ARTICLE

Construction of a Parent-Derived Questionnaire to Measure End-of-Life Care After Withdrawal of Life-Sustaining Treatment in the Neonatal Intensive Care Unit

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What's Known on This Subject

Previous work has described parent, patient, and family experiences in end-of-life and WLST in the adult ICU, PICU, and NICU; however, no tool exists to measure how consistently effective end-of-life care practices are carried out.

What This Study Adds

We developed a survey tool based on the experiences of bereaved parents and used this tool to measure the frequency of favorable and unfavorable practices seen during WLST in North American NICUs.

ABSTRACT

OBJECTIVES. The objective of this study was to develop and pretest a questionnaire to assess the practice of withdrawal of life-sustaining treatment in the NICU on the basis of the experiences of bereaved parents.

METHODS. We conducted semistructured interviews with 11 parents whose infants had undergone withdrawal of life-sustaining treatment in the NICU at McMaster University Medical Centre to obtain their views on helpful practices. Interviews continued until no new items were obtained (ie, saturation point). A total of 370 items were distilled into 82 questionnaire statements on care by a multidisciplinary team and grouped for analysis into 6 domains: communication, quality of care, quality of life, shared decision-making, withdrawal of life-sustaining treatment process, and bereavement care. Respondents were asked to rank how frequently events occurred on a 7-point Likert scale anchored from 1 = never to 7 = always. A score of >5 was considered favorable. The questionnaire was distributed to a pretest sample of perinatal social workers who attended a bereavement workshop at an international conference.

RESULTS. The response rate was 48%. Respondents ranked items that pertained to the withdrawal of life-sustaining treatment process highest, indicating that items were done well. Items related to quality of care and bereavement care ranked lowest. Other domains ranked as follows: communication, shared decision-making, and quality of life. Consistency of items within domains was tested by Cronbach's α and split-half testing and were >0.6 for most domains.

CONCLUSIONS. Parents' views on important aspects of end-of-life care in the NICU were incorporated into a quality assurance questionnaire. Pretesting assessed the performance of the instrument and the perceptions of social workers on the effectiveness of end-of-life practices. Respondents identified that parents' practical needs were met during the withdrawal process but were not consistently met in regard to the quality of in-hospital and follow-up bereavement care. *Pediatrics* 2009;123:e87–e95

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Key Words
measuring quality of care, ethics, bereavement, palliative care, neonatal death, parental attitudes

Abbreviation
WLST—withdrawal of life-sustaining treatment

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DURING THE PAST 2 decades, admissions of immature and critically ill infants to the NICU have increased.[1,2] Correspondingly, medical and nursing teams recommend withdrawal of life-sustaining treatment (WLST) more frequently.[3] Between 40% and 93% of deaths in the NICU follow WLST,[4–8] varying by region and physician attitudes.[9–14] During WLST, parents balance the infant's well-being with their own emotions, ranging from attachment and separation to guilt, anger, and grief. These emotions are fueled by the challenges of accurately defining and predicting the future "quality-of-life" of the neonate. Additional evaluation of how "well" the complex practice of WLST is conducted from initial discussions to postbereavement care is needed; however, this is hampered by the lack of a robust instrument to evaluate good practice (from the parental perspective) during end-of-life care.

Our aim was to measure how consistently current practices of WLST in the NICU reflect what parents consider to be important; therefore, we developed a questionnaire that was based on the perceptions of parents whose infants had undergone WLST in the NICU. We then pretested the questionnaire on a group of American and Canadian perinatal registered social workers. We chose this profession as a pretest group because they function independent of nursing and medical staff but are also involved in counseling families around WLST in North America. They closely observe the nuances of communication between the medical staff and parents. Moreover, they are involved in follow-up with bereaved families and were mentioned by parents in the phase 1 interviews as a strong source of support. The questionnaire was therefore pretested with social workers, who were asked how often both favorable and unfavorable practices regarding WLST were seen in their units. This assessed the functioning of the questionnaire before widespread testing among parents, which helped to eliminate ethical concerns on approaching bereaved parents with an untested or inadequate instrument.

