Book Reviews

A Midwife through the Dying Process: Stories of Healing and Hard Choices at the End of Life

By Timothy E. Quill. 239 pp. Baltimore, Johns Hopkins University Press, 1996. $24.95. ISBN 0-8018-5516-0.

IN Timothy Quill's recounting of the deaths of nine patients, the final description is of the planned death of Jules: at home, surrounded by family members, and aided by a physician. It is a moving, true story, recounted in meticulous detail, from the first diagnosis to the final dose of barbiturates. But despite its many similarities, this is not the famous case of Diane, described by Dr. Quill in the *Journal* some six years ago in an account that launched much of the current discussion about physician-assisted suicide ("Death and Dignity: a Case of Individualized Decision Making." 1991;324:691-4). Jules's planned death involves the removal of a respirator on which amyotrophic lateral sclerosis has made him dependent. In this case, a planned death in the presence of the family and with the cooperation of the physician is possible because the patient happens to be dependent on a life-sustaining therapy that he can choose to discontinue — and thus deliberately and legally bring about his death.

With this and eight other carefully described cases from his own practice or with which he was associated, Dr. Quill explores the many ways in which death occurs with the assistance of a physician. Quill is best known for having facilitated, in the case of Diane, what is usually termed physician-assisted suicide, but in this clearly, engagingly, and expertly written book, he shows that "suicide" is only one of the ways physicians can assist in bringing about the deaths of their patients. He describes the part the physician plays in orchestrating death after a patient's refusal of treatment, in permitting death brought about by the refusal of nutrition and hydration, in allowing a "double effect" death involving the use of heavy doses of morphine, in facilitating death by deactivating a cardiac defibrillator, in bringing about death by sedation with barbiturates, and in assisting in a death caused by an overdose of barbiturates — a death aided by friends who, in the end, were forced to use a plastic bag.

Some of these cases go well both for the patient and for the physician, despite the technical complexities — carefully described — of the choice of treatment or nontreatment, drug doses, and the timing of their administration. Other cases do not go so well. Jules's death after the removal of the respirator is one of the easiest — at least for the patient. Jules is perfectly clear that this is what he wants, he has ample information about what kind of life he could expect otherwise, he makes an unhurried decision four months in advance and reinspects and reaffirms it repeatedly over the ensuing months, he is not subject to economic or managed-care pressures, he does not have to skirt the law, he has a supportive family, and he is genuinely grateful for the support and assistance of his physician. However, Jules's planned death is not so easy for his physician. Despite extensive consultation, she does not know how much of the barbiturate to administer in order to stay within the confines of the double effect while averting air hunger at the end, she does not know how to cope with the advance knowledge that he will be dead at a certain time, and she is unprepared for the final grimace and sigh that occur despite her most careful planning. We can almost see the beads of sweat on her forehead. Afterward, she says, "I hope I don't have to go through this again," even though she is perfectly clear that however difficult for her, it was the right thing to do.

The contrast between the cases of Jules, who requested the withdrawal of his respirator, and Diane, who requested a prescription for a lethal drug and was forced to take it by herself, alone, without direct assistance from Dr. Quill or from her family, is the very contrast addressed in the Second Circuit Court of Appeals case *Vacco* v. *Quill,* in which Dr. Quill is a principal. *Vacco* v. *Quill,* together with the Ninth Circuit case concerning Compassion in Dying, *Washington* v. *Glucksberg,* are the two cases on physician-assisted suicide now before the U.S. Supreme Court. The argument found persuasive by the Second Circuit Court is that it is a denial of equal protection if patients like Jules can lawfully engage in planning their deaths, with the direct assistance of their physicians and the open support of their families, whereas patients like Diane cannot do so because they do not happen to be receiving life-sustaining treatment that can be discontinued. *A Midwife through the Dying Process* allows us to see directly, with a detailed description of the medical situation, what makes the equal-protection argument in *Vacco* v. *Quill* so compelling.

