Complex Ethics Consultations

Volume 1

Cambridge University Press & Assessment 978-1-009-40095-4 — Complex Ethics Consultations Edited by Paul J. Ford , Denise M. Dudzinski Frontmatter <u>More Information</u>

"This rich anthology reminds us that clinical case consultation is more than an abstract exercise in philosophy. It is a complicated process that is personal and intuitive, often haunting practitioners with memories that are both disturbing and instructive. Professors Ford and Dudzinski have brilliantly capitalized on the pedagogical value of these musings and edited a volume that will enrich teaching in the seminar room or at the bedside. The cases are forthcoming and reveal what Aristotle would appreciate as the *phronesis*, or practical wisdom, of master clinical ethicists as they grapple with complex cases across the life cycle. A wonderful feature of this new edition is that it places the current generation of practitioners into conversation with their pioneering predecessors from the first edition, reminding readers of the enduring values that should inform case consultation. This volume belongs in the library of every student and teacher of bioethics."

Joseph J. Fins, MD, D.Hum.Litt. (hc), MACP, FRCP E. William Davis, Jr., MD Professor of Medical Ethics and Chief of the Division of Medical Ethics at Weill Cornell Medicine Chair of the Hastings Center Board of Trustees Author, *Rights Come to Mind: Brain Injury, Ethics, and the Struggle for Consciousness.*

Cambridge University Press & Assessment 978-1-009-40095-4 — Complex Ethics Consultations Edited by Paul J. Ford , Denise M. Dudzinski Frontmatter <u>More Information</u>

Complex Ethics Consultations

Cases that Haunt Us

Volume 1

Second Edition

Edited by **Paul J. Ford** The Cleveland Clinic Foundation, Cleveland

Denise M. Dudzinski University of Washington School of Medicine, Seattle



Cambridge University Press & Assessment 978-1-009-40095-4 — Complex Ethics Consultations Edited by Paul J. Ford , Denise M. Dudzinski Frontmatter More Information



Shaftesbury Road, Cambridge CB2 8EA, United Kingdom

One Liberty Plaza, 20th Floor, New York, NY 10006, USA

477 Williamstown Road, Port Melbourne, VIC 3207, Australia

314–321, 3rd Floor, Plot 3, Splendor Forum, Jasola District Centre, New Delhi – 110025, India

103 Penang Road, #05-06/07, Visioncrest Commercial, Singapore 238467

Cambridge University Press is part of Cambridge University Press & Assessment, a department of the University of Cambridge.

We share the University's mission to contribute to society through the pursuit of education, learning and research at the highest international levels of excellence.

www.cambridge.org

Information on this title: www.cambridge.org/9781009400954

DOI: 10.1017/9781009400947

First Edition © P. J. Ford and D. M. Dudzinski 2008 Second Edition © Cambridge University Press & Assessment 2025

This publication is in copyright. Subject to statutory exception and to the provisions of relevant collective licensing agreements, no reproduction of any part may take place without the written permission of Cambridge University Press & Assessment.

When citing this work, please include a reference to the DOI 10.1017/9781009400947

First published 2008 Second edition 2025

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

Library of Congress Cataloging-in-Publication Data

Names: Ford, Paul J., 1971- editor | Dudzinski, Denise M., 1969- editor

Title: Complex ethics consultations : cases that haunt us / edited by Paul J. Ford, the Cleveland Clinic

Foundation, Cleveland Denise M. Dudzinski, University of Washington School of Medicine, Seattle. Description: Second edition. | Cambridge, United Kingdom ; New York, NY, USA : Cambridge University Press, [2025] | Includes bibliographical references and index.

Identifiers: LCCN 2024055306 (print) | LCCN 2024055307 (ebook) | ISBN 9781009400954 paperback | ISBN 9781009400947 epub

Subjects: LCSH: Medical ethics–Case studies | MESH: Ethics, Clinical | Ethics Consultation Classification: LCC R724 .C6165 2008 (print) | LCC R724 (ebook) | DDC 174.2–dc23/eng/20250210

LC record available at https://lccn.loc.gov/2024055306

LC ebook record available at https://lccn.loc.gov/2024055307

ISBN 978-1-009-40095-4 Paperback

Cambridge University Press & Assessment has no responsibility for the persistence or accuracy of URLs for external or third-party internet websites referred to in this publication and does not guarantee that any content on such websites is, or will remain accurate or appropriate.

