

ORIGINAL ARTICLE

An interdisciplinary, family-focused approach to relational learning in neonatal intensive care

EC Meyer^{1,2,3}, D Brodsky^{2,4}, AR Hansen^{2,5,6}, G Lamiani^{2,7}, DE Sellers⁸ and DM Browning^{2,8,9}

¹Division of Critical Care Medicine, Children's Hospital Boston, Boston, MA, USA; ²Institute for Professionalism and Ethical Practice, Waltham, MA, USA; ³Department of Psychiatry, Harvard Medical School, Boston, MA, USA; ⁴Department of Neonatology, Beth Israel Deaconess Medical Center, Boston, MA, USA; ⁵Division of Newborn Medicine, Children's Hospital Boston, Boston, MA, USA; ⁶Department of Pediatrics, Harvard Medical School, Boston, MA, USA; ⁷Department of Medicine, Surgery and Dentistry, University of Milan, Italy; ⁸Education Development Center, Inc., Newton, MA, USA and ⁹Department of Anaesthesia, Harvard Medical School, Boston, MA, USA

Objective: The aim of this study is to show the efficacy of the Program to Enhance Relational and Communication Skills—Neonatal Intensive Care Unit (PERCS-NICU).

Study Design: In this study, 74 practitioners attended workshops and completed baseline, post-training and follow-up questionnaires.

Result: On yes/no questions, 93 to 100% reported improved preparation, communication skills and confidence post-training and follow-up. A total of 94 and 83% improved their ability to establish relationships, and 76 and 83% reported reduced anxiety post-training and follow-up, respectively. On Likert items, 59 and 64% improved preparation, 45 and 60% improved communication skills and confidence, 25 and 53% decreased anxiety and 16 and 32% improved relationships post-training and follow-up, respectively. Qualitative themes included integrating new communication and relational abilities, honoring the family perspective, appreciating interdisciplinary collaboration, personal/human connection and valuing the learning. In total, 93% applied skills learned, three-quarters transformed practice and 100% recommended PERCS-NICU.

Conclusion: After PERCS-NICU, clinicians improved preparation, communication and relational abilities, confidence and reduced anxiety when holding difficult neonatal conversations.

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Introduction

The field of neonatology has expanded beyond the primary aim of saving infants' lives to minimizing survivors' long-term

complications, and thus extending clinicians' responsibilities beyond the baby to the broader family. This shift in focus to family-centered care has magnified the importance of communication and relational abilities in the neonatal intensive care unit (NICU).^{1–3} The quality of these communications has a significant impact on families' appraisal of their care, bereavement experience and memories.^{4–7}

Conversations in the NICU present unique challenges, and conveying difficult news in the NICU can shatter parents' expectations of a healthy baby. Information provided prenatally or post-birth may not be definitive because clinicians are limited in their ability to accurately forecast long-term outcomes. Unpredictable changes in an infant's clinical status can cast neonatal practitioners as rescuers in the delivery room only to render them bearers of bad news hours, days or weeks later. The dilemma of whether to continue or withdraw life-sustaining treatment for an infant is among the most emotionally complex and morally stressful decisions.^{8–10} These challenges are further exacerbated by the lack of continuity of care related to daily shift changes, clinical rotations and staff turnover.

Communication in the NICU and the associated ethical and cultural issues raised are receiving more scrutiny in the United States and abroad.^{11–14} In 2002, the Institute for Professionalism and Ethical Practice at Children's Hospital Boston launched the Program to Enhance Relational and Communication Skills (PERCS), to reflect on and practice difficult conversations in an interdisciplinary learning environment.^{15,16} At the request of neonatal practitioners, a customized PERCS-NICU program was developed. The purpose of this study was to show the efficacy of the program and to verify the transferability of the learning paradigm.

Methods

Participants

Participants included physicians, nurses, social workers, psychologists, chaplains and medical interpreters from Children's

Correspondence: Dr EC Meyer, Institute for Professionalism and Ethical Practice, Children's Hospital Boston at Waltham, 9 Hope Avenue, Waltham, MA 02453, USA.

E-mail: elaine.meyer@childrens.harvard.edu

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Hospital Boston, Beth Israel Deaconess Medical Center, and Brigham and Women's Hospital. Participants received training during seven 6-h workshops conducted between November 2005 and June 2007.

