
Introduction

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Issues in Medical Ethics: Special Challenges in Pediatrics

SINCE THE END OF WORLD WAR II, the ethical issues that arise in modern medicine have grown more and more complex and challenging. As a result, an entirely new field of study, called medical ethics or bioethics, has emerged. Or rather, it has been created by the ethicists and clinicians who frequently wrestle with medical problems and seek to share their insights with patients, their families, other medical professionals, policy makers and laypersons who feel the need for guidance in resolving the ethical questions posed by modern medicine.

To a great extent, the morally demanding questions of bioethics are related to medicine's rapidly evolving technology. Clearly, that technology has provided medical interventions that can prolong life and can also provide a good deal of information about people's current health and their predisposition to future diseases and disability. Yet both the interventions and the information raise challenging ethical issues. Should life always be extended? Do some burdens and some costs make life extension immoral or unreasonable? Is there some information that we are better off not knowing? And always, who should make the decision for whom? Sometimes it is extremely difficult to formulate clear answers to such questions. And even when some authorities seem confident about their answers, their answers may disagree with those of other authorities. People often feel passionately about their own positions and just as passionately about the stands of those who hold opposing views.

As difficult as it is to arrive at near certainty or even consensus in medical ethics, the level of controversy rises dramatically whenever children are involved. People tend to call for a high level of protection for children; they recognize a social duty to promote their good and protect them from harm. For this reason, it is almost expected that clinical decisions involving the lives and futures of children will become charged with emotion and controversy.

In addition to our protectiveness with regard to children and the moral ambiguity of the medical decisions that have to be made, two characteristics of children make ethical decisions in pediatrics more difficult than in other areas of medicine. One is that they are younger than adults. Children who survive a health crisis are, therefore, likely to live with the consequences of the medical decisions for a relatively long time. Also, because of their size and their stage of development, medical interventions may have more beneficial or harmful effects on them than they might have on adults. (It is also true that, because of their plasticity and resilience, children can sometimes overcome injuries that would devastate an adult.)

Children are different from most adults in that they lack the capacity to make autonomous decisions about their own medical care. This legal incapacity is based on observable fact. Very young children are not able to make any decisions at all. Older children may sometimes be able to understand their situation and the choices that have to be made, but their thinking is different from mature thinking in numerous respects. The young tend to think of themselves as immortal and invulnerable, they tend to focus on short-term consequences and ignore or undervalue more distant effects, they fail to make subtle but significant distinctions, they tend to give great weight to the projected opinions of peers, and they tend to behave in ways that oppose the conclusions of their own reflection.

In addition to these factors, the place of parental authority complicates the ethics of pediatrics. For the most part, our society allows parental discretion a wide latitude. Parents have great freedom

when it comes to naming their children, deciding whether or not they will have a religious education, where they will live, and which of their talents will be nurtured and which activities they will pursue. Parents are also allowed the freedom to choose the kinds of food their children will eat, the education that they have, and the medical and dental care that they will or will not receive.

At the same time, other people in society, such as teachers and physicians, are assigned some responsibility for the welfare of children who come to their attention. And their responsibilities may clash with the rights of the children's parents. Parents and pediatricians may find themselves in situations where they strongly disagree about whether a course of treatment will be good for a child and also about whether a child has decisional capacity. In addition, the child may have his or her own strongly held view, and there may be no incontrovertible way to determine which party is right or even if any is wrong.

The papers in this issue of *The Mount Sinai Journal of Medicine* address some of the difficult ethical dilemmas that arise in the care of children. The authors bring to bear insights they have developed through years of work as clinicians and ethi-

cists. They offer conceptual frameworks that can be put to use in addressing a range of similar circumstances. Arthur Kopelman, Linda Siegel and John Lantos each address aspects of the controversial ethical issues in situations where a child's life can be prolonged, but at a significant cost, and when the medical professionals and family members have different views about what should be done. A team from the Mount Sinai Adolescent Health Center—Daniel Summers, Ivanya Alpert, Thaina Rousseau-Pierre, Mara Minguez, Simone Manigault, Sharon Edwards, Anne Nucci, and Angela Diaz—consider some of the moral questions about benefit, decisional capacity, parental discretion, and law that arise in the context of providing care for adolescent patients. Loretta Kopelman addresses questions of risk, harm, and the need for knowledge in the context of research that involves children. Mary Kay Pelias and Rosamond Rhodes consider the moral issues involved in designing policy to govern the testing of children for adult onset genetic diseases that are not readily amenable to prevention or treatment. Taken together, this collection of papers seeks to advance our understanding of the challenging ethical issues in pediatrics.