The questions of how to define futile treatments and how to find agreement among the various stakeholders in decisions about life-sustaining interventions are among the most challenging in medical practice. This book surveys the clinical, ethical, religious, legal, economic, and personal dimensions of decision making in situations where the choice is between extending costly medical treatment of uncertain effectiveness and terminating treatment, thereby ending the patient’s life.

Contributors from a wide range of disciplines offer perspectives on issues ranging from the definition of medical futility to the implications for care in various clinical settings, including intensive care, neonatal and pediatric practice, and nursing homes. Notable legal cases are examined, including many that have helped to define the issues and move forward the debate, and there is powerful testimony from the point of view of families of patients in futile treatment situations.

Although a consensus on what constitutes futile treatment remains elusive, the eloquence and concern manifested in this book, and its critical analysis of positions that are frequently conflicting, will certainly contribute in a large way toward the more humane and consistent handling of these situations. *Medical Futility* will be obligatory reading for health care professionals, students, and scholars concerned with ethical standards in medical care.
MEDICAL FUTILITY
MEDICAL FUTILITY

and the evaluation of life-sustaining interventions

Edited by

MARJORIE B. ZUCKER
Choice In Dying
New York

HOWARD D. ZUCKER
The Mount Sinai School of Medicine
New York

Foreword by Alexander Morgan Capron
University of Southern California
Los Angeles
PUBLISHED BY THE PRESS SYNDICATE OF THE UNIVERSITY OF CAMBRIDGE
The Pitt Building, Trumpington Street, Cambridge CB2 1RP, United Kingdom

CAMBRIDGE UNIVERSITY PRESS
The Edinburgh Building, Cambridge CB2 2RU, United Kingdom
40 West 20th Street, New York, NY 10011-4211, USA
10 Stamford Road, Oakleigh, Melbourne 3166, Australia

© Cambridge University Press 1997

This book 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.

First published 1997

Typeset in Times Roman

Library of Congress Cataloging-in-Publication Data
p. cm.
Includes index.
R726.M36 1997
362.1’75 – dc20 96-46070

A catalog record for this book is available from the British Library

ISBN 0-521-56877-3 paperback

Transferred to digital printing 2004
Contents

Preface  
Foreword  Alexander Morgan Capron, LL.B.  ix
Contributors  xiv

1  Medical futility: a useful concept?  Howard Brody, M.D., Ph.D.  1
2  Death with dignity?  Patricia Brophy, R.N.  15
3  Physicians and medical futility: experience in the critical care setting  Harry S. Rafkin, M.D., and Thomas Rainey, M.D.  24
4  Physicians and medical futility: experience in the setting of general medical care  Norton Spritz, M.D., J.D.  36
5  Futility issues in pediatrics  Joel E. Frader, M.D., and Jon Watchko, M.D.  48
6  Medical futility: a nursing home perspective  Ellen Knapik Bartoldus, M.S.W.  58
7  Alternative medicine and medical futility  Joseph J. Jacobs, M.D., M.B.A.  65
8  How culture and religion affect attitudes toward medical futility  Mary F. Morrison, M.D., and Sarah Gelbach DeMichele, M.D.  71
10  Conflict resolution: experience of consultation-liaison psychiatrists  James J. Strain, M.D., Stephen L. Snyder, M.D., and Martin Drooker, M.D.  98
11  Ethics committees and end-of-life decision making  Alice Herb, J.D., LL.M., and Eliot J. Lazar, M.D.  110
Contents

12 The economics of futile interventions
   Donald J. Murphy, M.D. 123

13 Medical futility: a legal perspective
   William Prip, M.A., and
   Anna Moretti, R.N., J.D. 136

14 Professional and public community projects for developing
   medical futility guidelines
   Linda Johnson, M.S.W., and
   Robert Lyman Potter, M.D., Ph.D. 155

15 Community futility policies: the illusion of
   consensus? Bethany Spielman, Ph.D., J.D. 168

16 Not quite the last word: scenarios and solutions
   Karen Orloff Kaplan, M.P.H., Sc.D. 179

Index of cited authors, cases, and statutes 193

Subject index 198
Preface

One of us (M.B.Z.), a retired bench scientist via a medical family, has had a long commitment to Choice In Dying, a national not-for-profit organization dedicated to fostering communication about complex end-of-life decisions among individuals, their loved ones, and health care professionals. The organization is well known for inventing living wills in 1967 and providing the only national hotline to respond to patients and families during end-of-life crises. Choice In Dying also provides award-winning educational materials, public and physician education, and ongoing monitoring of changes in state and federal right-to-die legislation.

