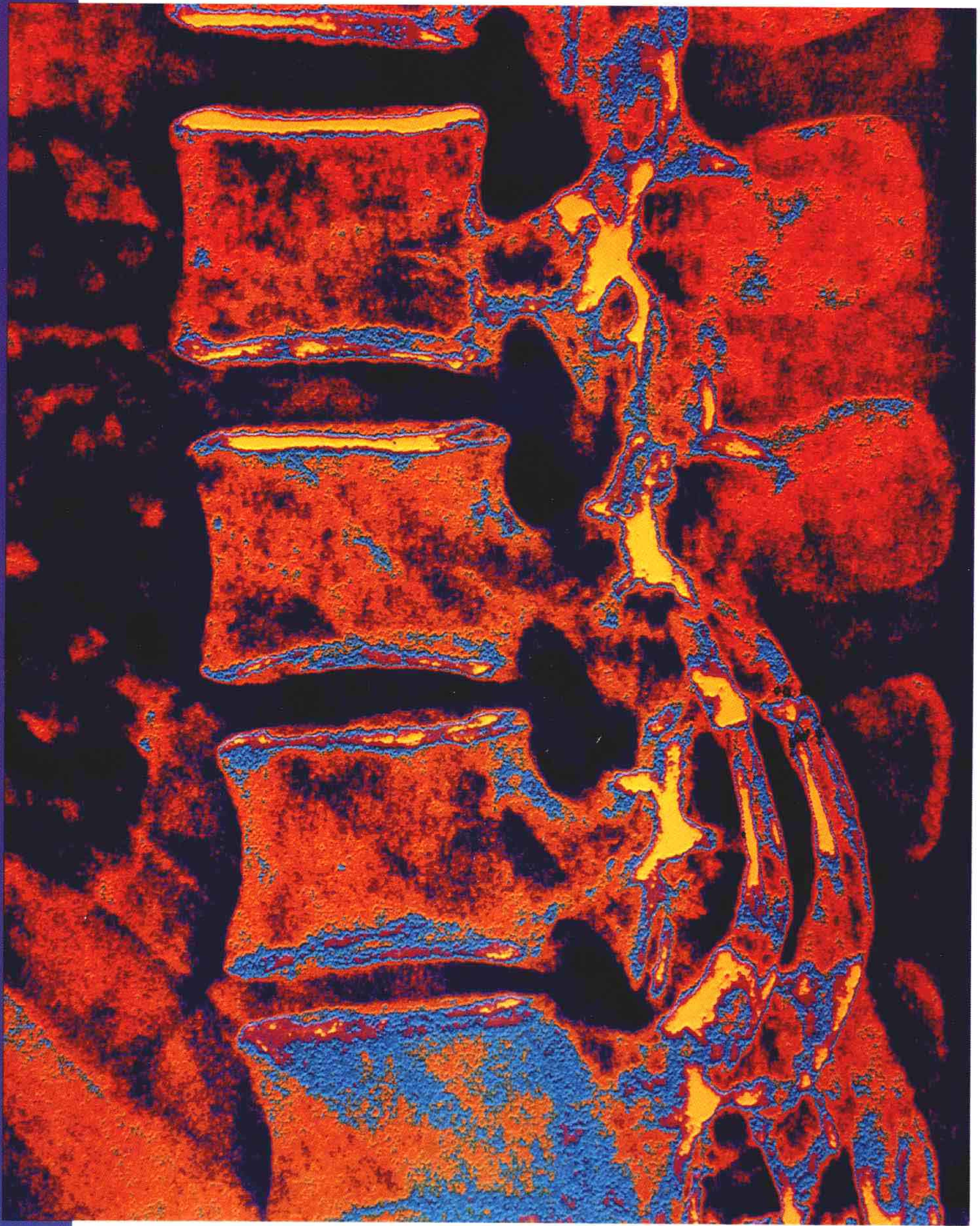
Ethical Issues in Modern Medicine

FIFTH EDITION



John D. Arras / Bonnie Steinbock

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Fifth Edition

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To Daniel Callahan and John Fletcher
with appreciation and gratitude
and
In memory of Benjamin Freedman

PREFACE

As users of *Ethical Issues in Modern Medicine* know, the previous edition represented a complete overhaul of the entire book. It was a job that neither of us was eager to tackle again. Indeed, we expected the new edition to remain relevant for five years, so that we would not have to revise before the year 2000. Enormous technological, legal, and policy developments in several areas, however, made that plan obsolete, and when our editor, Ken King, suggested to me that we needed to do a new edition, we reluctantly conceded that he was right. (John's initial reaction to the idea was something like, "I can't believe we're having this conversation.")