Intervention

PERCS is an educational program based on the principles of relational learning.^{15,16} Workshops enrolled 10 to 15 interdisciplinary participants and included three faculty facilitators: a neonatologist, psychosocial professional and family faculty member. Clinicians began with a collaborative exercise in which they offered communication strategies that they had found helpful in their own clinical practice. By sharing their existing skills and expertise, attendees became comfortable with each other and were empowered. Participants then viewed an educational film in which family members describe their experience with end-of-life care for their child.¹⁷ Workshops also included a brief didactic presentation summarizing common communication challenges, current approaches for conveying difficult news and ethical guidelines for withdrawal of life-sustaining therapy.

A neonatal case scenario depicted an extremely preterm infant who had developed bilateral intraventricular hemorrhages with ventricular dilation and a unilateral intraparenchymal brain hemorrhage.¹⁸ The infant's parents and maternal aunt were portrayed by professional actors. Different interdisciplinary teams volunteered to interact with the 'family' during each of the three successive conversations while their peers observed the discussion through live video feed. Although each workshop used the same scenario, conversations were unique in that the actors responded improvisationally based on how each team of clinicians communicated. After each conversation, participants had the opportunity to reflect on the encounter, obtain feedback from their colleagues and parent-actors and review important excerpts of the videotaped conversations. At the conclusion of the workshop, participants and faculty members shared with the group the most noteworthy aspects and ideas they planned to incorporate into their own clinical practice.

Study design

A pre–post-study design was used to evaluate the practitioners' sense of preparation, communication skills, relational abilities, confidence and anxiety during difficult neonatal conversations. Participants completed confidential questionnaires before and after the training and upon follow-up. The baseline questionnaire included questions about discipline, years of experience, previous training and sociodemographic characteristics, and inquired about the number of times the respondent had observed or led difficult conversations. Immediately after the training, participants completed a post-questionnaire. The follow-up questionnaire was administered an average of 12 months after training by standard mail and e-mail. On all three questionnaires (baseline, post and follow-up), participants were asked to assess, on a five-point Likert

scale, their preparation, communication skills, relational capacities, confidence and degree of anxiety. The post- and follow-up questionnaires also asked (yes/no responses) whether the program had helped them to improve these skills. Open-ended questions assessed the participant's learning, the most and least helpful aspects of the program, and suggestions for improvement.

Data analysis

Statistical analyses were completed in SAS v8.2 (SAS Institute, Cary NC, USA). Cross-tabulations were used to summarize and describe outcomes. The χ^2 tests of independence were used to assess differences by discipline, years of experience, previous training, experiences observing or leading difficult conversations and sociodemographic characteristics (age, gender and race/ethnicity). Statistical significance was set at $P < 0.05$ for all comparisons. Linear and logistic regressions were used to examine whether discipline, years of experience, number of difficult discussions observed in the past year, any previous learning opportunities and the availability of a mentor were associated with improvements in self-appraisal of preparation, communication skills, confidence, ability to develop and maintain relationships and anxiety. Age, gender and ethnicity were not included because age was highly correlated with years of experience, and age and gender were nearly completely collinear with profession (see Table 1). In the linear regression, the change score in each rating for each time point (post and follow-up) was regressed on the corresponding baseline measure and the covariates listed above. In addition, for each outcome at each time point, the same set of covariates was included in a logistic regression comparing those who improved by one or more Likert categories versus those who stayed the same or declined in their rating.

The participants' responses to the open-ended questions were typed into an ACCESS database. Content analysis was conducted through a process of reading and marking key words and phrases to identify topics and issues of importance to participants.^{19–21} Agreement about thematic content and labeling for the themes was then reached through a process of discussion and successive refinement of language.

Research ethics

The Institutional Review Board of Children's Hospital Boston determined that the study met exemption criteria 1 under the Health and Human Services regulations 45 Code of Federal Regulations 46. Each participant signed a consent form granting permission to be videotaped and for questionnaires to be used for educational and research purposes.

