

The ALIGN Framework: A Parent-Informed Approach to Prognostic Communication in the Neonatal Intensive Care Unit

Simran Bansal¹, Mary Carol Barks², Debra Brandon, PhD, RN, CNS³, Kathryn Pollak, PhD³, Hannah Glass, MD, MAS⁴, Peter Ubel, MD³, Monica Lemmon, MD³

¹Trinity College of Arts and Sciences, Duke University, ²Duke-Margolis Center for Health Policy, ³Duke School of Medicine, ⁴UCSF Benioff Children's Hospital

BACKGROUND

In the neonatal intensive care unit (NICU)...

1 Parents of critically ill infants must cope with grief, anxiety, and fear related to their child's uncertain outcome

2 Clinicians must deliver complex, uncertain, and distressing prognostic information to parents

Good communication is key to helping (a) parents manage overwhelming emotions and (b) clinicians facilitate productive discussions about prognosis

* Yet, few tools exist to guide these conversations

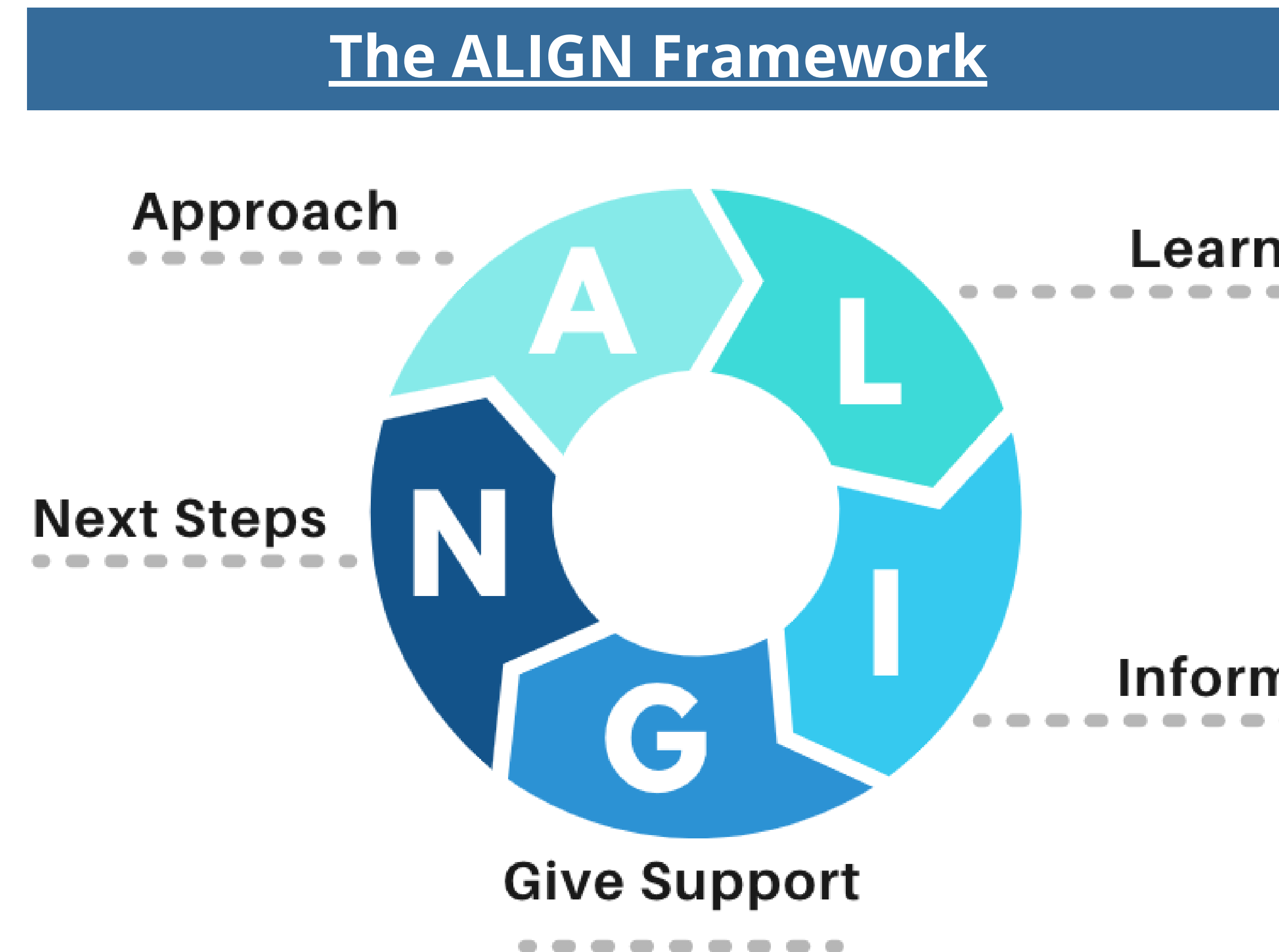
We aimed to address this gap by developing a parent-informed framework for communicating prognostic information in the NICU context.

METHODS

Conducted semi-structured interviews with 52 parents of 37 infants after meetings with the medical team, at hospital discharge, and 6 months post-discharge

Used conventional content analysis to identify and refine codes, independently coded transcribed interviews in NVivo, and resolved discrepancies in consensus

RESULTS



THEME	KEY SUBTHEMES
APPROACH	<ul style="list-style-type: none"> Provide consistency Allow time to process information
LEARN	<ul style="list-style-type: none"> Facilitate & assess understanding Assess communication preferences
INFORM	<ul style="list-style-type: none"> Admit to uncertainty Be thorough Be transparent, upfront, & honest Don't name infant's path Leave room for hope & provide balanced information Manage expectations
GIVE SUPPORT	<ul style="list-style-type: none"> Show empathy Provide emotional support
NEXT STEPS	<ul style="list-style-type: none"> Connect to resources

Select Quotes From Parent Interviews

On **assessing communication preferences**: "One of the most traumatizing parts of all of this is not having any control, so **giving parents control over something as basic as how much information they want...even that is empowering.**" (Mom of a premature infant with IVH)

On **showing empathy**: "I know you all get paid to have this whole character and stuff, but **at the end of the day we still, we are both human.** Talk to me on a personal level, not with all this medical stuff, but from deeply in your soul." (Mom of an infant with a mitochondrial disorder)

On **being transparent, upfront, and honest**: "**I'd rather you be transparent and straightforward** because this has to do with her health and life. I don't want a doctor or a nurse on a team that's timid about what they have to say." (Mom of an infant with congenital heart disease)

SUMMARY

Our results indicated five key themes, organized into phases of communication (Table 1). Parents valued

- * **consistent** updates from trusted clinicians
- * discussions **individualized** to their preferences
- * **honest, thorough,** and **balanced** information
- * real-time **support** and **connection to resources**

CONCLUSION: *The ALIGN framework offers a novel, parent-informed strategy to guide prognostic discussions, while allowing for flexibility and acknowledging that steps are iterative. Future studies should examine how using this framework in practice impacts parent-provider communication.*