METHODS

Parent Interviews

Seventy-nine eligible parents of infants who had undergone WLST from 2003 to 2005 at the NICU of McMaster University Medical Centre (Hamilton, Ontario, Canada) were identified from a bereavement list and invited via mail to take part in the study. Of these, 13 letters were stamped "returned to sender," resulting in a pool of 66 potential interviewees. Consenting parents could choose to be interviewed at the hospital or a separate location. Hospital ethics board approval was obtained for the study.

Eleven parents (response rate: 17%) took part in interviews. They were predominantly English speaking, Christian, married, and nonimmigrant. Completed education level varied from high school to university, as did size of household and presence of other children. Their infants were representative of the most common diagnoses that contribute to North American perinatal mortality: congenital malformations, genetic syndromes, and prematurity. Infants died after noninitiation of life-sustaining treatment or WLST at ages 1 day to 2 months of life. There was 1 set of twins, and 1 family had a history of 2 neonatal deaths. Because of Canadian privacy legislation[15] and the sensitive nature of the subject, we collected no data on nonresponders.

The interprofessional research team (2 physicians, 1 neonatal nurse, 3 neonatal social workers, 1 anthropologist, and 2 parent advocates) developed an interview guide after an extensive literature search. In addition, interviews were conducted with 40 interprofessional neonatal health care workers, whose experiences and suggestions were used to refine the guide. The interview guide was pilot tested with informed parents ($n = 2$) before administration (see Appendix 1: Parent Interview Guide). Individual, open-ended interviews were then conducted with 11 parents of 8 infants. They were asked to describe the events in hospital that occurred at the time of their infant's death surrounding decision-making, WLST, and follow-up care.

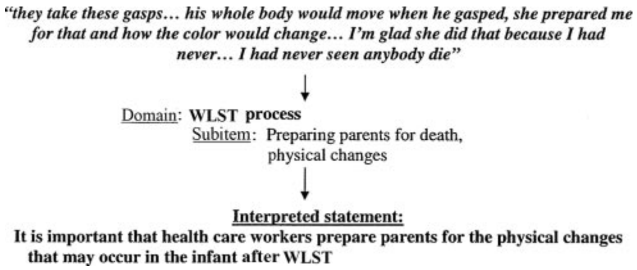

FIGURE 1
Derivation of statements and domains by the multidisciplinary team who performed the analysis of parent interviews.

Following standard practice in qualitative research, data collection continued until "saturation" was reached, or, in other words, when no new items of importance that had not previously been articulated were voiced by bereaved parents.[16,17] This point was identified by group discussion. Interviews lasted between 1 and 3 hours each. They were tape-recorded and transcribed, and all names and descriptors were removed. A full print copy was independently analyzed by 7 members of the research team on the basis of the editing style of Miller and Crabtree.[18] This allows analysts to organize data into unique domains and subdomains and is not guided by a fixed codebook. After extensive discussion, consensus was reached on which items to retain such that each relevant statement was coded as a unique item and subsequently organized into 1 of 6 domains.[19,20] Figure 1 illustrates an example of the group iterative process involved.

The team identified 370 statements and reduced these to 139 unique items, reflective of issues of importance to parents. Items that were specifically related to the experience of WLST (82 [59%] of 139) were retained by the team. Retained items were grouped into 6 distinct domains: communication ($n = 12$ items); quality of care ($n = 14$ items); quality of life ($n = 3$ items); shared decision making, or the extent to which parents felt able to participate in decisions around WLST ($n = 8$ items); the WLST process ($n = 18$ items); and bereavement care ($n = 27$ items).

