

Book Reviews

Privacy and Health Care

James M. Humber and Robert F. Almeder, eds.

Humana Press, Totowa, NJ, 2001, 190 pp., \$49.50 (hardcover)

THIS COLLECTION OF ESSAYS IS VERY timely, given current discussions of the federal Final Rule on "Standards for Privacy of Individually Identifiable Health Information," scheduled to be implemented by April 2003. Because the Catholic Health Association and its members have expressed concern about various aspects of these regulations, a

volume devoted to the ethical and legal aspects of medical privacy is welcome.

The collected essays are revisions of presentations made at a conference held in November 1999. Completed in early 2000, the essays refer to proposed federal regulations that were later substantially revised. For example, the Final Rule applies to personal medical records in all forms, although the proposed regulations applied only to electronic records. The Final Rule requires patient consent for routine disclosures of health records, although the earlier version allowed disclosure without consent for purposes of treatment, payment and "health care

operations." The comments of the contributors to this volume may have influenced such changes, many of which were made in response to public comments. However, it is unfortunate that the changes were not noted in the various essays where pertinent, at least in footnotes.

The book does include an updated postscript provided by one of the editors. It presents not only a concise summary of the Final Rule but also an interpretive commentary. If readers are not to be misled by now-obsolete statements in some of the other essays, they must compare them with this postscript.

The essays themselves cover a wide range of topics related to medical privacy. Charity Scott's essay, "Is Too Much Privacy Bad for Your Health?" is a superb overview of the law and ethics of medical privacy. It is clear, balanced, and accurate (bearing in mind that Scott was working with the proposed rather than final federal privacy rules).

David Korn's discussion of medical privacy in relation to research is also an outstanding contribution. Presumably speaking on behalf of his organization, the Association of American Medical Colleges, he points out the pitfalls of *too much* privacy protection, including the possibility that such protection could hamper research. Korn takes strong advocacy positions that could be debated. For example, after tracing historically how medical research has relied on patient archives, both records and stored tissue samples, he argues that because we have all been beneficiaries of this research, we are obligated to make a similar contribution of our personal medical information for future research. Here he invokes the ethical principle of justice.

The most deeply philosophic contribution is Patrick Boleyn-Fitzgerald's argument that the ethical principle of equality, rather than the principle of autonomy, is the basis for protecting medical privacy. Although Boleyn-

BOOK BRIEFS

Giving a Voice to Sorrow: Personal Responses to Death and Mourning

Steve Zeitlin and Ilana Harlow, *The Berkley Publishing Group, NY, 224 pp., \$13.95 (paperback), 2001*

There are no rules for mourning. There is no time frame for grieving. At this intensely personal, deeply emotional time, each of us must find our own path to enduring loss. An intimate grief support group in book form, *Giving a Voice to Sorrow* is an exploration of unique ways many courageous individuals shaped and enacted grief through storytelling, personal ritual, and memorials. The authors provide an inspiring look at the creative and personal ways individuals and communities confront their own deaths and come together to celebrate the lives and memories of those they have lost—and find a balance between remembrance and letting go.

Who Will Pay for Long Term Care? Insights from the Partnership Programs

Nelda McCall, editor, *Health Administration Press, Chicago, 333 pp., \$49.00 (paperback) 2001*

As the baby-boomer generation ages, the United States must address the looming problem of how to finance long-term care. This book details the Partnership for Long Term Care, a project funded by the Robert Wood Johnson Foundation. The Partnership finds funding for long-term care by coordinating efforts between private insurance companies and the Medicaid program. The book offers insights on topics such as the politics of health care financing, the workings of the insurance market, the process of state health financing reform, the role of philanthropy in encouraging innovation in the health care field, and the important role of actuarial analysis in designing insurance systems.

