

# Virtual Mentor

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## OP-ED

### What We Don't Know about How We Decide

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#### Introduction

What ethical issues arise in the practice of pediatric palliative care that warrant empirical research? Typically questions about ethics and research involve aspects of protections for human research subjects, as codified in the United States, in the 1974 National Research Act, the 1979 publication of the Belmont Report, and the promulgation of the federal Common Rule, as first expressed in 1991 in the Code of Federal Regulations at entry 45 CFR 46 [1]. Based on these foundations, the three so-called pillars of protections have emerged to guide much of the discussion regarding ethically appropriate research practices: (1) review by a properly constituted ethics review committee or institutional review board; (2) meaningful evaluation of potential harms and potential benefits; and (3) meaningful informed consent. These protections are as important for pediatric palliative care research as they are elsewhere, and a recent article has highlighted some of the challenges that can complicate, and perhaps thwart, pediatric palliative care research in the course of safeguarding these protections [2].

My goal here, however, is to pursue a different set of ethical issues, stemming not from the act of doing pediatric palliative care research, but rather from the challenges of taking care of children with life-threatening diseases and conditions. I believe there are three areas of ethical import in which we could—and should—conduct empirical research to better understand how patients, parents, clinicians, and others grapple with the ethical challenges we confront when caring for these children. These are: how we evaluate the quality of life of others; how having a critically ill child affects others in the family and whether those effects, in turn, influence decision making for the child who is ill; and what form of decision making—shared or otherwise—parents prefer when making decisions for their children.

To make this discussion more tangible, let's imagine the following clinical scenario: a full-term baby was born 10 days ago after a placental abruption and suffered extensive brain injury. After breathing on his own for 5 days, the infant had a prolonged seizure and needed to be reintubated. Head imaging studies showed marked advanced signs of hypoxic-ischemic encephalopathy. The neurologists are concerned that the child will have severe motor and cognitive impairments, but they still cannot be certain about his prognosis. The clinical team and the parents are questioning whether it is now ethically appropriate to consider palliative care, including the possibility of extubating the infant with a “do not resuscitate” order in

place. Within this vignette are at least three (and probably many more) ethical issues that warrant empirical research.

### **Whence and Whither Values?**

So much depends, in the provision of pediatric palliative care, on value-based judgments regarding quality of life that we would do well to understand the factors that shape an individual's values over time. Yet despite various studies about what people value—say, for example, how individuals rate the value of different health states—we have little understanding of why we value what we value. Beyond the notion that values in general are influenced by society and culture, we do know in the realm of health that people's perception of the quality of life associated with a given set of health problems or impairments such as cerebral palsy or spinal cord injury changes as they gain more information about the day-to-day life of those who have the impairment [3, 4].

These changes in how we evaluate quality of life, which occur with the passage of time and mounting personal experience and knowledge, raise several important issues. First, how do we in health care help patients and their families gauge how their values might change, so that the decisions they make today can account for the likelihood of these changes? Second, would this “anticipatory guidance” about the likelihood of changing values be appropriate and effective—would patients and families find such guidance helpful, or presumptuous and off-putting? Third, who should be making these evaluative judgments when policy decisions about the relative merits of various medical treatments are being made? Should it be people with personal knowledge about the health condition (who have lived expertise but also unavoidable bias), or people who are more objective members of the general public (who are thus putatively less biased, but also relatively ignorant about the day-to-day realities of the condition and perhaps with general biases against disabilities or certain illnesses)? How much do these two potential sources of value-based judgments differ? Each of these questions is germane to both pediatric palliative care clinical practice and policy-making, especially in our era of comparative effectiveness with the mounting pressure to perform cost-utility analyses. In my rounds as a pediatrician, I have walked into many rooms where loving families have judged the quality of life for their child—perhaps after a recent acute event similar to that described in the vignette above, perhaps years later after providing ongoing total care for the child—to be far better than others would deem; and I have also walked into an equal number of rooms, having been told by others that the child had no meaningful quality of life, only to find that child playing gleefully with siblings.

### **Family Matters?**

In the vignette, I did not spell out whether this was the parents' only child: would it matter if the infant were born into a family with 3 other young children? Typically, the standard of ethical decision making for pediatric cases is the child's best interest—not the family's [5]. From this point of view, whether the parents have other children is irrelevant, as is the potential impact of any medical decision on the

well-being of these possible siblings. Yet, in my experience (and as argued by others [6]), parents and many clinicians view decision making for the child patient in the broader context of the family, and do factor in—or, at the very least, worry a great deal about—the effect on siblings. We do not know the degree to which decisions are influenced by considerations of all the indirect effects of medical care on others. Nor do we know the impact upon siblings of having a sister or brother with a life-threatening condition. Data on these questions will not resolve the debate; simply knowing that a child's illness has major collateral impact on siblings and families will not tell us that we “ought” to weigh this impact in our decision making. But it will give us some information to use in arguing whether or not we ought to do so. Suppose that the parents in the vignette had other children. Would we counsel differently if we knew of data to support the theory that these siblings are likely to feel neglected if the baby survives in a severely impaired state...or perhaps data that the siblings are more likely to pursue a career in health care or service to others? Are these considerations even relevant to the baby's best interest?

### **Deciding How to Decide**

As the pendulum of medical ethics has swung from the physician paternalism of early 20th century medicine to the patient-autonomy ethos that first took hold just after mid-century, we may currently be seeing a rapprochement between patients and doctors in the form of shared decision making [7]. What we may be looking at now is, in fact, a meta-decision, namely how the patient and family decide to collaborate with the health care team in making a variety of decisions about specific medical treatment options. We know from some research with adult patients that many prefer to not make medical decisions in a completely autonomous manner, but prefer instead to either share the decision or even delegate it completely to the physician [8]. What we do not know is how parents prefer to make medical decisions for children with life-threatening conditions, nor do we know the reasons or values underlying these preferences. If we had such data, we would be on a research path that would greatly deepen our understanding of the pros and cons of different modes of collaborative decision making. And while waiting for research data about parents in general, we should not be shy in clinical practice to simply ask the question: how can I best work with you and help you make the decisions that lie ahead?

Let me end by summarizing and emphasizing the main point: there is not only research ethics, but also research about ethics. Given the vastness and vagueness of the core ethical principles we have been trying to interpret and use since the 1970s—beneficence and respect for autonomy, nonmaleficence and justice—coupled with the psychological and social challenges of evaluating, judging, and enacting a plan of care for anyone confronting life-threatening conditions, let alone a child—we should not be surprised that we have a lot still left to learn, nor fail to realize our ethical obligation to do so.

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