Results

Quantitative findings

Seventy-four participants attended PERCS-NICU workshops. Sixty-nine (93%) completed both the baseline and post-training

Table 1 Characteristics of participants who completed both the baseline and the post-questionnaires

Characteristic	Doctors	Nurses	Other	Total
<i>Years of experience</i>				
0–1	0%	6%	0%	2 (3%)
2–5	32%	15%	31%	16 (24%)
6–15	41%	27%	8%	19 (28%)
16+	27%	52%	62%	31 (46%)
<i>n</i>	22	33	13	68
<i>Age</i>				
Mean (s.d.)	39 (11.4)	39 (8.5)	49 (12.4)	41 (10.7)
<i>Gender</i>				
Female	56%	100%	93%	58 (84%)
<i>n</i>	22	33	14	69
<i>Ethnicity</i>				
White	77%	97%	93%	62 (90%)
<i>n</i>	22	33	13	69
<i>Previous learning opportunities</i>				
Yes	82%	82%	79%	56 (81%)
<i>n</i>	22	33	14	69
<i>Observed difficult conversations</i>				
None	0%	0%	8%	1 (1%)
1–10	23%	20%	15%	13 (20%)
11–24	23%	17%	15%	12 (19%)
25+	56%	63%	62%	39 (60%)
<i>n</i>	22	30	13	65
<i>Led difficult conversations</i>				
None	0%	38%	36%	15 (23%)
1–10	41%	14%	45%	18 (29%)
11–24	23%	14%	0%	9 (15%)
25+	36%	34%	18%	20 (32%)
<i>n</i>	22	29	11	62
<i>Mentor/role model</i>				
Yes	43%	30%	43%	25 (37%)
<i>n</i>	21	33	14	68

Respondents were asked (yes/no format) if they had a 'mentor/role model in learning how to have difficult conversations with patients and their families.' This question was intended to identify those respondents who had the benefit of a mentor or role model to learn how to conduct difficult conversations.

questionnaires. Of those, 32% were physicians, 48% were nurses and 20% were psychosocial professionals (Table 1). Nurses and psychosocial clinicians were more likely than physicians to be female, Caucasian and to have 16 or more years of experience. Psychosocial professionals were older than nurses and physicians, but physicians and nurses were more likely than psychosocial

clinicians to have led 11 or more difficult conversations in the past year.

Twelve of the 74 participants could not be contacted for follow-up. Of the 62 who were reached, 45 (73%) returned completed questionnaires. One follow-up questionnaire was excluded from the analysis because the corresponding baseline questionnaire was not completed. Follow-up questionnaires were completed on average 12 months (range = 3 to 23; s.d. = 7.2 months) after the training. There were no significant differences in the follow-up response rate by sociodemographic characteristics or previous experience of the participants. However, participants who rated the quality of the program as excellent on the post-questionnaire were more likely (68 versus 33%) to return the follow-up questionnaire.

On yes/no questions, participants were nearly unanimous (93 to 100%) that PERCS-NICU had improved their sense of preparation, communication skills and confidence at post-training and follow-up evaluation. In the post-training and follow-up, respectively, 94 and 83% of participants reported that the training had improved their ability to develop and maintain relationships with families. Fewer participants, 76 and 83% at post-training and follow-up, respectively, reported that the training reduced their sense of anxiety.

With respect to self-appraisal of preparation, about 6 of 10 participants reported an improvement of one or more categories on the five-point Likert scale from baseline to post-training (59%) and follow-up questionnaires (64%). For communication skills and confidence, about 45 and 60% reported an improvement of one or more units at post-training and follow-up, respectively. Reduction in anxiety was more modest, with 25 and 53% reporting a decrease of one or more categories. Improvement in the ability to develop and maintain relationships was smallest, with only 16 and 32% reporting improvement from baseline to post-training and follow-up, respectively.

Participants whose self-appraisal of preparation, communication skills, ability to develop and maintain relationships and confidence was lower and whose degree of anxiety was higher at baseline were more likely to report improvements. For example (see Table 2), of those who rated themselves as not at all or a little prepared at baseline ($n = 15$), 47 and 40% increased their perceived confidence by one category and two or more categories, respectively, at post-training. In contrast, of those who rated themselves as quite or very prepared ($n = 19$), only 21% reported an increase. A similar pattern, which is consistent with regression to the mean, holds for confidence, degree of anxiety and communication skills for both the post- and follow-up periods (Table 2). This pattern may explain the low levels of improvement in the ability to develop and maintain relationships in which 87% rated themselves as quite or very capable at baseline.

To examine whether the training was more beneficial for a particular type of participant, two sets of analyses were undertaken.

