Difficult Conversations in the Neonatal Intensive Care Unit

Susan Izatt, MD*

Abstract
The ability to communicate effectively with families in the neonatal intensive care unit (NICU) is an essential skill for clinicians. Parental satisfaction and trust depend on the perception of open communication that reflects compassion, honesty, and caring. Families struggling with difficult situations in the NICU derive great benefit from discussions in which information is provided clearly and with empathy. Strategies for delivering bad news have been developed within the medical community and can be adapted for difficult discussions in the NICU. Such strategies can be integrated within an interactive curriculum that emphasizes simulation and role play to promote competency in communication skills.

Introduction
More than 500,000 infants were born at less than 37 weeks’ gestation in the United States in 2005, with nearly 80,000 born at less than 32 weeks’ gestation. (1) The hospitalization of such infants in the NICU is very stressful and frightening for their families. (2) Effective and compassionate communication that permits the development of a trusting relationship between clinicians and families is essential for the provision of excellent care during this time, especially at times when difficult information must be delivered. (3)

Difficult conversations within the NICU include discussions surrounding the initiation and continuation of care for extremely preterm critically ill infants, the delivery of bad news regarding diagnoses and complications, and deliberations about the prolongation of life. Intertwined intimately in these conversations are multiple complexities, such as language, cultural diversity, and philosophical principles of the clinicians and the families.

Instructional strategies that focus on communication skills presently are very limited. Neonatology fellowship training historically has focused on medical knowledge and clinical care, with limited emphasis on communication and interpersonal skills. Such skills are essential to support family-centered care in the NICU. Modeling has been the primary instructional strategy used to train fellows in communication, employing methods such as participation in prenatal consultations and family meetings. Incorporation of novel teaching strategies that focus on communication skills in neonatology fellowship training is necessary.

Development of Trust
The creation of the “Principles for Family-centered Neonatal Care” in 1993 was led by 10 parents of preterm infants, with the goal of improving family participation in the care of and decision-making about their infants in the NICU. (4) The first principle states that “family-centered neonatal care should be
based on open and honest communication between parents and professionals on medical and ethical issues.” Establishing effective communication can form the foundation of trust that is essential for optimal care in the NICU.

In an observational study examining decision-making and communication in the NICU, King (5) recorded the number of contacts between clinicians and parents during each NICU hospital day as well as the content of conversations. Clinicians typically had many contacts with families on the first and second day of the infant’s NICU stay, but minimal subsequent contacts until discharge unless a crisis arose. During the first days of frequent contact, the clinicians spent much time gathering information about the infant and often delayed discussing the actual condition and prognosis until the assessment period had ended. King described clinicians telling families, “The first 24 to 72 hours are the most critical for your child, and we will know a lot more about how he’s likely to do after that; meanwhile, we’re doing everything possible.” She observed that families were gathering information at the same time, much of it from the nursing staff. By the time the clinicians met with the family to discuss the individual infant, the communication was a “one-way” transfer of information rather than a situation in which the family and clinician walked the path of learning and integrating information together, which leads to shared decision-making.

The “transparency” model for informed consent outlined by Brody (6) is cited by King as a strategy for improving communication with families in the NICU. In the model, “(1) The physician discloses the basis on which the proposed treatment, or alternative treatments, has been chosen; and (2) the patient is allowed to ask questions suggested by the disclosure of the physician’s reasoning, and those questions are answered to the patient’s satisfaction.” This model allows the family to participate in the entire decision-making process, with an emphasis on inclusion during the initial period of assessment.

Incorporation of the “transparency” model from the onset of the NICU hospitalization promotes relationships with families that are based on trust and mutual respect. Wocial (7) suggests that the most important aspect of family meetings is not the information presented, but whether the family believes it. Byrnes and colleagues (8) also have documented increased satisfaction with informing interviews for cleft lip and palate repair. Other studies have shown that “results in a cognitive, behavioral, or emotional deficit in the person receiving the news that persists for some time after the news is received.” Families who have an infant hospitalized in the NICU already are experiencing tremendous stress and emotional turmoil. Although individual reactions to bad news are highly variable, a consistent approach that incorporates established parent preferences while allowing clinicians to respond uniquely to each family is desirable when information that may be viewed as negative must be presented.