Not all the patients described in this book choose to die. Some who are as clearly at death's door as the others choose to continue to live as long as they can, also with the active assistance and support of their physicians. Their cases make another point central to the current discussion of end-of-life issues: not all patients in similar circumstances will make the same choices about when and how to die, and physicians ought not to expect or require that they should.

Most compelling for a medical audience is the complexity of these portraits of physicians assisting patients in dying. Idealizing and descriptive features, tightly interwoven, make the portraits vivid. Quill portrays the ideal physician as a kind of midwife who can help the patient make the transition from life to death, which is understood as analogous to the way helping a woman who is delivering a baby facilitates the transition to life outside the womb: dying, like being born, is a natural process, but one that compassionate, expert physicians can make go very much better. Hospice care has long recognized this point, but the prospect of more direct physician assistance in suicide also raises it. When their patients ask them for assistance in dying, these ideal physicians do not flinch, nor do they minimize or ignore their patients' requests; they regard assisting a patient in seeking a humane and dignified death as a "genuine privilege," not a threat to be avoided. Most important, Quill points out, such physicians do not assume that all requests for assistance in dying stem from undertreated pain, unrecognized depression, or some kind of character flaw.

Complementing this idealistic picture of the physician,

however, Quill's narratives are perceptively realistic about the multiple ways in which assisting patients in dying can be difficult for physicians. One source of difficulty involves the tenuousness of the line between intending to relieve suffering but not intending to cause death, as the principle of double effect demands; we see how strained this distinction is in practice. Discomfort for the physician also comes from having to recognize that the patient is dying and that it is no longer possible to prevent death except by prolonging the process of dying, a situation some physicians interpret as their own failure or the failure of their craft. The difficulty is compounded by inadequate medical training in the pharmacology involved in providing assistance with dying and the lack of professional preparation for assuming this role. In some cases, the difficulty comes from being forced to provide help out of sight of the law, in the secrecy of homes or in the privacy of particularly close physician–patient relationships. The legal risk makes the provision of assistance in dying uncomfortable for physicians, even when the process is apparently legal, as with the use of increasing doses of morphine under the principle of double effect, since the charade that one's sole intention is to relieve suffering is so difficult to maintain. Finally, some of the difficulty in assisting a patient in dying — whether or not it is illegal to do so — comes from the simple grief of losing a patient one has come to care about.

One of the many arguments against the legalization of physician-assisted suicide is that it would be too difficult for physicians. Quill's narratives allow us to see more clearly why assistance in dying is important and what it is about a patient's dying that is difficult for physicians, as well as the ways in which the illegality or legality of assisting affects this. Quill insists that the answer to these difficulties is not to avoid assisting in the death of a patient who seeks help; the answer is to regard the patient who is dying badly as an occasion for a vigorous medical response — a "medical emergency," demanding the conscientious, humane, expert involvement of a caring physician who can make the dying go better, if it has to happen at all, for this patient. Assisting a patient in dying does not always involve breaking the law; it can and should happen within the law as well, and Quill shows clearly how a conscientious physician can provide such assistance.

This does not mean that legalization of physician-assisted suicide, as *Vacco* v. *Quill* addresses it, is not a crucial issue, but only that it is not the only issue at hand. Part of the point of both Quill's Supreme Court case and his book is that the line drawn between legally permitted and legally prohibited assistance in dying is clinically untenable and morally indefensible. The implausibility of this line compounds the difficulties for physicians in caring for their patients.

The answers to the questions Quill's narratives raise about assistance in dying and what makes it difficult for physicians to provide such assistance are more fully explored in 11 challenges he poses in the book's final chapter. Among them are these: "Physicians, nurses, and other health care providers who care for severely ill patients must become experts in comfort-oriented care," "We must learn how to talk openly with those who wish for death," and "The main public policy question is whether patients would be better served by safeguards controlling a more explicit, open process than they are by the current unstated policy requiring secrecy and ambiguity whenever death is eased." Internists, oncologists, geriatricians, family-practice and primary care physicians, nurses, and other health care providers will be challenged by these assertions, but so will lawyers, social theorists, religious thinkers, policy makers, and many others. This book is accessible to a broad audience but of compelling importance to any physician whose patient may die.