Every effort has been made in preparing this book to provide accurate and up-to-date information that 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

List of Additional Contributors to the Second Edition ix List of Contributors to the First Edition xi Foreword to the First Edition xv Acknowledgments xix

Introduction 1 Denise M. Dudzinski and Paul J. Ford

Live and Learn: Courage, Honesty, and Vulnerability (Introduction to the First Edition) 4 Paul J. Ford and Denise M. Dudzinski

Part I Starting at the Beginning: Prenatal and Neonatal Issues

- 1 **Quality of Life and of Ethics Consultation – in the NICU** 15 Robert C. Macauley and Robert D. Orr
- 2 When a Baby Dies in Pain 21 Thomas R. McCormick and David Woodrum
- 3 But How Can We Choose? 27 Richard M. Zaner
- 4 Maternal–Fetal Surgery and the "Profoundest Question in Ethics" 33 Mark J. Bliton

Commentary 1 Reflections on Part I 39 Lucia D. Wocial

Part II The Most Vulnerable of Us: Pediatrics

5 **She Was the Life of the Party** 47 Douglas S. Diekema

- 6 **The Sound of Chains** 53 Jeffrey Spike
- 7 Susie's Voice 59
 Rosa Lynn Pinkus, Stella L. Smetanka, and Nathan A. Kottkamp
- Access to an Infant's Family: Lingering Effects of Not Talking with Parents 65
 D. Micah Hester

Commentary 2 Reflections on Part II 70 Nneka Sederstrom

Part III Diversity of Desires and Limits of Liberty: Psychiatric and Psychological Issues

- 9 Helping Staff Help a "Hateful"
 Patient: The Case of TJ 79
 Joy D. Skeel and Kristi S. Williams
- 10 Ulysses Contract 84 Barbara J. Daly and Cynthia Griggins
- Misjudging Needs: A Messy Spiral of Complexity 90
 Paul J. Ford
- 12 When the Patient Refusesto Eat 96Debra Craig and Gerald R. Winslow

Cambridge University Press & Assessment 978-1-009-40095-4 — Complex Ethics Consultations Edited by Paul J. Ford , Denise M. Dudzinski Frontmatter <u>More Information</u>

vi

Contents

Commentary 3 Reflections on Part III 102 Maya Scott

Part IV Withholding Therapy with a Twist

- 13 Listening to the Husband 109 Ellen W. Bernal
- 14 You're the Ethicist; I'm Just the Surgeon 115 Joseph P. DeMarco and Paul J. Ford
- 15 Haunted by a Good Outcome: The Case of Sister Jane 121George J. Agich
- 16 Is a Broken Jaw a Terminal Condition? 127Stuart G. Finder

Commentary 4 Reflections on Part IV 133 Crystal Brown

Part V The Unspeakable/ Unassailable: Religious and Cultural Beliefs

- 17 Adolescent Pregnancy, Confidentiality, and Culture 139 Donald Brunnquell
- 18 "Tanya, the One with Jonathan's Kidney": A Living Unrelated Donor Case of Church Associates 144
 Tarris D. Rosell
- 19 **Futility, Islam, and Death** 150 Kathryn L. Weise
- 20 **Suffering as God's Will** 156 Kathrin Ohnsorge and Paul J. Ford

Commentary 5 Reflections on Part V 162 Mahwish U. Ahmad

Part VI Human Guinea Pigs and Miracles: Clinical Innovations and Unorthodox Treatment

- 21 Amputate My Arm, Please. I Don't Want It Anymore 169 Denise M. Dudzinski
- 22 Feuding Surrogates, Herbal Therapies, and a Dying Patient 175 Alissa Hurwitz Swota
- 23 One Way Out: Destination Therapy by Default 181Alice Chang and Denise M. Dudzinski
- 24 Altruistic Organ Donation: Credible? Acceptable? 187 Ronald B. Miller

Commentary 6 Reflections on Part VI 194 Kaarkuzhali B. Krishnamurthy

Part VII The Big Picture: Organizational Issues

- 25 It's Not My Responsibility 201 Mary Beth Foglia and Robert A. Pearlman
- Intraoperative Exposure to Sporadic Creutzfeldt–Jakob Disease: To Disclose or Not to Disclose 207 Joel Potash
- 27 Why Do We Have to Discharge This Patient? 213 Sarah E. Shannon

Contents

vii

 28 Who's That Sleeping in My Bed? An Institutional Response to an Organizational Ethics Problem 219 Daryl Pullman, Rick Singleton, and Janet Templeton

Commentary 7 Reflections on Part VII 225 Ruchika Mishra Conclusions, Educational Activities, and References (Revised for Second Edition) 232 Denise M. Dudzinski and Paul J. Ford

Index 249

Additional Contributors to the Second Edition

Mahwish U. Ahmad, MD, MPH, HEC-C, has recently joined the team at Cleveland Clinic Abu Dhabi (CCAD) in 2022, as Program Lead/Director of Clinical and Transplant Ethics and Chairs the CCAD Clinical Ethics Committee. She comes from the Center for Bioethics at Cleveland Clinic Main Campus, Ohio, having served as a staff ethicist there for six years. Before her time at the Cleveland Clinic Foundation, she completed her master's in public health with a concentration on health policy and hospital management & family and adolescent health at Columbia University, New York. As a physician, she completed her medical training with experience in obstetrics and gynecology.