Krahn and colleagues (10) interviewed parents of children who had developmental disabilities about their experiences with the informing interviews to determine parent preferences for how to be given bad news. The results are consistent with similar surveys in the adult oncology literature that have led to published protocols for communicating bad news. (11)(12) Six steps for the delivery of bad news in the NICU can be extrapolated from the existing literature, including the SPIKES protocol. (11)

**Step 1: Preparing for the Family Meeting**

Families report the need for a private, quiet location for discussions of difficult news. Both parents generally wish to be present, often with other support persons such as extended family and clergy. Clinicians must arrange to have adequate uninterrupted time to meet with the family without distractions such as pagers and cell phones. Sitting with the family, maintaining eye contact, and acknowledging the infant by name are important in establishing rapport with the family. (10)(11)(13)

**Step 2: Assessing the Families’ Understanding of the Situation**

Effective communication begins with clinicians developing an understanding of the families’ perception of their infant’s medical condition. Misinterpretation of earlier discussions or incorrect information may hinder the ability of the family to listen to and comprehend the information in the current meeting. This assessment also may help the family feel that the health-care team is seeking to work with them, rather than...
simply talking to them. Examples of questions that can be asked include:

- How do you feel your son has been doing the past day in the NICU?
- Can you tell me what we discussed about your daughter the last time we spoke?

**Step 3: Delivering the Information**

Families focus on the perceived humility and caring of clinicians when struggling with difficult decisions such as withholding and withdrawing care. In delivering bad news, Quill and colleagues (14) suggest that the phrase “I wish . . .” provides a verbal expression of empathy that permits the physician to be seen as a human being. They suggest several phrases that can be used in discussion of very bad news, including:

- “I wish I had some better news to give you.”
- “I wish I had some other kind of news to give you.”

The pace at which information is delivered during a family meeting is crucial. Presentation of step-by-step information, with frequent pauses for questions, allows the family time to assimilate difficult news. Wocial (7) determined that families want information and appreciate clinicians who are direct and straightforward, encouraging questions. Medical information should be provided in simple words rather than technical terms.

**Step 4: Responding to the Families’ Emotions**

The response of a family to difficult news is unpredictable. The healthcare team must respond empathetically and offer support at this critical time. Adapting the definition by Coulehan and colleagues, (15) empathy is “the ability to understand the families’ situation, perspectives, and feelings and to communicate that understanding to the family.” It is not sympathy or apology.

Empathic responses by clinicians require observation and identification of the emotions experienced by the family members. If unsure, gentle questioning may be used to explore the feelings of the participants in the meetings. The emotions and responses of the family can be acknowledged with a connecting statement that reflects empathy and support. Sample connecting responses from Quill and associates (14) include:

- “I can understand how disappointing this is for you. I too wish we had been able to do more for your son.”
- “This is so hard for you, just when our hopes were so high, for your daughter to have this complication. I wish it had been otherwise.”

**Step 5: Discussing the Implications and Future Directions**

If the family is emotionally ready, shared discussion and decision-making about the future medical care of their infant is undertaken next. (12) Hope does not need to be taken away during these discussions, but it must be acknowledged that some events cannot be corrected or prevented. (16) The focus on hope during these conversations may be centered on pain control, family support, and dignity for the family facing their infant’s death. For families facing medical diagnoses that have long-term consequences, community resources and support groups may be the subsequent focus of the discussion.

Ubel (17) has written about the role of physician recommendations in decision-making around end-of-life care. He advocates that a physician recommend to a family that a family member not be resuscitated and then ask if the family agrees with the medical team’s recommendations rather than asking if the family wants the family member not to be resuscitated. With this approach, the physician and health-care team carry the responsibility of the decision not to resuscitate, thereby relieving some families of some of the guilt that accompanies difficult life support decisions. Careful attention to wording as well as the beliefs and needs of the family is vital during these difficult discussions.

**Step 6: Summarizing the Discussion**

Summarizing the discussion may help the family’s understanding, while allowing emphasis and clarification of key points. (16) It is important to validate that much information was discussed that may need further time for reflection before questions can be formulated by the family. Clinicians should stress their availability for future meetings if further questions or concerns arise and schedule a follow-up meeting if appropriate. Reinforcing the concept that there are no stupid questions by both words and approach further encourages ongoing, open communication. (12)

**Teaching Communication Skills**

The Accreditation Council for Graduate Medical Education (ACGME) Outcome Project (18) has identified interpersonal and communication skills as one of the six core competencies in residency education. Historically taught via the instructional strategy of modeling, significant focus recently has been put on communication skills training in the delivery of bad news. (19)(20) Examples of educational methods that are cited in the ACGME toolbox for training of interpersonal and communication skills include small group discussions, standardized patients (individ-
uals trained to simulate specific scenarios and illnesses accurately), small group role play, case-based seminars, and guided readings. (21)

The Oncotalk communication workshop for oncology fellows employs simulated patients who pretend to be at different points in their illness for sequential skill practice in the delivery of bad news and the transition to palliative care. (19) Educational strategies used in the curriculum include overview meetings for review of content material, skills practice sessions with the simulated patients and specified content, and reflective discussions. The curriculum is taught in small groups of five learners and one facilitator, with the facilitators and simulated patients receiving training prior to the workshop. Assessment of the curriculum by preintervention and postintervention observations and audio recordings demonstrated improved communication skills in the study participants.

