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## Communicating Prognosis with Parents of Critically Ill Infants: Direct Observation of Clinician Behaviors

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### Abstract

**Objective**—Delivering prognostic information to families requires clinicians to forecast an infant’s illness course and future. We lack robust empirical data about how prognosis is shared and how that impacts clinician-family concordance regarding infant outcomes.

**Study Design**—Prospective audiorecording of NICU family conferences, immediately followed by parent/ clinician surveys. Existing qualitative analysis frameworks were applied.

**Results**—We analyzed 19 conferences. Most prognostic discussion targeted predicted infant functional needs, e.g. medications or feeding. There was little discussion of how infant prognosis would impact infant/ family quality of life. Prognostic framing was typically optimistic. Most parents left the conference believing their infant’s prognosis to be more optimistic than did clinicians.

**Conclusions**—Clinician approach to prognostic disclosure in these audiotaped family conferences tended to be broad and optimistic, without detail regarding implications of infant health for infant/ family quality of life. Families and clinicians left these conversations with little consensus about infant prognosis.

### Keywords

Neonatal intensive care; Communication; Family

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## Introduction

Delivering prognostic information to families in the Neonatal Intensive Care Unit (NICU) requires clinicians to forecast an infant's illness course, often with predictions about quality and length of life. Discussing infant prognosis and helping parents understand what the future may hold for their infant is a key element of collaborative decision-making. This information can impact parental choices about treatment intensity and prepare families for their future.<sup>1</sup>

Formulating a prognosis is not simple. It requires clinicians to make judgments in conditions of uncertainty about both short- and long-term infant outcomes. Clinicians may face the challenge of disclosing to a family that their infant could experience disability or early death. Because several components of judging and conveying prognostic information are subjective, different clinicians may present families with different predictions of the future.

Data from a variety of medical disciplines suggest potential pitfalls in clinician and patient/family discussions about prognosis for serious conditions. A recent review of literature regarding surgical resection of malignant disease suggests that, while most patients/families want to know their prognosis, few clinicians share information about life expectancy.<sup>2</sup> Multiple authors have shown that clinicians are often overly optimistic when sharing bad or uncertain information.<sup>3,4</sup> In contrast, pessimistic framing of prognosis has been associated with improved clinician-patient agreement about prognosis.<sup>4</sup> Nyborn et al interviewed parents of children with advanced cancer who reported that excessive clinician optimism about prognosis actually undermines parent trust that clinicians will help them prepare for their child's decline.<sup>5</sup>

It remains unclear how prognostic information is delivered in usual NICU practice or how aspects of these conversations might enhance or impair parents' understanding, or impact parent-clinician trust. This gap in data is largely due to methodological challenges: most of what we know about clinician-parent communication in the NICU is drawn from parent or physician recall of prior conversations. While these data are important, they cannot uncover what is actually said in a conversation—versus what parents and clinicians think was said. Here we present an analysis of family-clinician communication about infant prognosis using a repository of audio-recorded NICU family meetings. We also examine how elements of these discussions are associated with clinician and family concordance regarding infant prognosis.

## Participants and Methods

### Participants & Data Collection

This study was conducted at an urban academic medical center with a 45-bed level IV NICU and diverse pediatric medical and surgical subspecialists. Between October 2012–October 2013 we prospectively identified parent-clinician conferences that the attending physician believed would involve “difficult news,” such as discussions about severe intracranial hemorrhage, encephalopathy, or genetic diagnoses, or that included serious decision-making, for example, regarding cardiopulmonary resuscitation or home ventilation. We then

approached families for consent to audiotape the conference. Up to 2 family members, one physician and one nurse completed surveys following the taped conversation. Detailed study methods have been reported elsewhere.<sup>6</sup> As recommended by Meert et al,<sup>7</sup> parent recruitment emphasized voluntariness of participation, and we deferred to clinician concerns that a family might be too distressed for study recruitment. The study was approved by the institutional review board and a Certificate of Confidentiality from the National Institutes of Health was obtained. All participants provided written consent.