Crystal Brown, MD, MA, is Assistant Professor, Division of Pulmonary, Critical Care and Sleep Medicine; Adjunct Assistant Professor, Department of Bioethics and Humanities; and a recipient of the Robert Wood Johnson Foundation Harold Amos Award Scholar. She practices at Harborview Medical Center. Her work and scholarship include palliative care, bioethics, and ethics consultation.

Kaarkuzhali B. Krishnamurthy, MD, MBE,

earned her engineering degree at Johns Hopkins University in Baltimore, Maryland, and her medical degree at University of Maryland School of Medicine, also in Baltimore. She completed her internship in internal medicine at the Yale-New Haven Primary Care Program in Connecticut, and her residency in neurology at the Harvard-Longwood Area Neurology Program where she served as chief resident. Her fellowship training in clinical neurophysiology was completed at Beth Israel Hospital and Children's Hospital in Boston. Dr. Krishnamurthy also earned a master of bioethics from Harvard Medical School in 2016.

Ruchika Mishra, PhD, is System Director for Sutter Health's Program in Medicine and Human Values, San Francisco, California. She was Associate Editor for the ninth edition of Jonsen, Siegler, and Winslade's *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine.* She is a section editor for the *Cambridge Quarterly of Healthcare Ethics.* She serves on the board of directors for the American Society for Bioethics and Humanities and the Council on Program Accreditation for Clinical Ethicist Training.

Maya Scott, MSW, LICSW, is a social worker and ethicist, with her clinical training in pediatric palliative care and bereavement. Maya is the Director of the Center for Diversity and Health Equity at Seattle Children's Hospital and is responsible for the advancement and integration of health equity, antiracism, and the reduction and elimination of health disparities.

Nneka Sederstrom, PhD, MPH, MA, FCCP, FCCM, is Chief Health Equity

Cambridge University Press & Assessment 978-1-009-40095-4 — Complex Ethics Consultations Edited by Paul J. Ford , Denise M. Dudzinski Frontmatter More Information

x

Additional Contributors to the Second Edition

Officer at Hennepin Healthcare. In this role, Dr. Sederstrom leads the work to assess, build, and execute strategies across the system to cultivate a culture of diversity, equity, and inclusion and transform how care is delivered for our community. Dr. Sederstrom has served as Director of the Clinical Ethics Department at Children's Minnesota and the Center for Ethics at MedStar Washington Hospital Center in Washington, DC, where she also led the Spiritual Care Department and was the creator and Executive Director of the Journal of Hospital Ethics. Dr. Sederstrom earned a BA in philosophy from George Washington University, MA in philosophy and PhD in sociology from Howard University, and an MPH in global health management from George Washington University. She is a Fellow of the American College of Chest Physicians and the American College of Critical Care Medicine and an affiliate faculty member of the University of Minnesota Center for Bioethics.

Lucia D. Wocial, PhD, RN, FAAN, HEC-C, is the senior clinical ethicist at the John J. Lynch Center for Ethics at Medstar

Washington Hospital Center (MWHC) in Washington, DC. She is the former nurse ethicist and program leader in Nursing Ethics for the Fairbanks Center for Medical Ethics (FCME) at Indiana University Health) in Indianapolis, Indiana and remains a senior affiliate faculty member with FCME. She chairs the ethics consultation service subcommittee and is an active member of the ethics consultation service at MWHC. She is a certified Healthcare Ethics Consultant and serves on the Commission for Healthcare Clinical Ethics Consultation Certification. She was the project director for the Woltman Inter-professional Communication Project with the Indiana University School of Nursing where she was an adjunct assistant professor. She is a senior associate faculty for VitalTalk. Dr. Wocial has expertise in ethics, moral distress, and difficult communication that takes place in the ICU setting, particularly around surrogate decision making. She is a co-principal investigator on a National Institutes of Health funded grant evaluating the impact of advance care planning conversations on community dwelling elder adults.

Contributors to the First Edition (Original Biographies from the First Edition)

⁺ indicates authors who are deceased.

George J. Agich, PhD, is Director of the BGeXperience (University Values) Program and Professor of Philosophy at Bowling Green State University. His books include *Dependence and Autonomy in Old Age* (Cambridge, 2003) and his research interests include autonomy in long-term care, as well as clinical, organizational, and research ethics.

Ellen W. Bernal[†], PhD, is Director of Ethics at St. Vincent Mercy Medical Center in Toledo, Ohio. Her research interests include quality in end-of-life care and ethics consultation. She leads ethics education in residency programs and is a past president of the Bioethics Network of Ohio.

Mark J. Bliton, PhD, is Associate Professor of Medical Ethics and of Obstetrics and Gynecology at the Vanderbilt University School of Medicine. His areas of academic and clinical interests include the values expressed in innovative maternal-fetal surgical interventions – the focus of *Parental Voices in Maternal–Fetal Surgery*, a Symposium in the 2005 volume of *Clinical Obstetrics and Gynecology*, which he coedited with Larry R. Churchill.

