# UCSF UC San Francisco Previously Published Works

# Title

The ALIGN Framework: A Parent-Informed Approach to Prognostic Communication for Infants With Neurologic Conditions.

# Permalink

https://escholarship.org/uc/item/9gq3471f

**Journal** Neurology, 100(8)

# Authors

Lemmon, Monica Barks, Mary Bansal, Simran <u>et al.</u>

**Publication Date** 

2023-02-21

# DOI

10.1212/WNL.000000000201600

Peer reviewed

# The ALIGN Framework

# A Parent-Informed Approach to Prognostic Communication for Infants With

# Neurologic Conditions

Monica E. Lemmon, MD, Mary C. Barks, MA, Simran Bansal, Sarah Bernstein, MD, MHA, Erica C. Kaye, MD, MPH, Hannah C. Glass, MD, Peter A. Ubel, MD, Debra Brandon, PhD, and Kathryn I. Pollak, PhD

Neurology<sup>®</sup> 2023;100:e800-e807. doi:10.1212/WNL.000000000201600

# Abstract

# **Background and Objectives**

Clinicians often communicate complex, uncertain, and distressing information about neurologic prognosis to parents of critically ill infants. Although communication tools have been developed in other disciplines and settings, none address the unique needs of the neonatal and pediatric neurology context. We aimed to develop a parent-informed framework to guide clinicians in communicating information about neurologic prognosis.

# Methods

Parents of infants with neurologic conditions in the intensive care unit were enrolled in a longitudinal study of shared decision-making from 2018 to 2020. Parents completed semistructured interviews following recorded family meetings with the health care team, at hospital discharge, and 6 months after discharge. All interviews targeted information about parent preferences for prognostic disclosure. We analyzed the data using a conventional content analysis approach. Two study team members independently coded all interview transcripts, and discrepancies were resolved in consensus. We used NVIVO 12 qualitative software to index and organize codes.

## Results

Fifty-two parents of 37 infants completed 123 interviews. Parents were predominantly mothers (n = 37/52, 71%) with a median age of 31 (range 19–46) years. Half were Black (n = 26/52, 50%), and a minority reported Hispanic ethnicity (n = 2/52, 4%). Inductive analysis resulted in the emergence of 5 phases of prognostic communication (Approach, Learn, Inform, Give support, and Next steps: ALIGN): (1) Approach: parents appreciated receiving consistent information about their child's neurologic outcome from clinicians who knew their child well. (2) Learn: parents valued when clinicians asked them how they preferred receiving information and what they already knew about their child's outcome prior to information delivery. (3) Inform: parents valued honest, thorough, and balanced information that disclosed prognostic uncertainty and acknowledged room for hope. (4) Give support: parents valued empathic communication and appreciated clinicians who offered real-time emotional support. (5) Next steps: parents appreciated clinicians who connected them to resources, including peer support.

# Discussion

The ALIGN framework offers a novel, parent-informed strategy to effectively communicate neurologic prognosis. Although ALIGN represents key elements of a conversation about prognosis, each clinician can adapt this framework to their own approach. Future work will assess the effectiveness of this framework on communication quality and prognostic understanding.

Correspondence

Dr. Lemmon monica.lemmon@duke.edu

### RELATED ARTICLE

### 🕜 Editorial

What Do Parents of Seriously Ill Infants With Neurologic Conditions Want From Their Medical Team? Starting Out With Care Page 361

MORE ONLINE

From the Departments of Pediatrics (M.E.L., M.C.B., S. Bansal, S. Bernstein), Population Health Sciences (M.E.L., K.I.P.), Duke University School of Medicine, Durham, NC; University of Utah School of Medicine (S. Bernstein), Salt Lack City; Department of Oncology (E.C.K.), St. Jude Children's Research Hospital, Memphis, TN; Departments of Neurology and Pediatrics (E.C.K.), UCSF Benioff Children's Hospital and Department of Epidemiology & Biostatistics (H.C.G.), University of California, San Francisco; Fuqua School of Business and Sanford School of Public Policy (P.A.U.), Duke University, Durham; and Duke University School of Nursing (D.B.), Durham; Cancer Prevention and Control (KIP), Duke Cancer Institute, Durham, NC.

Go to Neurology.org/N for full disclosures. Funding information and disclosures deemed relevant by the authors, if any, are provided at the end of the article.

# Glossary

ICU = intensive care unit.

Communicating with families about clinical outcomes is a key role of a child neurologist. For infants with neurologic conditions, conversations about outcome help families prepare for life at home, conceptualize their child's future quality of life, and make decisions about health care.<sup>1-3</sup> Despite the complexity and frequency of prognostic communication for children with neurologic conditions, little is known about how caregivers and patients prefer information about outcome to be shared.