One of those developments concerns the debate over physician-assisted suicide (PAS). The Supreme Court considered, and rejected, a constitutional right to physician-assisted suicide, but its decision in *Vacco* v. *Quill* and *Washington* v. *Glucksberg* has merely returned the debate to the states, not ended it. California and Washington voters rejected measures legalizing PAS, and Oregon is so far the only state to have legalized it, although as of this writing the law has not been implemented. Thus, our expanded section on the moral and policy arguments for and against PAS in Part Two remains timely and urgent.

The field of reproductive medicine continues to grow, and each new development raises moral questions. Since the last edition, the world has seen the birth of a baby to a 63-year-old woman, the development of technology that would permit the freezing of eggs, and the birth of the first surviving set of septuplets. Most dramatic of all, Dr. Ian Wilmut announced the birth of Dolly, a lamb cloned from a cell of an adult sheep. This feat, and the potential for cloning a human being, has given rise to so much debate and speculation that we felt an entire section of Part Four should be devoted to cloning. Although some critics of cloning object to asexual reproduction (or replication) per se, others object to the potential for manipulating the genome, and the creation of children "to spec." Defenders of genetic manipulation respond that we already attempt to make our children healthier and smarter by environmental intervention (from prenatal behavior to diet to piano lessons): the question is, then, whether there is something about genetic intervention that is different and morally problematic.

It must be emphasized that the ability to determine behavior by manipulating genes is greatly exaggerated in the public mind. The belief that genes determine what we are is the "fallacy of genetic determinism," which was strongly criticized in the National Bioethics Advisory Commission Report on Cloning Human Beings. Although many personality traits and susceptibility to many diseases have a genetic component, it does not follow that an individual's behavioral characteristics can be determined through manipulation of his or her genes. Diseases, much less behaviors, are rarely the result of a defect on a single, identifiable gene. Genes interact with each other in complex ways, and genes interact with environmental influences in even more complicated ways. It is simply not the case now or in the foreseeable future that we will be able to determine the level of intelligence, or the degree of compassion or boldness, in an individual by genetic manipulation. Nevertheless, even within the confines of what is scientifically possible, there is room for moral debate about the kinds of traits, if any, it is morally permissible to attempt to control.

The increasing influence of managed care is another development that has required considerable revision, as reflected in two parts in this edition: in "Conflicts of Interest and Informed Consent in Managed Care" in Part One, Sections Three and Four, and in Part Six, Sections Two and Three, on rationing health care. The aim in both places is to give readers a better understanding of the economic forces that have led to the implacable rise of managed care, and of how essential cost-cutting might be accomplished according to just principles and fair procedures.

Despite a firm commitment to the principle "If it ain't broke, don't fix it," we ended up making more changes than we had anticipated. The fifth edition has over 40 new readings—almost as many new readings as the fourth edition. And while some sections remain substantially the same, many are radically changed, and sometimes renamed. Part Six, "Allocation, Social Justice, Health Policy," is a good example of a chapter that required a great deal of rethinking, adding, and subtracting. John did a yeoman's job on this part, with a little help (no, a lot of help, actually) from his friends, especially Len Fleck (Michigan State University) and Peggy Battin (University of Utah). In addition, there are new articles on informed consent, the definition of death, advance directives, abortion, procreative autonomy and responsibility, commodification and the family, and experimentation on human subjects. Some completely new sections have been added, including "Controversies over Contraception," and "'Vulnerable' Populations" in Part Five, "Experimentation on Human Subjects." The book also has 16 case studies, 8 of them new to this edition. We have tried to achieve a balance between application and analysis, because (to paraphrase Kant) analysis without application is empty, while application without analysis is blind.

Two sections were reluctantly deleted: medical futility and maternal-fetal conflicts. As always, adding current material necessitates the sacrifice of something else. We agreed that the debate over medical futility often masked other issues, such as patient self-determination, professional responsibility, and cost, and was best discussed under those headings. As for maternal-fetal conflict, we felt that this topic was cogent only in regard to the legal system's response to pregnant addicts. Within the medical community, there has been a growing consensus that forcing a competent patient to undergo a cesarean section against her will, even when deemed necessary to protect the nearly born fetus, is neither legal nor good medical practice. With such consensus, the issue has become less pressing.