Donald Brunnquell, PhD, is Director of the Office of Ethics at Children's Hospitals and Clinics of Minnesota. His training as a child clinical psychologist informs his work in clinical ethics. He also teaches at the University of Minnesota. Alice Chang, MSW, LICSW, is a transplant social worker at the University of Washington Medical Center. She is also a member of the Ethics Consultation Service, as well as the Ethics Advisory Committee for the medical center.

Debra Craig, MD, MA, is Associate Professor of Internal Medicine at Loma Linda University. She is trained as an internist, geriatrician, and clinical ethicist. Her interest is in the ethical challenges at the end of life.

Barbara J. Daly, PhD, RN, FAAN, is Director of Clinical Ethics, University Hospitals of Cleveland, and Professor in the School of Nursing and School of Medicine, University Hospitals Case Medical Center, Cleveland, Ohio.

Joseph P. DeMarco, PhD, is Professor Emeritus of Philosophy at Cleveland State University. His books include A Coherence Theory in Ethics (1994). He is coauthor of Law & Bioethics: A Multimedia Presentation (2007).

Douglas S. Diekema, MD, MPH, is Director of Education at the Treuman Katz Center for Pediatric Bioethics at Children's Hospital and Regional Medical Center in Seattle, Washington, where he also practices pediatric emergency medicine. He is Professor of Pediatrics at the University of Washington, with adjunct appointments in the Department of Medical History and Ethics and the School of Public Health.

Cambridge University Press & Assessment 978-1-009-40095-4 — Complex Ethics Consultations Edited by Paul J. Ford , Denise M. Dudzinski Frontmatter More Information

xii

Contributors to the First Edition

Denise M. Dudzinski, PhD, MTS, is Assistant Professor in the Department of Medical History and Ethics, University of Washington School of Medicine. She is Chief of the Ethics Consultation Service and provides organizational ethics consultation at the University of Washington Medical Center.

Stuart G. Finder, PhD, is Director of the Center for Healthcare Ethics at Cedars-Sinai Medical Center in Los Angeles. As both clinician and researcher, he is interested in exploring the complexity and implications of moral experiences as actualized in healthcare contexts.

Mary Beth Foglia, MA, RN, PhD, is Director of Preventive Ethics and a senior ethics consultant at the Veterans Health Administration's National Center for Ethics in Health Care. Her interests include empirical ethics, ethics and quality improvement, and organizational influences on ethical healthcare practice.

Paul J. Ford, PhD, is Associate Staff, Bioethics and Neurology, at the Cleveland Clinic Foundation and Assistant Professor at Cleveland Clinic Lerner College of Medicine of Case Western Reserve University, Cleveland. His interests center on ethical issues in complex neurosurgical procedures, as well as, more broadly, on ethics consultation.

Cynthia Griggins, PhD, MA, is a neuropsychologist and ethics consultant at University Hospitals Case Medical Center and Co-Director of its Clinical Ethics Service. Her special interests include mental health and neuroethics, as well as ethics education in developing countries.

D. Micah Hester, PhD, is Associate Professor of Medical Humanities and Pediatrics at the University of Arkansas for Medical Sciences, Arkansas Children's Hospital. He has authored and edited seven books, including *Community as Healing* (2001) and *Ethics by Committee* (2008).

Albert R. Jonsen[†], PhD, is Professor Emeritus of Ethics in Medicine at the School of Medicine, University of Washington, and Senior Ethics Scholar in Residence at the California Pacific Medical Center, San Francisco.

Nathan A. Kottkamp, JD, is a healthcare attorney, practicing with McGuireWoods in Richmond, Virginia. He serves on several ethics committees and is the founder of the Virginia Advance Directives Day and National Healthcare Decisions Day initiatives.

Robert C. Macauley, MD, is Medical Director of Clinical Ethics at the University of Vermont College of Medicine and Fletcher Allen Health Care and a pediatric palliative-care physician. His research interests include end-of-life care and the influence of spirituality on clinical decision making.

Thomas R. McCormick[†], MDiv, DMin, is Senior Lecturer Emeritus at the University of Washington School of Medicine. His interests and research include general bioethics and transcultural issues in decision making and the care of dying patients.

Ronald B. Miller[†], MD, is Clinical Professor of Medicine Emeritus, at the University of California, Irvine, where he was founding Chief of the Renal Division in 1968 and founding Director of the Program in Medical Ethics in 1989. His primary interests are the ethics of nephrology, dialysis, and transplantation and of reproductive technology, stem-cell research, therapy, public policy, and endof-life care.

Contributors to the First Edition

xiii

Kathrin Ohnsorge, lic.Phil, MAS, is a research assistant at the Unit for Ethics in Biosciences at the University of Basel, Switzerland. Her research interests are in ethics of end-of-life care, deliberative and hermeneutic approaches in bioethics, and the democratic legitimation of ethical decision making.