To illustrate the domain contents, the following parent statements are organized into domains:

1. Communication: encourage parents to ask questions; allow parents time to digest the details of diagnosis and prognosis; adequately explain the likely outcomes in words that parents understand
2. Quality of care: support parents through their anger, fear, and guilt; be respectful; avoid intimidating parents with medical knowledge; use the child's first name; maintain consistency of care
3. Quality of life: explain the child's future ability to interact, see, and hear; balance pain and suffering in

life with long-term outcomes; respect parents' view about their child's quality of life

4. Shared decision-making: support parents whatever their decision; respect when parents do not want to make a decision; make parents feel that the right decision has been made
5. WLST process: treat the child with dignity; encourage parents to hold the child; acknowledge that timing of death may be uncertain; prepare parents for the physical changes that occur with death; ensure that the child does not suffer; provide keepsakes (foot/hand prints, memory boxes); respect parents' religious beliefs at the time of death and during discussion of autopsy
6. Bereavement care: provide appropriate medical and psychosocial follow-up, including counseling about marital stress and sibling grief; ensure that autopsy results are reviewed in a timely manner; attend the child's funeral when appropriate; provide a grief package with information regarding funeral arrangements, emergency contact numbers, and group supports

A full list of the statements incorporated into the questionnaire, organized by domain, is provided in Appendix 2.

Construction and Assessment of the Survey Instrument

The questionnaire was evaluated in the interprofessional team for wording and comprehension. It was then pretested in a convenience sample of ~100 perinatal registered social workers from the United States and Canada.

For pretesting, each of the 82 statements was incorporated into a survey question by using a stem prefix: "How often does the following occur at your center?" The statements were distributed in random order to break up the domains. Statements were phrased in both negative and positive scaling. Each question required a response on a 7-point Likert scale anchored at the following points: 1 = never, 4 = unsure, and 7 = always. This questionnaire aimed to assess the frequency with which respondents observed both favorable and unfavorable practices in their units. In addition, 6 questions were added to capture the background and experience of the respondents.

Analysis

Responses were analyzed by using frequency distribution and median and range. Means with SDs were calculated for the total domain scores. We considered rankings >5 to be done frequently enough as to indicate favorable practices. We also examined the most effective or most favorable practices by using a cutoff point of 6. Regression analysis was used to identify whether the size of unit or the number of years of experience of the respondent was related to their unit ratings for each of the 6 domains. We calculated pairwise correlations between domains as well as Cronbach's α and split-half analysis within domains to assess the internal consistency of the questionnaire. We considered values of >0.6 as having acceptable correlation and >0.75 as highly correlated.

TABLE 1 **Demographic Characteristics of Social Worker Sample Respondents**

Characteristics	*n*	%
Years of work experience		
<1	0	0
1–5	6	12
6–10	12	25
11–20	17	35
>20	13	27
Settings of practice[a]		
Obstetric/perinatal	11	23
Level 2 nursery	13	27
Level 3 nursery	43	90
No. of NICU beds in their center[b]		
<10	0	0
10–20	5	10
21–30	6	12
31–40	10	21
>40	25	52
Location of practice		
United States	44	92
Canada	4	8
Directly involved with families undergoing WLST	43	90

[a] Social workers' settings of practice often overlapped across obstetric/perinatal care and both secondary and tertiary NICU coverage.

[b] Including levels 2 and 3 neonatal beds.

RESULTS

The questionnaire was completed by 48 North American perinatal social workers (response rate: 48%) who were attending a workshop entitled "With Care: Developing an Instrument to Teach Withdrawal of Life-Sustaining Treatment in the NICU Based on Parental Perceptions" during the National Association of Perinatal Social Workers Conference in Las Vegas, April 2006. Table 1 describes the respondents. Forty-three (90%) stated direct involvement with WLST at their institutions. Although the level of experience of the sample varied, 62% had >10 years of experience, and most (73%) worked in large units (>30 neonatal beds).

The calculated per-item means with SDs and medians with range for each domain are expressed in Table 2. Items pertaining to the WLST process ranked highest (mean: 5.93 [SD: 0.59]), and those related to domains of quality of care (mean: 4.92 [SD: 0.53]) and bereavement care (mean: 5.07 [SD: 0.56]) ranked lowest. We exam-

TABLE 2 **Item Scores Analyzed According to Domain**

Domain	No. of Items	Mean (SD)[a]	Median (Range)[a]	Statements With Median ≥ 6, *n* (%)
WLST process	18	5.9 (0.6)	6.2 (5.5–6.3)	16 (89)
Shared decision-making	8	5.4 (0.5)	5.4 (5.0–6.0)	4 (50)
Communication	12	5.4 (0.7)	5.5 (4.9–5.9)	5 (42)
Quality of life	3	5.3 (0.8)	5.3 (4.7–5.9)	1 (33)
Bereavement care	27	5.1 (0.6)	5.1 (4.7–5.5)	9 (33)
Quality of care	14	4.9 (0.5)	5.0 (4.5–5.3)	4 (22)

[a] Per-item score (out of 7 on Likert scale), reported by domain.

