Cambridge University Press
978-0-521-17361-2 - Clinical Ethics in Pediatrics: A Case-Based Textbook
Edited by Douglas S. Diekema, Mark R. Mercurio and Mary B. Adam
Frontmatter
More information

Clinical Ethics in Pediatrics

A Case-Based Textbook

Clinical Ethics in Pediatrics

A Case-Based Textbook

Edited by
Douglas S. Diekema MD, MPH
Professor of Pediatrics and Adjunct Professor of Bioethics & Humanities, University of Washington School of Medicine; Director of Education, Treuman Katz Center for Pediatric Bioethics, Seattle Children's Hospital, Seattle, WA, USA
Mark R. Mercurio MD, MA
Director, Program for Biomedical Ethics and Professor of Pediatrics, Yale University School of Medicine, New Haven, CT, USA
Mary B. Adam MD, MA, PhD
Clinical Lecturer in Pediatrics, University of Arizona College of Medicine; Research Fellow in Evaluation, Research, and Development Unit, Department of Psychology, University of Arizona, Tucson, AZ, USA

CAMBRIDGE
UNIVERSITY PRESS

CAMBRIDGE UNIVERSITY PRESS
Cambridge, New York, Melbourne, Madrid, Cape Town,
Singapore, São Paulo, Delhi, Tokyo, Mexico City

Cambridge University Press
The Edinburgh Building, Cambridge CB2 8RU, UK

Published in the United States of America by Cambridge University Press, New York

www.cambridge.org
Information on this title: www.cambridge.org/9780521173612

First published 2011

Printed in the United Kingdom at the University Press, Cambridge

A catalogue record for this publication is available from the British Library

Library of Congress Cataloguing in Publication data
Clinical ethics in pediatrics : a case-based textbook / [edited by] Douglas S. Diekema, Mark R. Mercurio, Mary B. Adam.
p. ; cm.
Includes bibliographical references and index.
ISBN 978-0-521-17361-2 (pbk.)
1. Pediatrics–Moral and ethical aspects–Case studies. 2. Professional ethics.
I. Diekema, Douglas S. II. Mercurio, Mark R. III. Adam, Mary B. IV. Title.
[DNLM: 1. Pediatrics–ethics–Case Reports. 2. Ethics, Medical–Case Reports.
3. Ethics, Professional–Case Reports. WS 21]
RJ47.8.C55 2011
174.2′9892–dc23
2011017978

ISBN 978-0-521-17361-2 Paperback

Every effort has been made in preparing this book to provide accurate and up-to-date information which is in accord with accepted standards and practice at the time of publication. Although case histories are drawn from actual cases, every effort has been made to disguise the identities of the individuals involved. Nevertheless, the authors, editors and publishers can make no warranties that the information contained herein is totally free from error, not least because clinical standards are constantly changing through research and regulation. The authors, editors and publishers therefore disclaim all liability for direct or consequential damages resulting from the use of material contained in this book. Readers are strongly advised to pay careful attention to information provided by the manufacturer of any drugs or equipment that they plan to use.

Contents

Section 1 – Core issues in clinical pediatric ethics

Section 2 – Ethical issues at the beginning of life: perinatology and neonatology

Section 3 – When a child dies: ethical issues at the end of life

Section 4 – Ethical issues posed by advances in medical technology and science

Section 5 – Children, public health, and justice

Section 6 – Special topics in pediatric ethics

Contributors

Armand H. Matheny Antommaria, MD, PhD
Associate Professor, Division of Pediatric Inpatient Medicine
Adjunct Associate Professor, Division of Medical Ethics and Humanities
University of Utah School of Medicine
Salt Lake City, Utah, USA

Andrew C. Beckstrom, MD
Fellow, Department of Pediatrics, Division of Neonatology
University of Washington School of Medicine
Seattle, Washington, USA

Jessica Wilen Berg, JD, MPH
Professor of Law, Bioethics & Public Health
Case Western Reserve University
Cleveland, Ohio, USA

Valarie Blake, JD, MA
Fellow, Cleveland Fellowship in Advanced Bioethics
Department of Bioethics, Cleveland Clinic
Cleveland, Ohio, USA

