

Book Reviews

When Others Must Choose: Deciding for Patients without Capacity

New York State Task Force on Life and the Law

Health Education Services, Albany, NY, 1992, 288 pp., \$11

IN 1985 THE NEW YORK STATE TASK Force on Life and the Law convened with the goal of enhancing public understanding on a host of social, legal, and ethical issues raised by medical advances, and, when appropriate, recommending regulations and legislation. In March 1992 the task force released its eighth report, *When Others Must Choose: Deciding for Patients without Capacity*, which examines decision making for patients who lack decision-making capacity and who have not signed advanced directives for healthcare decisions. The task force's discussion builds on two of its prior reports: *Do Not Resuscitate Orders* (1986) and *Life-sustaining Treatment: Making Decisions and Appointing a Health Care Agent* (1987).

The explicit goal of the latest report, like all previous ones, is to inform and focus public debate in New York State. The task force acknowledges, however, that the report's scope and interest goes far beyond the state's borders. Anyone interested in learning about surrogate decision making will find *When Others Must Choose* useful. Clearly written and well organized, the report touches on the social, legal, and ethical components associated with such decisions. It is also encyclopedic in detail, citing most major works addressing the issue, as well as every major court case that has informed recent law. As an introduction to the complexities associated with surrogate decisions, I recommend it.

However, an important caveat is called for. Although this report covers

much ground, it is not without limits. Its discussion of the issues and the outline of policy recommendations provided are clearly couched in the language of autonomy, beneficence, and justice as these theoretical principles are commonly understood by the applied ethics community (e.g., Beauchamp and Childress, Veatch¹). But this kind of theoretical approach to the ethics of healthcare is problematic.² Its difficulties are thus equally present in the task force's report and may be best appreciated by turning to the text itself.

Part I presents three contextual considerations associated with surrogate decision making: social, legal, and ethical issues.

Social considerations are addressed in the first chapter, where the task force examines the various medical and social settings in which surrogate decision making may occur and the influences of these settings on decisions. Discussion centers on the influences brought about by differences among kinds of healthcare facilities—hospitals, nursing homes, hospices—and those among facilities of the same kind, such as location (rural versus urban), size (number of beds), patient population, affiliation (religious versus secular), and community standing (private versus public).

The second chapter, devoted to legal considerations, begins with a brief outline of the different kinds of decisions surrogates may face. The chapter then reviews existing common laws, statutes, and regulations that govern these kinds of decisions. Although the emphasis is on New York law, an extensive overview of federal law is also presented. Beginning with a brief discourse on the 1914 case that provided the legal foundation for the right of self-determination, the task force covers all the major legal cases through the Supreme Court's 1990 Cruzan decision.

In chapter three the task force's particular slant on ethics is most clearly evident in the three questions posed at the beginning: Who should speak for

patients lacking capacity and without advance directives? What standards should guide surrogate decisions? And what should be the boundaries of surrogate authority? Here, the task force explicitly presents the principles of autonomy, beneficence, and justice and their standard philosophical interpretations. How to answer these three questions is then sketched against this background of principles.

In part II the task force presents 14 recommendations for the construction of an adequate public policy governing surrogate decisions. The recommendations range from purely procedural concerns (how to select a surrogate) to overtly substantive considerations (the obligations of attending physicians), although most recommendations combine both procedural and substantive points. Each recommendation is preceded by a brief summary of the issue it is meant to address, as well as a justification for the recommendation.

The discussions preceding the recommendations concerning surrogate decisions for minor children and for adults without surrogates are given extensive treatment in light of the unique characteristics of these two groups. Historically, both groups have been recognized as different from other kinds of patients. In the case of children, this is because of special legal and moral status given to the parent-child bond. In its recommendations, the task force attempts to take this special status into account. Adults who lack both decisional capacity and a surrogate, on the other hand, amplify all the difficulties associated with deciding for others: Little guidance is available for deciding what *should* be done beyond the purely medical considerations, which in themselves only reveal what *can* be done.³ Because decision making associated with children and adults without surrogates is complex, the task force recommends the establishment of institutional bioethics review boards, which are discussed in part II.

