Published in final edited form as:
Arch Pediatr Adolesc Med. 2009 September ; 163(9): 783–788. doi:10.1001/archpediatrics.2009.155.

Neonatologist Training to Guide Family Decision-Making for Critically Ill Infants

Renee D. Boss, M.D.,
Division of Neonatology, Department of Pediatrics, Johns Hopkins University School of Medicine, 600 North Wolfe Street, Nelson 2-133, Baltimore, MD. 21287, 410-955-5259 (phone) 410-955-0298 (fax), rboss1@jhmi.edu

Nancy Hutton, M.D.,
Department of Pediatrics, Johns Hopkins University School of Medicine

Pamela K. Donohue, Sc.D., PA-C, and
Department of Pediatrics, Johns Hopkins University School of Medicine and Department of Population, Family and Reproductive Health, Johns Hopkins Bloomberg School of Public Health

Robert M. Arnold, M.D.
Division of General Internal Medicine, Section of Palliative Care and Medical Ethics, Montefiore University Hospital

Abstract

Objective—A core skill for neonatologists is the ability to guide family decision-making for high-risk newborns. Families identify several critical communication skills for physicians in these scenarios. We aimed to assess neonatology fellow training in those skills.

Design—A web-based national survey.

Setting—Neonatal-Perinatal Training Programs in the United States

Participants—Graduating fellows in their final month of fellowship.

Outcome Measures—Fellow's perceived training and preparedness to communicate with families about decision-making.

Results—The response rate was 72%, representing 83% of accredited training programs. Fellows had a great deal of training in the medical management of extremely premature and dying infants. However, they reported much less training to communicate and make collaborative decisions with the families of these infants. Over 40% of fellows reported no communication training in the form of didactic sessions, role play, or simulated patient scenarios, or clinical communication skills training the form of supervision and feedback of fellow-led family meetings. Fellows felt least trained to discuss palliative care, families' religious and spiritual needs, and managing conflicts of opinion between families and staff or amongst staff. Fellows perceived communication skills training to be of a higher priority to them than to faculty. 93% of fellows feel that training in this area should be improved.

Conclusions—Graduating neonatology fellows are highly trained in the technical skills necessary to care for critically ill and dying neonates, but are inadequately trained in the communication skills that families identify as critically important when facing end of life decisions.

Correspondence to: Renee D. Boss.

Introduction

Prematurity and congenital malformations impact more than 500,000 neonates and their families in the United States each year. Many of these infants are at risk of death or serious disability in the neonatal period, with decisions needed about instituting or continuing life-sustaining therapies. A central role of the neonatologist is to facilitate decision-making with the families of these high risk newborns.

The American Academy of Pediatrics (AAP) prioritizes shared decision-making between parents and physicians in these scenarios [1]. Studies confirm that most families wish to participate, to some degree, in decision-making 2 3 4. While truly collaborative decision-making is difficult under any circumstances, [5–8] in neonatology prognostic uncertainty, the urgency of time and the fact there are two patients – the infant and the mother – complicate the situation. Families who have endured similar scenarios emphasize how important it is for physicians to help them decipher technical information, articulate goals and values, contend with emotions, confront religious and spiritual concerns, and maintain focus on making collaborative decisions in the best interest of the infant. [9, 10]

Given this, it is important that neonatologists learn the skills integral to collaborating with families during decision-making. While the Accreditation Council for Graduate Medical Education (ACGME) [11] lists "interpersonal and communication skills" among the core competencies for neonatology fellowship training, it is not clear how this training is operationalized or evaluated by individual fellowship programs. Neither is it known whether fellows, upon completion of their training, feel prepared to lead family discussions and guide decision-making.

The purpose of this study is to determine the type and extent of training in communication and decision-making that neonatology fellows receive, and graduating fellows' perceived preparedness to lead family discussions.

Subjects and Methods

We obtained a listing from the AAP Section on Perinatal Pediatrics [12] of all senior fellows at ACGME-accredited Neonatal-Perinatal training programs in the United States (n= 164) in May 2008. In the final month of their training, potential respondents were sent an email describing the study with an invitation and link to complete the web-based survey. The survey was conducted using web-based survey software (SurveyMonkey.com, copyright © 1999–2008). Two follow-up emails were sent to non-responders. All responses were anonymous, and all potential respondents received a $5 gift certificate incentive. The study was exempted from review by the Johns Hopkins Medicine Institutional Review Board.