TABLE 3 **Ways in Which HCWs Most and Least Effectively Support Parents Facing WLST in the NICU**

Statement (Domain)	Median (Range)
Most effective	
HCWs officially recognize the child's existence (BC)	7.0 (5.0–7.0)
HCWs provide parents with a grief package (BC)	7.0 (4.0–7.0)
Parents are given specific keepsakes (eg, photo) (WP)	7.0 (4.0–7.0)
HCWs encourage parents to hold their child when he or she dies (WP)	7.0 (4.0–7.0)
The child is treated with dignity during WLST (WP)	7.0 (4.0–7.0)
WLST is done with compassion (WP)	7.0 (4.0–7.0)
Parents have adequate time with their child before WLST (WP)	6.5 (4.0–7.0)
Parents are encouraged to ask questions (C)	6.5 (5.0–7.0)
Least effective	
Government agencies are made aware of the child's death to ensure that inappropriate reminders do not occur (eg, follow-up vaccinations) (BC)	4.0 (1.0–7.0)
HCWs provide specific counseling in dealing with sibling grief (BC)	4.0 (2.0–7.0)
Autopsy results are sent to both parents and their family physician (BC)	4.0 (1.0–7.0)
Parents are offered a prompt discussion regarding autopsy results (BC)	4.0 (2.0–7.0)
HCWs respect when parents do not want to make a decision (SDM)	4.5 (1.0–6.0)

Most effectively: median score ≥6.5 of 7; least effectively: median ≤4.5 of 7. HCW indicates health care worker; BC, bereavement care, WP, WLST process; C, communication; SDM, shared decision-making.

ined the practices that were ranked favorably and most favorably by selecting median cutoff scores of ≥5 and ≥6, respectively, on the Likert scale. The former analysis resulted in 71 (87%) of 82 items, and the latter resulted in 39 (48%) of 82 items. Table 2 highlights the number and percentage of items within each domain with median ≥6. Eighty-nine percent of items related to the WLST process were ranked most favorably, whereas ≤33% of the items in quality of life, bereavement care, and quality of care received this rank. Table 3 lists the items that were ranked most and least favorably by respondents.

Table 4 describes the mean item scores by domain and according to 2 respondent characteristics: the size of NICU and the experience of the respondents. These 2 variables were not significant determinants of any of the 6 domain scores in either univariable or multivariable linear regressions. The other characteristics, such as settings of practice, had too much overlap among respondents to use in the analysis. In addition, the location of practice, America versus Canada, was too unequally distributed (4 Canadians vs 44 Americans) for meaningful statistical analysis.

TABLE 4 **Mean (SD) Scores Per Item Reported According to Domain and Respondent Characteristics**

Domain	Size of NICU		Experience of Respondents	
	≤30 Beds	>30 Beds	<10 y	≥10 y
WLST process	5.9 (0.5)	6.0 (0.6)	5.9 (0.5)	6.0 (0.6)
Shared decision-making	5.3 (0.5)	5.5 (0.6)	5.3 (0.5)	5.5 (0.6)
Communication	5.1 (0.7)	5.4 (0.6)	5.2 (0.7)	5.5 (0.6)
Quality of life	5.2 (1.0)	5.3 (0.7)	5.4 (0.8)	5.3 (0.8)
Bereavement care	5.1 (0.4)	5.1 (0.6)	5.0 (0.6)	5.1 (0.5)
Quality of care	4.8 (0.4)	4.9 (0.5)	4.8 (0.6)	5.0 (0.5)

Mean calculated score of 7 on a Likert scale. Linear regression found these 2 variables not significant determinants of any of the 6 domain scores in either univariable or multivariable regressions.