BOOK BRIEFS

Religion and Prevention in Mental Health: Research, Vision, and Action

Kenneth I. Pargament, Kenneth I. Maton, and Robert E. Hess, eds., Haworth Press, Binghamton, NY, 1993, 333 pp., \$54.95 (hard cover), \$43.95 (paperback)

Through conceptual, empirical, and practical examples, the authors demonstrate that religion is a valuable resource for preventive action. They focus on the framework for living that religions provide, which helps believers anticipate, avoid, or modify problems before they develop. For human service professionals willing to build a collaborative relationship with religious systems, the book depicts the richness and diversity of religion and shows the interface of religion, well-being, and prevention.

Leadership for the Common Good: Tackling Public Problems in a Shared-Power World

John M. Bryson and Barbara C. Crosby, Jossey-Bass, San Francisco, 1992, 436 pp., \$32.95

No one institution or individual has the authority to act on public issues

and make substantial headway against the problems that threaten us all. If we are to survive and prosper, we must find ways to think and act more effectively in shared-power contexts. The authors describe how leaders can plan and manage each phase of policy change, from identifying public problems and exploring solutions to developing specific proposals and implementing new plans. They include practical information, negotiation techniques, and networking strategies to help leaders inspire and mobilize collective action.

BOOKS RECEIVED

Befriending: A Self-Guided Retreat for Busy People, Joseph A. Payne, Paulist Press, Mahwah, NJ, 1992

The Facts about Drug Use: Coping with Drugs and Alcohol in Your Family, at Work, in Your Community, Barry Stimmel, Haworth Medical Press, Binghamton, NY, 1993

From Chocolate to Morphine: Everything You Need to Know about Mind-altering Drugs, Andrew

Weil and Winifred Rosen, Houghton Mifflin, New York City, 1993

If Only You Recognized God's Gift: John's Gospel as an Illustration of Theological Reflection, Robert L. Kinast, Wm. B. Eerdmans, Grand Rapids, MI, 1993

Managed Care in Medicaid: Lessons for Policy and Program Design, Robert E. Hurley, Deborah A. Freund, and John E. Paul, Health Administration Press, Ann Arbor, MI, 1993

A Medical and Spiritual Guide to Living with Cancer: A Complete Handbook for Patients and Their Families, William A. Fintel and Gerald R. McDermott, Word Publishing, Dallas, 1993

The Self-Help Sourcebook: Finding and Forming Mutual Aid Self-Help Groups, 4th ed., Barbara J. White and Edward J. Madara, eds., American Self-Help Clearinghouse, Denville, NJ, 1992

A Swing-Bed Planning Guide for Rural Hospitals, rev. 1993 ed., Sarah A. Grim, ed., American Hospital Publishing, Chicago, 1993

Finally, the task force discusses four issues central to decisions to forgo life-sustaining treatment: withholding and withdrawal of treatment, the moral significance of intentions, artificial nutrition and hydration, and euthanasia. Clarification of these issues helps further define healthcare providers' obligations and the parameters of surrogate authority.

Briefly, the task force recommends that if and when an attending physician, along with another healthcare professional, determines that an adult patient

lacks the capacity to make healthcare decisions and has no advance directive, a surrogate decision maker should be appointed. The surrogate is to be chosen in accordance with a prioritized list developed by the task force. Family members or other individuals closely associated with a patient are thought to be the best surrogates.

Surrogates are to be given the same decision-making authority as competent patients. Surrogates should base decisions on patients' own preferences when

these are known ("substituted judgment"). If patients' preferences are unknown, decisions should be based on what is in their best interests ("best-interest standard"). Surrogates may decide to forgo life-sustaining treatment as long as the treatment would be an "excessive burden" (as defined by the task force) to the patient and at least one of the following circumstances is present: The patient's condition is terminal, the patient is permanently unconscious, the attending physician and bioethics

review committee approve the decision, or judicial approval is given.