Quill's portraits of his own role and that of other physicians who have aided their patients in dying are direct, honest, and extremely informative — as well as compelling, engagingly written stories. Some readers may think the degree of concern about how these patients die excessive or the questioning of amorphous legal boundaries unprofessional, and some will think that such physician–patient relationships are increasingly threatened in contemporary, cost-pressured medicine. But many readers will see Quill's composite portrait as the best, most evocative description of a physician's appropriate role in assisting a patient who is dying, that of "midwife through the dying process" — a phrase he borrowed from one of his patients.

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THE ETHICS OF HUMAN GENE THERAPY

By LeRoy Walters and Julie Gage Palmer. 209 pp., illustrated. New York, Oxford University Press, 1997. $27.95. ISBN 0-19-505955-7.

THERE is extensive debate in science, ethics, and public policy about gene therapy for humans. Immersed in this literature, Walters and Palmer have coauthored a book at the leading edge of the subject. Using fine illustrations and sketches, they lucidly explain the scientific and medical background as well as the ethical issues. The quality of the book is due in part to Walters's chairing of the Working Group on Human Gene Therapy, which was created in 1984 as an arm of the Recombinant DNA Advisory Committee of the National Institutes of Health (NIH). Until 1996, when the NIH director revised the authority of the committee, it publicly reviewed all U.S. trials of gene therapy. Palmer, a practicing attorney with postgraduate training in medical ethics, has an impressive knowledge of the technical and scientific aspects of the field.

In the introduction, the authors recall David (1971–1984), a boy with severe combined immunodeficiency who lived in a protective bubble until two weeks before his death. David's case points up the magnitude of the human suffering that can be caused by heredity. In industrialized societies, about a quarter of hospitalized children have hereditary disorders.

Chapter 1, a primer on genes and heredity, will help the general reader and will pass muster with biologists. Chapter 2 explains gene therapy involving somatic cells and traces the history of the first 100 protocols approved by the Recombinant DNA Advisory Committee (1990–1995). Chapter 3 examines the ethical arguments for and against germ-line experiments. The authors answer objections with

reasonable and logical arguments, except when they offer mere assertions in lieu of ethical arguments in their defense of research on embryos. In chapter 4, they discuss the prospects for "enhancement genetic engineering," the genetic method of promoting or enhancing physical attributes such as height or weight and intellectual powers such as memory or intelligence, and of diminishing moral characteristics such as aggression. This chapter is a tour de force that will be widely anthologized and used in discussions of the policy implications of behavioral genetics.

Five appendixes add value: a section by Gelehrter and Collins on mitosis and meiosis; a primer on mendelian inheritance from a document published by the Office of Technology Assessment; an overview of methods of delivering genes to cells; the advisory committee's now-famous "Points to Consider" document; and Capecchi's article on homologous recombination or "gene targeting," the holy grail of all gene therapists.

Up to chapter 5, the book succeeds because of its clarity and persuasive ethical reasoning. Although the authors' own ethical views differ in important respects, there is a shared core of ethical pragmatism at the heart of their project, accompanied by an unyielding adherence to the idea that genetic services should be provided on a voluntary basis. They are willing, in principle, to submit the most controversial possibilities of gene therapy to the tempering fires of self-correcting experience, but only within an ethos of the utmost respect for reproductive choices.

This book is needed, given the sentiment in some quarters to condemn and ban the first steps toward germ-line or enhancement gene therapy. Genetic research is popularly portrayed in American culture (and more so in Europe) as having an aura of dangerousness. This book argues that the public need not fear taking the long view and should debate all options, but that testing for safe, effective, and affordable approaches to somatic-cell therapy should have priority. Any literate citizen will be able to read and appreciate the account of the need for techniques to replace rather than add genes.