Multiple frameworks exist to guide prognostic communication or the delivery of bad news, including several developed in the adult critical care, oncology, and end-of-life contexts.<sup>49</sup> These useful frameworks offer a starting place to guide conversations about neurologic outcome in childhood, recognizing that many tenets of high-quality communication are universal. Conversations with parents of infants with neurologic conditions, however, differ from prognostic conversations in adult settings in several ways. For the majority of infants with neurologic conditions, clinicians lack adequate data to estimate prognosis with the same degree of certainty present in other disciplines.<sup>10-13</sup> Many existing prognostic communication frameworks were developed to support conversations about the potential for survival.<sup>14</sup> Conversations in the neonatal and infant context are rarely about survival and more often center on the potential for life with neurologic impairment.<sup>15</sup> These differences underscore the need for dedicated study of parent preferences for prognostic communication in the context of potential neurologic impairment.

The ouR-HOPE framework has been presented as an important guide for clinicians to identify their own biases about neurologic prognosis for infants with neurologic conditions. This framework centers the principles of reflection, humility, open-mindedness, partnership, and engagement and encourages clinicians to complete a guided self-assessment.<sup>8,16</sup> Although this important work helps clinicians reflect on their prognostication practices, it does not offer guidance around communication strategies or behaviors. A critical next step of this work is to provide clinicians with concrete advice about how to approach and execute discussions about neurologic prognosis.

Developing a framework for prognostic discussion for infants with neurologic disease requires empiric data from parents. We aimed to (1) characterize parent preferences for prognostic communication and (2) develop a parent-informed framework for prognostic disclosure.

# Methods

# **Study Design and Participants**

We enrolled parents of critically ill infants with neurologic conditions in a longitudinal descriptive study of decision-making between the years of 2018–2020. Infants were eligible if they met the following inclusion criteria: (1) hospitalization in an intensive care unit (ICU), (2) age less than 1 year, (3) diagnosed neurologic condition, and (4) planned family meeting to discuss the withdrawal or initiation of life-sustaining treatment or medical technology. Exclusion criteria included (1) maternal age <18 years, (2) maternal hearing and/or speech impairment, or (3) inability to read and speak in English. Our methodologic approach has been outlined in previous publications from this cohort.<sup>15,17-19</sup>

We collected parent demographic information via survey and infant characteristics via medical record review. Study staff interviewed parents at 3 distinct time points: (1) following recorded family conferences, (2) at discharge from the hospital, and (3) 6 months following hospital discharge. For infants for whom discharge was anticipated within 1 week of a family meeting with the health care team, these interviews were combined. All interviews were semistructured and included questions centered on understanding how parents preferred information about prognosis be disclosed, including questions like "What has the team done well as they've talked with you about your child's future?" and "What advice do you have for doctors who need to talk with families about their child's future?"

# Standard Protocol Approvals, Registrations, and Patient Consents

All parent participants provided written informed consent. The Duke University Health System Institutional Review Board approved the study protocol.

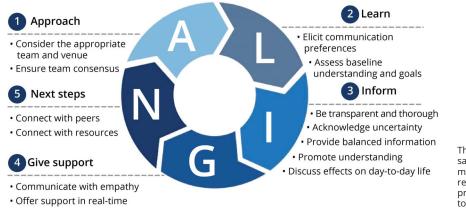
## **Statistical Analysis**

Demographic characteristics were summarized using descriptive statistics. We summarized continuous variables primarily using median and range. We summarized categorical variables using frequency counts and percentages. All statistical analyses for demographics were performed using R software Version 4 (or higher).

## **Qualitative Analysis**

The study team included neurology clinicians (M.E.L. and H.C.G.), neonatology clinicians (S.B.), qualitative analysts (M.E.L., M.C.B., E.C.K., S.B., and D.B.), nurse-scientists (D.B.), and communication researchers (M.E.L., E.C.K., P.A.U., and K.I.P.). Interviews were audio recorded. Each interview was transcribed and deidentified. We analyzed qualitative data using a conventional content analysis inductive approach.<sup>20</sup> In the absence of a consensus framework to approach prognostic disclosure, we developed and refined a novel codebook. The initial codebook was tested on a randomly selected set of interviews to ensure completeness and consistency in code application. The codebook was refined through iterative discussion and pilot testing. Using the final

#### Figure 1 ALIGN Framework



The ALIGN framework acknowledges that conversations about prognosis are often iterative and must be revisited over time. Although ALIGN represents key elements of a conversation about prognosis, each clinician can adapt this framework to their own approach.

codebook, 2 study team members (M.C.B. and S.B.) coded all interview transcripts independently. Discrepancies were resolved via consensus and adjudicated by the senior author (M.E.L.). All available interviews were analyzed. In some cases, participants discussed prognostic communication preferences outside of the times in which they were explicitly asked and/or did not answer the posed questions directly. For this reason, all interview content was reviewed and coded when applicable. In cases in which the interview content was unclear and/or subject to multiple interpretations, other data sources (for example, recorded family conference data) were referenced to offer additional context. We used NVIVO 12 qualitative software to index and organize codes.