Ellen L. Blank, MD, MA
Associate Professor of Pediatrics and Bioethics
Medical College of Wisconsin
Pediatric Gastroenterologist, Children's Hospital of Wisconsin
Milwaukee, Wisconsin, USA

Jeffrey R. Botkin, MD, MPH
Professor of Pediatrics
Chief, Division of Medical Ethics and Humanities
Associate Vice President for Research Integrity
University of Utah
Salt Lake City, Utah, USA

Donald Brunnquell, PhD, MA, LP
Director, Office of Ethics
Children's Hospitals and Clinics of Minnesota
Minneapolis and St. Paul, Minnesota, USA

Jeffrey P. Burns, MD, MPH
Chief, Division of Critical Care Medicine
Children's Hospital Boston
Edward & Barbara Shapiro Chair of Critical Care Medicine
Associate Professor of Anesthesia and Pediatrics
Harvard Medical School
Boston, Massachusetts, USA

E. Charlisse Caga-anan, JD
Fellow, Cleveland Fellowship in Advanced Bioethics
Department of Bioethics, Cleveland Clinic
Cleveland, Ohio, USA

John C. Carey, MD, MPH
Professor and Vice Chair, Academic Affairs
Department of Pediatrics, University of Utah
Editor-in-Chief, *American Journal of Medical Genetics*
Salt Lake City, Utah, USA

Christy L. Cummings, MD
Department of Pediatrics, Division of Neonatal-Perinatal Medicine
Yale Pediatric Ethics Program
Yale University School of Medicine
New Haven, Connecticut, USA

Douglas S. Diekema, MD, MPH
Professor of Pediatrics, University of Washington School of Medicine
Director of Education, Treuman Katz Center for Pediatric Bioethics
Seattle Children's Hospital
Seattle, Washington, USA

Denise M. Dudzinski, PhD, MTS
Associate Professor & Director of Graduate Studies
Department of Bioethics and Humanities
University of Washington School of Medicine
Seattle, Washington, USA

List of contributors

Jeffrey Ecker, MD
Associate Professor
Massachusetts General Hospital
Harvard Medical School
Boston, Massachusetts, USA

Norman Fost, MD, MPH
Professor, Departments of Pediatrics and Medical History & Bioethics
University of Wisconsin School of Medicine and Public Health
Madison, Wisconsin, USA

Joel Frader, MD, MA
A Todd Davis Professor of General Academic Pediatrics
Professor of Medical Humanities and Bioethics
Feinberg School of Medicine, Northwestern University and Children's Memorial Hospital
Chicago, Illinois, USA

Thomas H. Gallagher, MD
Associate Professor of Medicine, Bioethics & Humanities
University of Washington School of Medicine
Seattle, Washington, USA

Aviva M. Goldberg, MD, MA
Assistant Professor, Section of Pediatrics and Child Health
Faculty of Medicine, University of Manitoba
Winnipeg, Manitoba, Canada

Emily C. Goodlander, JD
Baltimore, Maryland, USA

Jennifer Guon, JD, MA
Fellow, Treuman Katz Center for Pediatric Bioethics
Seattle Children's Hospital
Seattle, Washington, USA

Rebecca M. Harris
Medical Scientist Training Program Candidate
Medical Humanities and Bioethics Candidate
Feinberg School of Medicine, Northwestern University
Chicago, Illinois, USA

Christine Harrison, PhD
Associate Professor, Department of Paediatrics and The Joint Centre for Bioethics
University of Toronto
Toronto, Ontario, Canada

D. Micah Hester, PhD
Chief, Division of Medical Humanities
Associate Professor of Medical Humanities and Pediatrics
University of Arkansas for Medical Sciences, College of Medicine
Clinical Ethicist, Arkansas Children's Hospital
Little Rock, Arkansas, USA

Ian R. Holzman, MD
Professor of Pediatrics, Obstetrics, Gynecology and Reproductive Sciences
Chief, Division of Newborn Medicine
Vice Chair for Clinical Affairs
Department of Pediatrics, Mount Sinai School of Medicine
New York, New York, USA