TABLE 5 **Intradomain Correlations**

Parent-Derived Domain	No. of Items	Cronbach's α	Split-half Analyses[a]
WLST process	18	.885	.885
Communication	12	.847	.863
Bereavement care	27	.831	.781
Quality of care	14	.758	.809
Shared decision-making	8	.678	.670
Quality of life	3	.435	.597

[a] Guttman split-half coefficient.

Performance Characteristics of the Questionnaire

Table 5 describes intradomain item consistency by using Cronbach's α and split-half analyses. With the exception of the 3 items under the domain quality of life, the correlation of items within domains was >0.6, indicating that these items were grouped appropriately and are measuring similar concepts. Table 6 describes interdomain relationships by using Pearson correlation. No 2 domains seemed to be so highly correlated that they were redundantly measuring the same things. The domain quality of life had the lowest correlations with all other groups, indicating that this was a unique domain.

DISCUSSION

Health care workers express concerns about how to support parents effectively through the WLST process in the NICU. Although parental challenges are described[21–25] no instrument to measure the delivery of end-of-life care in the NICU is available. We describe the construction and use of a questionnaire based on the experiences of recently bereaved parents.

The domains and items in the questionnaire resemble parent or patient experiences as previously described in NICU,[21–25] PICU,[26] and adult ICU literature,[27] conferring face validity on our selected items. Like the previous pediatric studies, our report shares a limitation in that the parent sample was predominantly white, Christian, and English-speaking. Furthermore, like others, we suffered a selection bias, in that most parents invited did not respond. Wocial[22] interviewed 17 (54%) of 31 eligible parents, and Brosig et al[25] interviewed 19 (28%) of 67. This self-selection bias may result in a group with special characteristics. Potential barriers to participation include language, socioeconomic status, or a reluctance to revisit painful memories. Admittedly, this is a potential methodologic flaw in the development of a tool for wider use; however, we saw no ethical way to elicit additional information from the nonresponders. Additional testing

TABLE 6 **Interdomain Correlations**

Domain	Communication	Quality of Care	Quality of Life	Shared Decision-making	WLST Process	Bereavement Care
Communication	1.000	0.663	0.638	0.784	0.711	0.666
Quality of care		1.000	0.420	0.684	0.484	0.559
Quality of life			1.000	0.485	0.545	0.411
Shared decision-making				1.000	0.687	0.768
WLST process					1.000	0.766
Bereavement care						1.000

Pairwise correlations between domains by using 2-tailed Pearson correlation.

in parent groups should try to assess the impact of this potential bias.

Before the instrument is used more extensively, a consideration of its methodologic properties is needed. The questionnaire within 4 domains (WLST process, communication, bereavement care, and quality of care) displayed high interitem correlations by both Cronbach's α and split-half analysis (Table 5). The items under shared decision-making were of acceptable consistency; however those in quality of life showed a significantly lower correlation. Additional analysis showed that question 50, "Health care workers respect parents' views about their child's quality of life," showed a poor correlation with the other 2 questions such that, when removed, the Cronbach's α value increased from 0.435 to 0.672 for that domain. This suggests that this particular statement may be ambiguous and should be removed from this domain. Because the quality-of-life domain was poorly correlated with the other domains (Table 6), it likely does address a unique aspect of WLST. This argues to retain the domain in additional iterations of the questionnaire.

The majority of domains showed correlation with values between 0.663 and 0.760 (Table 6), and none were so close to 1 as to make items seem redundant. Lower correlations were found with the quality-of-life domain (mentioned previously) and in 2 cases quality of care with WLST and bereavement care. As mentioned, these will require additional examination before future iterations of the instrument. Finally, it is unwise to calculate a total score for the questionnaire because each of the domains represents important issues for parents that were not relatively weighted. Additional refinement of the instrument would be required to give a simple arithmetic summation of these scores if this were even appropriate.