As always, we owe thanks to the many people who have helped us with suggestions, background information, comments, and criticisms. In particular, we would like to single out George Annas, Boston University; Ira Byock, American Academy of Hospice and Palliative Medicine; Jim Childress, Paul Lombardo, Jonathan Moreno, Robert Crouch, and Mark Douglas, University of Virginia; Norman Daniels, Tufts; Rebecca Dresser, Case Western Reserve; Alan Fleischman, New York Academy of Medicine; Norman Fost, University of Wisconsin; Eric T. Juengst, Case Western Reserve; Don Marquis, University of Kansas; Erik Parens, the Hastings Center; Mark Sheldon, Indiana University; Jeffrey Spike, University of Rochester; Benjamin Wilfond, University of Arizona; and the five anonymous reviewers of the fourth edition.

We both owe an enormous debt of gratitude to the members of our "UVa production team," who worked tirelessly and efficiently on all the important and seemingly endless chores involved in the preparation of this book. Carolyn Randolph, the administrative assistant (and heart and soul) of our Bioethics Program, and Sasha Yamshchikov, an outstanding third-year premed and bioethics major, did superlative work on the dreaded job of cutting and pasting the entire manuscript, securing permissions, and updating our lists of contributors and "Resources in Bioethics." Alex John London, a Ph.D. candidate in classical philosophy and bioethics, updated and vastly expanded the bibliographies at the end of each part, wrote an excellent case study for Part Six, and provided timely and sound pedagogical advice on the proposed readings. And Robert Crouch, also a doctoral student in philosophy, helped with both valuable textual suggestions and proofreading. The members of this production crew were unfailingly precise and remarkably good humored from beginning to end. Although their work has taken place behind the scenes, it shows on literally every page. Heartfelt thanks to you all!

In addition, John would like to thank his academic colleagues at the University of Virginia for providing such a welcoming and stimulating intellectual environment. First and foremost, thanks to John Fletcher, who brought John here from New York and has given selflessly of his friendship, time, and knowledge of the field. Now that John Fletcher is in semi-retirement (the equivalent of full-time work for the rest of us), John will cherish their past and future intellectual exchanges, particularly the one that changed John Fletcher's mind on physician-assisted suicide. John also thanks Jim Childress (Religious Studies), Richard Bonnie, Paul Lombardo and Walter Wadlington (Law School), the members of the UVa Philosophy Department, and the Division of Medical Humanities for making his life here in Charlottesville so interesting and challenging.

Bonnie Steinbock owes a debt of gratitude to the members of the working groups on which she has served over the last three years: the National Study Group for Ethics, Genetics, and Alzheimer's Disease, at the Center for Biomedical Ethics, Case Western Reserve University, headed by Stephen Post; the Project on Prenatal Testing for Genetic Disability, at The Hastings Center, headed by Erik Parens; and the Project on Reproductive Choice and Control of Fertility, at the Centre for Social Ethics and Policy, University of Manchester, England, headed by Margot Brazier. From all of these groups, she learned a great deal, enabling her to do a better job updating *Ethical Issues in Modern Medicine.*

We are indebted as well to the following individuals for their thoughtful review of the manuscript for this edition: Ben Bradley, University of Massachusetts at Amherst; Patti L. Brandt, Virginia Commonwealth University; William Harper, University of Alabama; Nelson P. Lande, University of Massachusetts at Boston; Bruce Landesman, University of Utah; Greg Lobean, Center for Bio-ethics at University of Pennsylvania; Cynthia L. Owen, University of Toledo; and William Ruddick, New York University.

For turning the sow's ear of our bulging and tattered manuscript into this silk purse of a book, we are thankful once again to the production staff at Mayfield Publishing Company, this time to April Wells-Hayes and Josh Tepfer. Our friends at Publication Services, ably headed by Dawn Longfellow and Jan Fisher, did what we had hardly thought possible: to bring this book from rough manuscript to finished product within a few short months. Hats off to one and all!

Finally, we wish to thank Ken King, our new editor at Mayfield. He is a fountain of good ideas, good sense, and good humor, and we are immensely grateful for his support, guidance, and gentle *nudzhing.*

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