The 5-minute survey about fellows' attitudes, training, and competence regarding helping families make decisions for critically-ill infants was developed based on literature review [2, 13–17] and discussion with experts in palliative care, neonatology and medical ethics. We adapted several items from existing instruments that have been used to evaluate nephrologists, geriatricians, and medical school faculty's end-of-life educational experiences. [18 19–21] The survey was pretested with neonatology fellows from a single institution for wording, content, and willingness to participate. The survey was modified based on their feedback, and their responses were not included in the final subject sample.

The finalized survey consisted of 28 multiple choice and Likert-type questions and a single open-ended question. Possible responses to the Likert-type questions were on a scale from 1 to 7 (1= "Not at all" and 7 = "Very well). Respondents were told that they survey items focused on those infants for whom "severe morbidities or mortality were very likely" and for whom

"medical decisions are often made in collaboration with the family." The survey included the following domains: perceived importance of learning communication skills, quantity and quality of training in areas of communication relevant to end of life care in the neonatal intensive care unit (NICU), perceived preparedness to guide family decision-making, perceptions about family satisfaction with fellows' communication in actual clinical scenarios. Finally we collected demographic information regarding the fellows including their gender, size of their fellowship and its location.

Statistical analyses were performed using Stata 10 (StataCorp LP). Descriptive statistics included means, medians, frequencies, and proportions. Chi-square tests were used to compare proportions. Student t-test or the Mann-Whitney U were used as appropriate to compare means or medians. Linear regression was used to model fellow perceptions about family satisfaction with discussions about religion and spirituality as related to decision-making. Qualitative responses to the open-ended question were reviewed for themes by 3 of the authors (RB, PK, RA); themes found in at least 20% of responses are reported.

Results

Of the 162 eligible fellows, we were able to obtain 140 working email addresses (86%). Of these, 101 fellows completed the survey, for a 72% response rate (62% of all graduating fellows). These fellows came from 83% of total Neonatal-Perinatal Training Programs with graduating fellows in 29 states and Puerto Rico. 91% of respondents were completing their 3rd year of fellowship; 9% were completing their fourth year. 63% were female. The median number of fellows at all training programs was 7; 40% of respondents came from smaller programs (range 1–6), 60% came from programs with at least 7 fellows (range 7–18).

Educational Opportunities for Communication Skills Training

96% of fellows reported that they had received "a lot of training" in the medical management of an infant with extreme prematurity, and 89% stated that they had "a lot of training" in the medical management of a dying infant. In contrast to their extensive training in the medical management of these high risk infants, fellows report less training about how to communicate with the families of such infants. (Table 1) Overall, 41% of respondents had no formal training of any kind during fellowship specifically focused on communication skills: 43% of fellows reported receiving no specific didactic conferences or courses, 75% had never participated in a relevant role play or simulated patient scenario, and only 6% had taken a clinical rotation that was primarily focused on developing communication skills.

In addition to asking about formal communication skills education, we also asked about a common clinical training opportunity: the family meeting. 94% of fellows reported that they "sometimes" or "always" were responsible for leading family meetings to discuss goals of care. Unfortunately, fellows frequently did not receive feedback on how they did. 40% of fellows stated that an attending was "always" present in the room during these meetings and consistently gave feedback to the fellows about the way that they led these meetings. 14% of fellows reported that they had never received feedback from any attending after any family meeting. Programs without formal communications training were no more likely to provide consistent attending supervision and feedback for fellow-led family meetings than were programs with formal communications training. There were no differences by program size.

Table 2 summarizes fellows' perceptions of the quality of their training on specific topics common to guiding family decision-making. 81% of fellows thought it very important to receive formal communication skills training in this area. They perceived that training to discuss treatment goals with families was significantly less important to faculty than it was to them (mean 5.7, CI 5.4, 6.0, vs. mean of 6.3, CI 6.0, 6.6, $p<.01$).

93% of fellows reported that training to discuss goals and decision-making with families needed to be improved. More than half thought that didactic sessions (64%) or role play (59%) would be useful teaching methods. Of note, 37% thought that a clinical rotation focused on communication skills would be useful, although only 6% reported having this opportunity. Others preferred fellow-led family meetings with direct faculty supervision and feedback. One participant stated, "Involving oneself in multiple family meetings after observing a skilled faculty member followed by constructive criticism is the best method."

Fellows' Perceptions of Family Satisfaction with Communication

When asked to reflect on their most recent actual clinical experience with the family of a critically ill infant (Table 3), fellows perceived these families to have a fairly good understanding of their infant's medical problems (5.2 ± 1.5), the possibility of a bad outcome (5.1 ± 1.6), and the available treatment options (5.3 ± 1.6). Fellows also perceived these families to be quite satisfied with the ultimate management decisions (5.5 ± 1.3).