The results of our questionnaire in this pretest population assist the future development of instruments to measure the perceptions of larger multiprofessional groups and, more important, bereaved parents. Perinatal social workers have a unique position for involvement in WLST discussions. They were therefore used as a proxy indicator of practice, whose approach to care is potentially less reactive or defensive as compared with that of the medical or nursing team. Nonetheless, this sample of convenience has limitations. Social workers' perceptions may not reflect parents' experiences. In addition, they are unlikely to be present for all interactions between parents and the health care team. Pragmatically, no individual profession within the health care team can fully reflect all aspects of the WLST process. To obtain a more complete picture of how the practice of WLST unfolds, sampling a larger interprofessional population of health care workers is needed. Finally, sampling a wider group of bereaved parents is a more meaningful indicator of the effectiveness of practice.

Despite the limitations of our convenience sample of social workers, some insights can be gained from this pretesting. It is interesting that we did not find a relationship in responses to either the years of experience of the respondents or size of unit in which they practiced. This may be because our numbers were too small or because unit size is relatively homogeneous in tertiary care referral units. Possibly, the years of experience may not equate to the sensitivity of the respondents to the parameters being tested. Additional samples of a wider cohort may determine other meaningful characteristics.

Overall, the respondents indicated that parents are well supported through the actual process of WLST. This includes the opportunity to spend time with and hold the infant, as well as witnessing staff treating dying infants with dignity, compassion, and respect (Table 3). In addition, our sample of both parents and social workers concur on the importance of respecting the cultural and religious views of families at the time of WLST ("parents' religious beliefs are respected at the time of their child's death" score 6.0 [3.0–7.0]) and during discussion of autopsy ("when discussing consent for autopsy, parents' religious beliefs are respected" score 6.0 [3.0–7.0]). After a perinatal loss, culture and ethnicity have an impact on grief,[28] thus requiring sensitivity and special training on the part of health care workers. These are areas that by self-report are lacking[29]; therefore, in future studies, a broader, more diverse ethnic sample of parents would be important.

Within all of these limitations, the respondents nonetheless identified some key areas with potential for improvement. One such item highlighted by both parents in the construction phase of the study and the pretest social worker population was a lack of consistency of care, as demonstrated by the statement, "The care plan is consistent," which received a low median score of 4.0 (2.0–6.0; Table 3). Similar concerns were noted by other groups.[13,26,27] A related item concerns team members' passing value judgments. One parent expressed this as, "Some of them basically said to us, 'You're wasting our time and our money, just turn off the machine and let her die. . . .' " The social workers pretested concurred that such attitudes were a problem: "Health care workers avoid passing value judgments" scoring only 4.0 (1.0–7.0; Table 3).

These problems arise as part of the challenges of shared decision-making between parents and the health care team.[30,31] Another challenge indicated by our pretest population is that health care workers were less comfortable dealing with parents who do not want to take part in the decision-making process ("health care workers respect when parents do not want to make a decision" with median 4.5 [1.0–6.0]; Table 3). Some parents find it difficult to take responsibility for making their child's final treatment decisions.[13] Decision-making becomes a delicate balance in these cases.

Provision of follow-up support during bereavement seems poor in general, with low scores on our social worker survey, yet bereaved parents value efforts to find out how they are coping and to be given full and frank information.[24,25] Deficiencies included the lack of specific medical follow-up; the prompt discussion of autopsy results; and the lack of counseling on sibling grief, marital stress, and returning to "normalcy" (Table 3). Some centers have follow-up as part of their own palliative/end-of-life protocols,[32–34] and widespread institution of similar protocols might improve our sample's observed variability of responses. Our parent sample expressed an appreciation of health care workers who attended their child's funeral and for the hospital memorial service recognizing the identity of their child. Keeping the child's memory "alive" helps parents to cope with their loss.[24]

Variation across units is seen in aspects of NICU care, such as rates of nosocomial infection or bronchopulmonary dysplasia.[35] We note a wide range for medians across all domains in Table 3, indicating a possible variation in practice across centers. Ethical variations in NICU practice by geography are described.[9–13] Other potential influences on practice variation include legal guidelines, culture, religion, or the neonatologist's own personal fear of death.[14] In addition, whether suboptimal variations in this practice can be improved, as shown by the Vermont Oxford Network[35] for other aspects of care (infection rates and bronchopulmonary dysplasia), is unknown.

