of palliative care in my unit	2.76 (1.15)	3.73 (1.03)	3.37 (1.17)	<0.001*
When a baby dies in my unit, counseling is available if I need it	3.31 (1.06)	3.78 (1.19)	3.60 (1.17)	0.012*
When a baby dies in my unit, I have sufficient time to spend with the family	2.98 (1.33)	3.73 (1.03)	3.45 (1.21)	0.002*
Average resources subscale	2.77 (0.80)	3.39 (0.67)	3.16 (0.77)	<0.001*

\**p* value <0.05.

TABLE 5. CLINICIAN SUBSCALE COMPARISON

<i>NiPCAS item</i>	<i>Medical mean score (SD)</i>	<i>Nursing mean score (SD)</i>	<i>All respondents mean score (SD)</i>	<i>p</i>
In my unit, the staff go beyond what they feel comfortable with in using technological life support <sup>a</sup>	2.73 (1.25)	2.13 (0.91)	2.36 (1.09)	0.007*
In my unit, staff are asked by parents to continue life-extending care beyond what they feel is right <sup>a</sup>	2.10 (0.96)	2.17 (1.06)	2.14 (1.02)	0.8
Average clinician subscale	2.42 (0.99)	2.15 (0.87)	2.25 (0.92)	0.13

\**p* value <0.05.

<sup>a</sup>Responses were coded in reverse.

<0.001). It has been postulated that neonatologists have a “rescue culture” due to decades of progress in the subspecialty and improving outcomes for infants with life-threatening conditions,<sup>14</sup> and thus, may be more inclined to pursue curative care over palliative care.

While both medical and nursing staff strongly agreed that parents are involved in decision making, medical staff's level of agreement (mean score  $4.72 \pm 0.61$ ) was significantly higher than nursing staff's (mean score  $4.36 \pm 0.93$ ) (*p* value 0.026). In a prior study, Wool had found that physicians felt more confident in their ability to counsel patients than nurses,<sup>13</sup> perhaps leading to the medical staff having an increased perception of parental involvement.

Both groups strongly agreed about the necessity of neonatal palliative care education (total mean score  $4.90 \pm 0.49$ ). The importance of palliative care education to providers has been previously examined in several studies.<sup>15,16</sup> In a study of pediatric residents receiving palliative care education, Fischer et al. found that anxiety levels were high in participants whose knowledge about palliative care was low.<sup>17</sup> However, there was a statistically significant difference in responses regarding palliative care education. More nursing staff (mean score  $3.11 \pm 1.41$ ) reported receiving education on the subject than medical staff (mean score  $2.41 \pm 1.29$ ) (*p* value 0.005).

Finally, both medical and nursing respondents strongly agreed that pain relief is a priority for dying neonates (total mean score  $4.84 \pm 0.44$ ). Pain management is a key aspect in providing comfort.<sup>1,18</sup> Among national institutions with neonatal palliative care guidelines, the vast majority (81%) address pain management in their policies.<sup>6</sup>

### Barriers to neonatal palliative care

The findings from this research highlight three barriers to neonatal palliative care: (1) a physical environment that is not conducive to providing palliative care, (2) technological obligations and parental demands, and (3) the societal belief that babies should not die. Barriers were designated as those survey elements that had an overwhelmingly negative response by participants (mean score <3).

Both medical and nursing staff agreed that the physical environment of the NICU was not ideal for providing palliative care (total mean score  $1.85 \pm 1.02$ ). At the time of the survey administration, the NICU layout at the primary study institution was an open-bay format, which was later updated to a single-family room design. Previous research showed multiple medical benefits to a single-family room compared with open-bay layout,<sup>19</sup> and it is likely that improved utilization of palliative care would be another benefit.

Both groups agreed that parents ask to continue life-extending care beyond what staff feel is right (total mean score  $2.14 \pm 1.02$ ) and that staff go beyond what they feel comfortable with in using technological life support (total mean score  $2.36 \pm 1.09$ ).

Medical and nursing staff agreed that there is a societal belief that infants should not die (total mean score  $2.91 \pm 1.28$ ). This is in accordance with prior literature, where physicians and nurses reported a lack of societal support for neonatal palliative care.<sup>13</sup>

### Differences between medical and nursing staffs' attitudes

Medical staff had statistically significant more negative perceptions regarding multiple resource-related items: assistance from peers (*p* value <0.001), availability of counseling (*p* value 0.012), and ability to spend time with families of dying neonates (*p* value 0.002). In a survey of neonatal clinicians, Peng et al. found that participants reported greater levels of confidence in a more supportive workplace.<sup>20</sup> It is recommended that staff who provide palliative care should receive psychosocial support<sup>21</sup>; however, Haug et al. found that 39% of NICUs did not address physician compassion fatigue or burnout secondary to palliative care.<sup>6</sup>

In addition, medical staff disagreed about the presence of neonatal palliative care policies or guidelines, while nurses responded positively (*p* value <0.001). At the time of survey administration, there were no neonatal palliative care guidelines in place at the study site. Upon discussion with nursing staff after the survey was closed, it was revealed that nurses considered previously established hospital bereavement care guidelines to fall within the domain of palliative care. Recommendations for implementation of palliative care stress that guidelines should be in place and accessible to all staff.<sup>21,22</sup>

### Conclusion

Several facilitators and barriers of neonatal palliative care were identified. There were similarities and differences in perceptions of neonatal palliative care between medical and nursing staff. More work should be done to strengthen facilitators. Palliative care education was a strong theme in this survey; education of staff could reinforce support of palliative care. It is also important to mitigate barriers: working to identify goals of care with families could decrease tension between staff and parents.

