

Trends in Health Care Decisionmaking

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SYMPOSIUM

TRENDS IN HEALTH CARE DECISIONMAKING INTRODUCTION

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"Every life is different from any that has gone before it," writes Dr. Sherwin Nuland in his recent account of the dying process, "and so is every death. The uniqueness of each of us extends even to the way we die."¹ Can law accommodate itself to that uniqueness? Can the legal system safeguard the range of individual choices about dying?

Maryland is a test case of sorts. It has moved from a legal framework that had large gaps and needless restrictions to one that is avowedly comprehensive and supportive of individual choice. The contributors to this Symposium place the Maryland developments in context, suggest the strengths and potential weaknesses of the new Maryland law, and give policy-makers elsewhere in the country much to think about as they consider how their laws ought to be changed to reflect the changed world at the bed-side.

Certainly, Maryland law before 1988 was wholly inadequate to the task. In 1988, near the beginning of a long opinion that sought to clarify the law at the time, the Attorney General of Maryland observed that decisions about life-sustaining medical treatment were being

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1. SHERWIN B. NULAND, *HOW WE DIE* 1 (1994).

made "against a background of legal confusion."² Attorney General J. Joseph Curran, Jr. went on to identify the main areas of confusion:

Some believe that the Living Will Law prohibits the withholding or cessation of artificially administered sustenance under any circumstances. Others question whether a medical durable power of attorney is a proper means to state a person's desire to forgo artificially administered sustenance. On the question of surrogate decisionmaking, the uncertainty is even worse.³

The absence of clear ground rules encouraged the wrong people to make the decisions—hospital risk managers instead of doctors, doctors instead of patients, judges instead of family members. Those who decided had insufficient legal guidance when they sought to identify the proper decisional standards. And uncertainty about who had decisional authority, coupled with health care providers' pervasive nervousness about liability, led to overtreatment.

The 1988 Attorney General's opinion answered a number of questions by weaving together strands of constitutional and common law reasoning and statutory construction. The opinion, by validating the use of the durable power of attorney as an instrument of health care planning and by strongly affirming the right to refuse artificially supplied nutrition and hydration, sought to expand the range of individual choice beyond the severe limitations of the then-Living Will Law. Almost everyone found something to disagree with in the opinion; nevertheless, for the most part, health care practitioners and lawyers accepted the opinion as an acceptable way-station toward legislation that would codify sound practice.

Nobody, least of all the Attorney General, thought that the opinion was a *substitute* for legislation. If an opinion of the Attorney General is soundly reasoned, then it makes good predictions about how the courts would resolve issues under current law. But an opinion cannot create law. So, for example, the 1988 Attorney General's opinion found only a narrowly circumscribed role for family members in declining life-sustaining procedures for an incapacitated patient, and the opinion had to stretch to do that much.⁴

Of course, the Maryland Court of Appeals can make law if it wishes to, but only within the confines of the cases that happen to reach it. In *Mack v. Mack*,⁵ the Court described a framework for

2. 73 Op. Att'y Gen. 162, 169 (1988).

3. *Id.*

4. *Id.* at 196-201.

5. 329 Md. 188, 618 A.2d 744 (1993).

health care decisionmaking largely paralleling that foreshadowed in the 1988 Attorney General's opinion. Keeping to its proper role, however, the Court in *Mack* actually determined no more than was necessary to resolve the narrow case before it—that of a patient in a persistent vegetative state, under guardianship, where close family members disagreed over whether the patient would want a feeding tube maintained. Like courts elsewhere in cases of this kind, the Court of Appeals avoided policy pronouncements that it thought were best left to the legislature.⁶

In short, the known inadequacies and the several uncertainties of Maryland law could only be addressed by comprehensive legislation. Thus began a several-year process that combined an intensive focus on the issues and, ultimately, an equally intensive lobbying effort to gain passage of what became the Health Care Decisions Act of 1993.

The Act is Maryland's new set of ground rules, a thoughtful and progressive effort to ensure that the right people, applying the right standards, make health care decisions. The Act has five main goals:

- To foster patient control over health care choices by providing flexible tools for advanced planning;
- To keep health care decisionmaking on behalf of incapacitated patients in the clinical setting and out of court, by broadening the power of surrogates, subject to defined limits and patient-oriented decisional standards;
- To protect incapacitated patients against wrongful decisions to forgo life-sustaining procedures;
- To reaffirm the independence of physicians within a properly circumscribed sphere of professional expertise;
- To give guidance to judges in deciding the cases about life-sustaining procedures that inevitably will still come to court.