Robert R. Orr[†], MD, CM, is an ethics consultant at Fletcher Allen Health Care in Burlington, Vermont, and Professor of Bioethics in the Bioethics Program, Graduate College, Union University, Schenectady, New York. He writes and teaches about the ethics consultation process and end-of-life care.

Robert A. Pearlman, MD, MPH, is Professor of Medicine at the University of Washington, Director of the Ethics Program at VA Puget Sound Health Care System, and Chief of Evaluation at the National Center for Ethics in Health Care (Veterans Health Administration). His interests include empirical ethics, the interplay between ethics and quality improvement, and ethical leadership.

Rosa Lynn Pinkus, PhD, is Professor of Medicine/Neurosurgery; Director, Consortium Ethics Program; and Associate Director, Center for Bioethics and Health Law at the University of Pittsburgh. Her books include (with Mark Kuczewski) An Ethics Casebook for Hospitals: Practical Approaches to Everyday Ethics (1999).

Joel Potash, MD, is a family physician and Emeritus Professor at the Center for Bioethics and Humanities and Clinical Professor (voluntary) in the Department of Family Medicine, Upstate Medical University, Syracuse, New York. He is also board certified by the American Board of Hospice and Palliative Medicine. **Daryl Pullman, PhD,** is Professor of Medical Ethics in the Faculty of Medicine, Memorial University, Newfoundland and Labrador, Canada. He is a member of a number of national ethics committees, including the Canadian Institutes of Health Research Standing Committee on Ethics. He has published widely in both research and clinical ethics.

Tarris D. Rosell, DMin, PhD, is Associate Professor of Pastoral Theology in Ethics and Ministry Praxis at Central Baptist Theological Seminary, and a Program Associate at the Center for Practical Bioethics. He is a clinical ethics consultant at St. Luke's Cancer Institute and also does adjunctive bioethics instruction for William Jewell College and the Kansas City University of Medicine and Biosciences.

Sarah E. Shannon, PhD, RN, is Associate Professor in the School of Nursing and Adjunct Professor in the School of Medicine at the University of Washington, Seattle. Her research interests include endof-life decision making with families of critically ill patients and team disclosure of errors to patients.

Rick Singleton, DMin, is Director of Pastoral Care and Ethics with Eastern Health in Newfoundland and Labrador, Canada. His interests and involvements include clinical ethics and facilitation of ethics consultations. He is Chair of the Canadian Institute of Health Research Ethics Designates Caucus.

Joy D. Skeel[†], BSN, MDiv, is Professor in the Departments of Psychiatry and Internal Medicine, University of Toledo College of Medicine. She is Director of the Clinical Ethics Consultation Service and Director of the Ethics Program at the University of Toledo Medical Center.

Cambridge University Press & Assessment 978-1-009-40095-4 — Complex Ethics Consultations Edited by Paul J. Ford , Denise M. Dudzinski Frontmatter More Information

xiv

Contributors to the First Edition

Stella L. Smetanka, Esq., is Clinical Professor of Law at the University of Pittsburgh School of Law. She directs and supervises law student practice in its Health Law Clinic through which lowincome clients are afforded legal assistance related to their health care.

Jeffrey Spike, PhD, is Associate Professor of Medical Humanities and Social Sciences at the Florida State University College of Medicine. He has published 20 case studies in the *Journal of Law, Medicine, and Ethics* and the *Journal of Clinical Ethics*. His professional focus has been on defining standards for the consultation process and the proper training for consultants and on the specific competency of assessing decision-making capacity, which he believes is at the core of most ethics consults. He is member of the editorial board of the *American Journal of Bioethics*.

Alissa Hurwitz Swota, PhD, is Assistant Professor in the Department of Philosophy, University of North Florida. She is Senior Fellow in Bioethics at the Blue Cross Blue Shield of Northeast Florida Center for Ethics, Public Policy, and the Professions. Her research interests include clinical ethics, cultural issues in the clinical setting, and pediatric bioethics.

Janet Templeton, BN, RN, is Regional Director of Clinical Efficiency for Eastern Health in Newfoundland and Labrador, Canada. In her role, she is responsible for patient flow and was responsible for developing and implementing the firstavailable-bed policy in the city hospitals.

Kathryn L. Weise, MD, MA, is a pediatric intensive care physician and ethics

consultant at the Cleveland Clinic. She also serves as a member of the Cleveland Clinic Ethics Committee, as Fellowship Director of the Cleveland Fellowship in Advanced Bioethics, and as Director of Pediatric Palliative Care.

Kristi S. Williams, MD, is Associate Professor of Psychiatry at the University of Toledo College of Medicine. She is Director of Adult Outpatient Services and Director of the General Psychiatry Residency Program.

Gerald R. Winslow, PhD, is Professor of Ethics at Loma Linda University and Vice President for Mission and Culture at Loma Linda University Medical Center. His books include *Triage and Justice* (1982) and *Facing Limits* (1993).

