From the Editor

Everyday Ethics and Partnering with Families in Children's Hospitals

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ABSTRACT

Partnering with families is everyday ethical work. We meet families where they at in their life and rarely is this a place that was ready to take on a hospitalization. Rather than focusing on difficulties, we ought to provide equitable work at partnering with families where they are at, not where we might want them to be. Partnering with families begins at the point of entry into the hospital and extends to building partnerships in departments and units. Recognizing that this is ethical work and providing this to families within a pluralistic society is often the unspoken hard work of clinicians and hospitals. This issue of the *Journal of Pediatric Ethics* is focused on this space that greatly impacts the ethical climate within the hospital walls.

Partnering with families is an integral part of caring for children. Every child and family are unique, bringing their own strengths, values, struggles, and perspectives. Clinicians must meet these families where they are at in the world, which is sometimes not the ideal place we might like them to be. Schopenhauer wrote, "the present is always inadequate, but the future is uncertain, and the past irrecoverable."[1] Envisioning ideal situations distracts us from the task in front of us. The present situation is always inadequate if we are constantly trying to avoid accepting the past and hoping for some certain solution in the future. Rather, we should accept where we are and start from there.

The families of children who become ill may already be facing challenges and stressors, and the hospitalization of their child adds to this. How well we meet families in these situations can have significant impacts on the children we are caring for.

Partnering with families isn't only done through clinicians at the bedside, it starts at the first point of entry into the healthcare environment. Families enter hospitals with their children through emergency departments or transfers from other institutions. Families may enter by way of a front desk in a clinic or a welcome center in a hospital. First impressions can make significant impacts that can resonate through communities.

Partnering with families in an ethical manner starts at the institutional level through visitation policies, equitable welcoming environments, and community engagement. These continue in the departmental level in how each department meets the needs of and works to build relationships with the families they serve. Individual clinicians and healthcare staff must learn to be skillful in connecting with families from a multitude of backgrounds, cultures, and faiths.

This is ethical work, and how well these pieces fit together impacts the ethical climate. In this issue of the *Journal of Pediatric Ethics,* we present an important and novel investigation into visitation poli-

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cies in a children's hospital. Shim and colleagues investigate visitation policies through the practice of exceptions to restrictive visitation COVID-19-era protocols.[2] COVID-19 necessitated visitor restrictions for reasons beneficial to all patients and staff in hospitals. It also provided a look at how structural racism may insidiously affect families with hospitalized children. While there has been considerable discussion around racism in visitation policies in the COVID-19 era, the authors point out while COVID-19 provides a visible and measurable case, policies such as these exist in "normal" times in hospitals in the United States.

Clinical ethicists are often faced with difficult situations, in which parents find themselves in awful scenarios with no good choices; clinicians who are trying to do their best to balance what they see as their professional obligations to patients, to their family, and to the team sometimes feel the stress of seemingly competing obligations.

Shim and colleagues provide a systematic descriptive analysis of the nature of requests for exceptions to pediatric visitation policies, as well as an analysis of the demographics associated with requesting and receiving these exceptions. Their major findings highlight an important aspect of how institutional policy can impact partnerships with families. They found that families of younger patients who identified as either White or Hispanic/Latino were more likely to request exceptions to visitation policies. They also found small but significant evidence of this same bias in critical care units where Black families were less likely to have their request for an exception granted. A major factor the authors point out is that the granting of these exceptions is disparate, but, more importantly, the requests were as well. They offer some thoughtful discussion as to why this might be, and it has direct implications for the ethics of how we partner with families.

Also in this issue of *JPE,* Wolfe and Turk provide a clinical report that highlights the complex intersection of social policy, law, and institutional policy and the pitfalls that can have real ethical implications in how we partner with families.[3] Many clinicians and families never consider the nuances of parental rights, nor do they consider the different ways that ethical and legal rights might intersect. The authors point out that there is an important difference in how we conceptualize a parent who has lost legal rights and a parent who has not legally established parental rights. It is easy for clinicians to consider these to be synonymous, but this easily comes at the peril of the parent.

Finally, our "Family Voices" provide two important narratives from the parent perspective in partnering with clinicians. A mother, Amanda Bekric, writes about the importance of a care team having transparent conversations and building a strong partnership.[4] A cancer diagnosis sparked a journey through the complex world of healthcare. As the journey progressed, it became increasingly difficult. Having a strong partnership with the team, as well as the team's continuing to center parents in the space with the child, helped the family and team understand one another and navigate difficult ethical and moral spaces that arose in the child's course.

Beth Wakefield writes about an experience in which even experienced parents of a medically complex child felt overwhelmed and stressed.[5] This space she writes about is one that often goes unnoticed: when members of the same care team give a family differing opinions. Parents are unfortunately often stuck between difficult choices in children's hospitals, and how teams partner with families and how they approach communication, both with the family and between the rotating clinicians, can have significant impacts on the family and the child.

Clinical ethicists are often faced with difficult situations in which parents find themselves in awful scenarios with no good choices; clinicians who are trying to do their best to balance what they see as their professional obligations to the patient, to the family, and to the care team sometimes feel the stress of seemingly competing obligations. Often, as many things go in ethics, there are no good solutions, or what is "best" is in dispute. Recommendations in these situations often take a more pragmatic approach that focuses on how we engage and approach the situation. This approach recognizes the parents' narrative while it validates the clinical difficulty of the situation, while it seeks to reframe the situation as partners in care, rather than as adversaries. A focus on "everyday ethics," sometimes called micro ethics, is a recognition of the ordinary but integral factors involved in everyday clinical encounters.[6] An everyday ethics approach to partnering with families might start with the following assumptions and questions.

Parents want what is best for their child, clinicians do as well, and most people we interact with on a daily basis are not walking around doing unethical actions. We meet parents where they are at, not where we might want them to be. They come with their own grief experience, their own trauma, and their own ways of coping. Clinicians want to provide what they feel is good care. How can we partner with *this* family going forward, even if we disagree with their choices, recognizing (assuming) that their choices are within an ethical zone of parental discretion? What are our obligations to the patient and family in this partnership? How can we satisfy these obligations and be there for the family and patient, allowing them grace and compassion?

NOTES

1. A. Schopenhauer, ed. E. Thacker, *On the Suffering of the World* (London, U.K.: Repeater Books, 2020).

2. A. Shim et al. "Do the Rules Always Apply? An Analysis of Exceptions to a COVID19-Era Pediatric Visitation Policy," in this issue of the *Journal of Pediatric Ethics* 2, no. 1 (2022).

3. I.D. Wolf and D. Turk, "Paternal Rights: The Ethics of Misunderstanding the 'Legal Right to a Child," in this issue of the *Journal of Pediatric Ethics* 2, no. 1 (2022).

4. A. Bekric, "Transparency Conversations that Build Strong Partnerships," in this issue of the *Journal of Pediatric Ethics* 2, no. 1 (2022).

5. B. Wakefield, "Help Me Understand—Contemplating a Novel Therapy Versus Waiting and Hoping," in this issue of the *Journal of Pediatric Ethics* 2, no. 1 (2022).

6. S. Kalevor, M. Kurtz Uveges, and E.C. Meyer, "Using Everyday Ethics to Address Bias and Racism in Clinical Care," *AACN Advanced Critical Care* 33, no. 1 (2022): 111-8.