The other (H.D.Z.), in addition to sharing his spouse’s interests, was in medical practice before becoming a consultation-liaison psychiatrist. He thus has had practical experience with dying patients as well as in teaching medical students and residents at the Mount Sinai Medical Center. When the opportunity arose to edit a book on medical futility, it seemed natural to do so as coeditors.

We are obligated to all who contributed chapters for taking on the task in the midst of their very busy lives and for their flexibility in accepting suggestions and making revisions. We hope that the resulting book proves timely and stimulating to readers of all ages and many disciplines and that it helps introduce younger readers to some of the issues relating to end-of-life care.

We are pleased to acknowledge another collaboration: the production of four children and our enjoyment of them and of our four children-in-law, and our eight grandchildren.

Marjorie B. Zucker, Ph.D.
Howard D. Zucker, M.D.
Foreword

ALEXANDER MORGAN CAPRON, LL.B.

University Professor of Law and Medicine,
University of Southern California, Los Angeles

Many aspects of modern medicine provoke spirited ethical argument, but few engender as much disagreement about what exactly is at issue as does the futility debate. The relationships of physicians and nurses, on the one side, and patients (especially dying patients dependent on extensive medical support) and their families, on the other, are viewed very differently by various commentators. As characterized by some, physicians have become pathetic characters in a modern day Molière play, technically sophisticated servants doing the bidding of their patients. Professionals with this perception feel misused and justify their rebelliousness by invoking medical futility. The simple recognition of the limits of medicine’s power to cure and to extend life denotes that health care professionals should not be obliged to provide further treatment or, more powerfully, that they would exceed their role-based authority as healers to continue to do so. Yet other commentators claim that medical futility is an empty concept that does not provide any ground for decision that would not be present had the concept never been coined. They characterize medical futility as nothing more than a cover for physician’s rearguard action to regain the dominance in decision making that they possessed before autonomy and informed consent shifted authority to patients and their families beginning in the 1960s.

Although much of the futility debate of recent years has been premised on the notion that one ought to pick among these (and many other) sharply contrasting conceptions, each advocated with great conviction, it may be just as reasonable to regard these different descriptions as distinct facets of the larger whole of medical futility. If medical futility is likened to the fabled elephant, these various commentators are the blind men, each describing the beast differently because each feels a different part of its anatomy.

Why all this concern about medical futility? Three factors may account for its emergence as the subject of lively debate. The first is the nature of
Foreword

medicine as practiced in the United States in the second half of the twentieth century. Fed by an ever increasing array of life-sustaining technologies – most notably, those connected with cardiopulmonary resuscitation (CPR) and those that constitute the foundation of the intensive care unit (ICU) – medicine has not only extended the lives of many critically ill patients and changed the way people die but also made it necessary to make choices about when to use and when to forgo these powerful but imperfect interventions. Disputes about how and by whom these choices should be made provoked heated debate within health care institutions that, in the 1970s, became increasingly public. Typically, such disagreements pitted a patient, such as Elizabeth Bouvia, or a family, such as the parents of Karen Ann Quinlan, who wanted to discontinue treatment, against physicians and others who insisted that the resulting death would be wrong morally, professionally, and legally. By 1990, when the United States Supreme Court addressed the issue in its landmark Cruzan decision, it was generally agreed that a decision to forgo treatment – whether made by a patient contemporaneously or through an advance directive, or by a surrogate legally authorized to act on the patient’s behalf – ought usually to be respected, even when stopping (or not starting) the treatment would probably result in the patient’s death. The existence of a broad consensus on this point has not, however, removed the need for choices to be made, nor has it eliminated all disputes. Health care providers and patients (and families) continue to disagree in some cases about whether it is appropriate to forgo treatment. Today, however, in the most contentious cases, the roles are reversed from the pattern of the 1970s and 1980s, with patients and families now insisting on further interventions, and physicians and others in health care wanting to stop.