David Woodrum, MD, is Professor of Pediatrics at the University of Washington School of Medicine; an ethics consultant and member of the Ethics Advisory Committee at the University of Washington Medical Center; a member of the Truman Katz Center for Pediatric Bioethics; and an ethics consultant and Chairman of the Ethics Committee at Children's Hospital and Regional Medical Center.

Richard M. Zaner, PhD, is Ann Geddes Stahlman Professor Emeritus of Medical Ethics and Philosophy of Medicine, Vanderbilt University Medical Center, Nashville, Tennessee. He currently lives in Houston, where he continues to write and present papers and narratives at various conferences. His books include *Ethics and the Clinical Encounter* (1988, 2005) and *Conversations on the Edge* (2004).

Foreword to the First Edition

A book on "Cases that Haunt Us" is a summons to realism in clinical ethics. Since the origins of bioethics in the 1970s, and since its turn into the clinical world in the 1980s, bioethicists have fretted over theories, principles, and methods. They have explored the theories that philosophers have created to think about and resolve ethical problems, filling pages with explanations of deontology and consequentialism. They have argued over the definitions and priorities of autonomy, beneficence, and justice. They have delved into antique methods, such as casuistry, and devised new ones, such as Rawlsian reflective equilibrium. In all of these efforts, ethics appears as a rational activity, striving to define, analyze, and resolve a problem. Certainly, some approaches, such as narrative ethics, discount the claims of excessive rationality, and casuistry disclaims the value of rational deduction. Still, bioethicists, particularly those who engage in clinical consultation, have hoped to be "solvers" of problems.

In the opening days of bioethics, one of its founders, Dan Callahan, called for the construction of a discipline that employed philosophical logic and explored "the unfettered imagination, the ability to envision alternatives, to get into people's ethical agonies ... and sensitivity to feelings and emotions." Still, in its conclusions, bioethical thinking should reach "reasonably specific and clear decisions in the circumstances of medicine and science" (D. Callahan, Bioethics as a discipline. *Hastings Center Studies*, 1973; 1: 66–73).

"The circumstances of medicine" do present a basic problem to philosophical ethics. "Reasonably clear and specific decisions" are often confounded by the tragedies of death and disability, the uncertainty of diagnosis and treatments, and the complexity of cases that include not only a patient and a doctor but a surrounding family, religion, money, hospital, and many other social structures. Indeed, the very notion of a "case" is perplexing. Its etymology is properly from the Latin word casus, which literally means "an event, an occasion." We know that any event, say a birthday party, is not simply a gathering between walls for a few hours. It radiates into the lives of many people before and after the instant occasion. But another Latin word, capsa, becomes cassa and caja in the Romance languages and "case" in English. This "case" means a box or a container, as in "briefcase" or "suitcase." The coincidence of words is suggestive: bioethicists try to fit the almost infinite complications of an event into a box, where they can be studied in hopes of reaching a judgment about how they relate to each other. Of course, medicine and law do exactly the same. Their cases are defined and circumscribed sets of facts put into boxes drawn by the parameters of statutes or of pathophysiology. The process of reaching a conclusion, whether it is made by judge or physician, requires that complexity be put into order.

The clinical ethicist works with the same paradigm. However, something may be missing from that paradigm. At the heart of many ethical cases lies genuine paradox. The fine British moral philosopher, Stuart Hampshire, wrote a book titled *Morality and Conflict*. He confessed to a significant shift in his thought about morality. He once believed that

the basis of morality is found principally in powers of mind that are common to all mankind ... improvement of human life is to come from improved reasoning ... Slowly, I have come to disbelieve that reason, in its recognized forms, can have, and should have,

Cambridge University Press & Assessment 978-1-009-40095-4 — Complex Ethics Consultations Edited by Paul J. Ford , Denise M. Dudzinski Frontmatter <u>More Information</u>

xvi

Foreword to the First Edition

that overriding role ... I argue that morality and conflict are inseparable: conflict between different admirable ways of life and between different defensible moral ideals, conflict of obligations, conflict between essential, but incompatible interests.

(S. Hampshire, Morality and Conflict. Cambridge: Harvard University Press, 1983; p. 1)

The ethicist is very likely to encounter conflict at the heart of a case, and the conflict is often irreconcilable. A judicial decision can slice through the conflicts of law, and a physician can leap into the uncertainties of diagnosis. An ethicist may have to simply stand before irreconcilable conflict of principle. Indeed, we often speak of ethical dilemmas in which either conflicting answer to a question makes equal sense. We speak of ethical "perplexity," unconsciously evoking the ancient meaning of that word, "tangled in a net." In common conversation, people often say that moral problems are unsolvable. We ethicists may bristle at that statement because if it is true, we would seem to be superfluous. We may answer that the difficult problems are compounded of unclear thinking and missing information. We will resolve them once we resolve those issues. This answer is correct, but not always.