Annie Janvier, MD, PhD, FRCPC
Associate Professor of Pediatrics, University of Montreal
Neonatologist and Clinical Ethicist, Sainte-Justine Hospital
Montreal, Quebec, Canada

Maureen Kelley, PhD
Assistant Professor of Pediatrics, Division of Bioethics
University of Washington School of Medicine
Scholar, Treuman Katz Center for Pediatric Bioethics
Seattle Children's Hospital
Seattle, Washington, USA

Jennifer C. Kesselheim, MD, MBE, M.Ed.
Instructor in Pediatrics, Harvard Medical School
Division of Pediatric Hematology-Oncology
Dana-Farber/Children's Hospital Cancer Center
Boston, Massachusetts, USA

Eric Kodish, MD
Center for Ethics, Humanities and Spiritual Care
F.J. O'Neill Professor and Chair, Department of Bioethics
Professor of Pediatrics, Lerner College of Medicine
Cleveland Clinic
Cleveland, Ohio, USA

Alexander A. Kon, MD, FAAP, FCCM
Chief, Pediatric Critical Care Medicine
Medical Director, Pediatric Intensive Care Unit
Naval Medical Center San Diego
San Diego, California, USA

Carolyn Korfiatis, BA
Research Associate, Treuman Katz Center for Pediatric Bioethics
Seattle Children's Hospital
Seattle, Washington, USA

John D. Lantos, MD
Director, Children's Mercy Bioethics Center
Children's Mercy Hospital
Professor of Pediatrics, University of Missouri – Kansas City
Kansas City, Missouri, USA

Steven Leuthner, MD, MA
Professor of Bioethics and Medical Humanities
Medical College of Wisconsin
Director of the Fetal Concerns Program
Children's Hospital of Wisconsin
Milwaukee, Wisconsin, USA

Marcia Levetown, MD
Principal, Health Care Communication Associates
Houston, Texas, USA

David J. Loren, MD
Assistant Professor of Pediatrics, Division of Neonatology
University of Washington School of Medicine
Seattle Children's Hospital
Seattle, Washington, USA

Mark R. Mercurio, MD, MA
Professor of Pediatrics
Director, Program for Biomedical Ethics
Yale School of Medicine
Director, Pediatric Ethics Program
Yale-New Haven Children's Hospital
New Haven, Connecticut, USA

Kelly Michelson, MD, MPH
Assistant Professor of Pediatrics
Division of Critical Care Medicine, Children's Memorial Hospital
Northwestern University Feinberg School of Medicine
Associate Physician, Buehler Center on Aging, Health & Society
Chicago, Illinois, USA

Geoffrey Miller, MA, MB, MPhil, MD, FRCP, FRACP
Professor of Pediatrics and Neurology
Yale University
New Haven, Connecticut, USA

Howard Minkoff, MD
Distinguished Professor Obstetrics and Gynecology
State University of New York Downstate
Chair, Department of Obstetrics and Gynecology
Maimonides Medical Center
Brooklyn, New York, USA

Christine Mitchell, RN, MS, MTS
Director, Office of Ethics
Children's Hospital Boston
Associate Director, Clinical Ethics
Harvard Medical School
Division of Medical Ethics
Boston, MA, USA

Douglas J. Opel, MD, MPH
Acting Assistant Professor of Pediatrics
University of Washington School of Medicine
Scholar, Treuman Katz Center for Pediatric Bioethics
Seattle Children's Hospital
Seattle, Washington, USA

Malcolm Parker, MB BS, MLitt, LLM
Associate Professor of Medical Ethics
School of Medicine, University of Queensland
Brisbane, Australia

Lainie Friedman Ross, MD, PhD
Carolyn and Matthew Bucksbaum Professor of Clinical Ethics
Professor in the Departments of Pediatrics, Medicine, Surgery and the College
Associate Director of the MacLean Center for Clinical Medical Ethics
University of Chicago
Chicago, Illinois, USA

Stephanya B. Shear, MD
Rochester, New York, USA

Halle Showalter Salas, MPhil
Research and Family Liaison, Seattle Children's Research Institute
Seattle, Washington, USA