A strength of this study is that it is the first to utilize a validated survey to compare perceptions about neonatal palliative care between medical and nursing staff. Limitations of

this study are the small sample size and limitation to a single center. Additionally, the response rate was about two-thirds of participants. Perhaps if the survey period was longer than one month, the response rate would increase. Recommendations for future research would be to compare medical and nursing staff's perceptions about neonatal palliative care from multiple institutions. Another next step could be to conduct qualitative interviews with participants to identify and further explore other themes. Finally, because neonatal palliative care education was such a prevalent theme, future research could study the effects of a neonatal palliative care educational intervention.

### Author Disclosure Statement

No competing financial interests exist.

### References

1. Parravicini E: Neonatal palliative care. *Curr Opin Pediatr* 2017;29:135–140.
2. Institute of Medicine: Summary. In: Field MJ, Behrman RE (eds): *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. Washington, D.C: National Academy Press, 2003.
3. Garten L, Ohlig S, Metze B, Bühner C: Prevalence and characteristics of neonatal comfort care patients: A single-center, 5-year, retrospective, observational study. *Front Pediatr* 2018;6:221.
4. American Academy of Pediatrics: Pediatric palliative care and hospice care commitments, guidelines, and recommendations. *Pediatrics* 2013;132:966–972.
5. Cortezzo DE, Sanders MR, Brownell EA, Moss K: End-of-life care in the neonatal intensive care unit: Experiences of staff and parents. *Am J Perinatol* 2015;32:713–724.
6. Haug S, Farooqi S, Wilson CG, et al.: Survey on neonatal end-of-life comfort care guidelines across america. *J Pain Symptom Manage* 2018;55:984.e2.
7. Twamley K, Craig F, Kelly P, et al.: Underlying barriers to referral to paediatric palliative care services. *J Child Health Care* 2014;18:19–30.
8. Kain V, Gardner G, Yates P: Neonatal palliative care attitude scale: Development of an instrument to measure the barriers to and facilitators of palliative care in neonatal nursing. *Pediatrics* 2009;123:e213.
9. Wright V, Prasun MA, Hilgenberg C: Why is end-of-life care delivery sporadic?: A quantitative look at the barriers to and facilitators of providing end-of-life care in the neonatal intensive care unit. *Adv Neonatal Care* 2011;11:29–36.
10. Chen C, Huang L, Liu H, et al.: To explore the neonatal nurses' beliefs and attitudes towards caring for dying neonates in Taiwan. *Matern Child Health J* 2013;17:1793–1801.
11. Azzizadeh Forouzi M, Banazadeh M, Ahmadi JS, Razban F: Barriers of palliative care in neonatal intensive care units: Attitude of neonatal nurses in Southeast Iran. *Am J Hosp Palliat Med* 2017;34:205–211.
12. Jones BL, Sampson M, Greathouse J, et al.: Comfort and confidence levels of health care professionals providing pediatric palliative care in the intensive care unit. *J Soc Work End Life Palliat Care* 2007;3:39–58.
13. Wool C: Clinician perspectives of barriers in perinatal palliative care. *MCN Am J Matern Child Nurs* 2015;40:44–50.
14. Marc-Aurele, KL, English, NK: Primary palliative care in neonatal intensive care. *Semin Perinatol* 2016;41:133–139.
15. Michelson KN, Ryan AD, Jovanovic B, Frader J: Pediatric residents' and fellows' perspectives on palliative care education. *J Palliat Med* 2009;12:451–457.
16. Kilcullen M, Ireland S: Palliative care in the neonatal unit: Neonatal nursing staff perceptions of facilitators and barriers in a regional tertiary nursery. *BMC Palliat Care* 2017;16:32.
17. Fischer SM, Gozansky WS, Kutner JS, et al.: Palliative care education: An intervention to improve medical residents' knowledge and attitudes. *J Palliat Med* 2003;6:391–399.
18. Carter BS, Jones PM: Evidence-based comfort care for neonates towards the end of life. *Semin Fetal Neonatal Med* 2013;18:88–92.
19. Lester BM, Hawes K, Abar B, et al.: Single-family room care and neurobehavioral and medical outcomes in preterm infants. *Pediatrics* 2014;134:754–760.
20. Peng N, Liu H, Wang T, et al.: Evaluation of comfort and confidence of neonatal clinicians in providing palliative care. *J Palliat Med* 2018;21:1558–1565.
21. Kenner C, Press J, Ryan D: Recommendations for palliative and bereavement care in the NICU: A family-centered integrative approach. *J Perinatol* 2015;35(S1):S23.
22. Quinn M, Gephart S: Evidence for implementation strategies to provide palliative care in the neonatal intensive care unit. *Adv Neonatal Care* 2016;16:430–438.

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