When asked to rate perceived family satisfaction with their discussions with the medical team about religious or spiritual topics related to decision-making, 26% of fellows indicated that this question was "not applicable" to their clinical experience. For those fellows who found this question applicable, they judged family satisfaction with these discussions to be quite high (5.6 ±2.7). The more training fellows received about how to address families' religious and spiritual concerns, the less optimistic they were about family satisfaction with their discussions of these issues (β=.65, 95% C.I. .40, .89; $p<0.001$). The more training that a fellow had to discuss families' religious and spiritual concerns, the less likely they were to state that the question about family satisfaction with these discussions was "not applicable" (O.R. .70, 95% C.I. .54, .90).

64% of respondents answered the open-ended question *"How you know that you have addressed the issues most important to families when you discuss goals of care for critically ill infants?"* Nearly one third of responses did not directly answer the question about family needs, but instead discussed how they assess whether the family understands the information given to them by the medical team.

"I ask them to explain their baby's condition from what they understood from care conference."

"When they can tell me options and potential outcomes and verbally state child's condition."

"Once I have told them about the infant's condition and our treatment options, I summarize our meeting for them and attempt to set short term and long term goals for the NICU team and family. Sometimes, if I think the family is still not understanding the situation, I will politely ask them to repeat what I said about their child's condition and our treatment options."

Of the fellows whose responses more directly addressed family needs, about half of respondents described directly asking the family to verbalize what is most important to them; the remaining half rely on parent initiative to identify unaddressed concerns.

"You have to ask what issues are important to the families. You cannot just assume. You also must make it a point to have multiple discussions with the families, they do not always bring up all their issues at the initial session"

"I try to ask what their goals are for their child."

"We ask the family if they want to discuss anything else."

"Encourage questions at end of discussion."

Only 5 respondents specifically named feelings and emotions among the important issues to address with families; a single respondent mentioned religious beliefs. Others described that gratefulness on the part of the family towards the medical staff is implicit evidence that the family's concerns have been met. Several respondents reported that they are not sure of how to address family's most important concerns.

Discussion

This is the first study of neonatology fellows' training and perceived competence to talk with families about decision-making for critically ill infants, a core skill for practicing neonatologists. Despite this, fellows report little formal training in communication skills targeted to guiding family decision-making, and perceive that this topic is of less importance to faculty than it is to them. More than forty percent of graduating fellows report no formal training of any kind on this topic. While fellows felt well-trained to discuss the more cognitively-based information with families, such as predictions of morbidity and mortality and treatment options, they felt less trained to address the more emotional and social issues such as palliative care, addressing conflicting goals among staff or between staff and families, and discussing families' spiritual and religious needs.

Our findings are corroborated by studies of practicing neonatologists. Bastek et al surveyed practicing neonatologists who were, on average, in practice more than ten years.[15] Participants defined their primary priority during prenatal counseling to be the review of factual information; nearly half rarely or never discussed families' religious or spiritual beliefs. This is in contrast to data from families suggesting that factual predictions of morbidity and mortality are often not central to parents' end of life decision-making. [9 22 23]

Fellows in our study felt the least trained to address families' religious and spiritual distress during decision-making; in fact, 25% of fellows found these issues irrelevant to discussions with families about goals of care. This is in stark contrast with what families say is important to their decision making. [9, 24 25 26–28] Some families have emphasized that they must be allowed to address their spiritual distress in order to fully participate in decision-making for their child. [25] Some physicians perceive that these issues are best addressed by social workers or chaplains,[29 30] and certainly hospital and community chaplains are integral members of the interdisciplinary team. But data suggest that patients not infrequently wish to discuss these issues with their physicians, especially as illness severity increases. [31 32 25, 33] Interestingly, in our study, those fellows with more training to address families' religious and spiritual beliefs were less confidant that they could do so adequately. This may reflect a phenomenon well-described in the psychology literature where individuals with minimal training tend to be overoptimistic about their skills, while those with more training have increased awareness of what they do not know. [34, 35]

Fellows also told us that they felt inadequately trained to resolve conflicts of opinion over the goals of care. Health care staff frequently perceive some degree of conflict with families when navigating end-of-life care, [36–38] and vice versa.[39] Parents are often aware of these conflicts, and report that they compromise their willingness to collaborate in decision-making. On the other hand, when staff manage these conflicts well, trust on the part of the family is increased. [26 40] Given that perceived collaboration in decision-making has been described as the most important determinant of parent satisfaction with end of life care in the NICU, [27] conflict resolution is a needed skill for neonatologists.