Anthony J. Thomas, Jr., MD, MA, FACS
Professor of Surgery
Department of Bioethics
Center for Bioethics, Humanities and Spiritual Care
Cleveland Clinic
Cleveland, Ohio, USA

Cambridge University Press
978-0-521-17361-2 - Clinical Ethics in Pediatrics: A Case-Based Textbook
Edited by Douglas S. Diekema, Mark R. Mercurio and Mary B. Adam
Frontmatter
More information

Yoram Unguru, MD, MS, MA
Attending Physician
Division of Pediatric Hematology/Oncology
The Herman and Walter Samuelson Children's Hospital at Sinai
Berman Institute of Bioethics, Johns Hopkins University
Baltimore, Maryland, USA

A.A. Eduard Verhagen, MD, PhD, JD
Head of Section General Pediatrics, Dept of Pediatrics
University Medical Center Groningen,
Groningen, the Netherlands

Benjamin S. Wilfond, MD
Professor and Chair, Division of Bioethics, Department of Pediatrics
University of Washington School of Medicine
Director, Treuman Katz Center for Pediatric Bioethics
Seattle Children's Hospital
Seattle, Washington, USA

David E. Woodrum, MD
Professor of Pediatrics, Division of Neonatology
University of Washington School of Medicine
Scholar, Treuman Katz Center for Pediatric Bioethics
Seattle Children's Hospital
Seattle, Washington, USA

Roger Worthington, PhD
Lecturer and Law and Ethics Lead
Keele University School of Medicine
City General Hospital, Stoke-on-Trent, UK
Assistant (Adjunct) Professor of Medicine
Department of General Internal Medicine
Yale University
New Haven, Connecticut, USA

John Wyatt, MBBS, FRCP
Professor of Ethics & Perinatology
Institute for Women's Health
University College London
London, UK

Preface

Douglas S. Diekema, Mark R. Mercurio, and Mary B. Adam

This is a book for individuals who struggle with the ethical issues that inevitably arise when providing medical care to children. The contributing authors possess expertise in clinical ethics and experience in the clinical world. Most of the authors are clinicians, intimately familiar with the issues they discuss in their chapters. Those who are not clinicians serve as ethics consultants in clinical settings. All of the authors have struggled with difficult ethical situations involving children.

The three of us have been teaching clinical ethics to undergraduates, medical students, and residents for a combined total of over 50 years. Because our clinical practice is pediatrics, most of our teaching involves clinical ethics as it relates to the care of children and their families. Twenty years ago, one of us (DSD) developed a structured curriculum for teaching clinical ethics to the pediatric residents at Seattle Children's Hospital. A description of that curriculum was published in *Archives of Pediatrics and Adolescent Medicine* in 1997 (Diekema & Shugerman, 1997). That article generated significant interest, including pleas from residency programs around the country for resources to help teach the topics outlined in that paper. At the same time physicians and trainees frequently ask whether we can recommend a book that provides a good overview of pediatric ethics. But while there are some terrific books that deal with specific areas within the field (research ethics, neonatal ethics, decision-making on behalf of children), we find ourselves at a loss in identifying a volume that provides a comprehensive overview of the rich array of issues faced by those who care for children in the medical context. This volume is an attempt to provide such a resource.

The aim of this book is to provide a comprehensive overview of the ethical issues faced in pediatric practice. Each chapter begins with a case that illustrates the topic. The discussion that follows in each chapter is grounded by the specific case. We wanted this text to be accessible to readers who did not necessarily have an extensive background in ethics or philosophy, but who wanted to deepen their understanding of the ethical issues faced in pediatrics. Our hope is that this volume will be a useful resource for health care providers who take care of children – an introductory text for those who want to learn about and better understand ethical issues in pediatrics as well as a teaching resource for those who might teach these topics in a residency program, medical school, or undergraduate setting.

Why a case-based textbook of clinical pediatric ethics?