Fitzgerald offers interesting examples to bolster his case, his line of argument is unconvincing. For example, he notes that the autonomy of employers or insurers seeking a patient's medical information is in ethical conflict with the autonomy of the patient who wants to keep it private. Because the principle of autonomy seems to support both claims, he argues that autonomy cannot be the justification for protecting patient privacy. But surely my autonomy with regard to controlling my own medical information has a different moral status from that of a person or organization wishing to have access to my information, for whatever purpose.

In actuality, Boleyn-Fitzgerald's defense of equality as the basic ethical principle is really a defense based on nonmaleficence (do not harm). For he concludes: "Respecting privacy contributes to a safe space for patients. A patient need not worry that seeing a doctor *will result in harm* to their personal relationships, a loss of insurance, or denial of a career opportunity" (p. 65, emphasis added).

Both Korn's and Boleyn-Fitzgerald's essays raise questions that need to be responded to. The volume as a whole would be stronger if the various authors had engaged each other's ideas more directly. While Korn advocates placing fewer restrictions on the use of medical data, and Bill Allen and Ray Moseley propose more restrictions, Korn's discussion focuses on the context of medical research, whereas Allen and Moseley are concerned about the privacy of genetic tests in relation to health insurance. Hence these two essays do not really engage each other.

Similarly, authors take positions on such debatable topics as whether genetic information should be protected more stringently than other medical information, and what should be the relationship between federal and state privacy laws (i.e., whether federal laws should

preempt state laws). But the debate on these topics is not really engaged by the authors, and their arguments seem to miss each other.

No one except the editor, in his postscript, addresses the interesting issue of the penalties for violation of laws and regulations on medical privacy. From the perspective of a health care organization, the penalties imposed may seem very onerous. Yet as the editor notes, they are not nearly severe enough to deter truly malicious or criminal invasions of medical records by hackers, for example. This aspect of the federal regulations has been overlooked by most commentators, including the other authors in this book.

The volume has several helpful fea-

tures to assist the reader. Each essay is preceded by a carefully written abstract of the essay. Thus the reader can use the abstracts to decide which essays to read in their entirety. The index is detailed and helpful. The postscript on the Final Rule, added in view of significant changes that were made to the proposed regulations, is crucial to understanding the current state of affairs in federal privacy regulation, as well as to understanding the other essays in the book.

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The Health Care Professional and Healer: Building on the Work of Edmund D. Pellegrino

David C. Thomasma and Judith Lee Kissell,
eds.

Georgetown University Press, Washington, DC,
2000, 320 pp., \$65 (hardcover), \$24.95 (paper-
back)

HAVING REACHED THE ENVIABLE AGE OF fourscore years, Edmund D. Pellegrino, MD, might have relegated himself to his dusty shelves of trophies and accolades and enjoyed his just rewards. Instead, this titan of medical, philosophic, and ethical thinking has continued his campaign against the contemporary tendency (misguided in his view) to turn the traditional physician into a positivistic technocrat—*sans* empathy, compassion and humanity.

David Thomasma, MD, and Judith Kissell, PhD, editors of the book under review here, have undertaken to build on Dr. Pellegrino's tenets and principles. They note in the preface that contributors were invited to consider the wide-ranging field of Dr. Pellegrino's interests and to describe the way his ideas have

influenced their own thinking. The editors seemingly searched the capacious mysteries of Mount Etna and, from the 100 hands of the mythological Enceladus buried beneath it, chose 22 candidates from a variety of disciplines and asked them to expound on the myriad expressions, themes, and publications of this prolific academician.

Let me emphatically state that this book is not a Festschrift in his honor. Nor is it an eclat or an assemblage panegyric. Indeed, the book is none of these, but rather a recognition of Dr. Pellegrino's prominence in health care as a role model, friend, and healer. Still, in spite of the honorific disinclination, the contributor listing is a subtly encomiastic tribute in itself.

My own background—first as a pediatrician for 38 years serving the tiny and helpless and, more recently, as a clinical bioethicist—gives me a certain perspective in these matters. I have witnessed the extraordinary transformation of the clas-

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