The second factor driving the medical futility debate is the current reexamination of the principle of autonomy. Not just in the end-of-life context but more generally, the dominance of this principle is being challenged both in bioethics theory and in the policies and rules that guide health care. Are there not times when the claims of the community outweigh individual preferences? Or when a decision cannot be left solely to the patient but must bow to the conscience of the physician or other health care provider in practicing his or her profession? One reason that the futility debate engenders such heated exchanges is precisely because, on the one hand, some physicians believe that yielding to the wishes of patients and, even more so, next-of-kin that futile treatment be continued is an abdication of their role as medical professionals. They argue that, consistent with the goals of medicine since the time of Hippocrates, physicians not only have no obligation to treat – or even to present such options to patients and families – when medical inter-
Foreword

ventions cannot produce a sufficient quality of life (such as restoring consciousness and the ability to live without continuous life support) but also that physicians cease behaving professionally if they persist even when no medically valid goal remains. On the other hand, advocates for patient rights see this position as simply a new instance of medical paternalism. Even those who would admit that the pendulum of decision-making authority may have swung too far in the direction of patient autonomy are worried that accepting the concept of medical futility would propel the pendulum back to the side of expert domination of health care decisions. In their view, questions of quality of life are inherently personal, not technical, and hence provide no ground for physicians or other professionals to impose their ideas of what constitutes an outcome of sufficient value to justify further treatment.

Although these two factors – the choices that modern medicine generates about end-of-life care and the reexamination of the meaning of autonomy in medical decision making – would be enough to ensure medical futility a prominent place in bioethics discussions and an occasional court case, a third force accounts for futility’s becoming a conspicuous part of the broader public debates over health care. That force is the emergence of managed care as the dominant mode of health care delivery in this country. Like a tidal wave, managed care is sweeping aside old ways of providing care, reconfiguring the relationships of physicians, hospitals, insurers, payers, and the insured population. The explanation for this rapid transformation lies not in any wish of providers to reorganize themselves nor even in the understandable desire of employers and insurers to shift some of the risk of escalating health care costs onto other shoulders. The real attraction of managed care, to corporate payers as well as to public policymakers and perhaps even to individuals, is its promise to reduce health care expenditures by eliminating nonbeneficial interventions. Whether or not the skeptics are right that the impressive results of some managed care programs are just one-time savings achieved by forcing physicians and hospitals to discount their prices without halting the upward spiral that comes from new medical technologies and an aging population, it is generally agreed that eliminating truly useless medical interventions will not be enough. Some care that might provide benefit (yet at a low probability) or that will provide marginal benefit (yet at great cost) must also be eliminated if managed care or any other system is to succeed in controlling health care expenditures.

Particularly in the context of critically ill, dying patients, the provision of care that cannot reverse their decline might well be described as a futile effort. Thus, the terminology that has emerged in the current debates, that medical futility has both a quantitative dimension (when the probability of getting the
desired result is very small) and a qualitative one (when the best projected outcome would not truly benefit the patient), not only fits into managed care’s paradigm of limiting marginal care but actually provides what for such commentators as Daniel Callahan and Richard Lamm seems a particularly compelling illustration of the wisdom of imposing such limits: at the end of a long life, patients should not seek, and society should not provide, treatments aimed at holding off the natural process of degeneration but should instead seek to make their dying an integrated and accepted part of living. Better, they claim, that health care dollars be spent where, on average, they have a better chance to provide true benefits than to pour the large percentage we now do into the final days and weeks of life. Of course, such a position has yet to be adopted by most Americans, philosophically or emotionally, and decisions defended on the grounds of futility are likely to be resisted by the individuals who would thus be denied care and to become rallying points in the judicial and legislative arenas for advocates objecting to the goals or the means of the managed care firms and politicians who are trying to limit patients’ access to the full range of medical interventions.

This book is intended both to clarify the questions at issue in the futility debate and to move beyond the theoretical contours of that debate and illuminate how decisions about care are and ought to be made in a variety of settings and with a variety of patients. Currently, much of the discussion of futility has focused on acute care settings, such as ICUs and emergency rooms, and on emergency interventions, such as CPR. Although the book opens by attending to these issues, subsequent chapters explore general medical, pediatric, and nursing home care and the influence of ethnicity and related factors on patients’ and physicians’ views of what it means to give up on medical care. The authors then address the cultural, religious, and psychologic influences in conflicts about futility as well as the economic aspects of limiting treatment that has been labeled “futile.” Next, the book examines the roles of ethics committees, the courts, the professions, the community, and health care institutions in setting standards for, and helping to resolve disputes about, decisions at the end of life. The volume closes with warnings about some of the significant risks related to medical futility: abuse of vulnerable populations, a return to medical dominance, decision making either polarized in courtroom confrontations or sent askew by misguided institutional policies, and clinical and financial pressures that may override patients’ best interests.