Table 2 Change in self-appraisal of preparation, communication skills, ability to develop and maintain relationships, confidence and anxiety at post-training and follow-up by level of self-appraisal before training

Change in self-appraisal before training and follow-up	Post-training			Follow-up		
	Level of assessment before training					
	Not at all, a little	Somewhat	Quite, very	Not at all, a little	Somewhat	Quite, very
<i>How prepared do you consider yourself to be to have difficult discussions?</i>						
Worse	0%	0%	0%	0%	0%	0%
Same	13%	31%	79%	25%	20%	64%
Improved 1 unit	47% ^a	66%	21%	38%	75%	36%
Improved 2+ units	40%	3%	0%	38%	5%	0%
<i>n</i>	15	29	19	8	20	14
<i>How would you assess your own communication skills in having difficult discussions?</i>						
Worse	0%	0%	3%	0%	0%	4%
Same	0%	35%	79%	0%	7%	60%
Improved 1 unit	50%	65%	18%	33%	93%	36%
Improved 2+ units	50%	0%	0%	67%	0%	0%
<i>n</i>	6	23	33	3	15	25
<i>How would you assess your ability to develop and maintain relationships?</i>						
Worse	0%	0%	7%	0%		
Same	0%	25%	85%	0%	14%	65%
Improved 1 unit	0%	75%	7%	0%	86%	21%
Improved 2+ units	0%	0%	0%	100%	0%	0%
<i>n</i>	0	8	55	0	7	34
<i>How confident are you when having difficult discussions?</i>						
Worse	0%	0%	6%	0%	0%	23%
Same	7%	53%	88%	0%	33%	54%
Improved 1 unit	71%	44%	6%	56%	67%	23%
Improved 2+ units	21%	3%	0%	44%	0%	0%
<i>n</i>	14	32	17	9	21	13
<i>How anxious are you about having difficult discussions?</i>						
Worse	37%	9%	0%	38%	0%	0%
Same	58%	78%	25%	46%	45%	0%
Improved 1 unit	5%	9%	62%	15%	50%	56%
Improved 2+ units	0%	3%	12%	0%	5%	44%
<i>n</i>	19	32	16	13	20	9

^aEach cell reports the percentage of participants in that column who showed the level of improvement indicated in that row. For example, of the 15 participants who rated themselves as not at all or a little prepared at baseline, 47% increased their assessment by one category on the same question in the post-questionnaire.

First, the change score in each rating for each time point was regressed on the corresponding baseline measure, discipline, years of experience, number of difficult discussions led in the past year, previous learning opportunities and availability of a mentor. In addition, for each outcome at each time point, the same set of covariates was included in a logistic regression comparing those who improved one or more categories versus those who stayed the same or declined in their rating. The pattern of results was similar in the two sets of analyses, so only the ordinary least squares

regression results are reported (Table 3). Consistent with the effects of regression to the mean, the major predictor (r-square ranged from 0.28 to 0.50) of change for all outcomes at both post-training and follow-up was the corresponding baseline value. For preparation, communication skills, the ability to develop and maintain relationships and confidence, for every one unit increase in the baseline score, the change from baseline to post-training or follow-up decreased by about half a point on the five-point scale. In 8 out of 10 regression analyses, the addition of the other

Table 3 Regression of previous experience and self-appraisal before training on self-appraisal of preparation, communication skills, ability to develop and maintain relationships, confidence and anxiety at post-training and follow-up

	Preparation		Communication		Relationships		Confidence		Anxiety	
	Post-training	Fup ^a	Post-training	Fup	Post-training	Fup	Post-training	Fup	Post-training	Fup
<i>n</i>	62	39	62	40	63	39	62	40	66	39
Intercept	0.53+	1.04*	0.71*	0.91*	0.04	0.46	0.10	0.48	-0.12	0.43
Baseline	-0.50*	-0.47*	-0.51*	-0.66*	-0.46*	-0.65*	-0.60	-0.70*	0.59*	0.77*
Adjusted r-square	0.377	0.279	0.405	0.525	0.365	0.439	0.489	0.502	0.318	0.486
Nurse	0.15	-0.19	0.02	-0.29	-0.09	-0.14	-0.07	-0.16	-0.16	-0.50
Psychosocial clinicians	-0.17	-0.65	-0.09	-0.40	-0.22	-0.18	0.15	-0.18	-0.11	-0.40
Years of experience	0.01	0.01	-0.00	0.01	0.00	0.00	-0.00	0.03+	0.02	0.01
Discussions led	0.00	-0.06	-0.00	-0.20	0.05	0.02	0.11	-0.40	-0.07	0.37
Any previous education	-0.12	-0.25	-0.31	-0.14	0.09	-0.03	0.19	0.07	0.13	0.03
Mentor	0.41*	0.23	0.11	0.04	0.06	-0.29+	0.50*	0.05	-0.03	0.11
Adjusted r-square change	0.083	0.026	0.007	-0.025	-0.007	-0.028	0.108	0.038	-0.015	0.031
Adjusted r-square	0.460	0.305	0.398	0.500	0.358	0.411	0.597	0.540	0.303	0.517

* $P < 0.01$, + $0.01 < P < 0.05$.