#### Data Availability

Some data not provided in the article because of space limitations may be shared (anonymized) at the request of any qualified investigator for purposes of replicating procedures and results. Due to the nature of the qualitative data presented, some limitations on full data sharing may be necessary to align with consent procedures and ensure adequate de-identification.

# Results

We enrolled 61 parents (n = 40 mothers; n = 21 fathers) of 40 infants with neurologic conditions in the ICU. Of these, 52 parents (n = 37 mothers; n = 15 fathers) completed 123 interviews. Nine parents did not complete interviews. Parents had a median age of 31 (range 19–46) years. Half identified as Black (n = 26/52, 50%), and a minority reported Hispanic ethnicity (n = 2/52, 4%). Nearly half of infants were born premature (n = 18, 49%), and approximately one-third had seizures (n = 12, 32%) and/or a genetic condition (n = 12, 32%) (Tables 1 and 2).

Via inductive analysis, we identified 5 phases of prognostic communication (Approach, Learn, Inform, Give support, and Next steps: ALIGN): (1) Approach: parents appreciated

receiving consistent information about their child's outcome from clinicians who knew their child well. (2) Learn: parents valued when clinicians asked them how they preferred receiving information and what they already knew about their child's outcome prior to information delivery. (3) Inform: parents valued honest, thorough, and balanced information that disclosed prognostic uncertainty and acknowledged room for hope. (4) Give support: parents valued empathic communication and appreciated clinicians who offered real-time emotional support. (5) Next steps: parents appreciated clinicians who connected them to resources, including peer support (Table 2).

### Approach

#### **Consider the Appropriate Team and Venue**

Parents described the importance of ensuring prognostic information was delivered by clinicians who knew their child well. Parents valued when clinicians identified those team members with whom parents had an established relationship and invited them to major conversations. A parent of an infant with a brain malformation explained:

You have to tell this family that their child has this and it might be really hard to digest. Maybe figure out who that family has a pretty good rapport with. Who on the staff is really good at dealing with the family? So, ask the family: "Hey, we want to have a little sit down with you later, is there anyone who you might want to be there?"

Some parents described the benefits of certain venues; for example, team meetings where multiple providers were present at once allowed for efficient communication from multiple teams. Others, however, described the challenges associated with large team meetings, including the sentiment that meeting with a large team could be overwhelming. As shared by one father of an infant with hydrocephalus: "It feels like you're at the zoo. You feel like you're being looked at."

#### **Ensure Team Consensus**

Some parents described the importance of teams ensuring consensus prior to sharing prognostic information. Parents

### Table 1 Infant Characteristics

Characteristic	Median (range) or n (%)	
Infant characteristics (n = 37)		
Gestational age at birth, wk	37	(23–41)
Sex, female	19	(51)
Medical condition		
Prematurity (<37 wk)	18	(49)
Seizures	12	(32)
Genetic diagnosis	12	(32)
Brain malformation	10	(27)
Intraventricular hemorrhage	9	(24)
Hypoxic ischemic encephalopathy	7	(19)
Stroke	6	(16)
Periventricular leukomalacia	5	(14)
Interventions (%)		
Mechanical ventilation	30	(81)
Surgical feeding tube placement	18	(49)
Tracheostomy placement	7	(19)
Therapeutic hypothermia	6	(16)
Median length of hospital stay (range)	76	(8–344)
Death during study enrollment (%)	6	(16)

appreciated when clinicians gave consistent information among members of the team. Some parents reported distress when clinicians disagreed about their infant's neurologic prognosis. One mother of an infant with a brain malformation shared:

Have them get themselves together what the doctors telling me. One of the doctors telling me that she had brain disease that was progressively getting worse and she had a week to live; the other doctors telling me that wasn't true. I wish everyone had it together.

#### Learn

#### **Elicit Communication Preferences**

Parents appreciated when clinicians asked how they liked to receive information. Some parents underscored that each parent may have a different style of learning, for example, appreciating statistics or visual aids. One father described wishing that clinicians routinely asked, "What is the best way to communicate this to you?"

Other parents described the need for clinicians to pace information to allow time for processing. For some parents, having control over information was described as empowering. As one mother of an infant with intraventricular hemorrhage explained: "Give parents control over something as basic as 'How much information do you want?' Even that is empowering."