It does not respond to the kinds of cases reported in this book. It does not respond to the cases of conflict over "different admirable ways of life, different defensible moral ideals, conflicts of obligations, of essential but incompatible interests." It does not address the elements of consultation that the authors report in this book. These cases are filled with Hampshire's conflicts of obligations and of interests. As I read their sensitive stories and reflections, the cases of my own 30 years as a consultant floated back into my memory. Almost every case echoed in my own experience. As I now reflect on their stories and on my career as consultant, I believe that, in addition to the conflicts pointed out by Hampshire, the moral experiences encountered by ethics consultants demonstrate two ineradicable features of moral life not often discussed in moral treatises. They are the embedding of the moral problem in time and the density of the human crowd that surrounds it. The dimension of time and of a space filled with people is, I think, common to moral life in general. It is vividly present in the activities of ethics consultation in clinical medicine.

In my immature days as a scholar of ethics, ethical problems appeared in my books as timeless moments: whether or not to tell a lie, whether or not to save a threatened life. Also, these ethical problems existed in the conscience of the one who must choose, or between several persons debating right and wrong. When I entered the world of clinical medicine, ethical problems suddenly were swept into a temporal sea, moving, changing, sweeping to an ever-receding horizon. Cases concerned persons with a developing illness, an immanent crisis, a constantly shifting physiological picture, and deepening emotional responses. I was surprised by the clinicians' oft uttered phrase, "We should give this some time." For me, ethics was timelessly true.

In this book, many stories involve time. Macauley and Orr tell of a "quick" decision to withdraw life support from a neonate; Woodrum and McCormick, in contrast, are distressed by how long a case "drags out." Diekema and Spike ponder the problem of deciding prematurely or tardily. Sarah Shannon speaks of "slowing down the train" that speeds to a decision, often so fast that significant features of the case are blurred or missed. Many other chapters show the case evolving in time. Time, in medicine, may not "heal all," but certainly, it is the theater in which ethically relevant features, such as seriousness of disease, futility of treatment, hope of cure, all are played out. Bioethicists,

Foreword to the First Edition

xvii

such as those who write these chapters, have discovered that ethical problems are not static, and, much to their own moral distress, they and others often miss the opportune moment (if there is one).

The second intractable feature of moral decisions, as they appear in a clinical ethics consultation, is the density of the human crowd surrounding the patient. The ethical problem is not a proposition isolated in the mind of one or two actors – it dwells within a pressing crowd of persons, each with a distinct and rich store of interests, understandings, emotions, and personal histories. I realized, on my introduction into the world of medicine that I was no longer a priest in a confessional, which I had been for some years. The ethical experience of confession and counseling is a closed, private one. I now found myself in a hospital room, the patient in the bed, the doctors and nurses at bedside, the family waiting anxiously outside, and many other unseen participants, such as the hospital administrators, the insurers, the legal counsel, the ministers, and congregation of a church. Each of these participants views the case differently, some perhaps drastically so.

Many of the cases in this book describe the ways in which that crowd affects the consultation. Pinkus, Smetanka, and Kottkamp show a child attempting to control her treatment amid the powerful influences of family, doctors, and lawyers. Ford's patient is also caught in this crowd. Bioethicists often propose themselves as mediators and facilitators, but often, the crowd is so dense and the interests of its members so intense that mediation is futile. We try to thin out the crowd, narrow down the participants to "appropriate" ones, but sometimes fail. When some in the crowd are strangers in belief and culture to the providers and the ethicists, the negotiation becomes even more difficult. Those in the crowd may stand with banners of deeply held principles on which they will never compromise. Ohnsorge and Ford, Rosell, and Weise present versions of this story. The density of the crowd surrounding the patient puts ethics into a maelstrom of conflicting values.

These two features of moral reality make for difficult, indeed, haunting cases. They haunt in two ways. In a troubling but less profound way, they linger in the memory. We cannot get out of our heads the face of a dying child whose parents disagree over her treatment; we cannot erase the distress of an immigrant family caught in a system they do not understand. But more problematic, these hauntings are an indefinable presence dwelling in the house of bioethics. It is important for bioethicists to acknowledge that presence and to know they cannot exorcize it. It is a presence that, despite its ghostly form, puts realism into their work. They should be conscious that, often enough, they are working around, or helping others to work around, irreconcilable conflict. They should continue their task of helping unravel an ethical conflict with humility, remaining sensitive to the idea that the perplexity they encounter when they begin may still be present when they conclude their best efforts.

We modern folk, particularly those of us who revere science and scientific thinking, may be troubled by this feature of ethics. We do want to draw "reasonably specific and clear" answers out of confusing questions. We want to believe that we can devise a method of logical analysis for an ethical problem. We want the "boxes" of our cases to be uncluttered, well-sorted containers of facts and principles. Our patron philosopher, although he is unacknowledged in contemporary bioethics, may be Baruch Spinoza, who strove to create an "ethics according to geometric methods." Short of that desire for clarity, what can we ethicists do in the face of our haunting ghosts of irreconcilable conflict, the rush of time, and the density of crowds?