Professor Sandra Johnson's historical essay⁷ places in perspective these developments in Maryland law. The 1988 Attorney General's opinion and *Mack v. Mack* were surely part of what Professor Johnson calls the "principalism" phase in the evolution of bioethics, a phase dominated by court decisions that sought to identify and apply the legal principles undergirding individual patient rights. The enactment of the Health Care Decisions Act reflects what Professor Johnson identifies as a new phase in which legislation emerges as a result

6. See David Orentlicher, *The Limitations of Legislation*, 53 MD. L. REV. 1255, 1257 & n.8 (1994) (citing cases).

7. Sandra H. Johnson, *The Changing Nature of the Bioethics Movement*, 53 MD. L. REV. 1051 (1994).

of an increase in public debate, political compromise, and direct democracy.⁸

Professor Johnson predicts that the next phase in the evolution of bioethics will involve the submerging of autonomy-based decisional principles in favor of the imperatives of "communitarianism" and rationing. For one who has worked to establish a firm base in Maryland law for individual choice, however, this transformation of bioethical thought, if indeed it does occur, will not be a welcome one.

In her richly detailed account of the background to the Health Care Decisions Act,⁹ Professor Diane Hoffmann describes the intellectual debate and ultimate political compromise that resulted in the Act's passage. Her description of the Act's main provisions underscores the magnitude of the achievement in attaining enactment of so comprehensive and advanced a law. And as a principal architect of both the substance of the Act and the coalition politics that was crucial in securing its passage, Professor Hoffmann has a special entitlement to tell the story.

Yet Professor Hoffmann's main thesis has a certain Manichean cast to it: that the forces of darkness, promoting their agenda of governmental heavy-handedness through the device of legal obscurantism, were put to rout on the fields of Annapolis by the forces of light, holding aloft the banner of populism and plain English.

From my perspective, this picture is overdrawn; the similarities between the initially competing bills were far more numerous than the differences, which indeed narrowed even further as the legislative session drew closer. The compromise between the bills that allowed the Act to pass was always within reach. Since it is hard to run double-blind studies of alternative legislative approaches, no one can say for sure what would have happened if either the "coalition bill" or the "committee bill," as Professor Hoffmann dubs them, had been enacted intact. I suspect there would have been less actual impact than Professor Hoffmann's article suggests.

Some of the differences between the two bills reflected honest disagreement over whether a greater amount of detail in the law would ultimately promote the values underlying the coalition bill itself. What two commentators asked about a law professor's theory (in a wholly different context) is an apt set of questions about this or any

8. *Id.* at 1059.

9. Diane E. Hoffmann, *The Maryland Health Care Decisions Act: Achieving the Right Balance?*, 53 MD. L. REV. 1064 (1994). For another perspective on the evolution of the Health Care Decisions Act, see John Carroll Byrnes, *The Health Care Decisions Act of 1993*, 23 U. BALT. L. REV. (forthcoming Feb. 1995).

statute: "Is it shadow or substance? Does it clearly separate what's permitted from what's forbidden? Or does it turn on broad generalities that look fine on the printed page but are too vague for real-life application?"¹⁰

For example, the coalition bill had no definition at all of the key term "best interest." Yet private decisionmakers are helped, not hindered, if the law gives them a common understanding of a concept that all agree is a potential basis for decision. As Dr. Levenson observes in his piece in this Symposium, "Paradoxically, the [Health Care Decisions Act's] greater complexity compared to past laws ultimately facilitates the decisionmaking process and allows greater latitude for both patients and health care providers"¹¹

Professor Hoffmann also criticizes the committee bill for its apparent belief "that legislation should be designed for the 'bad actors' in our society."¹² Indeed so; the job of the Legislature, after all, is to address contingencies: What is the desired outcome if the following problem comes up? There is no harm in ignoring rarities, but if a problem occurs frequently or has grave consequences—like someone's life at stake—it must be addressed. The trick is to do so, as Professor Hoffmann rightly argues, without unduly burdening the vast majority of "good actors." The Health Care Decisions Act, as enacted, achieves this balance.

