INQUIRIES IN
Bioethics

STEPHEN G. POST

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Preface

The field of bioethics is fascinating because it provides an opportunity to encounter great and perennial themes of human moral inquiry, yet with a heightened sense of urgency pressed upon the consciousness of all citizens by the advancing technologies of the life sciences and of health care. New knowledge and technology force us to examine basic questions of human genetic malleability and perfectibility, of moral relations with nonhuman animals and the wider environment, of human reproduction, of the human struggle with mortality and finitude, and of virtually every other significant moral and existential concern that has an impassioned place in the history of the western and non-western mind.

No single book can do more than select themes and topics that are a reflection of the author's interests. Fortunately, the full interdisciplinary scope of the field of bioethics is splendidly presented in the *Encyclopedia of Bioethics,* edited by Warren T. Reich. I have had the opportunity to learn much from Professor Reich in working with him over the past several years, and wish to express my gratitude. Another person who serves as a model of the interdisciplinary approach to bioethics is James M. Gustafson, whose work I have followed since being among his many students a decade ago at the University of Chicago.

The Center for Biomedical Ethics in the School of Medicine at Case Western Reserve University has provided me with sufficient time and stimulation to pursue the thoughts developed in this book. Teaching in a medical school presents the humanities scholar with myriad new problematics. This is always challenging and often fruitful. Much of my interest in bioethics and gerontology results from an invaluable collaboration with Robert H. Binstock, Henry R. Luce, Professor of Aging, Health and Society at Case Western; with Joseph M. Foley, a much admired physician in the field of Alzheimer's disease, and with Peter J. Whitehouse, director of the Alzheimer's Center at University Hospitals of Cleveland.

My wife Mitsuko and my daughter Emma Yoko were very supportive in my work, in understanding the priorities and hopes that engaged me in this endeavor. Thanks to them especially.

STEPHEN G. POST

Acknowledgments

Grateful acknowledgment is made to the editors and publishers for permission to publish those portions of this book that are revisions of previously published articles.

Chapter 1, "Designer Babies, Selective Abortion, and Human Perfection," is a revision of "Selective Abortion and Gene Therapy: Reflections on Human Limits," *Human Gene Therapy* 2, no. 3 (1991): 229–233.

Chapter 2, "The Moral Meaning of Relinquishing an Infant: Reflections on Adoption," is a revision of an article of the same title appearing in *Thought* 67, no. 265 (June 1992): 207–220.

Chapter 3, "Adolescents in Time of AIDS," is a revision of "Adolescents in Time of AIDS: Preventive Education," *America* 167, no. 11 (October 1992): 278–282.

Chapter 4, "Psychiatry and the Challenge of Religious Toleration," is a revision of "Psychiatry, Religious Conversion and Bioethics," *Kennedy Institute of Ethics Journal* 1, no. 3 (March 1991): 207–223.

Chapter 5, "American Culture and Good Death," is a revision of "American Culture and Euthanasia," *Health Progress* 72, no. 10 (December 1991): 32–39. The article was awarded second place by the Catholic Press Association of the United States and Canada for "best article originating with a professional journal" in 1991.

Chapter 6, "The Covenant of Basic Caring," is previously unpublished, but some of its ideas are taken from "Family Caretaking: Stewardship and Commitment," *Second Opinion: Health, Faith, and Ethics* 8 (July 1988): 114–127.

Chapter 8, "The Legacy of Racial Hygiene: Death and Data," is a revision of "The Legacy of Racial Hygiene: Hearing the Voice of Victims," *Soundings: An Interdisciplinary Journal* 74 nos. 3 and 4 (Fall/Winter 1991): 541–558.

Chapter 9, "The Emergence of Species Impartiality: A Medical Critique of Biocentrism," is a revision of an article of the same title previously published in *Perspectives in Biology and Medicine* 36, no. 2 (1993): 289–300.

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Introduction

Bioethics is an interdisciplinary field concerned with issues in the life sciences, health, and health care. In this book I explore nine representative bioethical issues loosely organized in a sequence from birth and youth to aging and death. I have drawn on the insights of religious studies, history, philosophy, and health care in order to develop broad perspectives for an interdisciplinary readership. My method is shaped by no overarching foundational moral theory, although general principles such as "do no harm" (nonmaleficence) are presumed. I attempt to present perspectives in the tradition of the public intellectual concerned that too much work in bioethics is overly theory-driven and intended for specialized peer groups. My attention to a spectrum of broad, perennial, humanistic themes such as human perfectibility, trust, care, and the contingency of human experience will, I hope, prove engaging and possibly refreshing. Throughout the book I place emphasis on the cultural changes that underlie and shape our presuppositions about the right and the good. In the end, the reader will rightfully detect that I am not a consistent defender of modernity.

