

# PEDIATRICS PERSPECTIVES

## Facing Persistent Challenges in Pediatric Decision-Making: New Hastings Center Guidelines

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### KEY WORDS

best interests, communication, decision-making, end-of-life care, ethics, palliative care

Dr Berlinger directed the research project that produced the guidelines cited in this manuscript, was the first author of the guidelines themselves, and drafted, reviewed, and revised this manuscript; Drs Barfield and Fleischman were members of the working group for the research project that produced the guidelines cited in this manuscript and critically reviewed and revised this manuscript; and all authors approved the final manuscript as submitted.

[www.pediatrics.org/cgi/doi/10.1542/peds.2013-1378](http://www.pediatrics.org/cgi/doi/10.1542/peds.2013-1378)

doi:10.1542/peds.2013-1378

Accepted for publication Jun 25, 2013

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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**FINANCIAL DISCLOSURE:** The authors have indicated they have no financial relationships relevant to this article to disclose.

**FUNDING:** External funding for the research project that produced the guidelines cited in this article was provided by the Albert Sussman Charitable Remainder Annuity Trust, the Patrick and Catherine Weldon Donaghue Medical Research Foundation, and the Anika Papanek Memorial Fund at the Hastings Center. Nancy Berlinger received partial salary support from these funding sources in her capacity as project director.

**POTENTIAL CONFLICT OF INTEREST:** The authors have indicated they have no potential conflicts of interest to disclose.

Approximately 50 000 deaths occur among pediatric patients (neonates, infants, children, and adolescents) in the United States each year. These deaths are a small fraction of the 2.5 million annual deaths in the United States, but they have an immense impact on the families and clinicians who care for these patients.

Persistent challenges in providing care to seriously ill pediatric patients continue, despite evidence-based approaches to treatment decision-making, the emergence of pediatric palliative care as an interdisciplinary subspecialty, and the growing number of children's hospitals. Clinicians report significant lack of knowledge about ethical and legal issues that have been addressed and seemingly resolved by consensus groups and major pediatric organizations.<sup>1</sup> They voice concerns of conscience about providing end-of-life care. Most agree that we sometimes save the life of a child without sufficient regard for the profound consequences of our interventions on a child's subsequent quality of life. These knowledge gaps and professional concerns may lead to tension within teams and confusion about how to provide good care. This article is written to introduce pediatric clinicians to several relevant aspects of a set of ethics guidelines recently published by the Hastings Center, an independent, nonprofit bioethics research institution that since 1969 has been a major source of interdisciplinary research on ethical challenges in clinical medicine.<sup>2</sup> The new guidelines update the first edition (1987) and include a major new section on pediatric decision-making, with other material relevant to the care of children, building on research and practice insights from pediatric subspecialties, pediatric palliative care, and interdisciplinary bioethics. We will address key challenges and their implications for all professionals who aim to understand, respect, and provide good care to children and families, throughout treatment and at the end of life.

### UNDERSTANDING BEST INTERESTS AND THE PATIENT'S PERSPECTIVE

Serving as a surrogate decision-maker for any patient can be psychologically difficult.<sup>3</sup> Assessing care options and the benefits and burdens of life-sustaining interventions pose special challenges when a patient is too young to have formed values a surrogate can know or infer. In the NICU and in the care of infants and young children who are not yet developmentally capable of making treatment decisions or expressing treatment preferences, parents or guardians should be

able to collaborate with physicians and other professionals to discuss goals of care, how to make informed decisions about different interventions with reference to goals, and how to proceed when goals may need to be revisited. These expectations require clinicians to understand and be able to explain “best interests” decision-making, in which the interests of the child are explicitly identified and are the focus of discussion and decisions.<sup>2</sup> When the child’s interests are not articulated, poorly informed decisions, undue burdens, family distress, and conflict can result.

Even very young children can hold and express preferences about what they like or try to avoid, especially in the chronic care context in which children gain experiential knowledge about living with disease and being exposed to interventions. Discussing patient preferences matters immensely in decision-making even if preferences are not explicitly about treatment, because they help all parties understand who the child is and how the child could be helped or harmed by the experience of treatment. Professionals should strive to help children and parents recognize these preferences and should talk concretely and compassionately about the impact of a treatment on the child’s experience of living. Among pediatric patients, electronic media are often primary means of communicating and exploring the world. For this reason some children and adolescents may find electronic decision-making tools engaging and useful in clarifying preferences.<sup>4</sup>

Pediatric patients are usually accompanied by parents or guardians. Although pediatric settings are often identified as “family centered” or “family focused,” these settings must also be “patient centered,” focused on and respectful of the child and the effects of treatment on this still-developing person.<sup>5</sup> Providing patient-centered pediatric care may

require professionals to support the perspective of the patient who disagrees with a parent. These situations may arise when an older child or adolescent asserts new preferences, or a dying child of any age expresses wishes, fears, or concerns that could justify a change in the care plan. Including the child’s perspective, mindful that this patient may not be able to grasp all consequences of a choice, while helping parents face the reality of a child’s worsening condition, takes patience, time, and strong communication skills. Consultation with ethics professionals, or with family social workers on the health care team, can be helpful in these situations.