## Data Analysis

As we are aware of no existing communication analysis framework relevant to the neonatal ICU, our analytic framework for the process and content of prognostic communication was drawn from two sources. First, we incorporated the schema Gramling et al<sup>8</sup> described in their analysis of clinician-family discussions regarding prognosis for seriously ill adult patients. This schema included 4 domains: 1) speaker (clinician vs. family), 2) topic of prognosis (length of life vs. quality of life), 3) focus of prognosis (population-based vs. individual), and 4) affective framing (pessimistic vs. optimistic). We extended this schema by incorporating the work of van Vleit et al to include 2 additional domains: 5) explicitness of prognosis (high vs. low) and 6) assurance of nonabandonment by clinicians (present vs. not).<sup>9</sup>

We made three principle adaptations to these domains for our population. First, we added a domain for timeframe of prognosis: short-term (in the next week) vs. mid-term (prior to NICU discharge) vs. long-term (after NICU discharge). Second, because our patient population did not necessarily have life-limiting conditions, we expanded “topic of prognosis” to include survival (length of life) vs. functional outcome (medical needs, disability) vs. quality of life (lived experience). And third, we anticipated that discussions of quality of life might relate to both infant and family experiences and we sought to highlight these separate yet related topics. Table 1 summarizes the analytic framework with example quotations.

Transcripts from the audiotaped parent-clinician conferences were reviewed jointly by 3 authors (RDB, MEL, PKD). Together we identified every conversation section (“block”) of prognostic communication within each transcript, following Gramling’s definition of prognostic information as “any forecast relating to the infant’s future outcome.”<sup>8</sup> For each block of prognostic information, we coded uninterrupted speaker turns (“speaker segments”) using the 7 a priori codes. Where disagreement occurred among coders regarding prognostic blocks or speaker segments, joint discussion continued until consensus was reached. Speaker segments were excluded if they were brief and lacked information (eg, “Okay” or “Alright.”). For each transcript, we determined the number of blocks of prognostic communication, followed by the number of speaker segments per block. Finally, within each speaker segment, we calculated the frequencies for the 7 a priori codes.

Clinician and family surveys asked participants to estimate the likelihood (0–10%, 11–25%, 26–50%, 51–75%, or >75%) that the infant would survive without serious problems. Clinicians were asked to judge whether life-sustaining therapy could or should be withheld/

withdrawn from the infant, and to rate their comfort with delivering bad news. Descriptive statistics were used to analyze these data.

## Results

### Participant and conference characteristics

A total of 19 conversations were recorded and involved 23 different clinicians (“primary clinicians”) and 31 family members. Infant diagnoses along with demographic characteristics of family and clinician participants are described in Table 2. Most primary clinicians were neonatology attending physicians or fellows. Twelve conversations included non-physician team members (9 nurses, 7 social workers, 4 trainees, 1 case manager, 1 respiratory therapist, 1 physician assistant).

The conversations occurred at variable points during the NICU hospitalization (range infant day of life 1 to 5 months). Five of 19 infants died in the NICU or were discharged to hospice care.

Clinician’s reported comfort with giving bad news varied, but was generally high. The majority (66%) indicated that they felt very/ pretty comfortable discussing bad news with families, 25% felt comfortable, and 9% felt not very/ not at all comfortable.

### Discussions of prognosis

Sixteen of 19 (84%) conversations contained at least one block of prognostic communication and were included in the analyses. Of the 3 excluded conversations, one child had signs of severe neurodevelopmental impairment, one had a major congenital anomaly and was trach-dependent, and another had worsening pulmonary hypertension. All 3 conversations included decisions with implications for both quality and length of life.

For the 16 conversations with prognostic information, there were a median of 10 blocks of prognostic communication, with a range from 2 to 17 blocks (Table 3). Clinicians were the first to raise the topic of prognosis in 69% of discussions. Most discussion of prognosis addressed infant outcome after NICU discharge and emphasized predicted functional needs such as daily medications or feeding regimens. There was little discussion of how an infant’s prognosis would impact infant or family quality of life. Prognostic statements were twice as likely to be optimistic as pessimistic. Clinician expressions of nonabandonment were uncommon.

### Perceptions of prognosis

Table 4 compares clinician and parent perceptions of long-term prognosis for individual infants. In 2 cases there was complete clinician-parent agreement about infant prognosis; both infants were discharged to hospice. In all but one of the remaining cases, one/ both parents believed the prognosis to be more optimistic than did clinicians. In 10/16 (63%) of cases, clinicians believed the infant had less than a 10% chance of surviving with no/ minor disability; for just over half of those patients (60%), a clinician believed life sustaining therapies *could* be withheld/ withdrawn. No clinician indicated that such therapies *should* be limited for any infant. Table 5 demonstrates that individual elements of prognostic

communication were no different in those cases where clinicians estimated the most severe infant prognosis.

When asked “*If you had to name one thing, what is most important to you about what happens with your baby?*” infant quality of life was the most common parent response (n=10), followed by good communication with medical team (n=6), infant health (n=5) and infant survival (n=4).