The biological revolution that is currently taking place, with its attendant technological powers to alter nature and human nature, requires of all thoughtful people a fundamental and cautionary reflection on questions of the highest ethical importance. In the first chapter, "Designer Babies, Selective Abortion, and Human Perfection," I raise serious questions about the advent of new magnitudes of genetic knowledge that can narrow parental images of human normalcy in a culture prone to forget that what human perfection is available to us is, as Aristotle understood, largely a matter of good character forged in response to the lessons of experience. Our eyes wrongly turn toward the appearance of the human vessel rather than to the virtues of the person. That almighty data replace the mystery of the womb is a mixed blessing and, increasingly, a cultural mandate.

My defense, in chapter 2, of relinquishing an infant for the benefit of childless couples who wish to experience parenthood will disturb some critics who exaggerate the harms this practice inflicts on the child. In response to anticipated criticism, I consider these alleged harms in a balanced manner in the first section of the chapter. I propose greater moral emphasis on the value of relinquishing a child for adoption as an idealistic alternative to abortion. Such idealism, however, neither can nor should be required. The relinquishing of a child by the biological mother has in our current culture been denigrated, in distinct contrast to earlier historical periods in which it was understood more positively. We have something to learn from this history.

Chapter 3, "Adolescents in Time of AIDS," is a shift from birth ethics to a tragic epidemic that threatens the young, and about which all parents are concerned as they see their children growing up. The Committee on Adolescence of the American Academy of Pediatrics issued a report entitled "Contraception and Adolescents" in 1990. The report deserves more attention than it has received. It is noteworthy first for its opening directive that pediatricians should be "active participants in the effort to reduce the negative consequences of adolescent sexual activity." The second sentence is this: "Preventive measures include counseling teenagers and their families on responsible sexual decisionmaking, including abstinence, and providing contraceptive services for sexually active patients, when requested." Throughout the report, a special concern is with the transmission of the human immunodeficiency virus (HIV), in response to which pediatricians are to encourage patients to "postpone first intercourse until they are physiologically and psychologically mature."[1] Throughout, the pediatrician is to remain nonjudgmental and nonthreatening. This support for prevention is grounded in the experiences of pediatricians who have witnessed the huge impact of infectious diseases from *Chlamydia* *trachomatis* and *Treponema pallidum* to herpes simplex virus and HIV. Pediatricians seem able to transcend our various "culture wars" regarding sexual morality in order to focus on the one value that every citizen shares, especially with regard to young lives, the avoidance of disease and death. Because this issue is increasingly significant for parents and children, it is a fit area for serious ethical discussion.

Some theories of moral development suggest that adolescents and young adults often go through a phase in which they quest for an absolute and all-encompassing worldview. Sociologists, among them Peter Berger, emphasize the psychic burden of growing up in a modern culture with many competing worldviews that relativize all assertions about ultimate reality. Uprooted and traditionless, the "homeless mind" struggles to find meaning in modernity, often migrating from worldview to worldview in a search for the one and only truth. It is remarkable how many of my peers in the 1970s and 1980s joined rigorous and in some cases relatively authoritarian political, social, or religious movements only to pass through the revolving door of utopianism back into the world, generally a bit wiser for the experience. Migrations into the more radical religious movements stirred particular controversy among their parents and attracted wide attention from psychiatrists. In chapter 4, "Psychiatry and the Challenge of Religious Toleration," I discuss ethics, psychiatry, and parental response to socially unaccepted ideological movements. I deal with the so-called "deprogramming" controversy, as parents attempt to rescue their young adult children from intense organizations, sometimes with assistance from psychiatrists and often unaware of the extraordinarily high attrition rates that naturally occur in these organizations as naïveté gives rise to suspicion. I review literature from the American Psychiatric Association in the light of a wider discussion of modernity, family interests, and anomie. This chapter is dedicated to my old friend Jake, whom I met while a college student. Jake migrated through no less than three intense religious movements between 1970 and 1974 before settling into a tree house in the forests of Oregon to find his own truth. He is now an insightful anti-utopian and a Catholic.

The end of youth might be defined as the dawning of our sense of finitude and our desire to leave behind something meaningful in the time allotted to us. A central bioethical concern is the human response to the temporal limits imposed by our biological embeddedness. One of the perennial questions in all cultures is how to respond morally to inevitable bodily and very often mental decline. In the last analysis, a divide separates those who would strike out against this decline by preemptive suicide or voluntary mercy killing and those who prefer to leave the hour of their deaths in the hands of nature or of nature's God. I discuss these issues in chapter 5, "American Culture and Good Death." Of course, those who wish no preemptive suicide may require considerable care and attention from loved ones or other care givers. Thus, the issues considered in the sixth chapter, "The Covenant of Basic Caring," are linked with those in chapter 5.

In these two chapters, I avoid the words "active euthanasia" and "passive euthanasia" because they suggest two instances of what is more or less the same action. It is better to speak of killing and allowing to die, emphasizing a moral difference between aiming to end a life and removing treatments in the knowledge that if the patient continues to live he or she will be cared for steadfastly. In the second instance, if the patient dies, the result is the same as killing, but what the physician *does* and *becomes* as an intentional moral agent is very different.