^aFup refers to the follow-up questionnaire.

covariates, none of which achieved statistical significance, increased the explained variance by very little. Exceptions were a positive impact of having a mentor on self-appraisal of preparation ($b = 0.41$, $P < 0.01$) and confidence ($b = 0.50$, $P < 0.01$) in the post-questionnaire. Thus, the impact of the training was not related to discipline, years of experience, number of discussion led or previous learning opportunities.

PERCS-NICU was viewed as quite or very useful by 99% of participants in the post-training and 92% in the follow-up questionnaires. The quality of the training was perceived as very good or excellent by 98% of participants after the workshop and by 95% on follow-up. There were no differences by discipline in the ratings of the program's usefulness or quality. As testament to the value of the program, 93% reported that they had drawn upon what they had learned, 74% had made changes in their clinical practice or professional life, and 100% would recommend the program to other colleagues.

Qualitative findings

Six themes emerged from the open-ended questions including Integrating New Communication Skills and Relational Capacities, Honoring the Family Perspective, Appreciating Interdisciplinary Collaboration, Personal/Human Connection, Shift in Practitioner Perspective and Valuing the Learning Itself (Table 4).

Integrating new communication skills and relational capacities. Participants reported learning and practicing a range of communication and relational skills through the combination of realistic enactments, observation of others, feedback and discussion. They emphasized the importance of eliciting the

family's concerns, asking open-ended questions, listening attentively and demonstrating empathy, '*I remember to ask families, how do you feel? Do you understand? I look for cues for how families are coping—anger, tears, confusion....*'

Honoring the family perspective. Many clinicians reported a heightened appreciation for understanding and validating the family's perspective. They described the importance of mutual agenda setting and supporting the family in clarifying their values, '*I am more proactive in exploring value questions with families so that we have a baseline information and trust before the critical moments of decision-making arise.*'

Appreciating interdisciplinary collaboration. Participants highlighted the value of interdisciplinary collaboration in delivering holistic care. The workshops provided an opportunity to learn about the unique contributions of different disciplines and promoted interprofessional trust and respect, '*I used to think my role as a chaplain was to ... meet with families afterwards to pick up the emotional and spiritual pieces. I learned that the medical and nursing team welcomes support and collaboration from a chaplain.*'

Personal/human connection. Several participants realized the importance of being connected personally to families yet remaining within their professional roles, and how that commitment can positively influence families' healthcare experiences and memories. For example, '*Make appropriate and helpful use of our humanity, rather than feeling we need to hide or overcome it*' and '*It was humbling and inspiring to see how influential our*

Table 4 Qualitative themes*Integrating new communication skills and relational capacities*

'The most consistent change I have made is to ask parents what they know or understand about the situation at the beginning of the conversation.'

'Overall, approaching them (the family) more softly, mindfully and with greater empathy, reminding myself to stop and slow down before entering the patient's room.'

'The power of and the importance of silence, that sometimes it isn't what you say, but just your presence that is so important to families.'

Honoring the family perspective

'The importance of giving the family space, of listening to what they are saying and attempting to meet them where they are at in a given situation.'

'Don't assume things but try to understand before making any conclusions.'

'Try to step into the parents' world—their language, their concerns, their fears.'

Appreciating interdisciplinary collaboration

'I am much more insistent about doing a pre-conference with provider(s) before difficult conversations. Being prepared for the conversation is key!'

'After (the conversation), I try to ask the other staff in the meeting how they think it went, so that we can all improve how we lead and participate in the conversations.'

Personal/human connection

'I was relieved to find out that most of us shared the same uneasy and difficult feelings in critical situations.'

'It's okay to be human and not have all the answers.'

Shift in practitioner perspective

'I learned that each (conversation) has to be tailored individually, and that it is okay to walk away not feeling good about the conversation as long as you are honest with yourself and the family.'

'I am more empathetic...I am more aware of the lasting impact my words and actions will have on the family in the days, months and years ahead.'

Valuing the learning itself

'What a great opportunity to be a 'fly on the wall'...getting to 'see' a family meeting take place as an observer is not something we have an ability to do in our everyday practice.'

'It was made clear as a new clinician that even I have something to offer a family receiving bad news.'