## Discussion

Frameworks for counseling parents with critically ill newborns remain largely empirical in the absence of robust observational data about how prognostic information is communicated between clinicians and families.<sup>10</sup> Here we present an analysis of real-time prognostic discussions between NICU parents and clinicians; more often than not, clinicians and families walked away from these conversations with different understandings of an infant’s potential length of life and quality of life. While the state of the science regarding clinician-parent communication in the NICU has generally been limited to parent or physician report of what happened in conversations, this study represents an important advance in our ability to analyze both what was actually said in a conversation and what parents and clinicians think was said. Here we explore aspects of these conversations that highlight challenges in sharing, and reaching consensus about, information regarding infant prognosis in the NICU.

First, clinicians raised the topic of infant prognosis in two thirds of the discussions. This finding suggests that clinicians cannot rely on parents to request prognostic information, though multiple studies in other pediatric populations demonstrate that parents want clinicians to provide straightforward information about their child’s future.<sup>5</sup> Data from parents of children with cancer would suggest that, while prognostic information is important and reduces uncertainty, it can be difficult to hear.<sup>5</sup> This ambivalence may undermine parent initiative, as has been described for adult patients, placing more responsibility on clinicians for explicitly raising discussions of prognosis.<sup>9</sup> It is notable that, for the 3 conversations in this study that did not include prognostic information, all 3 discussions included plans and decisions with implications for infant prognosis. Triggers for prognostic discussions, i.e. as part of structured family meetings or question prompt lists, could be studied for their ability to facilitate these conversations.<sup>11, 12</sup>

Second, the prognostic information that clinicians shared in these conversations was largely broad and the details that were included were largely pragmatic. For example, instead of being told that an infant was likely to have neurodevelopmental delay and what that might look like, a parent was told that the infant would need “developmental follow-up clinic” and was given instructions for making an appointment. When prognostic information lacks detail, it permits different interpretations; this may underlie why parents and clinicians in this study nearly always had discordant views about infant prognosis. We have previously shown that, even when clinicians feel that their conversations with a NICU parent have gone well, more than a third of parents underestimate their infants’ illness severity.<sup>13, 14</sup> Because conversations in our prior study were not recorded, it was unclear how explicit the dialogue about prognosis was. Anderson et al have shown that generalized prognostic information

may be favored by physicians, but families often want detailed information, including numeric estimates.<sup>15</sup> For adult patients, explicit prognostic discussions can increase understanding and decrease both uncertainty and anxiety.<sup>9, 16</sup> In the perinatal context, reliable numeric estimates of prognosis may not be available, and clinicians struggle to frame prognostic uncertainty without creating unrealistic hopes. Similar problems confront specialties such as surgery, where clinicians must speculate in the context of uncertainty. Communication tools that can elaborate prognostic detail, without relying on numeric precision, such as the “best case/ worst case/ most likely outcome” tool, have shown promise in other settings. Their usefulness to families in the NICU should be studied.<sup>17, 18</sup>

Third, while clinicians in this study indicated to the researchers that nearly every infant had <25% chance of surviving without serious problems, clinicians were twice as likely to be optimistic than pessimistic in their framing of prognosis to parents. The common use of optimistic framing could help explain why parents generally left these meetings with a more positive impression of their infant’s prognosis than did clinicians. Excess clinician optimism when discussing patient prognosis has been reported in a variety of other settings, an approach that clinicians may take out of a desire to preserve patient/ family hope.<sup>19–21</sup> In contrast, others have shown that parent hope is not tied to the prognosis for their child with a serious illness, but instead is an inherent part of their role as parent.<sup>22</sup> The effect that overly optimistic prognostic information may have on NICU parent-clinician trust is not known, and should be investigated. It has also been shown that when clinicians use a more pessimistic framing of prognosis with adult patients, patient understanding of their prognosis is increased.<sup>4</sup> Sharing a poor prognosis with a patient and family can provoke stress and anxiety for clinicians, making it a difficult skill.<sup>23, 24</sup> Clinicians in our study told us that they were quite comfortable giving bad news, but there may be room for communication training interventions that target less optimistic framing of prognostic information.