### Table 2 Parent Characteristics

Characteristic	Median (range) or n (%			
Parent characteristics (n = 52)				
Age, y	31	(19–46)		
Sex, female	37	(71)		
Race and ethnicity				
African American	26	(50)		
Asian	3	(6)		
Hispanic/Latinx	2	(4)		
White	23	(44)		
More than 1 race	3	(6)		
Other/not reported	1	(2)		
Level of education				
Less than high school	2	(4)		
High school/GED	13	(25)		
Some college	12	(23)		
Bachelor's degree	10	(19)		
Associate's degree	3	(6)		
Graduate or professional degree	12	(23)		
Annual household income				
Less than \$25,000	18	(35)		
\$25,000-\$34,999	10	(19)		
\$35,000-\$49,999	2	(4)		
\$50,000-\$74,999	5	(10)		
\$75,000-\$99,999	3	(6)		
\$100,000-\$149,999	7	(13)		
Greater than \$150,000	6	(12)		
Not reported	1	(2)		

#### **Assess Baseline Understanding and Goals**

Some parents described the need for clinicians to begin by assessing the parent's baseline understanding of prognosis, both to correct misunderstanding and to avoid repeating unnecessary information. As shared by one mother of an infant with intraventricular hemorrhage:

Dr. [name] said, "Tell me what you know about [name]'s head bleed..." And I think that's really important because it assesses where the family is, and then you can either build on or correct misinformation they may have and then that way you don't repeat things that they already know.

One parent described the potential benefit of allowing parents to share information, questions, and concerns in advance of a conversation with the medical team. A mother of a child with hypoxic ischemic encephalopathy highlighted how this strategy

could be especially useful for parents who may feel intimidated by large group conversations:

It might help some parents if there was some sort of form or questionnaire they could fill out prior to that conversation. That when they go in, the doctor may already have some idea of any big fears they may have... Everyone's not good sitting down and speaking in a room full of people...

## Inform

#### Be Transparent and Thorough

The majority of parents described wanting clinicians to be honest and comprehensive in their information delivery. Some parents described distress when clinicians sugar-coated information or did not fully disclose concerns. One mother of a child with complex congenital heart disease stated:

I definitely think overall being very upfront and honest is the best thing, regardless of how a parent is going to take it... Sometimes I felt like we just weren't told about everything they were thinking. Just be upfront, communicate about everything that is on your mind.

#### Acknowledge Uncertainty

Parents valued clinicians willing to acknowledge the inherent uncertainty of the clinical situation. Some parents equated naming uncertainty with honesty and humility, as shared by one father of a child with hydrocephalus: "I think what they could have done better, is they could not be afraid to be honest and say, 'We don't really know.'"

For some parents, this uncertainty allowed room for hope for a different outcome. Several parents described removing uncertainty or describing prognoses as certain as akin to defining their child's outcome. As the mother of an infant with a rare, neurodegenerative genetic condition explained: "I feel like everybody lost hope, even the genetics team. I feel like they all named his path."

#### **Provide Balanced Information**

Parents appreciated when clinicians presented information about potential function alongside information about potential impairment. As shared by one mother of an infant with congenital heart disease and hypoxic ischemic encephalopathy:

I just want to hear what he can do, not what he can't do. They pretty much are saying there's nothing else they can do for him, with his brain damage. I understand that, but there's things you all can have hope for, hope in that he can do things.

Several parents of infants with neurologic impairment described feeling as though the team repeated grim news unnecessarily. As shared by one parent of an infant with a genetic condition:

When they telling us she's not gonna live past a year... we understand that, but we don't need nobody to keep reminding us that she's not gonna have up to this time. Let us enjoy the time we do. We don't want you to keep reminded us that our time is limited.... You all always tell us the same thing. We get it. We understand.

### Promote Understanding

Parents described challenges with understanding medical information. Many parents emphasized the frequent use of jargon. Parents appreciated when clinicians used lay terms, as explained by a mother: "I want to know exactly what you're talking about and break it down for me, not in medical terms, but in people terms."

Several parents discussed the challenges associated with information overload and encouraged clinicians to pace information delivery to allow adequate time for processing. The mother of a child with myotonic dystrophy shared: "We tried to process some of the information, 'cause when we get so much information, it feels like our heads are about to explode."

Other parents discussed the challenges associated with emotional overload and the inability to process medical information after hearing difficult news. As described by the parent of an infant with intraventricular hemorrhage and periventricular leukomalacia: "If we're hearing something that I don't want to hear or that's upsetting, at that moment [I] focus on that one thing and I don't hear anything else." Many parents who offered guidance around the avoidance of information or emotional overload concurrently emphasized the importance of remaining transparent.

#### **Discuss Effect on Day-to-Day Life**

Parents appreciated when clinicians helped them manage their expectations about the future. Some families described their desire to hear the big picture and for clinicians to help them understand which details were key. The father of a child with intraventricular hemorrhage stated:

...Each doctor tends to get very granular and technical at times and I'm someone, just by the way I think, I think big picture. What are the three to five key things? And then we can dig in from there.

