A Cure for Prognostic Pessimism Among Neonatologists

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Do parents of an infant in the neonatal intensive care unit prefer optimistic or pessimistic framing of equivalent prognostic information? Based on the findings of the study from Forth et al,1 optimism triumphs. Through an experimental video vignette design, parents of surviving children born preterm were exposed to 2 standardized videos capturing simulated counseling about intraventricular hemorrhage. Most parents (89%) preferred the version in which a neonatologist framed discussion by the percentage of children who survive vs the percentage who die, and the chance of surviving without rather than with “impairment.” Parents evaluated neonatologists offering the optimistic framing to be more compassionate and professional.

Taking a step back, a central presumption of the study is that neonatologists are uncertain whether parents prefer optimistic or pessimistic framing of information about serious complications, and that clarity about parents’ preferences could and should alter neonatologists counseling practices. However, pessimism likely reflects something deeper than simply a choice (intentional or unwitting) about how to frame information. Indeed, neonatologists may be employing pessimism for several purposes. Each purpose—and parents’ corresponding rejection of pessimism—has different implications for incorporating this study’s findings into counseling.

First, a neonatologist may be pessimistic to meet what they perceive to be a need that parents have. Specifically, neonatologists may believe that parents need and want truthful information, and then—crucially—conflate pessimism and truthfulness. This is easy to do. In common parlance, we frequently combine the 2 concepts, as in the phrase “brutal truth.” Even in this article, the authors caution against excessive optimism, described as “sugar coating,” and cite an interview study where parents report having been inadequately or inaccurately informed about the dangers of necrotizing enterocolitis. This example, notably, is a problem not of excessive optimism but rather of misinformation. Distinguishing pessimism and truthfulness is essential to employing the findings of this and other work on communication in the neonatal intensive care unit. Parents want and deserve the truth. A grim truth should not be veiled in optimism to avoid the grimness of the truth. Yet must the truth be brutal? Even the bleakest news can be delivered with compassion and can leave space for parents to hope for something, which can range from a rare recovery to a peaceful death.2 Delivering bad news takes skill. While telling a bleak truth is challenging, telling this truth with compassion is even harder. Neonatologists need more training for delivering emotionally difficult information in a clear and truthful manner while fostering hope.

Second, neonatologists may be pessimistic because they perceive the potential outcome to be more grievous than parents do. Time after time, parents have been shown to be more accepting of disability than neonatologists.3 Physician-defined levels of impairment do not correlate well with the positive and negative attributes parents report for children born preterm.4 Even parents of children with trisomy 13 and 18, diagnoses neonatologists see as carrying a dismal prognosis, find meaning and joy in their children’s lives.5 These discrepancies exist for a number of reasons. The widespread bias of ableism leads outsiders to perceive lives with disability more negatively than those who live with or are close to disability. Neonatologists may be particularly susceptible to such bias because they see patients only in infancy and rarely when patients have grown into lives outside the hospital, complete with abilities and disabilities and a life in their homes and communities. A neonatologists’ experience with neonatal intensive care unit survivors is likely to have been shaped by seeing these children admitted to the hospital during their training—a sample likely to affirm a negative bias of the possible outcomes. Perhaps parents prefer optimistic framing because this viewpoint aligns with
the positive light in which they perceive their children or their children's expected futures. Better aligning perceptions of prognosis between neonatologists and parents will require more than simply recommending optimistic framing. Neonatologists need a more complete understanding of the complex concept that in this study was condensed to the word "impairment" to provide prognostic information that is, in content as well as framing, more balanced.

Third, neonatologists may be pessimistic as a way of transferring responsibility to parents. In the case portrayed in this study, neonatologists and parents face a decision about whether to transition to comfort-focused care. In such cases, neonatologists may portray information pessimistically to absolve themselves of responsibility if, in the future, parents regret decisions that result in the survival of a child with disabilities. Importantly, although physicians anticipate such regrets, parents almost never report them.6 Strategies for true shared decision making require that parents and clinicians instead align on the outcomes for which they choose to be optimistic.

Finally, both pessimism and optimism about prognosis may serve as tools for neonatologists to cultivate empathy. Delivering bad news effectively requires an emotional connection with parents and a shared processing of information.7 In this study, the optimistic clinician is more empathic, mirroring the parents' initial disbelief with her optimistic framing. In contrast, the pessimistic clinician seems not just negative but emotionally detached from the parents. Respondents may prefer the sense of connection as much as the optimistic framing of facts, which is further supported by their rating the optimistic neonatologist as more compassionate. Actual conversations grant neonatologists the opportunity to react to parents over time as they react to information. Reflecting parents' optimism as well as their pessimism can be used to convey empathy. In one scenario, one might optimistically say, "I am going to hope with you that Jonathan does better than any of these data suggest." In another scenario, a pessimistic statement might feel more supportive: "I can see how devastating this news is. One promise I can make is to continue taking care of Jayden and your whole family even if Jayden does worse than we expect." While neonatologists may be wise to start with an optimistic frame, flexibility in interpreting and reflecting parents' emotions, shifting from optimistic to pessimistic and back, may also be crucial for establishing empathy.

This important and rigorous study establishes a problem: we need a cure for neonatologists' prognostic pessimism. Simply encouraging optimistic framing is little more than offering symptom management. Finding a full cure will not be simple because pessimism indicates more than just how the risks of patient morbidity and mortality found in neonatal intensive care units are presented, extending down to the deeper-rooted problems we have outlined. A cure will require communication strategies that enable neonatologists to foster truth and hope together, dismantling ableism bias, and support for neonatologists in sharing responsibility for difficult decisions. Neonatologists will also need strategies to empathically connect with parents—mirroring their optimism as well as their pessimism.
REFERENCES