

Book Reviews

When Death Is Sought: Assisted Suicide and Euthanasia in the Medical Context

**The New York State Task Force on Life
and the Law**

New York City, 1995, 217 pp., \$9 (paperback)

PHYSICIAN-ASSISTED SUICIDE IS LIKELY TO be a focus of debate for some time. Dr. Jack Kevorkian's suicide machines and parked vans may be easily dismissed as publicity-seeking antics, but his espoused

goal of empowering patients strikes a sympathetic chord in many Americans. People are afraid of the prolonged and painful dying often associated with modern life-sustaining technology. Our society's decades-long emphasis on individual self-determination has led many to claim a new "right," the right not to suffer indignity and loss of control at the end of life. It seems plausible to many Americans that assisted dying is an appropriate extension of healthcare. We have seen a growing acceptance—and frequency—of physicians' helping patients die by removing unwanted or excessively burdensome life-prolonging therapy. The discussion has now moved beyond

letting nature take its course. In fact, surveys show that more than 60 percent of Americans favor legalization of some form of physician-assisted suicide (PAS). Oregon's citizens recently approved the first such initiative. Like abortion, this issue is likely to polarize the American public for years to come—and in the process generate more heated rhetoric than thoughtful discourse.

In New York, as in 31 other states, assisting suicide is currently a statutory offense; active euthanasia is illegal in every state. In 1992 the New York State Task Force on Life and the Law (NYSTFLL) set out to study the public policy implications of legalizing these practices.

RESOURCE BRIEFS

Procuring Organs for Transplant: The Debate over Non-Heart-Beating Cadaver Protocols

Robert M. Arnold, et al., eds., Johns Hopkins University Press, Baltimore, 1995, 249 pp., \$18.85 (paperback), \$50 (hardcover)

Most organs used for transplantation come from patients declared dead by neurologic criteria whose hearts are still beating. However, recent advances make it more feasible to procure organs from persons whose hearts have stopped beating and who are declared dead using cardiopulmonary criteria. In 19 chapters from various contributors, this book explores the ethical, psychosocial, and public policy implications of procuring organs from these non-heart-beating cadaver donors.

Health and Social Policy

Marvin D. Feit and Stanley F. Battle, eds., Haworth Press, Binghamton, NY, 1995, 290 pp., \$19.95 (paperback), \$39.95 (hardcover)

In a multidisciplinary approach, contributors to this text examine the health, medical, and social policy implications of a variety of issues: public policy issues such as patient dumping and HIV testing; planning issues such as designing services for the homeless; population issues such as changing family roles; cost issues such as cost-effectiveness analysis in policy formulation; and prevention and intervention issues such as policies for pregnant adolescents.

Euthanasia: Moral and Pastoral Perspectives

Richard M. Gula, Paulist Press, Mahwah, NJ, 1994, 85 pp., \$5.95 (paperback)

This book "focuses on the religious perspective from which the Catholic moral tradition derives its opposition to euthanasia and physician-assisted suicide," Fr. Gula writes in the introduction. The brief volume clarifies the object of the debate; examines the vision and values at stake; and frames these within the scope of autonomy,

prohibition against killing, and beneficence. The final chapter sketches a pastoral response to the euthanasia movement. Portions of this text were previously published in the Catholic Health Association's 1994 publication, *Euthanasia and Assisted Suicide: Positioning the Debate*.

BOOKS RECEIVED

Medical Practice in the Current Health Care Environment, Janine C. Edwards, ed., Johns Hopkins University Press, Baltimore, 1995

O Happy Fault: Personal Recovery through Spiritual Growth, Robert M. Garrity, Paulist Press, Mahwah, NJ, 1994

Stroke Survivors, William H. Bergquist, Rod McLean, and Barbara A. Kobylinski, Jossey-Bass, San Francisco, 1994

A Change in Perspective (video), Eastern Paralyzed Veterans Association, Jackson Heights, NY, 1994

The task force originated in 1985 when Governor Mario Cuomo charged it with making public policy recommendations about developments in medical science. This 25-member group, which includes physicians, nurses, lawyers, clergy, and bioethicists, has generated a number of carefully reasoned reports, including public proposals on do-not-resuscitate orders, the determination of death, decisions about withholding and withdrawing life-sustaining treatment, organ transplantation, and surrogate parenting. Several of these initiatives have subsequently been incorporated into New York law. Thus the publication of *When Death Is Sought*, the task force's report on PAS and euthanasia, was awaited with anticipation by both friends and foes of assisted dying.