Finally, these discussions we recorded rarely connected an infant’s expected health risks with the implications for infant or family quality of life. Yet parents, immediately following these discussions, most often named quality of life as their most important concern. Health-related quality of life is an essential component of overall quality of life, and is often central to the medical decisions that adult patients make in the context of serious illness.<sup>25</sup> When clinicians do not underscore the potential lived experience of visual impairment, intellectual disability, or chronic ventilator-dependence, families may be left unprepared. We have previously shown that NICU parents are distressed when clinicians do not explore “the big picture” of what to expect for their infant.<sup>26</sup> A mismatch of neonatologist and parent priority for quality of life discussions has been noted in prenatal counseling as well.<sup>27, 28</sup> Whether this truly reflects clinician priorities, or instead clinician skills, is unclear. It is interesting that just one-third of the physicians and nurses caring for those infants with the worst prognosis in our study felt that life-sustaining therapies could be withheld/ withdrawn from those patients, and that no clinician thought that life-sustaining therapies should be withdrawn from any study infant. While reluctance to limit interventions could reflect clinician perception of parent “buy-in” to ongoing therapies, it could also suggest that parents and clinicians prioritize quality of life differently when making decisions.<sup>29, 30</sup> Because parents tended to wait for clinicians to raise the topic of prognosis, and often perceived their infant’s prognosis to be more optimistic than clinicians did, it could be that

discussion of treatment limitations will only occur if clinicians raise it. When silent about this option, clinicians may not be fulfilling their duty to collaborative decision-making.

There are several limitations to this study. We recorded just one conversation in an infant's NICU course, and do not have insight into whether prognostic conversations had occurred at other times. Participants in these discussions may have altered their usual behavior because they knew they were being recorded. Potential differences based on parent race/ ethnicity, education, or socioeconomic status deserve further study. Finally, because we were unable to find a communication analysis framework relevant to the NICU, our analytic framework for prognostic communication was adapted from one for adult ICU conversations; future work should continue to refine this framework to more closely map NICU conversations.

Discussing infant prognosis with parents of sick newborns and helping parents understand what the future is likely to hold for their infant is a key element of collaborative decision-making. It often precedes decisions to escalate, or limit, treatment intensity in the NICU. It also reduces anxiety and helps parents plan for the future. Clinicians in this study provided prognostic information that was generally broad and optimistic, regardless of their belief that the infant was likely to have a good outcome. The information tended to be pragmatic, focused on the need for further therapies or follow-up, rather than on the implications of those needs. Future work should examine the impact of strategies to help both clinicians and families prepare for in discussions about infant prognosis and treatment intensity. These strategies could include clinician communication skills training, parent tools like question prompt lists, structured prognostic communication guides, or asking parents to “teach back” to ensure understanding. In addition, reliable evaluation of these strategies depends on continued refinement of methodologies to study clinician-family communication and decision-making.

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## Abbreviations

NICU      Neonatal Intensive Care Unit

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**Table 1**

## Discussions of Prognosis: Analytic Framework

<b>Coded Domains and Example Quotations</b>	
<b>1. Speaker</b>	<ul style="list-style-type: none"> <li>-- Clinician: <i>"We know that having areas with cysts in the brain can impact development"</i></li> <li>-- Family: <i>"Will he walk?"</i></li> </ul>
<b>2. Timeframe of Prognosis</b>	<ul style="list-style-type: none"> <li>-- Short-term: <i>"I don't think she's a risk of having a problem tonight."</i></li> <li>-- Mid-term: <i>"It may take a few weeks to know if he is going to be able to feed or not."</i></li> <li>-- Long-term: <i>"He's most likely going to need [the shunt] his whole life."</i></li> </ul>
<b>3. Topic of Prognosis</b>	<ul style="list-style-type: none"> <li>-- Survival: <i>"The likelihood of her surviving without the operation is very low."</i></li> <li>-- Functional outcome: <i>"He will likely be delayed with most of his milestones."</i></li> <li>-- Quality of life: <ul style="list-style-type: none"> <li>-- Infant Quality of Life: <i>"We don't want him conked out from the seizure medications, we want him to know we are there."</i></li> <li>-- Family Quality of Life: <i>"There's a whole family to take into consideration here."</i></li> </ul> </li> </ul>
<b>4. Focus of Prognosis</b>	<ul style="list-style-type: none"> <li>-- Population-based: <i>"As with any baby who has been in the NICU and has had brain issues, we will follow him closely."</i></li> <li>-- Individualized: <i>"She will sit later, crawl later, and walk later."</i></li> </ul>
<b>5. Explicitness of Prognosis</b>	<ul style="list-style-type: none"> <li>-- Broad: <i>"I wouldn't be surprised if he needed some assistance, at least for a while."</i></li> <li>-- Precise: <i>"The biggest challenge we have is to make sure that he can breathe on his own."</i></li> </ul>
<b>6. Affective Framing</b>	<ul style="list-style-type: none"> <li>-- Pessimistic: <i>"The feeding problem is going to be a challenge."</i></li> <li>-- Optimistic: <i>"He may outgrow it and not need it."</i></li> </ul>
<b>7. Clinician Assurance of Nonabandonment</b>	<ul style="list-style-type: none"> <li>-- Present: <i>"We will continue to work with you to figure out what to expect for your son."</i></li> </ul>