Dr. Steven Levenson's analysis of the rights and responsibilities of health care providers underscores an important point: The Health Care Decisions Act will fall far short of its promise if health care providers—especially physicians—are ignorant of it, misunderstand it, or are indifferent to it. As Dr. Levenson puts it: "Because physicians still have considerable authority to define reality and to guide treatment selection, they may help or hinder decisionmaking, depending on how they assert their rights and fulfill their responsibilities."¹³

10. Alex Kozinski & Eugene Volokh, *A Penumbra Too Far*, 106 HARV. L. REV. 1639, 1644 (1993).

11. Steven A. Levenson, *Maryland's 1993 Health Care Decisions Act—Implications for Health Care Practitioners*, 53 MD. L. REV. 1131, 1151 (1994).

12. Hoffmann, *supra* note 9, at 1102-03.

13. Levenson, *supra* note 11, at 1133. Awareness of the Act's careful definition of "medically ineffective treatment" is especially important, lest physicians assume broader decisionmaking authority than the law gives them. Indeed, Dr. Levenson himself provides an example that goes beyond the definition. *Id.* at 1145. If a patient will die from a blocked intestine without surgery, but surgery will remove the blockage and prevent death from that immediate cause, the surgery is not "medically ineffective," even if surgery is totally useless in dealing with the condition that caused the blockage in the first place. MD. CODE ANN., HEALTH-GEN. § 5-601(n) (1994). Perhaps the surgery is not what the patient would want, given the poor underlying condition, or perhaps surgery would not be in the

Perhaps the single most important step in implementing the Act is devising effective strategies for educating physicians about it and convincing them that paying attention to it will benefit them and their patients. As Ruth Macklin, a leading bioethicist, recently wrote,

[A]lthough the law can guarantee the moral rights of patients, physicians by and large are uninformed about legal details even when legislation or regulation bears directly on clinical practice. A case in point . . . is the law in New York State regarding DNR orders. Despite the fact that the law has been on the books for several years, many physicians remain woefully ignorant about its provisions.¹⁴

Dr. Levenson's article is a good start on the herculean task of educating physicians about the Health Care Decisions Act.

One of the most significant features of the Health Care Decisions Act is the role that it assigns to family members and others close to the patient as "surrogate decisionmakers."¹⁵ Professor Jacqueline Glover examines both the traditional justifications for a family role in medical decisionmaking and a justification grounded in the "moral authority of the intimate attachment itself."¹⁶

Then, more provocatively, Professor Glover suggests that the family's own interest, as distinct from that of its patient-member, is entitled to separate weight in the calculus of decisionmaking about the patient's health care choices: "Patients have obligations of justice [to their families], and families and health care professionals are not entitled to behave as though they do not."¹⁷ If this means that Grandma is morally (and legally) justified in filling out an advance directive declining life-sustaining procedures because she wants to preserve her estate for her grandchildren's college education, few would disagree. But if it means that a family surrogate, without knowing what Grandma would want and without regard to Grandma's best interest understood in terms of Grandma's life, is morally (or legally) justified

patient's best interest, but those are judgments committed to someone other than the physician.

14. RUTH MACKLIN, ENEMIES OF PATIENTS 235 (1993). One part of Dr. David Orentlicher's contribution to this Symposium is an account of how physicians "generally still consider it their responsibility to make treatment decisions that they believe are in the patient's best interest and that patient preferences should be ignored if they are inconsistent with the physician's view of the patient's best interests." Orentlicher, *supra* note 6, at 1281; see also Hoffmann, *supra* note 9, at 1092.

15. MD. CODE ANN., HEALTH-GEN. § 5-605 (1994).

16. Jacqueline J. Glover, *Should Families Make Health Care Decisions?*, 53 MD. L. REV. 1158, 1163 (1994).

17. *Id.* at 1170.

in rejecting life-sustaining procedures for her because the family decides that her money would be better spent on the grandchildren's education, then Professor Glover is describing a decisionmaking regime incompatible with Maryland law, or that of any other state. Of course, Professor Glover might be writing more as prophet than reporter. The law a decade hence may reflect her sense of family prerogatives, but it does not do so today.