In chapter 6 I provide an alternative to suicide and killing. A hospice physician, David Cundiff, notes that requests for mercy killing are uncommon according to polls of cancer specialists. What requests are made stem from poor pain control and/or inadequate psychosocial support. Those who make requests "almost always change their minds once their physical symptoms are controlled and they are placed in a caring, supportive, hospice environment." Cundiff's thesis is that "vastly improved hospice training for health care professionals, along with better quality and greater availability of hospice services can render the issues of euthanasia and assisted suicide essentially moot."[2] There is much to be said for the hospice viewpoint, or so I will argue.

In chapter 7, "Old-Age-Based Rationing, Dementia, and Quality of Life," I discuss preemptive suicide in cases of irreversible dementias in addition to providing criticism of the rationing of health care based on age. Alzheimer's disease is on the cutting edge of the national and international debate about physician-assisted suicide. While it is true that requests for suicide from the terminally ill are often shaped by untreated pain and inadequate psychosocial conditions, what of requests by people with diagnoses of progressive dementia that will ultimately lead to the loss of memory and hence of self-identity, and a decline over as many as fifteen years? Such cases are beyond the beneficent hand of hospice care. Reports consistently indicate that in the Netherlands, where assisted suicide and mercy killing are de facto accepted, about 10 percent of requests come from patients with chronic degenerative neurological disorders.[3] Margaret P. Battin writes of progressive dementia: "This is the condition the Dutch call *entluistering*, the 'effacement' or complete eclipse of human personality, and for the Dutch, *entluistering* rather than pain is a primary reason for choices of [active] euthanasia."[4] Battin defends assisted suicide or mercy killing in cases of progressive dementia if requested by a living will or by personal directive. I make no such defense but instead offer a compromise.

The eighth chapter, "The Legacy of Racial Hygiene: Death and Data," is about a time when medicine became murderous. The art of medicine slipped deeply into the habit of killing, and no discussion of the ethics of death is complete without recollecting this. I have in mind the incredible human destruction at the hands of the Nazi doctors. Whether the Nazi period has much analogical significance for the current discussion over assisted suicide and medical killing is unclear and a matter of continuing debate. Still, it is important to remind ourselves of this history.

Finally, in the last chapter, entitled "The Emergence of Species Impartiality: A Medical Critique of Biocentrism," I raise an underlying moral question: is a human life more important than any nonhuman animal's, even when that animal is relatively highly evolved? In a well-publicized case in 1992, Dr. Thomas E. Starzl transplanted a baboon liver into a thirty-five-year-old man who died seventy-one days later after a stroke. The case presents an opportunity for debate between those who would save a human life at the sacrifice of a baboon, and those who find such salvation morally disgraceful. Because human cruelty toward members of nonhuman species has occurred throughout history, it may be good that interspecies egalitarianism has emerged. Yet does interspecies egalitarianism leave us with a deeply distorted model of our proper rights and obligations? Many observers may question the particular choice of patient or other clinical-ethical aspects of Starzl's liver transplants. But Starzl has acted on the moral assumption that the human good remains appropriately the highest good, despite the cultural inroads of anthropomorphism.

NOTES

1. Committee on Adolescence, American Academy of Pediatrics, "Contraception and Adolescents," *Pediatrics* 86, no. 1 (July 1990): 134.

2. See David Cundiff, *Euthanasia Is Not the Answer: A Hospice Physician's View* (Totowa, New Jersey: Humana Press, 1992), p. 16.

3. Maurice A. M. de Wachter, "Euthanasia in the Netherlands," *Hastings Center Report* 22, no. 2 (March–April 1992): 23–30.

4. Margaret P. Battin, "Euthanasia in Alzheimer's Disease?" in Robert H. Binstock, Stephen G. Post, and Peter J. Whitehouse, eds., *Dementia and Aging: Ethics, Values and Policy Choices* (Baltimore: Johns Hopkins University Press, 1992), p. 123.

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Designer Babies, Selective Abortion, and Human Perfection

The project to map and sequence the human genome is under way. The number of gene abnormalities that can be tested for will dramatically increase from several hundred to many more within the decade and perhaps to thousands.[1] Prenatal, neonatal, carrier, and presymptomatic testing will reach new orders of magnitude.[2] Such testing will remain a matter of personal choice in our highly individualistic culture, unless restricted by health care rationing or some other aspect of social and distributive justice. Nevertheless, even if the individual has a legal right to any and all testing he or she can afford, there is room for moral discussion of the broad humanistic foundations of the choices that individuals will be making about selective abortion on the basis of genetic defects.

Lest this essay be misinterpreted, I must state immediately that those opposed to abortion should not, for that reason, frown on the human genome project to map chromosomally, or locate, all human genes. The emerging technology of somatic cell gene therapy will possibly provide an alternative for parents who might otherwise resort to selective abortion. Eve K. Nichols suggests a scenario in which prenatal diagnosis detects severe combined immune deficiency. Knowing of the disease in advance, physicians could prepare a germ-free “bubble” environment for the baby. Then, the adenosine deaminase gene could be inserted into the baby’s bone marrow cells. This autologous transplant would result in normal lymphocytes, and in a healthy child.[3] While we must not exaggerate the possibilities for human gene therapy, which is still largely speculative,