CONCLUSIONS

We used parents' views on end-life-care in the NICU to build an instrument to measure important aspects of WLST practices. According to a pretest sample of social workers, health care workers meet many of parents' preferences regarding the practical aspects of WLST; however, features of quality in-hospital care, continuity and consistency of care, and organized follow-up care can be improved. Future work should consider the use of the refined instrument in broader populations of health care workers and parents to assess "actual practice."

APPENDIX 1: PARENT INTERVIEW GUIDE

1. I'd like to start by asking you to tell me about the events that took place when [name of child] was in hospital.
2. Tell me about the discussions you had regarding [name's] treatment.
   a. When, how, and where did they occur?
   b. Who provided you with the majority of the information?
   c. Did you feel you understood what was said?
   d. Tell me about what you found helpful about these discussions.
   e. Tell me about what was less helpful.
3. Tell me about the decision to withdraw [name] from life support.
   a. Who do you feel made that decision?
   b. Do you believe now that it was the right decision?
   c. Do you feel the right person decided?
4. Tell me about the support you received at the hospital from the staff.
   a. Were there any particular individuals who stood out?
   b. In what way?
5. Describe the environment in which [name] received care.
   a. Was it what you expected?
   b. What would have made it more comfortable for you and [name]?
6. Some people have also talked about memorable moments spent with other families going through the same experience of having a very ill newborn. Do you recall any events like that when [name] was in the hospital?
7. I'd like to ask you now about what happened when [name]'s life support was withdrawn. Was it what you expected? If not, how did it differ?
8. Tell me about what happened when [name] died.
   a. How long was it between the discontinuation of life support and [name]'s death?
   b. How satisfied were you with the care you received?
   c. Was there anything else you would have found helpful?
   d. Was there discussion about an autopsy?
9. Tell me about wheat happened after you left the hospital.
   a. What kind of follow-up did you have with the medical/support team? When? With whom?
   b. What did you find helpful when you went home after [name] died?
   c. Is there anything else during that time that you would have found helpful from the staff at the hospital?
10. If I could pass a message along from you to the staff

at the NICU on how better to help families through the difficult process of having an infant die, what would that be?

APPENDIX 2: FULL LIST OF SURVEY QUESTIONS ORGANIZED BY DOMAIN

How often does the following occur in your setting? (Ranked on 7-point Likert scale)

Communication

5. Health care workers adequately explain the likely outcomes to parents.
11. Health care workers provide parents with sufficient number of discussions about withdrawal of life sustaining treatment.
15. Health care workers admit their uncertainty.
17. Health care workers make adequate use of aids such as notes and diagrams during discussions.
21. Health care workers try to understand how much information parents can absorb.
22. Family or other supports are allowed in discussions with the health care team.
34. Health care workers give parents the right amount of hope—no false hope, but not too little.
36. Health care workers are sensitive to the right time to approach parents about discussions of withdrawing life support (not too early, not too late).
44. Parents are encouraged to ask questions.
72. Health workers give parents enough time to absorb the details of diagnosis and prognosis.
78. Health care workers are frank and honest.
82. Health care workers avoid answering parents' questions.

Quality of Care

1. Health care workers understand and support parents if they are angry.
2. Health care workers respect parents' preferences in regard to the people caring for their child.
24. Health care workers recognize when parents feel intimidated by the number of health care workers on the team.
25. Health care workers are respectful.
26. Health care workers are polite.
54. Health care workers approach parents in a way that avoids creating feelings of intimidation as a result of their knowledge.
55. Health care workers understand and try to relieve parents' guilt.
58. Health care workers pass value judgments.
62. Health care workers use the child's first name.
63. Health care workers understand parents' emotional state.
68. Health care workers adequately explain hospital policies related to the child's care.
69. Health care workers understand when parents are afraid.
70. The care plan is consistent.
81. Geographic distance (from home to the hospital) is a problem for parents visiting or arranging meetings for discussions.

Quality of Life

8. Health care workers clearly explain to parents the child's likely future ability to interact, talk, eat, see, and hear.
13. Pain and suffering in life is balanced against long-term outcomes.
50. Health care workers respect parents' views about their child's quality of life.