Although members of the task force held different views about the morality of acts of PAS and euthanasia, they unanimously agreed that existing law should not be changed. They argued that the passage of such legislation would compromise the care of severely ill patients, enhance the power of physicians, pose profound risks to certain disadvantaged groups, and lead to unacceptable changes in the social fabric. They rejected proposed criteria and safeguards for physician-assisted death as vague, ill-founded, or unenforceable. Finally, the NYSTFLL argued strongly for improving the care of severely and terminally ill patients, including providing pain control, better diagnosis and treatment of depression, and more comprehensive palliative care.

When Death Is Sought is a nuanced account of the reasoning behind these recommendations. Though the book is written primarily for health professionals and policy makers, interested laypersons will also find it informative, albeit a bit dry.

The book begins with a series of chapters describing the clinical, legal, and ethical background of the debate over euthanasia and PAS. The first two chapters, for example, deal with the epidemiology and clinical features of suicide, especially as it occurs among the elderly

and chronically ill. In the third chapter, the task force examines current pain-management practices. Studies repeatedly show that only 20 percent to 60 percent of cancer pain is treated adequately, even though good control of pain and other symptoms is possible in more than 90 percent of cases. This failure arises from healthcare professionals' lack of knowledge about state-of-the-art pain management, as well as from false beliefs about the risks of addiction and respiratory depression. Chapter 4 reviews the legal status of euthanasia and PAS, and chapter 5 presents a tight, well-written account of the ethical principles at stake and their implications for public policy. Part II of the book summarizes the task force's deliberations and elaborates the recommendations.

Many argue that the right to choose the time and manner of one's death is an appropriate extension of the right to make informed decisions about healthcare and to refuse medical treatment. Certainly, the option of PAS appears to enhance personal autonomy. Self-determination is, in fact, central to the argument in *When Death Is Sought*. But the task force reaches the somewhat counter-intuitive conclusion that legalization of physician-assisted death would *decrease*, rather than increase, self-determination for the terminally ill.

This reasoning begins with the phenomenology of serious illness. Sick people are weak, are vulnerable, and feel out of control. Their autonomy is attenuated by disease itself. Physicians have the power to alleviate many or most of the severe symptoms that compromise their patients' sense of control. Yet, for various reasons, many still allow their patients to suffer more than necessary. Our healthcare system is deficient in precisely this type of symptomatic therapy (e.g., pain management, treatment of depression, and comprehensive palliative care). The NYSTFLL argues that, in this milieu, patients are especially vulnerable to pressure from physicians and others. Making PAS available would allow physicians to

add an "easy" medical option (i.e., compassionate death) without addressing the more difficult problem (i.e., compassionate care of the dying).

Would legalizing PAS encourage physicians to provide better palliative care? *When Death Is Sought* says no. In fact, the PAS option would have deeply troubling consequences for the patient-physician relationship, further eroding the commitment of physicians and other healthcare professionals to care for dying and incurably ill patients. "Patients in turn might be fearful that they would become candidates for these 'treatments', or might worry about the consequences of refusing these options once they are presented by their physician," say the authors (p. 139). Burdened as they are by pain, depression, and worries about the cost of care, patients with chronic illness would also be susceptible to other internal and external pressures to choose suicide. This might be particularly true of the more vulnerable segments of our population, including the aged and those of low socioeconomic status.

The task force also considers two types of "slippery slope" argument. First, given the self-determination argument, a newly established right to compassionate death could not be limited to those who are physically and emotionally able to perform the deed. Some provision would have to be made for patients who are paralyzed or too weak to take the fatal drugs. Thus a policy permitting PAS must in some cases permit voluntary euthanasia. Moreover, if competent adults are to be given the right to determine the time and manner of their death, the exercise of this right should also be provided for (e.g., through advance directives or healthcare proxies) in cases where patients lose their capacity for decision making.

The second "slippery slope" is based on compassion rather than autonomy. It would be inhumane to deny a patient the "best" therapeutic option simply because of his or her incapacity to consent. Some doctors might feel so strongly that

euthanasia is in the patient's best interest that they would promote assisted dying as an option for comatose, vegetative, and other clearly incompetent patients: "Once euthanasia becomes an accepted 'therapy' the expansion to include those who are incapable of consenting would be a logical, if not an inevitable progression," write the authors (p. 133). Recent experience in the Netherlands certainly suggests that such nonvoluntary euthanasia would occur.