Other parents valued when clinicians helped families anticipate and manage adjustments in their day-to-day life to accommodate the needs of a child with their infant's condition. As shared by one father of an infant with hydrocephalus:

If you can tell me that I'm always gonna need a house with X number of rooms plus one because she's probably always gonna need a room with us forever you know, then tell me I need a house with X plus one rooms. You know, just tell me that. If she's gonna grow with her wheelchair forever then hey, let me know that I'm always probably gonna need a van or something, you know?

#### Give Support, Communicate With Empathy

Parents appreciated clinicians whose communication style was empathic. Parents highlighted the importance of tone of voice, body language, and word choice. One mother of an infant with a brain malformation described how a neurologist was able to demonstrate empathy despite delivering difficult news:

She's very blunt, but at the same time, she's caring, she's very soft in delivering her blow. Like I'm gonna hit you where it hurts, but it's gonna be soft and loving and you're gonna know that I'm here for you. And she just has a big heart, but she tells me what I need to know.

e804 Neurology | Volume 100, Number 8 | February 21, 2023

#### **Offer Support in Real Time**

Parents valued clinicians who offered real-time support in response to emotional reactions. Some parents discussed the importance of watching parents for nonverbal cues of distress and missed opportunities to provide support. As shared by one parent of a child with a genetic condition:

I think they could try to pay attention more to the patient's or the parent's more to the body language... actually pay attention to the way they're reacting.

Parents discussed the value of staff with training and expertise in supporting parent well-being, including social workers and case managers. One parent of an infant born premature described the necessity to include these clinicians in major conversations: "Maybe have the therapist or the hospital social worker there [in the meeting] so that you can be there for that family when you deliver them that news..."

## **Next Steps**

#### **Connect With Peers**

Many parents described the value of peer support as a way to understand their child's future. Some discussed the need for enhanced peer support opportunities within the health care system. Others described the need for clinicians to connect parents with peers and peer support organizations. Parents described how connecting with peers could serve as both a source of hope and a way to set realistic expectations about the future. As shared by one mom of an infant with prematurity:

The resources that helped me the most was definitely talking to other families with children similar to us because it was something tangible, it was something for me to touch, to visualize, to see the outcome.

#### **Connect With Resources**

Parents appreciated the opportunity to gain additional information about their child's condition. Some parents described the lack of adequate informational resources relevant to their child's condition, as shared by one mother of an infant with periventricular leukomalacia: "I do wish that there was a portal where I could go with resources and websites and support groups that were vetted."

Others described the need for mental health and psychosocial support resources. One parent of an infant with congenital heart disease shared the need for resources to help siblings process information:

I know my [daughter], once she saw her for the first time, on the breathing tube and all that stuff, it wasn't good. It was tough for her. So, make sure that we have the proper resources... to be able to sit with her and explain everything to her.

# Discussion

We present parent-driven recommendations for the provision of information about neurologic prognosis. ALIGN represents a novel, inductively-derived framework that centers the voices and lived experiences of parents caring for critically ill children. These recommendations are organized by key phases of information delivery and can guide clinicians as they navigate conversations with caregivers of critically ill infants and support interventions to improve prognostic communication (Figure).

Parents emphasized components of communicationpreparation, assessing parent understanding, and attending to emotion—that extend beyond the delivery of news itself. As seen in other disciplines, parents appreciated team consensus and when conversations included trusted members of the health care team.<sup>21</sup> Interprofessional team meetings in advance of interactions with family members are one strategy to promote team consensus.<sup>22,23</sup> Parents emphasized the value of including team members with whom they shared a longitudinal relationship, supporting existing guidelines to implement primary nursing and longitudinal attending models.<sup>24</sup> This guidance also highlights the potential value of fetal neurology and neonatal neurocritical care models in which child neurology clinicians follow children longitudinally after an initial meeting in the fetal and/or neonatal period.<sup>25-27</sup> Parents appreciated when clinicians elicited their communication preferences and baseline understanding of their child's prognosis.