Professor Martha Minow's *Who's the Patient* seeks to place the interests of the family within a process of decisionmaking that continues to respect patient autonomy as a bedrock consideration. "[D]eparture from the individual patient," she writes, "cannot be sustained ethically or conceptually."¹⁸ As is true of many of the most difficult health care choices, the purely legal structure for decisionmaking cannot attempt to resolve the issues that Professor Minow assesses. The law says that a competent patient has the right to make an informed choice about health care alternatives; it does not, and should not, interfere with a broadening of the patient's frame of reference, and that of the patient's health care providers too, so that the factors influencing the patient's choice include the impact on those with whom the patient shares relationships. In fact, the Health Care Decisions Act expressly recognizes that the patient's solicitude for others is a valid consideration in determining what the patient would want done.¹⁹ The patient, Professor Minow points out, is "someone whose autonomy includes affirmed membership in families and social groups."²⁰

The Health Care Decisions Act also does something practical that will greatly benefit families: By expanding the scope of surrogate decisionmaking, most often the Act will keep families from having to endure the emotional and financial burdens of going to court. Judge John Fader's article²¹ explains why that is so, why it is a good thing, and what the decisional standards will be in the cases (mercifully few, we all hope) that still must come to court.

The philosophical essay by Father Kevin Wildes²² nicely complements Professor Hoffmann's account of the at-times difficult gestation of the Health Care Decisions Act, for in Father Wildes's view such legislative endeavors must be bedeviled by the impossibility of any

18. Martha Minow, *Who's the Patient*, 53 MD. L. REV. 1173, 1183 (1994).

19. MD. CODE ANN., HEALTH-GEN. § 5-605(c)(2)(vi) (1994); MD. CODE ANN., EST. & TRUSTS § 13-711(d)(8) (Supp. 1993).

20. Minow, *supra* note 18, at 1192.

21. John F. Fader II, *The Precarious Role of the Courts: Surrogate Health Care Decisionmaking*, 53 MD. L. REV. 1193 (1994).

22. Kevin Wm. Wildes, S.J., *Particularism in Bioethics: Balancing Secular and Religious Concerns*, 53 MD. L. REV. 1220 (1994).

shared moral underpinning for the legislative policy decisions.²³ Support for his point about the impossibility of moral consensus in a secular world may be found in the fact that some of the bitterest arguments over the Health Care Decisions Act took place over the wording of the preamble, the uncodified portion of the Act that sets out lofty principles. Consensus was easier to achieve, as Father Wildes explains, when the participants in the debate were focussed on specific procedural points. "People can bring closure to a moral controversy," he writes, "by negotiation and appeal to procedures. . . . If moral controversies cannot be resolved by a general consensus, participants may decide either to abide by some procedure to reach an answer or to apply external procedures that draw authority from the permission of those involved."²⁴ That focus is how the Maryland General Assembly came to closure on the Health Care Decisions Act.

From Father Wildes's view that secular endeavors like state laws on health care decisionmaking rest on a philosophical foundation of sand, we move to a world of radical simplicity in the new Uniform Health-Care Decisions Act, carefully parsed in Charles Sabatino's article.²⁵ The framers of the Uniform Act evidently viewed the world through a monocular: All is autonomy, spaciouly understood to include even surrogate decisionmaking.²⁶ In fact, the Uniform Law Commissioners were so intent on achieving the apotheosis of autonomy that they seem blind to threats to true autonomy. For example, Mr. Sabatino points out that "[e]xecution requirements such as witnessing are absent" from the Uniform Act's provisions on advanced health-care directives.²⁷ Mr. Sabatino writes that "[p]redictably, some will criticize the [Uniform] Act for dismissing widely used formalities such as witnessing protocols and witness restrictions."²⁸ I am happy to make Mr. Sabatino's prediction come true: An advance directive elicited by coercion or improper influence is hardly a manifestation of autonomy, and even minimal execution requirements are something of a safeguard.

23. Father Wildes's philosophical analysis supports this observation of Professor Hoffmann: "Unfortunately, in a pluralistic society with few universally agreed-upon moral precepts, there is no ethical yardstick by which to measure 'rightness' regarding these issues." Hoffmann, *supra* note 9, at 1129.

24. Wildes, *supra* note 22, at 1235.

25. Charles P. Sabatino, *The New Uniform Health Care Decisions Act: Paving a Health Decisions Superhighway?*, 53 MD. L. REV. 1238 (1994).

26. *Id.* at 1250 (stating that the Uniform Act "places substantial faith in the authority of surrogates as the best way to reinforce patient autonomy").

27. *Id.* at 1239.