Fellows in our study regularly led family meetings but were provided faculty supervision and feedback for these meetings less than half the time. In the adult literature, studies of family meetings have identified specific skills that are associated with family satisfaction and

psychological well-being. [41, 42 43] Fellows in our study inconsistently reported having these skills. For example, while fellows were very comfortable assessing parent's understanding of the medical details, many seemed to see this as a substitute for eliciting families' goals and values. And for those fellows who acknowledged the need to assess families' goals and values, many assessed these only indirectly using such prompts as "Do you have any other questions?" Families who did not bring up additional concerns were assumed to have had their needs met. Fellows overall perceived parents to have good understanding of their infants' medical problems and to be highly satisfied with decision-making, even as fellows recognized that they needed more training in how to guide these conversations.

Over the last ten years, multiple studies have shown that communication skills can be taught effectively. [44 45 46 47 48 49 50–52 53] Many of the interventions described in the literature are not time-intensive, involve small-group discussions or role play, and report at least short-term improvements in skills and attitudes of both the novice student and senior faculty. Faculty who have completed similar programs report increased confidence in their ability to teach these skills to trainees.[54] Several unique physician training programs targeted to addressing patients' religious and spiritual concerns have also been described. [55, 56 57]

Our study has several potential limitations. The primary limitation is the use of self-report to assess fellow training in communication skills. We did not confirm with individual training programs the structured opportunities offered to fellows, nor the number of fellows who participated in those opportunities. We felt that trainee self-assessment of skills was more relevant to clinical behavior than was documented fellowship curriculum. For those fellows who did report training in the skills to guide family decision-making, we did not ask them to specify whether that training was received as part of a neonatal ethics curriculum; it is possible that training programs could prepare fellows for difficult discussions by providing a foundation in neonatal ethics. Results about parent satisfaction with physician communication should be interpreted with caution in this study, as we asked fellows to report perceived family satisfaction, which they uniformly rated quite highly. Whether families were in fact satisfied cannot be assessed. The goal in this study was rather to characterize fellow perceptions as possible opportunities for targeting training interventions.

Conclusions

The ACGME has emphasized the importance of neonatology fellow training in interpersonal and communication skills, but training programs appear to falling short of their obligation, with over 40% of graduating fellows reporting no formal training in this area. Structured communication skills training has been described in other areas of medicine and could be adapted for relevance to neonatology. Unfortunately, the nature of critical illness in neonates not infrequently requires rapid decision-making; the optimal process for communicating and collaborating with families in these scenarios has not yet been well-explored. Parent-reported outcomes for physician communication training interventions should be assessed.

Acknowledgments

Dr. Boss received funding from a KL2 Junior Faculty Award to support this project. Dr. Boss had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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Table 1

Fellow Report of Training Opportunities

	Yes	No	Single session	1–5 sessions	>5 sessions
During fellowship, did you have…					
-didactic training to negotiate goals of care with families?	58%	42%	7%	73%	20%
-role play/ simulated scenarios to teach communication skills?	25%	75%	42%	46%	12%
-clinical rotation focused on communication skills?	6%	94%	-	-	-
			Never	Sometimes	Always
During fellowship, did you….					
-lead family meetings to discuss goals of care?			6%	82%	12%
- How often was an attending in the room?			6%	54%	40%
- How often did the attending give you feedback about how you led the meeting?			14%	45%	41%

Arch Pediatr Adolesc Med. Author manuscript; available in PMC 2010 September 1.

Table 2

Fellow Perceptions of Adequacy of Training

	Average ± SD
During fellowship, how well do you think you were trained to…	
-lead family meetings to discuss goals of care?	5.6 ± 1.4
-talk with families about predictions of morbidity and mortality?	5.5 ± 1.4
-present treatment options to families of critically ill infants?	5.4 ± 1.4
-present palliative care options to families?	5.1 ± 1.6
-discuss with families their spiritual or religious beliefs?	4.0 ± 2.0
-resolve conflicts of opinion between parents and providers about the management of critically ill infants?	4.6 ± 1.7
-resolve conflicts of opinion amongst providers about the management of these babies?	4.4 ± 1.7

On a scale of 0–7, 0=Not at all 7=very well

Table 3

Fellow Perceptions of Family Understanding and Satisfaction

	Average ± SD
Thinking about the most recent critically ill infant that you cared for, how well do you think the family…	
-understood their infant's medical problems?	5.2 ± 1.5
-understood the treatment options?	5.3 ± 1.6
-was prepared for a potentially bad outcome?	5.1 ± 1.6
How satisfied do you think the family was with…	
-the decisions that were made?	5.5 ± 1.3
-your discussions with them about religion or spirituality?	5.6 ± 2.7

On a scale of 0–7, 0=Not at all 7=very well