**Table 2**

Demographic Characteristics of Patients, Parents, and Primary Clinicians

Characteristic	Infants (n=19)	Parents (n= 31)	Primary Clinicians (n= 23)
Gender			
Female	9	21	18
Male	10	10	5
Race/ ethnicity			
White	12	19	15
African American	7	12	5
Asian or Pacific Islander	0	0	3
Primary diagnosis			
Extreme prematurity	5		
Congenital heart disease	4		
Major congenital anomaly	2		
Other genetic syndrome	4		
Hypoxic ischemic encephalopathy	1		
Other	3		
Relationship to infant			
Mother		19	
Father		10	
Grandparent		1	
Other relative		1	
Level of education			
High school or less		9	
Some college		9	
College graduate		10	
Graduate school		3	
Staff position			
Attending physician			11
Fellow			7
NP or PA			5
Pediatric specialty			
Neonatology			15
Neurosurgery			3
General surgery			1
Cardiology			1
Genetics			2
Palliative care			1
Years in practice			

Characteristic	Infants (n=19)	Parents (n= 31)	Primary Clinicians (n= 23)
<5			7
5–10			4
10–20			4
20+			8

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**Table 3**

## Characteristics of Prognostic Conversations

Domains		Number of Blocks of Prognostic Information Per Conversation
		Median (range)
Speaker	Clinician	10 (2–17)
	Parent	3.5 (0–13)
Timeframe of Prognosis	Short	1.5 (0–8)
	Mid	0 (0–7)
	Long	7.5 (0–22)
Topic of Prognosis	Survival	0 (0–10)
	Functional	6 (1–21)
	Quality of Life	
	Total	1 (0–14)
	Infant	0.5 (0–12)
	Family	0 (0–10)
Focus of Prognosis	Population	2 (0–12)
	Individual	9 (2–34)
Explicitness of Prognosis	Broad	6 (1–16)
	Precise	4 (1–16)
Affective Framing	Pessimistic	1.5 (0–9)
	Optimistic	3 (0–10)
Assurance of Nonabandonment	“We statement”	1 (0–3)

Survey Data: Perceptions of Infant Prognosis and Appropriateness of Limiting Therapies

Table 4

Case	“What do you think are the chances the baby will survive without any serious problems?”						“How strongly do you believe that life-sustaining therapy should be withheld or withdrawn for this baby?”	
	0–10%	11–25%	26–50%	51–75%	76–100%	“Should”	“Could”	“Should not”
1	C1		P1				C1	
2	C1		*				C1	
3	C2	P1	C2		P2			C1, C2
4	C2	C1		P2	P1		C1	C2
5	C1,C2,P1,P2						C2	C1
6	C1		P1					C1
7		C1		P2	P1			C1
8	C1, C2		P1		P2			C1, C2
9					C2,P1			C2
10	C1	C2,P2		P1			C1	C2
11	C1,C2,P1,P2						C2	C1
12				C1,P1	P2			C1
13	P2	C1	C2,P1					C1, C2
14	C1		C2,P2	P1				C1, C2
15		C1		C2	P1			C1, C2
16		C1			C2,P1,P2			C1, C2

C1=Physician, C2=nurse, P1=Mother, P2=Father/ other family member

\* Parent data missing



**Table 5**

Characteristics of Prognostic Conversations by Clinician Estimate of Survival

Domains		Clinician estimate of infant survival without serious problem	
		<10% Median (min, max)	>10% Median (min, max)
Speaker	Clinician	11 (2–16)	7 (3–17)
	Parent	4 (0–13)	3 (0–8)
Timeframe of Prognosis	Short	1.5 (0–8)	1 (0–4)
	Mid	0.50 (0–5)	0 (0–7)
	Long	12.5 (0–22)	7 (3–19)
Topic of Prognosis	Survival	0 (0–8)	0 (0–10)
	Functional	7 (1–21)	6 (3–13)
	Quality of Life	1 (0–14)	1 (0–6)
Focus of Prognosis	Population	4 (0–12)	1.5 (0–8)
	Individual	9 (2–23)	8.5 (4–34)
Explicitness of Prognosis	Broad	7 (1–16)	4.5 (2–10)
	Precise	6.5 (1–16)	3 (1–15)
Affective Framing	Pessimistic	3.5 (0–9)	1 (0–8)
	Optimistic	3.5 (1–10)	2 (1–10)
Assurance of Nonabandonment	“We statement”	1 (0–3)	0 (0–1)