Parents also offered key principles around how to best deliver prognostic information. Parents appreciated clinicians who offered transparency and avoided sugar-coating information. Although we lack data on clinician perspectives in this cohort, there are several reasons why clinicians may soften information delivery, including concern for parent emotional overload, discomfort sharing bad news, and optimism bias.<sup>28-33</sup> Our findings suggest that parents value honesty, even when the news is grim. Parents concurrently described the challenges associated with cognitive and emotional overload. Taken together, these findings suggest that parents value honest information and that strategies to reduce overload, including avoiding jargon, pacing information delivery, and providing real-time emotional support, are particularly critical in this context. Parents also valued clinician acknowledgment of any associated prognostic uncertainty. Although prognostic uncertainty has been demonstrated to be a source of distress for parents of critically ill infants, existing data also suggest that uncertainty can also allow room for hope.<sup>2,34-36</sup> Parents valued hearing balanced information about their child's anticipated functional abilities. This finding aligns with guidance from the Americans with Disabilities Act National Network to emphasize abilities ("your child will need braces or a walker to walk short distances") over limitations ("your child will not walk independently").<sup>37</sup>

In addition, parents valued the real-time provision of emotional support. Human connection, empathy, and intentional presence are key elements of facilitating therapeutic alliance.<sup>38</sup> Yet, existing data suggest that clinicians often miss empathic opportunities.<sup>39-41</sup> A study of pediatric ICU family conferences demonstrates that patient-centered communication behaviors, including discussion of emotion and use of empathic statements, result in improved parent satisfaction amidst critical illness.<sup>41</sup> Taken together, these studies suggest that clinicians should learn, practice, and hone their ability to recognize and effectively respond to empathic opportunities.

Although the majority of our conferences were led by clinicians, most meetings included professionals with expertise in providing psychosocial support, including social workers, case managers, and chaplains. Teams should ensure that major conversations with families include these critical members of the health care team.<sup>18</sup> Parents valued being connected to peer support. The effect of peer support programs on parent well-being is well established.<sup>42.44</sup> Our findings underscore that the value of peer support extends beyond psychosocial support alone; veteran parents can help new parents manage expectations, plan for the future, and imagine their day-to-day life at home.

The ALIGN framework builds on existing communication tools to support communication about prognosis and serious illness.<sup>4-9,14</sup> Several features of serious communication in child neurology differ from other settings, including a primary focus on the potential for survival with impairment and the presence of prognostic uncertainty. Our framework offers guidance tailored to this context and was derived directly from the lived experiences of caregivers. ALIGN uniquely prioritizes several communication strategies, including the emphasis on building team consensus, delivering balanced information that is mindful of its influence on family life, and centering the need for peer support. Many of the domains included within our framework overlap with those developed elsewhere, affirming that key tenets of high-quality communication are universal. This framework is not designed to replace existing tools; instead, clinicians can evaluate and use these complementary tools as best suits the clinical scenario and their communication style.

This study's strengths should be viewed in the context of its limitations. Interviews were audio recorded; video recording may have offered additional insight. Information on why certain parents did not complete interviews is not available, and these parents may have differed from the full cohort in systematic ways. Prognostic communication often begins antenatally and continues into childhood; future work should include attention to fetal counseling and prognostic communication across a child's developmental trajectory.<sup>45</sup> The single-site nature of our design limits generalizability to other health systems and contexts. Our study design limited participation by parents who did not converse in English and was not designed to explore how race and ethnicity influence prognostic communication preferences. Understanding prognostic communication preferences among diverse populations should be a priority in future work. Although this analysis focuses on the communication of neurologic prognosis, challenges in the estimation of neurologic prognosis, including cognitive biases and heuristics, are an

important area of additional study.<sup>46</sup> This analysis centers the parent perspective; a necessary next step of this work is to incorporate the perspectives of clinicians and other stakeholders.

The ALIGN framework offers a novel, parent-informed strategy to guide neurologists in the provision of prognostic communication. Although ALIGN represents key elements of a conversation about prognosis, each clinician can adapt this framework to their own approach. Future work will assess the effectiveness of this framework on communication quality and prognostic understanding.

### **Study Funding**

This work was supported by the National Institute of Neurological Disorders and Stroke (K23NS116453-01).

## Disclosures

The authors report no relevant disclosures. Go to Neurology. org/N for full disclosures.

#### **Publication History**

Received by *Neurology* June 16, 2022. Accepted in final form October 7, 2022. Submitted and externally peer reviewed. The handling editor was Associate Editor Renee Shellhaas, MD, MS.

#### Appendix Authors

Name	Location	Contribution	
Monica E. Lemmon, MD	Department of Pediatrics, Duke University School of Medicine, Durham, NC; Department of Population Health Sciences, Duke University School of Medicine, Durham, NC	Drafting/revision of the manuscript for content, including medical writing for content; study concept or design; and analysis or interpretation of data	
Mary C. Barks, MA	Department of Pediatrics, Duke University School of Medicine, Durham, NC	Major role in the acquisition of data and analysis or interpretation of data	
Simran Bansal	Department of Pediatrics, Duke University School of Medicine, Durham, NC	Drafting/revision of the manuscript for content, including medical writing for content, and analysis or interpretation of data	
Sarah Bernstein, MD, MHA	Department of Pediatrics, Duke University School of Medicine, Durham, NC; University of Utah School of Medicine, Salt Lack City, UT	Analysis or interpretation of data	
Erica C. Kaye, MD, MPH	Department of Oncology, St. Jude Children's Research Hospital, Memphis, TN; Departments of Neurology and Pediatrics, UCSF Benioff Children's Hospital, University of California, San Francisco, San Francisco, CA	Analysis or interpretation of data	
Hannah C. Glass, MD	Department of Epidemiology & Biostatistics, University of California, San Francisco, San Francisco, CA	Study concept or design and analysis or interpretation of data	