'After almost 30 years of working as a nurse, there is always something to learn.'

roles are in the care of these families not only in the present, but in their futures as well.'

Shift in practitioner perspective. PERCS-NICU offered ample opportunity to reflect on what constitutes good communication and interpersonal relationships with families. The learning experience seemed to facilitate the questioning of previous assumptions and a greater awareness of the moral complexity of these conversations, *'I try to listen better. I expect not to have all the answers, but to go into situations 'prepared to be unprepared' for the family's reaction.'*

Valuing the learning itself. Practicing difficult conversations in a safe and supportive learning environment was valued highly. Aspects of the workshop that were identified as especially meaningful included the live enactments, videotape review, feedback from actor-parents and access to family faculty, *'The simulations with the actors are invaluable. They provided an open practice forum to work out some of my biggest fears communicating with families.'*

Discussion

Being able to initiate and hold difficult conversations with family members is a central feature of neonatology practice and, for the sake of families' accurate understanding and emotional well-being,

needs to be carried out well.^{22–24} Although medical and nursing schools have incorporated communication skills into curricula,^{25–27} postgraduate medical training typically has not.^{28,29} Generally, clinicians haphazardly acquire specialty-specific communication skills through observation, trial and error, and experience. In a recent survey, 93% of neonatology fellows reported that communication training was lacking and should be improved.²⁹ True enough, the gifts of communication and interpersonal relatedness come naturally to some, but these abilities can be nurtured, learned and refined with practice and training opportunities.^{30–39}

Workshop participants valued the pragmatic emphasis on real-life NICU conversations and the chance to learn and practice with interdisciplinary colleagues. Our results suggest that PERCS-NICU successfully enhanced participants' sense of preparation, communication skills and confidence when holding difficult conversations, particularly for those who self-reported lower baseline levels. These benefits were not related to discipline, level of experience or previous educational opportunities, with the exception of an additional improvement in preparation and confidence for those having a mentor. This suggests that the training has wide-ranging usefulness across disciplines and level of experience, and that mentors may further enhance learning. An improvement in the ability to develop and maintain relationships and a reduction in anxiety was reported by 75% or more of participants at both post-training and follow-up. These results are

similar to those of the original PERCS program designed for pediatric critical care clinicians¹⁶ and further support the efficacy of the learning paradigm and its transferability.

The workshops hold the promise of addressing the unique communicative challenges in the NICU setting. The enactments mimicked the unpredictable and rapid changes in an infant's clinical status, thereby providing realistic opportunities for participants to express cautious optimism early in the infant's course, discuss complications of prematurity and explore quality of life issues. The enactments realistically portrayed staff turnover and encouraged interdisciplinary collaboration. Different teams engaged in pre-meeting interdisciplinary huddles to clarify the purpose, agenda and participant roles of family meetings, and then held conversations with the actor-parents. To promote self-reflective practice and solidify the learning, teams debriefed after each conversation to identify effective communication and relational strategies that could improve their professional practice.

PERCS-NICU evoked strong responses from participants about maintaining a personal/human connection, honoring the family perspective, questioning their own assumptions and learning in an interdisciplinary context. Participants related these responses to being part of a learning environment that fostered self-reflection and offered opportunities for dialogue with parent-actors, family faculty and representatives of multiple professional disciplines. This is a rare opportunity because clinicians are unaccustomed to receiving genuine, timely feedback from parents and team members.

Our study has several limitations. Generalizability may be limited because participants were from three hospitals and affiliated with the same academic medical center. A professional relationship between some of the participants and the neonatology faculty might have influenced the participants' evaluations, although precautions were taken to assure that questionnaires were confidential and identified only by subject number. As attendees were largely self-selected, the surveyed group might be more open to reflection and self-improvement than a randomly selected group. We relied upon self-evaluation measures; ideally, future research should examine the impact of communication and relational training on family members' experience, clinical decision making and infant outcome.

As the number of neonatology trainees climbs and the value of communication and relational learning is increasingly recognized, and even mandated, effective and logistically feasible training programs will be needed.²⁹ That nearly all participants in our study reported drawing upon the skills and principles they had learned in our workshops with 75% of attendees changing their clinical practice underscores the relevance and promise of this learning paradigm. Further studies are needed to determine the optimal frequency of these programs to ensure the maximal impact on family-centered care. We hope that this study spawns new ideas, enthusiasm and scientific questions, and enables the benefits of

relational learning to flourish for practitioners and the families they serve.

Conflict of interest

The authors declare no conflict of interest.

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