Readers need not despair, however, for this volume will enrich their understanding of health care decision making and provide rays of hope that greater attention will result in more research on the definition of futile care.
and the consequences of limiting it, and that the open development of policies and procedures for limiting care of marginal benefit can avoid arbitrary instances of forgoing treatment or even withholding information from patients when physicians feel incapable of producing results they judge to be beneficial. The clinically and theoretically diverse contributions to this volume provide an excellent starting point for all those who wish to get past the rhetoric of the futility debate. With our blindfolds removed, we can appreciate the separate parts of the medical futility elephant as manifestations of something that is complicated rather than contradictory and, with luck, arrive at an understanding of the subject in all its rich complexity.
Contributors

Ellen Knapik Bartoldus, M.S.W.
Assistant Administrator, Wartburg Lutheran Home for the Aging, Brooklyn, NY

Howard Brody, M.D., Ph.D.
Professor of Family Practice and Philosophy and Director, Center for Ethics and Humanities in the Life Sciences, Michigan State University, East Lansing, MI

Patricia Brophy, R.N.
South Easton, MA

Sarah Gelbach DeMichele, M.D.
Assistant Instructor of Psychiatry, University of Pennsylvania, Philadelphia, PA

Martin Drooker, M.D.
Assistant Clinical Professor of Psychiatry and Associate Director of the Psychiatric Consultation Service, The Mount Sinai Medical Center, New York, NY

Joel E. Frader, M.D.
Associate Professor of Pediatrics and of Anesthesiology and Critical Care Medicine and Associate Director, Center for Medical Ethics, University of Pittsburgh, Pittsburgh, PA

Alice Herb, J.D., LL.M.
Assistant Clinical Professor, Humanities in Medicine, SUNY Health Science Center, Brooklyn, NY

Joseph J. Jacobs, M.D., M.B.A.,
First Director, Office of Alternative Medicine, National Institutes of Health, Bethesda, MD (Present address, Guilford, CT)

Linda Johnson, M.S.W.
Project Facilitator, Midwest Bioethics Center, Kansas City, MO

xiv
Contributors

Karen Orloff Kaplan, M.P.H., Sc.D.
Executive Director, Choice In Dying, New York, NY

Eliot J. Lazar, M.D.
Chairman, Department of Medicine, The Brooklyn Hospital Center, and Associate Professor of Clinical Medicine, New York University School of Medicine, New York, NY

Anna Moretti, R.N., J.D.
Formerly Director of Program and Legal Services, Choice In Dying, New York, NY

Mary F. Morrison, M.D.
Assistant Professor of Psychiatry and Medicine, University of Pennsylvania, Philadelphia, PA

Donald J. Murphy, M.D.
Regional Medical Director, GeriMed of America, Inc., and Director, Colorado Collective for Medical Decisions, Inc., Denver, CO

John J. Paris, S.J., Ph.D.
Walsh Professor of Bioethics, Boston College, Chestnut Hill, MA, and Clinical Professor of Family Medicine and Community Health, Tufts University School of Medicine, Boston, MA

Mark Poorman, C.S.C., Ph.D.
Assistant Professor of Theology, University of Notre Dame, Notre Dame, IN

Robert Lyman Potter, M.D., Ph.D.
Clinical Ethics Scholar, Midwest Bioethics Center, Kansas City, MO

William Prip, M.A.
Formerly Program Associate for Legislative Affairs, Choice In Dying, New York, NY

Harry S. Rafkin, M.D.
Pittsburgh Critical Care Associates, St. Francis Medical Center, Pittsburgh, PA

Thomas Rainey, M.D.
Fellow, College of Critical Care Medicine; Director, Critical Care, Fairfax Hospital; President and CEO, Critical Med, Inc.; Adjunct Associate Professor of Anesthesia, George Washington University of Health Sciences; and Associate Clinical Professor of Internal Medicine, Georgetown University Hospital, Washington, DC

Stephen L. Snyder, M.D.
Assistant Clinical Professor of Psychiatry and Director of the Psychiatric Consultation Service, The Mount Sinai Medical Center, New York, NY
Contributors

Bethany Spielman, Ph.D., J.D.
Assistant Professor of Medical Humanities, Southern Illinois University School of Medicine, Springfield, IL, and Assistant Professor of Medical Jurisprudence, Southern Illinois University School of Law, Carbondale, IL

Norton Spritz, M.D., J.D.
Chief, Medical Service, Department of Veterans Affairs Medical Center, and Professor of Medicine, New York University School of Medicine, New York, NY

James J. Strain, M.D.
Professor of Psychiatry and Director, Division of Behavioral Medicine and Consultation Psychiatry, The Mount Sinai Medical Center, New York, NY

Jon Watchko, M.D.
Associate Professor of Pediatrics, Obstetrics, Gynecology and Reproductive Services, University of Pittsburgh School of Medicine, and Department of Pediatrics, Magee-Womens Hospital, Pittsburgh, PA