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Review of Families and the Gravely Ill: Roles, Rules, and Rights

Vanessa Merton

Elisabeth Haub School of Law at Pace University

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Reviews, Notes, and Listings

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General Internal Medicine

Families and the Gravely Ill: Roles, Rules, and Rights

By Richard Sherlock and C. Mary Dingus. 180 pages. Number 23 of *Contributions in Medical Studies*. Greenwood Press, Westport, Connecticut, 1988. \$37.95.

Who should decide when the patient cannot? This question may not arise frequently, but when it does, as it did for the physicians of Karen Ann Quinlan, Baby Jane Doe, and Joseph Saikewicz, it presents one of the more intractable problems of professional ethics. "The family" is an answer with certain appeal, but it raises further questions. Who counts as the family? What happens when family members disagree? What if the family wants treatment or nontreatment that is different from what the physician thinks is required? The authors of this book, a philosopher and a clinical psychologist, have produced a compact yet thorough analysis of every aspect of the role of the family in making health care decisions for incompetent patients.

By its own terms, the book is intended primarily as a review of the empirical data and theoretical literature available. It tries to clarify the debate, not win it, and it achieves that goal by listing the moral and practical arguments that could be used to limit or aggrandize the role of the family in such situations. Ultimately the authors suggest that participation of an incompetent patient's family is necessary, but not sufficient, for sound clinical decisions. Following the lead of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, they endorse the evolving institution of hospital ethics committees as an alternative.

Much of the book is an updated summary of material in the reports of the President's Commission, particularly *Making Health Care Decisions*. What is distinctive is its logical delineation of all the options for a physician whose incompetent patient faces a critical choice. By largely avoiding the preliminary issue of when and by whom a patient may be deemed incompetent, the authors present a complete account of the advantages and disadvantages of using various surrogate decision makers—the courts; physicians themselves; institutional ethics committees; and patients' families—once it is established that someone other than the patient must decide. The authors look thoughtfully at the pros and cons of each. For example, in discussing the out-of-favor notion that treatment of the incompetent patient should be determined by the physician, they report the data suggesting that most competent patients would prefer their physicians

to make treatment decisions rather than decide for themselves. They then note the significant differences between the patients surveyed and most incompetent patients.

The question of "who is the family?" has become more salient in this era of gay rights and the acquired immunodeficiency syndrome (AIDS). This book suggests a psychosocial definition of family that includes life partners and close friends. Obviously, blood relatives or persons related by marriage are not the only ones who can provide support and care for the patient or valid information about the patient's values and preferences, two of the important justifications for turning to the family. As the authors put it, a family is defined as much by its shared commitments as by its shared genetic pool. However, they fail to fully address the problems of line-drawing and authenticity posed by this less legalistic, more realistic definition. They seem to assume that health care professionals can readily identify persons who would qualify.

The section that discusses the development of competing philosophical theories for the mutual obligations of family members might have been omitted, at least for the average practitioner, but the rest of the text is straightforward and readable. To illustrate principles, it uses abbreviated case histories that should be familiar to clinicians, although such vignettes are always subject to criticism for their lack of texture and depth. The book admirably collates and integrates data on family participation in medical decision making, including some provocative studies that indicate that not only the subjective values but the objective circumstances of family members have a major impact on the substance of their decisions, for example, the different choices made by women who work outside the home and women who work in the home when deciding whether to aggressively treat an impaired neonate.

The authors distinguish the family's role in making decisions for formerly-competent adults from its preeminence in the health care of children, but emphasize the limitations on family power, because children's ability to exercise the competence they will presumably develop in the future must be preserved. The section on the special situation of the almost competent adolescent omits reference to Morrissey, Hoffmann, and Thrope's *Consent and Confidentiality in the Health Care of Children and Adolescents*, but in general the bibliographies are reasonably complete.

I must commend the measured treatment of the law of surrogate decision making. Without allowing doctrinal analysis to take over the discussion, the authors convey a good sense of the current state of the law, with appropriate focus on its variability from state to state. (The book includes a useful appendix of relevant case law and state statutes.) The authors recognize the necessarily limited use of legal rules, as compared with policy arguments, when courts are forced to decide these fact-specific cases, and the impracticality of relying on judicial intervention as these cases proliferate. In most instances, the course of treatment will ultimately be determined by the clinician's judgment of whom—colleagues, committees, family, friends, or self—to listen to. *Families and the Gravely Ill* lays out a conceptual framework that will not only improve the quality of the policy debate but can assist the clinician in responding to a concrete case. (Vanessa Merton, JD, CUNY Law School, Flushing, NY 11367)