28. *Id.* at 1241.

To be sure, there is much in the Uniform Act to be praised: for example, some useful and clear definitions, properly broad advance directives, and a workable (though dangerously boundless in scope) surrogate decisionmaking mechanism to keep cases out of court. State policy analysts considering a substantial overhaul of a law on health care decisions will want to look at the Uniform Act as a source of ideas. However, the Uniform Act's resolute refusal to give any priority to, or even to pay any attention to, risks to vulnerable patients will ensure it a much larger place in the footnotes of law reviews than on the statute books of the states.

Finally, to end the Symposium on a somewhat somber note, Dr. David Orentlicher²⁹ points to a host of what he views as problems that are embodied in, or derive from, a statute like the Health Care Decisions Act. For one thing, he writes, patients and health care providers sometimes erroneously act on an "assumption that certain rights do not exist without an enabling statute," and that "statutes enunciate the full extent of a patient's right."³⁰ So, for example, he points out that an advance directive law that limits the right to refuse life-sustaining procedures to a few specified conditions does not give full scope to the competent patient's constitutional right to refuse treatment no matter what the patient's condition.

In this regard, Dr. Orentlicher might be underestimating the importance of statutes that make effectuation of the constitutional right easy. No case holds that a state is constitutionally required to make procedural formalities minimal or to grant immunity to health care providers. Without a good statute, there could be even more of a gap between constitutional theory and bed-side reality than already exists.

That gap, indeed, is the central theme in Dr. Orentlicher's carefully documented critical essay, which is as persuasive as it is depressing: that statutes like the Maryland Health Care Decisions Act will fall far short of their promise so long as "end-of-life decisions, like other medical decisions, are driven primarily by physician preferences and values, rather than patient preferences and values."³¹

Dr. Orentlicher describes a number of factors that produce this result, including "professional resistance to a loss of authority."³² This resistance is understandable, for, as Ruth Macklin points out, physicians are besieged, their autonomy "under fire because of the perception that they have abused the health care system" by costing it too

29. Orentlicher, *supra* note 6.

30. *Id.* at 1263.

31. *Id.* at 1305.

32. *Id.* at 1294.

much money, their authority "to recommend what they believe is best for their individual patients [superseded by] hospital administrators, risk managers, and bureaucrats at a distance [who] have newfound authority to oversee and constrain physicians' decisions."³³

Dr. Orentlicher presents a number of ameliorative suggestions for this problem—better education of physicians about bioethical issues, more sensible reimbursement schemes, a strengthening of sanctions against physicians for violations of informed consent, and more disclosure by physicians of their own values.³⁴ Let us hope that these can be part of the new system of health care that, for better or worse, is inevitable. For as Dr. Orentlicher concludes pessimistically, "[u]ntil the dominance of physician values is addressed, no end of life statute can ensure that patient wishes will be fulfilled."³⁵

The French historian Albert Sorel once remarked that "there is an eternal dispute between those who imagine the world to suit their policy, and those who correct their policy to suit the world." This Symposium reflects that dispute, as well it should. Surely it is the role of critics, especially critics in the academy, to find shortcomings in a piece of legislation like the Health Care Decisions Act, measured against a world suited to their policies.

In politics, though, the pure achieve nothing. Flawed as it may be, the Health Care Decisions Act represents a remarkable transformation of Maryland policy to suit the complicated world of patients, families, and doctors. As Dr. Orentlicher in particular suggests, the Act by itself might not be enough to effect a comprehensive change in long-held and fiercely defended professional attitudes. Still, it is a brave effort that will, in many cases, achieve something of profound importance: It will spare dying patients and their families needless anguish. Is there any more noble endeavor of the law?

33. MACKLIN, *supra* note 14, at 244.

34. Orentlicher, *supra* note 6, at 1302-04.

35. *Id.* at 1305. One optimistic forecast about changes in the health care system over the next two decades suggests that patients armed with much more information, thanks to quantum leaps in technology, will at last be able to dominate the decisionmaking process: "As the health-care system switches to computers, and information begins to flow freely among doctors, nurses, drug makers and patients, the health-care market will become more transparent. . . . This will encourage more competitive buying not just by insurers and governments but by patients themselves, making doctors and other health care providers more accountable than ever before." Alexandra Wyke, *The Future of Medicine*, THE ECONOMIST, Mar. 19, 1994, at 16.