Chapter 5, a brief review of public policy and the oversight of gene therapy, is the one room in this house that needs improvement. It lacks the foresight of chapters 3 and 4. The authors do not map the obstacles to a public policy supportive of discoveries beyond somatic-cell therapy. All roads to experiments in germ-line therapy or health-related enhancements cross the torturous paths of public policy governing fetal and embryo research. The authors fail to warn Congress, the NIH, and the American people of the incoherence in policy, already evident by 1995, due to the collision of three factors: an avalanche of knowledge about genetics from a Human Genome Project funded in part by Congress in the hope of developing gene therapy; the prospect, fostered by research on embryo-derived stem cells, that gene therapy may be more feasible in embryos or fetuses than in living children; and the restrictions placed by President Bill Clinton and Congress on funding to study how some potentially treatable genetic disorders originate in embryos with specific parents at higher genetic risk.

The NIH's Human Embryo Research Panel recommended in 1994 that some research involving embryos be federally funded, including the controversial step of fertilizing ova for research. Public policy forbids the NIH from funding and conducting peer review of such projects, including the study of pathophysiology in embryos donated for research by couples at high risk of genetic disorders. Any scientifically credible approach to gene therapy for maladies that begin in the embryo must be based on a thorough understanding of the pathophysiology. The current policy regarding embryo research is a large but remediable obstacle to the public's hope for safe and effective human gene therapy. This fine book would have been improved if it had grappled thoroughly with this issue.

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CLINICAL CHALLENGES IN GASTROENTEROLOGY

Edited by Michael J.G. Farthing.
214 pp. St. Louis, Mosby, 1997. $75.
ISBN 1-85317-252-9.

DON'T be misled by the title. This book is not a series of difficult clinical cases complete with discussions and expert solutions. Rather, it is a collection of reviews that tackle "common and difficult problems that face gastroenterologists and hepatologists on a daily basis." The problems range from treating *Helicobacter pylori* infection, the irritable bowel syndrome, and hepatitis C to palliating esophageal cancer and managing difficult bile-duct stones. The management strategies aim to integrate the best evidence available with clinical judgment in order to be truly evidence-based. The book only partly fulfills its ambitious goals, however.

The chapters are generally well written and remarkably easy to read (in part because of the large print and excellent layout). There are a few black-and-white photographs and a reasonable number of good diagrams, and the paper feels and looks nice. All the contributors are from the United Kingdom, but the views reflect practice on both sides of the Atlantic (and even the Pacific). Each chapter ends with a novel section entitled "What would I do if I had . . ."; though brief, these personalized overviews are particularly enjoyable and insightful.

A common problem with multiauthored books is that the contributions are patchy (unless the editor rewrites most of them, as some do). This book is no exception. Some contributions are really outstanding, such as those on screening tests for celiac disease, the role of surveillance and surgery in Barrett's esophagus, and intestinal failure. But others tend to skim the surface of large topics, such as the treatment of refractory diarrhea in AIDS and the management of refractory Crohn's disease. Of course, no book can keep pace with the ever-expanding literature; most of the references here predate 1994. This limitation particularly affects rapidly evolving areas, such as combination therapies for *H. pylori* (which seem to change constantly) and the use of injections of botulinum toxin to treat achalasia (whose long-term value now looks questionable). It is also unfortunate that the authors do not give their strategies of searching the literature, so as to reassure the reader that a balanced view is being presented (although for

the most part the chapters do seem appropriately based on evidence).

Who should purchase the book? Despite shortcomings, it contains some truly valuable messages for practicing clinicians. However, the selection of topics (14 in all) is arbitrary and far from comprehensive. Problems such as the management of unexplained chronic abdominal pain, chronic constipation, fecal incontinence, and portal hypertensive gastropathy — to name just a few difficult areas of practice — are not discussed. On the other hand, a few topics, such as nutritional support as the primary therapy for Crohn's disease, are arguably of lesser interest and could have been omitted. Moreover, there is not quite enough detail for fellows in training, and like all books, this one is not current enough for practitioners, who will still have to conduct appropriate literature searches. I enjoyed the book's approach, but in its current form the appeal to gastroenterologists and hepatologists will be limited.

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EVOLVING CONCEPTS IN GASTROINTESTINAL MOTILITY

By Malcolm C. Champion and William C. Orr. 344 pp. Cambridge, Mass., Blackwell Science, 1996. $85. ISBN 0-86542-944-8.