Neurology.org/N

Appendix (continued)

Name	Location	Contribution
Peter A. Ubel, MD	Fuqua School of Business and Sanford School of Public Policy, Duke University, Durham, NC	Study concept or design
Debra Brandon, PhD	Duke University School of Nursing, Durham, NC	Study concept or design and analysis or interpretation of data
Kathryn I. Pollak, PhD	Department of Population Health Sciences, Duke University School of Medicine, Durham, NC; Cancer Prevention and Control, Duke Cancer Institute, Durham, NC	Study concept or design and analysis or interpretation of data

#### References

- Lemmon ME, Bonifacio SL, Shellhaas RA, et al. Characterization of death in infants with neonatal seizures. *Pediatr Neurol.* 2020;113:21-25.
- Lemmon ME, Boss RD, Bonifacio SL, Foster-Barber A, Barkovich AJ, Glass HC. Characterization of death in neonatal encephalopathy in the hypothermia era. J Child Neurol. 2017;32(4):360-365.
- Natarajan G, Mathur A, Zaniletti I, et al. Withdrawal of life-support in neonatal hypoxic-ischemic encephalopathy. *Pediatr Neurol.* 2019;91:20-26.
- Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. Oncologist. 2000;5(4):302-311.
- Clayton JM, Hancock KM, Butow PN, Tattersall MHN, Currow DC. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. J Aust Med Assoc. 2007; 186(S12):S77.
- Goodlin SJ, Quill TE, Arnold RM. Communication and decision-making about prognosis in heart failure care. J Card Fail. 2008;14(2):106-113.
- 7. Levin TT. Discussing cancer prognosis. Oncology. 2015;29(2):142-144, C3.
- Racine E, Bell E, Farlow B, et al. The 'ouR-HOPE' approach for ethics and communication about neonatal neurological injury. *Dev Med Child Neurol*. 2017;59(2):125-135.
- Prognosis Vital Talk Discussing. Using the ADAPT Tool to Guide You through Complex Conversations: VitalTalk; 2019.
- Janvier A, Farlow B, Baardsnes J, Pearce R, Barrington KJ. Measuring and communicating meaningful outcomes in neonatology: a family perspective. *Semin Perinatol.* 2016;40(8):571-577.
- Lemmon ME, Ubel PA, Janvier A. Estimating neurologic prognosis in children: high stakes, poor data. JAMA Neurol. 2019;76(8):879.
- 12. Ferriero DM, Bonifacio SL. The search continues for the elusive biomarkers of neonatal brain injury. J Pediatr. 2014;164(3):438-440.
- Wassink G, Harrison S, Dhillon S, Bennet L, Gunn AJ. Prognostic neurobiomarkers in neonatal encephalopathy. *Dev Neurosci.* 2022;44(4-5):331-343.
- Bloom JR, Marshall DC, Rodriguez-Russo C, Martin E, Jones JA, Dharmarajan KV. Prognostic disclosure in oncology - current communication models: a scoping review. *BMJ Support Palliat Care.* 2022;12(2):167-177.
- Gerrity C, Farley S, Barks MC, et al. Decision making for infants with neurologic conditions. J Child Neurol Febjournal Child Neurol. 2022;37(3):202-209.
- Bracken-Roche D, Shevell M, Racine E. Understanding and addressing barriers to communication in the context of neonatal neurologic injury: exploring the ouR-HOPE approach. *Handb Clin Neurol.* 2019;162:511-528.
- Barlet MH, Ubel PA, Weinfurt KP, et al. Decisional satisfaction, regret, and conflict among parents of infants with neurologic conditions. J Pediatr. 2022;245:81-88.e3.
- Farley S, Bansal S, Barks MC, et al. Role of social workers in family conferences for critically ill infants. J Palliat Med. 1420;25(8):1236-1242.
- Lemmon ME, Barks MC, Bernstein S, et al. Prognostic discussion for infants with neurologic conditions: qualitative analysis of family conferences. *Ann Neurol*. 2022:699-709.