Cases involving children have always been central to discussions of ethics in medicine. In *The Birth of Bioethics*, Albert Jonsen (1998) identifies the 1960s and 1970s as the beginning of the modern era of bioethics. While the Tuskegee Syphilis Studies and the case of Karen Ann Quinlan, among others, are representative of the case studies that initiated some of those early discussions, the truth is that many of the earliest cases discussed by philosophers and theologians in those years involved children. Saul Krugman's *Willowbrook Hepatitis studies* elicited intense discussion in the early 1960s. In 1970, Paul Ramsey published *The Patient as Person*, one of the first texts on medical ethics. A key chapter in that book centers on the question of whether children should serve as research subjects. One of the earliest clinical cases to engender public discourse on ethical issues was the Johns Hopkins Baby Doe story. The year was 1970, and the story involves the birth of a baby with trisomy 21 and multiple anomalies, including duodenal atresia. The parents chose not to allow surgery and the physicians agreed, with the baby dying after two weeks. Several members of the pediatric team, however, questioned the decision. A year later the Joseph P. Kennedy Foundation produced a film titled *Who Should Survive?* that re-enacted the events surrounding the baby's short life and death. That film was shown to thousands of medical students in the decades that followed and became a staple of medical ethics education in a time before clinical ethicists were a common sight in medical centers and medical schools. As an interesting side note, two of the physicians involved in the events surrounding the Hopkins baby, Norman Fost and William Bartholome, went on to become prominent academic bioethicists who helped maintain the focus on issues related to children.

It should be noted that cases remain central to the recognition and discussion of ethical issues in medicine. The early philosophical and theological explorations of ethical issues in the 1960s and 1970s were prompted by events like those that occurred at Willowbrook and Johns Hopkins. The events comprising those cases caused someone to raise an eyebrow, and then ask a question to which nobody could provide a satisfactory answer. Those questions became the source of ethical discourse that over time has changed the way we think about certain issues faced in the care of patients. As new cases arise, they continue to raise new questions that challenge our assumptions and existing standards. Clinical ethics is a living, breathing discipline that continues to evolve as a result of cases. And each of those cases represents a real person with real interests at stake.

Ethical issues faced by pediatricians certainly share features in common with those faced by providers in other specialties. Yet they can also be distinguished. Most decisions in pediatric medicine involve three parties – the clinician, the child/patient, and the parent. Infants and children cannot make decisions for themselves and have not yet developed the kind of narrative that allows a surrogate decision-maker to discern the patient's preferences regarding medical intervention. While we generally assume parents seek the best interests of their children, we may not always be convinced that a specific parental decision accomplishes that goal. A recurring theme through many of the chapters in this book is the struggle to identify the limits of parental decision-making authority, and determine when a parental decision should be challenged. Older children and adolescent patients add another dimension. These individuals may have the ability and desire to be involved in decision-making, but their capacity for "adult-like" decision-making may not yet be fully developed. Determining the right balance between respecting the preferences of an adolescent patient and protecting their future interests represents another common theme in pediatric bioethics. Even the so-called boundary issues may manifest themselves differently in pediatrics, since the boundary being delimited usually involves that between the clinician and the patient's parent or relative rather than between the clinician and the child/patient.

In addition to the clinical realm, health care professionals can be found on hospital ethics committees, institutional review boards, national committees that set policy related to ethics and law, national organ procurement agencies, local, state, and federal committees evaluating triage and scare resource allocation strategies, and state and federal committees concerned with vaccine allocation strategies (i.e., for pandemic influenza) or vaccination requirements for children. These responsibilities involve the application of ethical analysis to issues that affect policy, public health, and populations. Health care professionals who serve these roles will benefit from some understanding of ethical analysis.

The purpose of this book

This book is intended for a broad audience. Its intent is to serve as a primer on pediatric clinical ethics for health care professionals, undergraduates, graduate students, medical students, and residents who seek to better understand the issues that arise in pediatric practice. At the same time, we have written this book to provide a useful resource for those who teach pediatric clinical ethics. Each case-based chapter could easily form the basis of a course lecture, classroom or seminar discussion, small group discussion, or residency ethics conference. Cases represent the soul of each chapter and provide an anchor around which the discussion of each topic can take place. They also remind the reader that ethics is not simply about opinions and theories, but ultimately about coming to a reasoned solution to a difficult problem that involves a very real patient. Taken as a whole, the chapters not only provide an overview of the broad range of issues that comprise pediatric ethics, but also give the reader a sense for the common themes shared by seemingly different ethical issues.