Some bioethicists, including physicians like Dr. Timothy Quill, in his recent book *Death and Dignity: Making Choices and Taking Charge* (New York City, Norton, 1993), have argued for legalizing physician-assisted death under certain strict guidelines or conditions. One proposed guideline, for example, says that PAS should only be permitted in cases of terminal illness. But the NYSTFLL notes that "the logic of suicide as a compassionate choice for patients who are in pain or suffering suggests no such limit" (p. 132). Those who believe their lives intolerable because of chronic illness would have an equally plausible claim to assisted dying services. Moreover, the proposed requirement that PAS be the last option, offered only after other alternatives have failed, seems to the task force an unwarranted restriction, inconsistent with strong support for self-determination. Why should patients have to endure several failures of treatment before choosing suicide? Finally, Quill's suggested requirement that PAS be conducted within an established patient-physician relationship overlooks those patients who have no regular physician (e.g., because they lack health insurance); it also fails to define an "established" relationship.

The task force concludes that:

Medically assisted dying and direct medical killing are unacceptable societal responses to the problem of human suffering. Compared to the resources, caring, and compassion needed to respond to suffer-

ing individuals, a lethal prescription or injection would offer a simple solution for profoundly human and complex dilemmas. It would also extend medicine from the realm of care or cure to dispensing death for problems endemic to the human condition. (p. 136)

Instead, the NYSTFLL strongly recommends that physicians and other health professionals enhance their pain management skills, that hospitals and other healthcare institutions develop better palliative care services, and that insurance companies eliminate financial barriers to effective symptom management.

When Death Is Sought is a good introduction for anyone who wishes to learn more about the subtle and complex issue of legalizing PAS. There are, however, some missing pieces. Because the argument here turns primarily on policy implications of PAS, some readers may find too little analysis of its underlying morality. The report also tends to gloss over the fact that, even with the best palliative care, there is much suffering that simply cannot be alleviated. This includes perhaps 10 percent of severe physical pain, but, more important, it also includes much of the emotional and existential suffering experienced by the dying. Moreover, in its critique of proposed PAS guidelines, the task force does not do justice to the fact that, even if PAS were legalized, the state's need to balance individual self-determination and preservation of life would not be eliminated. Expression of self-determination would simply be given more weight. In that case, restrictive guidelines might well be warranted if they helped curb abuses, prevent mistakes, and otherwise promote the state's interests.

The main ingredient missing in *When Death Is Sought*, however, is the passion and immediacy that patient stories provide. Quill's *Death and Dignity* is an interesting counterpoint in this regard. Though both books consider the same moral terrain, Quill, relying greatly on the narrative method, presents a series of

patient stories that immediately engage the reader's attention. Both books argue that we have a moral imperative to improve the care of the dying patient. However, the reader who wants to understand more about the motives behind and moral justification for individual acts of PAS will find in *Death and Dignity* much that is missing in the NYSTFLL report. Quill, using a "bottom-up" approach that starts with individual cases, concludes that legalization of PAS (and in some cases voluntary active euthanasia) would help individual patients and be good public policy, provided that safeguards are built into the system. The task force, using a "top-down" expert panel approach, concludes that strengthening our commitment to palliative care without PAS is the better route because the potential threats of PAS and euthanasia to society would outweigh their potential benefits. I am not claiming here that logical argument is inferior to anecdote. I do believe, however, that serious moral discussion ought not lose sight of concrete human experience. In that sense, the two books complement one another.

With the passage of Oregon's Death with Dignity Act last November, legally sanctioned PAS became a reality in the United States. In the next few years, other states will likely join Oregon. The experience in these states will, one hopes, provide us with data to guide future public policy discussions. Meanwhile there is no question that, at least until palliative care is substantially improved and the public's fear of prolonged suffering relieved, PAS will enjoy widespread popular support.

John L. Coulehan, MD
Institute of Medicine in
Contemporary Society
State University of New York
at Stony Brook

Copies of *When Death Is Sought* are available from Health Education Services, PO Box 7126, Albany, NY, 12224, for \$9 plus \$2 postage and handling.