Whose Interests Count?

abstract

Whose interests should count and how should various interests be balanced at the pediatric patient’s bedside? The interests of the child patient clearly count. Recently, however, many authors have argued that the family’s interests also count. But how should we think about the interests of others? What does it mean to talk about “the family” in this context? Does it really just mean the interests of each individual family member? Or is the family itself a moral entity that has interests of its own independent of the interests of each of its members? Are such interests important only as they affect the patient’s interest or also for their own sake? In this special supplement to Pediatrics, a group of pediatricians, philosophers, and lawyers grapple with these questions. They examine these issues from different angles and reach different conclusions. Jointly, they demonstrate the ethical importance and, above all, the ethical complexity of the family’s role at the bedside. Pediatrics 2014;134:S78–S80

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A toddler develops leukemia, starts chemotherapy, and goes into septic shock. A teenager is hit by a car while walking to school and has a severe brain injury. A tiny infant is born at the borderline of viability and is struggling for breath in the NICU. The physicians and parents discuss whether to discontinue life-sustaining treatment. The bioethicists usually insist that the decision be based primarily on what is best for the critically ill child. Others, however, also have interests. Nurses suffer when they are required to perform painful procedures that they perceive as offering little benefit. Parents may think of their own lives and how those lives would be reshaped by the demands of caring for a child with a complex, chronic condition. They may have other children whose needs and interests are being neglected as they focus on the overwhelming needs of the critically ill child.

Whose interests should count, and how should various interests be balanced at the pediatric patient’s bedside? The interests of the child patient clearly count. Recently, however, many writers have argued that the family’s interests also matter. But how should we think about the interests of others? What does it mean to talk about “the family” in this context? Does it really just mean the interests of each individual family member? Or is the family itself a moral entity that has interests of its own independent of the interests of each of its members? Are such interests important only as they affect the patient’s interest or are they important also for their own sake? In this special supplement to Pediatrics, a group of pediatricians, philosophers, and lawyers grapple with these questions. They examine these issues from different angles and reach different conclusions. Jointly, they demonstrate the ethical importance and, above all, the ethical complexity of the family’s role at the bedside.

Daniel Groll starts the discussion by sketching 4 conceptual models for thinking about the interests of the family: family interests could be instrumentally valuable to the patient (the patient benefits from a reasonably flourishing family); family members’ interests are bound up with the patient’s interests (“my life goes better when my child’s life goes better”); the family as a whole may have interests in which the patient’s interests are a component; and other family members’ interests might compete with the patient’s interests. Groll argues that this last model is commonly used but rarely acknowledged. He defends this model as legitimate but also shows how its use requires some nuance and much humility.

Clancy Martin uses an episode from Dostoevsky’s The Brothers Karamazov to examine the ways in which physicians may sometimes legitimately deceive parents as a way of caring for them. Martin points out that communication among a dying child, parents, and physicians is a delicate communicative dance in which the truth about the child’s condition might be known and/or acknowledged to different degrees by the different parties. Using the novel as an example, Martin notes the ambiguities and tensions in the behavior and attitudes of Ilyusha, his father, and the 2 physicians who attend him. Nothing here is simple. It is not possible to tell the truth, the whole truth and nothing but the truth, he argues, and it would not be good to do so even if it were possible.

Hilde Lindemann argues that the family is a critical part of health care and health care decision-making. Lindemann’s focus is on the family as a nurturing and intrinsically valuable entity that is not reducible to the interests and contributions of its individual members. Lindemann points out that the family is the context in which a child is nurtured and in which the child can develop the autonomy and decisional capacity that will enable him or her to become an autonomous adult. There is, she claims, a texture and holism to family membership which sustains members in ways that nothing else can. This concept becomes crucial when a child is ill: certain forms of caring can only be done through the family. However, pediatric illness may place strains on the family and can lead to decision-making that the patient-centered paradigm cannot accommodate. As Lindemann notes, there can be a “clash between health care ethics, which is patient-centered and individualistic, and the ethics of families, which is neither.” Families involve many people and, therefore, many needs. Health care professionals often seem to expect that the family will sacrifice all other interests (of other family members as well as the health of the family structure as a whole) to the needs of the pediatric patient. In fact, in some cases, the pediatric patient’s needs are properly outweighed by the needs of others. Lindemann argues that, contrary to current practice, clinical ethics should acknowledge and accommodate the distinctive roles and interests of families.

George Hardart examines best-interest concepts in the context of genetic testing for children. He reviews a long-standing debate about genetic testing and/or disclosing the results of genetic testing of children for adult-onset diseases for which no therapy currently exists. He demonstrates how the policies of both the American Academy of Pediatrics and the American College of Medical Genetics take family interests into account. He argues that there will be times when physician and parental roles and obligations differ. When family interests advance the patient’s interest, physicians should be family advocates; when there is tension between the family and patient interests, physicians should not be family advocates. Hardart argues that the physicians’ focus should be the patient.

June Carbone discusses the central ways in which US courts have treated
the best interest of the child standard. She starts by sketching the historical background of the standard in family law, particularly cases of abuse and neglect and when courts have had to determine the proper custodial parent. Turning to the health care context, Carbone discusses a range of topics: courts’ tendencies to defer to parental decision-making to determine where the child’s best interest lies; the different types of cases in which such deference is overridden either by an independent standard for the child’s best interest or by some form of third-party interest (e.g., a public health interest). What emerges from Carbone’s analysis is an appreciation of the wide variation in ways the best-interest standard might be applied and/or overridden.

Rosamond Rhodes and Ian R. Holzman challenge the propriety of the best interests of the patient standard for surrogate decision-making. They argue that this standard has a range of problems, including its vagueness, its failure to consider the interests of anyone but the patient, its violation of the just outcome in some cases, its neglect of public health free-rider issues, and the ease with which it can be massaged to induce a surrogate to accede to the health care team’s preferences. Rhodes and Holzman argue that one can usually identify: (1) options that “people everywhere could not reasonably reject,” for example, to avoid death or pain; (2) important reasons (“core reasons”) to which different people will give different weights in different contexts; and (3) reasons that someone might reject options without being unreasonable. When surrogates are called upon to make decisions for a patient, Rhodes and Holzman argue that they should be accepted as long as those decisions are not unreasonable. They propose a “3-box model.” At one extreme are options that prolong dying and suffering with little or no hope of benefit; at the other extreme are options in which treatment guarantees serious and likely benefit and refusal of treatment guarantees serious and likely harm. Rhodes and Holzman argue that it would be unreasonable to insist on continued treatment in the first class of cases or to refuse it in the second: physicians should not accept such decisions from surrogates, especially in the second class of cases. In between these extremes is the box that contains “medical decisions without significant consequences and decisions about treatments with uncertain outcomes.” It is in this situation, Rhodes and Holzman argue, that physicians should defer to the surrogate’s decision.

Taken together, these essays should help clinicians think about the best-interest standard in new ways. As pediatricians, we should always focus on the child patient because our primary responsibility is to that individual. However, complex situations sometimes occur in which the interests of parents, siblings, health professionals, and even society must also be considered. Instead of pretending or hoping that such situations will never arise, these articles provide tools for thinking through the tradeoffs and balancing various relevant interests.
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