From the Editor

Navigating Facts and Values

Ian D. Wolfe

ABSTRACT

Decision making in pediatrics often involves how different people apply values to medical facts. This involves how facts are presented and contextualized. In most situations, the balance of burdens and benefits within medical treatments is clear. In other situations, different applications of value might result in different answers. This article discusses the theme of navigating facts and values in relation to this issue of *Journal of Pediatric Ethics.*

NAVIGATING FACTS AND VALUES

Medical interventions are neither good nor bad in and of themselves. Rather, they attain value based on the proportion of benefit they might achieve in relation to the burden they require. In many cases this balance is clear, yet in some instances different people might come to different and equally valid conclusions.

The goal of shared decision making in pediatrics is to join the medical facts to the context of the particular child along with the values of the family. A typical scenario is when a clinician provides the medical facts and a family applies their values to those facts. There are, of course, limits to what families can demand or refuse, but in between those rare situations, families maintain a zone of discretion, an area of ethical permissibility in which reasonable people might disagree and families are empowered to make a decision that best aligns with how they apply their values to facts.[1]

There are variations of nuance within shared decision making that are influenced by social and cultural factors. And in many areas of pediatrics, such as neonatology, prognostic uncertainty only heightens the difficulty of making choices. Often these areas of difficulty can lead to value conflicts.

The feature article in this issue of the *Journal of Pediatric Ethics,* "Parents' Perspectives on Values and Values Conflicts Impacting Shared Decision Making for Critically Ill Neonates," by Chris Krenz, Kayte Spector-Bagdady, Raymond De Vries, and Stephanie Kukora, explores how parents apply values to the medical facts and how value conflicts arise between parents and clinicians. Krenz and colleagues interviewed

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parents who faced a critical antenatal diagnosis that required difficult discussions around the goals of care.

The rich data reported by Krenz and colleagues provide a lens through which we can see how facts and values distinctions can create conflict. In cases of significant critical illness, clinicians tend to view the amount of burdens as increasingly disproportionate to the potential of attaining a "good" outcome, whereas parents and families often seem to focus more on their sense of duty towards their child when there is a chance of attaining a desired outcome. This difference in role perspective leads to differing views around the proportionality of medical interventions.

The idea of knowing can also elicit value conflicts, and increasingly this is seen in genetic testing in pediatrics, where knowledge can be helpful, but once something is known, it can't be unknown. Narratives are important to the literature around genetic testing in adolescents to inform how clinicians support these patients and their families who face the prospect of knowing genetic results. In "A Narrative Experience with Adolescent Genetic Testing," Katherine P. Wu, Amanda Ruth, and Daniel P. Mahoney provide a novel approach that weaves personal narrative into ethical considerations around genetic testing. This approach offers a unique perspective to guide clinicians in how they approach counseling around genetic testing for adolescents.

In "Difficult to Swallow: Epidermolysis Bullosa, Esophageal Stricture, and the Boundaries of Forgoing Medical Nutrition and Hydration," William Sveen and Nneka Sederstrom present a complex case on forgoing medical nutrition and hydration, and discuss an important aspect of how we think about death and dying. As childhood mortality has reached its lowest point in human history, the same medical advances that helped create this environment have changed how we think about the trajectory of an illness. Children increasingly survive with chronic conditions that don't adhere to a predictable trajectory.[2] Periods of relative stability that include significant morbidity require us to look at how we might apply our values to differing conceptualizations of "terminal." Children who have a chronic illness that includes significant morbidity, but relative stability, force us to consider what rights are part of being free from medical intervention, and how morbidity may have more ethical salience than mortality.

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Our clinician narrative in this issue comes from a pediatric intensive care nurse who describes her experience caring for a child requiring extraordinary treatment. In "A Day in the Life of a Pediatric Intensive Care Unit Nurse," Jamie L. Newton describes the experience of caring for critically ill children while also being a mother. Clinicians are, after all, more often the ones "doing things to" patients. And all the "things" clinicians do are burdensome, even when there is a proportional benefit. When clinicians start to feel these "things" are being "done to" rather than "done for" a child, their perspective of benefits weighs heavily on them. Parents have to live with the decisions they make, but clinicians also carry their experiences with them, even into their own lives.

The articles in this issue of the *Journal of Pediatric Ethics* speak to the importance of understanding value perspectives. One way to better understand value perspectives is through hearing individual experiences and stories. Communication is at the root of so many ethical challenges in pediatrics, yet so much focus is given to the interpretation of words, rather than on concepts. Concepts of "good," "bad," "terminal," and even "suffering" have significant underlying values associated with them. Defining a "good" death is more fraught in a population that is not supposed to die. How we conceptualize requests such as "do everything" impacts how we go forward in shared decision making, and influences how we navigate facts and values.

NOTES

1. J.D. Lantos, "Ethical problems in decision making in the neonatal ICU," *New England Journal of Medicine* 379, no. 19 (2018): 1851-60; M.R. Mercurio and C.L. Cummings, "Critical decision-making in neonatology and pediatrics: The I-P-O framework," *Journal of Perinatology* 41, no. 1 (1): 173-8.

2. J.S. Linebarger, V. Johnson, and R.D. Boss, "Guidance for Pediatric End-of-Life Care," *Pediatrics* 149, no. 5 (2022): e2022057011.