Parents or guardians are the legally recognized surrogates for minor children. The same standards set out for adult patients apply here as well. However, if a minor child has decision-making capacity, his or her consent is required for the decision to forgo life-sustaining treatment.

For adults without surrogates or advance directives, attending physicians should be allowed to make routine medical decisions. Decisions about major medical interventions should require the concurrence of a second physician. Decisions to forgo life-sustaining treatments should further require approval from the bioethics review committee.

Part II ends with a minority report by task force member J. David Bleich. Bleich suggests that preserving patient autonomy at the expense of the preservation of life may be justified when patients have the capacity to decide about their own treatment. But in the case of surrogates deciding whether to withhold or withdraw life-sustaining treatments, he contends this is an unacceptable devaluing of the sanctity of life. Surrogate decisions, he maintains, must be predicated on the assumption that the desired goal in light of which decisions are being made is cure or, de minimis, maximum prolongation of life. Bleich concludes that without patients' own fully informed consent, the decision to withhold or withdraw treatment is paramount to the decision to die, and he maintains that "the decision to die is far too awesome a matter to be delegated" to another.

Bleich's minority report may disagree with the task force's conclusions, but it clearly shares the task force's acceptance of autonomy as a central moral feature of clinical medical situations. But clinical encounters must be understood as involving complex webs of institutional and social relationships.⁴ Hence, even the suggestion that autonomy can function as a regulative ideal is problematic.

Implicit in the task force's presentation in the first chapter appears to be a similar recognition that regulation must account for the multiplicity of relationships as revealed through the diversity of social, legal, and ethical considerations. Yet, in the remainder of the report (including Bleich's minority view), the concept of autonomy serves as the paradigm against which surrogate decisions are to be compared, as if the contextual considerations discussed in chapter one are irrelevant.

In practice, the very idea of autonomous individuals—individuals separated from the influence of others—runs counter to daily experiences. In *Nicomachean Ethics* Aristotle noted that humans are social beings. Accordingly, the decisions facing individuals are already couched within broader social frameworks. Until the interrelationship between individual and community is more fully appreciated, both theoretically and practically, the kinds of recommendations presented in *When Others Must Choose* and in Bleich's response will fail to account for the moral dynamics of surrogate decision making.

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NOTES

1. Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 3d ed., Oxford University Press, New York City, 1989; Robert M. Veatch, *A Theory of Medical Ethics*, Basic Books, New York City, 1981.
2. Edmund D. Pellegrino and David C. Thomasma, *A Philosophical Basis of Medical Practice*, Oxford University Press, New York City, 1981; Albert R. Jonsen and Stephen Toulmin, *The Abuse of Casuistry*, University of California Press, Berkeley, 1988; Richard M. Zaner, *Ethics and the Clinical Encounter*, Prentice Hall, Englewood Cliffs, NJ, 1988.
3. Pellegrino and Thomasma.
4. Zaner.

Coming in the
Next Issue of
**Health
Progress**

**REPORT OF THE 78TH ANNUAL
CATHOLIC HEALTH ASSEMBLY**

A recap of this June meeting in New Orleans will include a look at the operational challenges and opportunities of healthcare reform. Harvard University theologian and ethicist Rev. J. Bryan Hehir will identify the ministry's role in advocating healthcare reform. Mercy Health Services President Judith C. Pelham will review the link between Catholic mission and values and the IDN concept. Princeton University economics professor Uwe E. Reinhardt will review the Clinton administration's proposal and the current reform debate. And representatives from the Clinton administration and Capitol Hill will discuss the state of the policy process. Other presentations will cover key factors for physician, policy, financial, and management integration.

ISSUES RELATED TO REFORM

Thomas P. Weil will describe what we can learn from Canada's and Germany's healthcare systems. Other articles will cover how conscience clauses can protect healthcare providers and how a system's board of directors links mission with social accountability.