Cambridge University Press & Assessment 978-1-009-40095-4 — Complex Ethics Consultations Edited by Paul J. Ford , Denise M. Dudzinski Frontmatter More Information

xviii

Foreword to the First Edition

Professor Hampshire has a suggestion that may salve our conscience. At the end of his book, he notes that "in . . . life, the practical need is often for sensitive observation of the easily missed features of the situation, not clear application of principles . . . We have no pressing need for satisfactory total explanations of our conduct and way of life. Our need is rather to construct and maintain a way of life of which we are not ashamed and which we shall not, on reflection, regret . . . and which we respect" (S. Hampshire, *Morality and Conflict*. Cambridge: Harvard University Press, 1983; p. 168). The clinical ethicist will often observe and point out to others "the easily missed features of the situation." This is not, in the complex world of contemporary health care, a negligible contribution. In the last analysis, however, the ethicist, the patient, the family, the physicians, and the nurses should come away from an ethical dilemma with a resolution of which they are not ashamed, if not with "a satisfactory total explanation of conduct." They can respect the fact that thoughtful, compassionate, honest attention has been given to a deeply troubling, perplexing human problem.

The moving stories and the thoughtful reflections in this book do, as I said earlier, summon us to realism about moral life and moral decisions within medicine. Read in isolation, they may convince some that the bioethicist's life is difficult and futile. However, these authors are obviously not discouraged. They are encouraged by the resolutions that result from thoughtful, compassionate attention a case often brings. They are gratified by the relief that comes to all participants when the tension of an ethical crisis, if not extinguished, is at least relaxed by their sensitive, wise involvement.

Fortunately, ethics is not, as Pullman, Singleton, and Templeton note in their concluding chapter, all hard cases. It is an amalgam of centuries of thought about the moral life of humans, broadly accepted moral principles of modern bioethics, and the collections of many cases. The "hard cases" appear within that broader perspective. The emotional discomfort and the intellectual puzzlement of these cases do not undermine the experience of respect, beneficence, compassion, and justice that bioethicists and, indeed, all providers of care can view as a guide to their professional endeavors. In this way, "respect," not "regret," will mark the life and work of this new profession.

Albert R. Jonsen[†] Professor Emeritus of Ethics in Medicine School of Medicine, University of Washington Senior Ethics Scholar in Residence California Pacific Medical Center San Francisco, California

Acknowledgments

The idea for this book arose during a dinner with our mentor Richard Zaner at a conference. We identified the need for sharing cases that emphasize the affective component of ethics consultation. Richard Zaner's influence can be seen throughout many aspects of this work, and we are greatly indebted to him. That conversation prompted us to present several panels discussing haunting cases and to edit a special section of the *Journal of Clinical Ethics* (JCE). We continue to be grateful to those at JCE who fostered the publication of the original cases that are included, with revision, in this book. We are especially grateful to Norman Quist, Randy Howe, Mary Gesford, and Leslie LeBlanc. We would like to thank those at Cambridge University Press. They include Richard Barling, Pauline Graham, and Rachael Lazenby and, more recently, Nicholas Dunton and Katie James. In particular for the current edition, we would like to thank Catherine Barnes, Kim Ingram, Sandra Kerka, and Robin Driscoll for helping with the final editing and organization of these chapters.

Denise is indebted to Paul Ford, who is a first-rate collaborator and whose talent, hard work, and humility make him a pleasure to work with. She is especially grateful to her husband, Michael Fanning and son, Max Fanning, for their unwavering support, encouragement, and patience. Denise greatly appreciates the late Al Jonsen, PhD and Thomas McCormick, DMin, for decades of support. Tom's friendship and academic partnership everything. She is also indebted to her parents, sister, and the staff and faculty in the Department of Bioethics and Humanities at the University of Washington.

Paul thanks Denise Dudzinski, who brought compassion, patience, and keen thinking without which completion and quality would have been uncertain for this project. He is grateful to the many clinicians and patients who taught him about medicine and the varieties of important relationships that are possible in life. He is particularly indebted to Patricia Mayer, MD, Andre Machado, MD, Imad Najm, MD, and Johanna Goldfarb, MD who have provided substantial mentoring. In addition, he would especially like to thank his parents, Gwen and Gary Ford for their generous support throughout his career and education. They instilled a strong sense of pragmatism and compassion that serves him well. Finally, his wife, Laura McMullen Ford, and children (Kallin and Duncan Ford) were important sources of insight and support during this project.

Many people whom we have not mentioned explicitly have commented and provided administrative support. We also appreciate their efforts.

Finally, we would like to acknowledge all of the patients, families, and healthcare providers who have had faith in the services of ethics consultants. Authors committed to protecting patient privacy throughout this text have altered or left vague some facts not relevant to the case to provide anonymity to those patients. We and our colleagues carry a significant responsibility when people place faith in us.