A case-based curriculum using simulated family members has been employed to improve the communication of bad news in the pediatric emergency department. (20) Two scenarios have been developed surrounding the need to inform a family of the death of a child on arrival in the emergency department (motor vehicle crash and sudden infant death syndrome). The simulated family members are trained to give effective feedback to the resident learners. The learners participate in the first scenario with no antecedent training and are given feedback after the encounter, with the desired effect being improvement with the second scenario. Each session is videotaped, allowing the investigators to determine if the simulation and feedback improves communication skills by examining the two sessions. Evaluation of this curriculum revealed that counseling skills improved with this intervention, as did resident confidence and satisfaction.

Communication skills, including the delivery of bad news, can be taught effectively in residency and fellowship training. Creative teaching strategies, including role play, simulated patients and families, fish bowl techniques (a subset of learners has a discussion that is observed by the remainder of the group), and videotaping for self-analysis, can be employed to enhance the skill and confidence of the learners.

Conclusion

Competency in communication skills is necessary for successful family-centered care in the NICU. The inclusion of the family early in the decision-making process related to their infant will help to establish a relationship of trust between the family and clinicians. This trust may aid in sustaining candid and dynamic discussion when difficult issues must be addressed. Incorporation of strategies for the delivery of bad news that emphasize empathy and respect further support improved family satisfaction and understanding as complicated issues are addressed. To develop excellent communication skills, thoughtful teaching strategies and active reflection by the learner must be incorporated into curriculum design.

References

giving bad news and discussing transitions to palliative care. *Arch Intern Med.* 2007; 167:453–460


# Educational Perspectives: Difficult Conversations in the Neonatal Intensive Care Unit

Susan Izatt

*NeoReviews* 2008;9;e321

DOI: 10.1542/neo.9-8-e321

<table>
<thead>
<tr>
<th>Updated Information &amp; Services</th>
<th>including high resolution figures, can be found at: <a href="http://neoreviews.aappublications.org/content/9/8/e321">http://neoreviews.aappublications.org/content/9/8/e321</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>References</td>
<td>This article cites 18 articles, 7 of which you can access for free at: <a href="http://neoreviews.aappublications.org/content/9/8/e321#BIBL">http://neoreviews.aappublications.org/content/9/8/e321#BIBL</a></td>
</tr>
<tr>
<td>Subspecialty Collections</td>
<td>This article, along with others on similar topics, appears in the following collection(s):</td>
</tr>
<tr>
<td></td>
<td><strong>Fetus/Newborn Infant</strong> <a href="http://classic.neoreviews.aappublications.org/cgi/collection/fetus:newborn_infant_sub">http://classic.neoreviews.aappublications.org/cgi/collection/fetus:newborn_infant_sub</a></td>
</tr>
<tr>
<td></td>
<td><strong>Medical Education</strong> <a href="http://classic.neoreviews.aappublications.org/cgi/collection/medical_education_sub">http://classic.neoreviews.aappublications.org/cgi/collection/medical_education_sub</a></td>
</tr>
<tr>
<td>Permissions &amp; Licensing</td>
<td>Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at: <a href="http://classic.neoreviews.aappublications.org/site/misc/Permissions.xhtml">http://classic.neoreviews.aappublications.org/site/misc/Permissions.xhtml</a></td>
</tr>
<tr>
<td>Reprints</td>
<td>Information about ordering reprints can be found online: <a href="http://classic.neoreviews.aappublications.org/site/misc/reprints.xhtml">http://classic.neoreviews.aappublications.org/site/misc/reprints.xhtml</a></td>
</tr>
</tbody>
</table>
Educational Perspectives: Difficult Conversations in the Neonatal Intensive Care Unit
Susan Izatt
*NeoReviews* 2008;9:e321
DOI: 10.1542/neo.9-8-e321

The online version of this article, along with updated information and services, is located on the World Wide Web at: http://neoreviews.aappublications.org/content/9/8/e321