### PREVENTING SUFFERING

Good care for seriously ill children fully integrates curative and palliative medicine, with palliative treatment and team members involved in patient care from diagnosis onward. Palliative medicine and nursing offer optimal support of pain and symptom management; this treatment remains part of the care plan as other treatment decisions are considered and made. Pediatric caregivers have been leaders in this approach. Promising parents that a child’s pain and symptoms will be expertly managed is part of what professionals can do, even amid great uncertainty about prognosis or long-term treatment consequences. Explaining palliative modalities in terms of their benefits for a child, and avoiding the confusing and off-putting language of “withdrawing care” when discussing the withdrawal of a life-sustaining treatment, helps parents understand that their ill or dying child will always be cared for. A child’s access to pain and symptom relief should not depend on an individual physician’s willingness to collaborate with palliative care colleagues or a subjective judgment about whether it’s time to involve them.

### COMMUNICATION AND TRUST IN TEAMWORK AND SHIFTWORK

Handoffs and shift changes are characteristic of inpatient pediatric care. Handoff procedures should ensure that new team members know about previously documented decisions and preferences and are ready to support whatever decision-making is at hand.<sup>2</sup> Teams need opportunities to discuss their own concerns, because differing perceptions or values can arise within teams, particularly during long hospitalizations. If unaddressed, these differences can imperil collaboration with families and between colleagues.

### CONCLUSION: TAKING THE NEXT STEPS IN FACING PERSISTENT CHALLENGES

The care of seriously ill neonates, infants, children, and adolescents remains tied to academic medical centers, because the specialty care needed is often available only in these settings. Whether we think of it that way or not, the NICU is an “end-of-life” setting: More than half of all pediatric deaths occur during the first year of life, often as the result of extreme prematurity. Providing good care in the NICU requires competence in care near the end of life and in the use of life-saving and life-sustaining technologies. The fact that most very low birth weight infants will survive their NICU stays does not lessen the need to develop family-centered approaches that prioritize family preferences and values in decision-making for premature infants at the threshold of viability and willingness to withhold or withdraw treatment. Clinician educators in all settings where seriously ill children receive treatment can take immediate, practical steps to support professional and family caregivers, and the process of learning, by modeling good care themselves, sharing information about care innovations, and integrating reflection about caring for children into clinical work.

Part of being a good pediatrician is being a good role model, by helping medical residents and students understand and cope with prognostically uncertain, ethically challenging, emotionally distressing situations arising in the care of critically and terminally ill patients. Modeling for residents how to communicate in rapidly changing conditions and how to work in close collaboration with nurses is also crucial. Many pediatric patients die in the hospital, and it is often difficult for parents to forgo curative interventions even when a child is near the end of life. Pediatricians should be aware of new and innovative health policies to pro-

vide better care. Under the Affordable Care Act, state Medicaid programs fund “concurrent care” for hospice-eligible children to provide access to hospice services during treatment.<sup>6</sup> Another innovation, the Physician Orders for Life-Sustaining Treatment model for documenting patient preferences as portable medical orders, has begun to be accessible to chronically ill children receiving care primarily at home.

Nevertheless, talking about hospice as an option for a child, or about changing goals of care or forgoing life-sustaining treatment, may still feel uncomfortable to many pediatric clinicians. The problem of moral distress (the perception of

“doing to” rather than “doing for” a dying child) is still common. The continuing integration of palliative care and expertise in communication into pediatric settings may help support difficult conversations and decisions. Technical skill in communication, and in pain and symptom relief, is part (but not the whole) of what is needed. Professionals caring for seriously ill children and their families also need opportunities to reflect on the personal experience of being immersed in a family’s distress, talking with a child or adolescent who knows that he or she may die, and grappling with the intense feeling engendered by the loss of a patient.

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*Pediatrics* originally published online October 7, 2013;

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The online version of this article, along with updated information and services, is located on the World Wide Web at:  
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