Clinical practice inevitably poses difficult ethical questions. Caring for patients will inevitably lead to situations in which there are disagreements over what is "best" for a patient, over which values should prevail in a given situation, about who ultimately should be able to decide what to do. Clinical practice is driven by the ethical principle of beneficence – the obligation to apply the tools of the health care professions for the good of the patient. This ideally involves the application of medical science. But it also inevitably requires value judgments; for every medical decision is premised on the assumption that what is being proposed medically is good or best for the patient. Disagreements will arise in those situations, and it is important for clinicians to recognize that those disagreements are, at their core, disagreements about values. Recognizing, understanding, and learning how to approach, mediate, and even solve ethical dilemmas requires applying the appropriate tools – the tools of ethical reasoning. Ethics is not ultimately about forming an opinion about a difficult issue, but about being able to give reasons and arguments that have the potential to convince others about the best approach in a difficult situation. These are serious questions that have significant impacts on patients. They deserve serious, thoughtful, well-considered, and reasoned solutions. We have given the chapter authors the freedom to approach their chapter topic as they see fit. This is intentional. Our hope is that it provides the reader with a sampling of different approaches to ethical issues. What is important, however, is that the authors have approached each topic thoughtfully – outlining the issues, making an argument to support a specific approach, and ultimately offering a resolution to the problem.

We do not expect the reader to agree with everything in these chapters. We have asked our expert contributors to provide an overview of each issue, but the issues are by nature controversial. We don't necessarily agree with everything written on these pages, and we don't expect that our readers will. Our hope, however, is that if nothing else the chapters will engender discussion, debate, and further reflection. If we can hope more grandly, our desire is that this book will provide a means for readers to enhance their ability to recognize ethical issues and improve their skills in seeking a reasonable resolution to difficult ethical dilemmas. In many cases, one will come to the conclusion that more than one approach is acceptable. Many ethical issues are difficult precisely because they offer no clearly good way to navigate the conflict. They represent conflicts between important values or commitments. They are frequently infused with uncertainty. In many cases, they are truly tragic in the sense that one must choose between two or more good options, but choosing for one good will forgo the other – as when one must choose between potential recipients in allocating a single kidney, liver, or heart for transplant. Alternatively, tragic ethical dilemmas in medicine take the other form – we must choose between options that can only be described as bad – as when those gathered around the bed of a child who has suffered a severe anoxic brain injury after a prolonged submersion event face the decision of whether to allow the child to die or continue to use medical technology that may maintain life, but life accompanied by a vegetative existence.

The structure and organization of this book

This volume provides a practical overview of the ethical issues arising in pediatric practice. The case-based approach grounds the bioethical concepts in real-life situations, covering a broad range of important and controversial topics encountered by those who provide health care to children, including informed consent, confidentiality, truthfulness and fidelity, ethical issues relating to perinatology and neonatology, end-of-life issues, new technologies, and problems of justice and public health in pediatrics. A dedicated section also addresses the topics of professionalism, including boundary issues, conflicts of interests and relationships with industry, ethical issues arising during training, and dealing with the impaired or unethical colleague. Each chapter contains a summary of the key issues covered and recommendations for approaching similar situations in other contexts.

We have organized this textbook around six sections. Section 1 addresses core issues in pediatric clinical ethics. These include the topics of parental permission and refusal, the assent of children, adolescent involvement in decision-making, confidentiality, disclosure and keeping diagnostic secrets from children and adolescents, truth-telling, disclosure of errors, parental refusals of certain treatments on the basis of religious or cultural beliefs, and requests for treatments that the physician may be uncomfortable providing.