Shared Decision-making

6. Decisions made reflect the consensus of the health care team.
14. Health care workers support parents in order for them to come to an agreement on decisions.
20. Health care workers respect when parents do not want to make a decision.
33. Health care workers involve both parents during decision-making.
37. Health care workers make parents feel that everything possible has been done.
45. Health care workers support parents, whatever their decision.
51. Health care workers encourage parents to provide mutual support and trust to each other.
76. Parents feel that the right decision is made regarding withdrawal of life-sustaining treatment.

WLST Process

4. The child is treated with dignity during withdrawal of life-sustaining treatment.
9. Health care workers are free to express sadness and grief during withdrawal of life-sustaining treatment.
12. Health care workers encourage parents to hold their child when he or she dies.
19. Health care workers prepare parents for the physical changes that occur in the infant after withdrawal of life-sustaining treatment.
23. Parents have adequate time with their child before withdrawal of life-sustaining treatment.
27. Health care workers acknowledge that the timing of

death after withdrawal of life-sustaining treatment is uncertain.

29. Health care workers clearly present the options to parents before the start of life-sustaining treatment.
32. Health care workers involve parents in the final parenting acts in the way they want (eg, bathing, choosing clothes, dressing).
41. Parents' religious beliefs are respected at the time of their child's death.
42. Parents are allowed to mourn openly to the extent they wish.
43. Parents are able to say goodbye to their child in a comfortable setting.
49. Withdrawal of life-sustaining treatment is done with compassion.
59. Parents are involved to the extent they wish in choosing the timing of the withdrawal of life-sustaining treatment.
65. Health care workers guide parents through the steps of withdrawal of life-sustaining treatment.
66. Parents and family have enough time and privacy to say goodbye.
71. The child does not suffer unnecessarily during withdrawal of life-sustaining treatment.
75. Health care workers clearly present the options to parents before the withdrawal of life-sustaining treatment.
80. Parents are given specific keepsakes (eg, memory boxes, foot and hand prints, good-quality photographs, locks of hair, bracelets, clothing).

Bereavement Care

3. Health care workers help parents to attain a sense of peace (closure).
7. In the case of multiple births, health care workers recognize the difficulty of balancing grief over the loss of 1 infant and joy over the well infant(s).
10. Health care workers encourage parents to share their grief with other parents who have had similar experiences.
16. When discussing consent for autopsy, parents' religious beliefs are respected.
18. Health care workers contact parents for follow-up and grief counseling after the death of their child.
28. Parents are offered a prompt discussion regarding autopsy results.
30. Health care workers provide specific counseling in dealing with sibling grief.
31. Health care workers assist parents to return to a "normal" life, including returning to work.
35. Health care workers help parents to retain the memory of their child's personality after death.
38. In the case of multiple births, health care workers recognize parent anxiety regarding the prognosis of the surviving infant(s).
39. Parents are given information about why an autopsy may be helpful.
40. Health care workers minimize parent reminders of their loss (eg, not having to return to the hospital, seeing other infants as they leave).
46. Health care workers provide help for the strain placed on parents' relationship during bereavement.
47. Health care workers are available to answer medical questions after the death of their child.
48. The hospital provides a memorial service.
52. Government and health care agencies are made aware of the child's death to ensure that inappropriate reminders do not occur (eg, follow-up vaccinations).
53. The autopsy investigations delay funeral arrangements.
56. Parents are provided with enough community support (eg, through their family physician, extended family, or funeral home services).
57. Health care workers attend the child's funeral.
60. Health care workers encourage parents to talk openly about their grief.
61. Health care workers officially recognize the child's existence.
64. Health care workers give parents emergency contact numbers during their bereavement (eg, help line).
67. Health care workers provide appropriate medical follow-up, including referral to high-risk obstetrics and genetic counseling with subsequent pregnancies.
73. Health care workers prepare parents for the insensitivity they may face in the community after the death of their child.
74. Health care workers provide parents with a grief package (eg, booklet containing contact numbers and parent support groups).
77. Health care workers provide specific counseling to parents about providing support to each other during the bereavement period.
79. Autopsy results are sent to both parents and their family physician.

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