- Miles MB, Huberman AM. Qualitative data analysis: an expanded sourcebook. In: *Qualitative Data Analysis: An Expanded Sourcebook*, 2nd ed. Sage Publications, Inc; 1994:338. xiv, 338-xiv.
- Lemmon ME, Glass HC, Shellhaas RA, et al. Family-centered care for children and families impacted by neonatal seizures: advice from parents. *Pediatr Neurol*. 2021;124: 26-32.
- Walter JK, Schall TE, DeWitt AG, et al. Interprofessional team member communication patterns, teamwork, and collaboration in pre-family meeting huddles in a pediatric cardiac intensive care unit. J Pain Symptom Manage 2019;58(1):11-18.
- Walter JK, Hill D, Drust WA, et al. Intervention codesign in the pediatric cardiac intensive care unit to improve family meetings. J Pain Symptom Manage 2022-03-23 2022;64(1):8-16. S0885-3924.
- Davidson JE, Powers K, Hedayat KM, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. *Critical Care Med.* 2007;35(2):605-622.
- Glass HC, Ferriero DM, Rowitch DH, Shimotake TK. The neurointensive nursery: concept, development, and insights gained. *Curr Opin Pediatr.* 20192019;31(2): 202-209.
- Rent S, Bidegain M, Bost MH, Hornik C, Lemmon ME. Neuropalliative care for neonates. J Child Neurol. 2021;36(12):1120-1127.
- Agarwal S, Scher MS. Fetal-neonatal neurology program development: continuum of care during the first 1000 days. J Perinatology: Official J Calif Perinatal Assoc. 2022; 42(2):165-168.
- Berkey FJ, Wiedemer JP, Vithalani ND. Delivering bad or life-altering news. Am Fam Physician. 2018;98(2):99-104.
- Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *BMJ (Clinical Res)* 2000;320(7233): 469-473.
- Lee SJ. Discrepancies between patient and physician estimates for the success of stem cell transplantation. JAMA. 2001;285(8):1034.
- Mack JW, Smith TJ. Reasons why physicians do not have discussions about poor prognosis, why it matters, and what can be improved. 2012;30(22):2715-2717.
- Anderlik MR, Pentz RD, Hess KR. Revisiting the truth-telling debate: a study of disclosure practices at a major cancer center. J Clin Ethics 2000;11(3):251-259.
- Lamont EB, Christakis NA. Prognostic disclosure to patients with cancer near the end of life. Ann Intern Med. 2001;134(12):1096-1105.
- Lemmon M, Glass H, Shellhaas RA, et al. Parent experience of caring for neonates with seizures. Archives of Disease in Childhood Fetal and Neonatal Edition; 2020. doi: 10.1136/archdischild-2019-318612.
- Lemmon ME, Huffstetler H, Barks MC, et al. Neurologic outcome after prematurity: perspectives of parents and clinicians. *Pediatrics*. 2019;144(1):e20183819.
- Kaye EC, Stall M, Woods C, et al. Prognostic communication between oncologists and parents of children with advanced cancer. *Pediatrics*. 2021;147(6):e2020044503.
- ADA National Network. Guidelines for Writing about People with Disabilities. Information, Guidance and Training on the Americans with Disabilities Act; 2022. Available at: adainfo.us/ADANNwriting.
- Kaye EC, Rockwell S, Woods C, et al. Facilitators associated with building and sustaining therapeutic alliance in advanced pediatric cancer. JAMA Netw Open. 2021; 4(8):e2120925.
- Hsu I, Saha S, Korthuis PT, et al. Providing support to patients in emotional encounters: a new perspective on missed empathic opportunities. *Patient Edu Couns*. 2012;88(3):436-442.
- Pollak KI, Arnold RM, Jeffreys AS, et al. Oncologist communication about emotion during visits with patients with advanced cancer. J Clin Oncol. 2007;25(36): 5748-5752.
- October TW, Hinds PS, Wang J, Dizon ZB, Cheng YI, Roter DL. Parent satisfaction with communication is associated with physician's patient-centered communication patterns during family conferences. *Pediatr Crit Care Med.* 2016;17(6):490-497.
- Dahan S, Bourque CJ, Reichherzer M, et al. Peer support groups for families in Neonatology: why and how to get started?. Acta Paediatr. 2020;109(12):2525-2531.
- Pilon B, Craig AK, Lemmon ME, Goeller A. Supporting families in their child's journey with neonatal encephalopathy and therapeutic hypothermia. *Semin Fetal Neonatal Med.* 2021;26(5):101278.
- Hall SL, Ryan DJ, Beatty J, Grubbs L. Recommendations for peer-to-peer support for NICU parents. J Perinatology 2015;35(S1):S9–S13.
- Scher MS. Fetal neurology: principles and practice with a life-course perspective. Handbook Clin Neurol. 2019;162:1-29.
- Croskerry P. The importance of cognitive errors in diagnosis and strategies to minimize them. Acad Med. 2003;78(8):775-780.

Neurology.org/N