THIS monograph covers motility in the gastrointestinal tract, from the esophagus to the anus. The authors are among the most active clinical investigators in the field. Each chapter has 50 to 145 references, and some of the clinically oriented chapters contain useful flow diagrams concerning management and treatment. Exception may be taken to some of the steps suggested, but they provide a useful starting point with which to approach common clinical problems.

The chapter entitled "Treatment of Gastroparesis" provides a summary discussion of the prokinetic drugs used to treat motility disorders. This discussion, however, includes many drugs that are not available to physicians practicing in the United States. Many of them, like domperidone, may never reach the American market. Nevertheless, these agents receive almost as much attention here as drugs now available.

Although the title of the monograph is *Evolving Concepts in Gastrointestinal Motility*, only the chapter entitled "Visceral Sensation and Perception in Functional Bowel Disorders" really lives up to that name. Much of the remainder of the book might more appropriately be called "Contemporary Approaches to Gastrointestinal Motility Disorders."

I had difficulty identifying the intended audience of the monograph. Some explanations are so simple and basic as to be appropriate for an introductory college physiology textbook. In other places, however, readers will find it difficult to follow the discussions if they are not familiar with the literature cited.

Several topics should have been included in a book that attempts to reflect recent advances in gastrointestinal motility. There is no mention of the interstitial cells of Cajal. Recent studies have established that these cells are the pacemakers governing the motility of the intestine and the colon. It would seem that if we are to understand dysfunction of alimentary tract motility, this cellular network must be recognized and studied. Second, although intraluminal manometry has been the method most widely used to study gastrointestinal motility for the past 40 years, it does not directly measure muscle activity. This point is made in relation to visceral sensation and perception, but it is not mentioned in the discussion of the limitations of clinical measurements of motility. Third, there are problems with motility that are encountered more frequently and that use many more medical resources than chronic idiopathic intestinal pseudo-obstruction. In recent years evaluation and treatment of dysfunction of the sphincter of Oddi have increased enormously. As with other obscure gastrointestinal syndromes presumed to result from disordered motility, treatment has been aimed at the recorded disturbance of motility without attending sufficiently to whether the symptoms are affected by sphincterotomy. Ogilvie's syndrome (massive idiopathic dilatation of the colon) is seen with increasing frequency as the population ages and more people spend the end of their lives in nursing homes. The pathogenesis of this disorder is not understood, and there is little or no agreement on the most effective approach to the care of patients with the syndrome.

This survey of current clinical research and practice relating to gastrointestinal motility has a large and up-to-date bibliography. The clinical flow diagrams should help the generalist develop cost-effective approaches to these motility problems.

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BOOKS RECEIVED

The receipt of these books is acknowledged, and this listing must be regarded as sufficient return for the courtesy of the sender. Books that appear to be of particular interest will be reviewed as space permits. The Journal *does not publish unsolicited reviews.*

HEALTH POLICY

Bioethics: An introduction to the history, methods, and practice. (Jones and Bartlett Series in Philosophy.) Edited by Nancy S. Jecker, Albert R. Jonsen, and Robert A. Pearlman. 416 pp. Boston, Jones & Bartlett, 1997. $31.25. ISBN 0-7637-0228-5.

Capitation in California: A study of physician organizations managing risk. By Maurice J. Penner. 281 pp. Chicago, Health Administration Press, 1997. $36. ISBN 1-56793-051-4.

Do We Still Need Doctors? By John D. Lantos. Approximately 206 pp. New York, Routledge, 1997. $24.95. ISBN 0-415-91852-9.

Economic Evaluation of Epilepsy Management. Edited by Christoph Pachlatko and Roy G. Beran. 112 pp. London, John Libbey, 1996. $37. ISBN 0-86196-556-6.

The Five Stages of Managed Care: Strategies for providers, HMOs, and suppliers. (Management Series.) By Russell C. Coile, Jr. 253 pp. Chicago, Health Administration Press, 1997. $36. ISBN 1-56793-050-6.