Many difficult ethical issues face prospective parents and clinicians during pregnancy and at the time of birth. Section 2 encompasses a broad range of ethical issues that arise during the perinatal and neonatal period. These include maternal–fetal conflicts, fetal therapy, the responsible use of assisted reproductive technology, preimplantation and prenatal genetic testing for inherited disorders, dispositions, or traits, and the ethical issues that arise in making decisions in the delivery room and in the newborn period regarding the initiation or continuation of life-sustaining interventions. We have included two chapters related to the latter topic that address quality of life assessment and international variations in the way these decisions get made.

Death is tragic when it occurs in children, and decisions surrounding the death of a child can be difficult for all involved. Section 3 addresses the ethical issues that arise at the end of a child's life, including resolving disputes that occur in making decisions about continuation or initiation of life-sustaining interventions, futility, advanced directives and do-not-resuscitate orders in children, the definition of death, physician-assisted death, and palliative care.

New technologies are frequently accompanied by ethical issues, in some cases ethical issues that have not previously been considered. Section 4 addresses several of the issues that new technologies in pediatrics pose for parents and providers. This section includes discussions of transplantation, enhancement technologies (growth hormone treatment, cognitive enhancement), genetic screening and testing, the introduction of innovative technology in practice, and ethical aspects of human subjects research. Three of the chapters in this section explore the impact of medical innovation or new technologies on groups that may or may not perceive the interventions as beneficial, either because they carry social implications for the group in question (cochlear implants and the Deaf community) or because of disagreement about whether the intervention provides net benefit to the child (sterilizing procedures in children with profound developmental delay and the surgical management of children with disorders of sex development).

Section 5 addresses issues of policy that directly impact the medical care of children. These include allocation decisions (related to resources during a pandemic or disaster) and policy related to school vaccine mandates. We have also included here a chapter that addresses the interesting question of whether health care providers should provide medical support at events that may pose significant risks to the participants (in this case youth boxing).

Finally, we have included a section to address the professional responsibilities of providers. These are topics frequently left unaddressed in other texts. While most of these issues are not directly related to clinical care, they do have implications for the care patients receive. Included in Section 6 are discussions about the impaired health care provider, ethical issues that arise in training (practicing procedures, disclosure of level of experience), physician relationships with industry, and boundary issues in pediatrics (gifts from patients, romantic relationships with patients/family members, caring for the children of friends/relatives). We have also included a final chapter in this section about ethics consultation and ethics committees, since these mechanisms provide an important resource for clinicians and families struggling with the issues raised in many of the other chapters in this book.

Acknowledgments

This text was truly a collaborative effort. We owe a debt of gratitude to the contributing authors for their stimulating and thoughtful chapters. It is truly remarkable that we could find 50 talented individuals to participate in this endeavor. Almost nobody we asked refused to write a chapter. For your willingness to work with us and for your wonderful contributions, we are deeply grateful.

We are also truly grateful to the wonderful editors at Cambridge University Press. In particular, Nick Dunton helped launch this project. It has been completed only because of his encouragement, patience, and persistence during the early phases of writing this book. Likewise, thanks to Richard Marley for taking over mid-stream and providing us with the support we needed to complete this project. Finally, we couldn't have asked for a better editor than Nisha Doshi. She gently kept us on task, provided superb organizational support, and offered us timely and helpful advice whenever we needed it. We are also grateful to Carolyn Korfiatis, research associate at the Treuman Katz Center for Pediatric Bioethics, whose organizational and editing skills helped make this a better book.

Mark would like to thank his wife, Anna, for her support, patience, and encouragement that made this and so many other professional projects possible. Mary would like to thank her husband, Rod, for his support and encouragement that allowed her the flexibility to pursue this project in the midst of transitioning their lives and work to Africa. Doug would like to thank his wife, Susan, for her support and encouragement, and his children, Nathan and Katie, for their inspiration and patience. All three displayed more patience and understanding as he labored to finish this book than he had a right to expect.

References

Diekema, D.S. & Shugerman, R.P. (1997). An ethics curriculum for the pediatric residency program: confronting barriers to implementation. *Archives of Pediatrics and Adolescent Medicine*, **151**, 609–614.

Jonsen, A.R. (1998). *The Birth of Bioethics*. New York: Oxford University Press.

Ramsey, P. (1970). *The Patient as Person*. New Haven, CT: Yale University Press.