

ETHICS AND RESEARCH WITH CHILDREN: A CASE-BASED APPROACH

Edited by Eric Kodish. 361 pp. New York, Oxford University Press, 2005. \$59.50. ISBN 0-19-517178-0.

DURING THE PAST 10 YEARS, THE ISSUE OF enlisting children in medical research has been discussed widely. It has gained even more attention since new legislation has offered incentives to conduct research involving children.

Ethical lapses in some research studies involving children have highlighted the need for more guidance for investigators. In *Ethics and Research with Children*, Eric Kodish, an experienced pediatric researcher and bioethicist, has assembled a group of 32 contributors (most of whom are practitioners of research involving children) who deal with practical ethical issues concerning the conduct of research involving children. The practical aspects of this book are its strength; its case-based approach will be most useful for researchers struggling with the ethical dilemmas raised by their investigations.

The book examines the challenge of balancing the need for new knowledge that might benefit children as a group against the protection of the individual child from potential harm. Kodish never forgets that he is dealing with children; in his introduction, he states that “research participation by children may never be morally obligatory.” The problem becomes more acute when sick children in need of treatment, who otherwise would not be available, are involved. Kodish guides readers through these troubling problems, with compelling arguments on both sides, without leading them to a preordained goal.

The book has three sections: “Research Involving Healthy Children,” “Research Involving At-Risk Children,” and “Research Involving Children with Serious Illness.” The chapters within these sections describe the cases and discuss the ethical analyses in a balanced manner. In a few instances, however, the ethical analysis tends to steer the reader into approval of the research protocol on weak grounds. The authors analyze their cases thoroughly, but sometimes they conclude that the studies were ethically justified even while recognizing that their conclusions run contrary to moral intuition. Using healthy children with no family history of disease in research experiments that have no potential medical benefits for the child, except in rare cases such as vaccine studies, runs contrary to common sense.

Two unique chapters deal with the ethics of

maternal–fetal and infant surgery. Both chapters describe fairly the various aspects of the badly needed research in this area, and they discuss the overwhelming hype about such surgeries that could mislead parents and persuade them to choose surgery for their children.

The chapter by Jessica Wilen Berg eloquently discusses the use of placebos in research that involves children. She states that “placebo use is ethically acceptable and may even be ethically required in some research trials, including those that involve children.” Nevertheless, Berg recognizes the need for greater scrutiny.

The book would have benefited from a chapter written by an advocate, a research subject, or a family member. The inclusion in these discussions of voices of human subjects and their families should become routine. This book will help researchers whose work involves children to navigate the ethical challenges of their investigations, and it will remind bioethicists of the practical concerns of researchers.

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CORRECTION

Modafinil for Excessive Sleepiness Associated with Shift-Work Sleep Disorder (August 4, 2005;353:476-86). On page 484, in the left-hand column, lines 23 through 26 should have read, “. . . and the mean duration of these lapses in the placebo group was nearly twice as long as that in the modafinil group,” rather than “. . . and the mean duration of these lapses in the modafinil group was nearly twice as long as that in the placebo group,” as printed.

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