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How to Make the Massachusetts Patients' Bill of Rights Work

by George J. Annas, J.D., M.P.H.

At one point in Edgar Allan Poe's *Narrative of Arthur Gordon Pym of Nantucket*, Pym, who has stowed away in the hold of a whaling vessel, believes he has been abandoned and that the hold will be his tomb. He expresses sensations of "extreme horror and dismay," and "the most gloomy imaginings, in which the dreadful deaths of thirst, famine, suffocation, and premature interment, crowded in as the prominent disasters to be encountered."

It is probably uncommon for hospitalized patients to feel as gloomy as Pym. Nevertheless, installed in a strange institution, separated from friends and family, forced to wear a degrading costume, confined to bed, and attended to by a variety of strangers who may or may not keep the patient informed of what they are doing, the average patient is intimidated and disoriented. Such an atmosphere encourages dependence and discourages the assertion of individual rights.

The movement for enhanced patients' rights is based on two premises: (1) citizens possess certain rights that are not automatically forfeited by entering into a relationship with a physician or health care facility; and (2) most physicians and health care facilities fail to recognize these rights, fail to provide for their protection or assertion, and limit their exercise without recourse.¹

The primary argument against patients' rights is that patients have "needs" and defining these needs in terms of rights leads to the creation of an unhealthy adversary relationship.² It is not, however, the creation of rights, but the disregard of them, that produces adversaries. When care provider and patient work together in an atmosphere of mutual trust and understanding, the articulation of rights can only enhance their relationship.

Many issues cannot be resolved entirely within the provider-patient rela-

tionship, however. Providers not only have formal relationships with their patients but also have relationships with other providers, health care institutions, and numerous governmental agencies. A provider's relationship with these institutions and individuals is often a very complex one, and providers often find themselves confused and therefore submissive in cases where they do not understand their own rights or those of their patients.

Rights in Health Care

In most instances, both the health care provider and the patient will be better off if the status of the law regarding both patient and provider rights is understood, and the means of change or challenge well delineated.³ I would go even further. An understanding of the law can be as important to the proper care of patients as an understanding of emergency medical procedures or proper drug dosages. But how are rights to be understood, and how does a person know that he or she has a "right" to something perceived as being desirable to some?

There is a formidable literature on rights in the archives of philosophy and jurisprudence. Rather than review it, let me note briefly the thoughts of two relatively recent entrants who have written with great insight. The first is John Rawls. In expounding his *Theory of Justice*,⁴ he imagines that a group of men and women come together to form a social contract. These individuals all have ordinary tastes, talents, ambitions and convictions — but each is temporarily unaware of his own personality and best interests and must agree to the terms of the contract before his awareness of his own identity is restored. The theory postulates that under such circumstances all will agree to two principles: (1) each person shall enjoy the most extensive liberty com-

patible with a like liberty for all; and (2) inequalities in wealth and power should exist only where they work to the benefit of the worst-off members of society. One could develop an entire system of patients' rights that would rest on these premises. Such a document would be strongly pro-patient since this group is currently the one that generally lacks rights and is always the group that will be viewed as "worst-off" in the health care setting.

A second approach is suggested by the writings of Ronald Dworkin in his essays in *Taking Rights Seriously*.⁵ Dworkin notes the great confusion in "rights language" generally created by attributing to it different meanings in different contexts: "In most cases when we say that someone has a right to something, we imply that it would be wrong to interfere with his doing it, or at least that some special grounds are needed for justifying any interference." An example is the "right" to spend one's money the way one pleases. This is, of course, different from saying that the way one spends one's money, e.g., gambling it away, is the "right" thing to do, or that there is nothing "wrong" with it. When we speak of patients' rights, this distinction may be critical to understanding what we're talking about. For example, a woman may have a legal right to have an abortion, but such a decision may still be considered "wrong" by her.

Dworkin argues further that there are some rights that can be said to be fundamental in the sense that the government is bound to recognize and protect them. Such rights, which we often denote as "legal rights," and less frequently as "constitutional rights," are generally spelled out in statutes and court decisions. By respecting such rights, the government guarantees to the weakest members of the society that they will not be trampled on by the

strongest. In Dworkin's words:

The bulk of the law — that part which defines and implements social, economic, and foreign policy — cannot be neutral. It must state, in its greatest part, the majority's view of the common good. The institution of rights is therefore crucial, because it represents the majority's promise to the minorities that their dignity and equality will be respected. When the divisions among the groups are most violent, then this gesture, if law is to work, must be most sincere . . . taking individual rights seriously is the one feature that distinguishes law from ordered brutality.⁶

Without going too far afield, one can apply Dworkin's notion directly to health care and note that rights can form a useful means of guaranteeing to defenseless patients that they will be treated with human dignity and respect. While the health care provider often has the power to deny certain rights almost at will, he or she does this only at the peril of the integrity of the health care system itself.

Previous Patients' Rights Bills

In 1972, the American Hospital Association adopted a twelve-point Patients' Bill of Rights.⁷ Just as we would have doubts about landlords defining rights for tenants; policemen defining rights for suspects; or banks defining rights for debtors; we are reasonably skeptical of hospital administrators defining rights for patients. Thus, it was not surprising when one commentator likened the AHA model to the fox telling the chickens what their rights are. It is vague, incomplete, and provider-oriented.

Only a few states, among them Minnesota, New York, California and Pennsylvania, have adopted patients' bills of rights by statute or regulation. Accordingly, the Massachusetts experience is still unusual enough to have national interest. Moreover, the Massachusetts law is unique in that it contains two sets of rights — one directed at institutions, and the other at physicians. The full-text of the law is printed on page 10.

The Massachusetts Experience

Signed into law on May 23, 1979,⁸ the Massachusetts statute was the result of more than six years of intense legislative activity. The statute is primarily an educational one, designed to tell patients and providers alike what rights patients have under the law.

Some of its provisions will need modification and clarification — and this should be done. The next step must be the addition of a workable enforcement mechanism if the law is to be more than a public relations piece.

Legislative History

Original impetus for the law came from the liberal element of the Massachusetts legislature, most notably Senators Chester Atkins and Jack Backman and Representative Lois Pines. Hearings held in 1973 and 1974 on comprehensive proposals that included enforcement provisions under the state's Consumer Protection Act evidenced significant divisions between consumer, hospital, and physician organizations.

The position of the Massachusetts Hospital Association (MHA) was that they would prefer a bill modeled on the American Hospital Association's Patients' Bill of Rights. The Massachusetts Medical Society (MMS) expressed "deep reservations" about the proposal, and published a statement prepared by their law firm, which argued — exactly contrary to MHA's position — that the major problems with the bill were that "the rights . . . proposed . . . [were] not exhaustive" and that several provisions were "unduly broad and vague . . . the rights as finally adopted [should] be spelled out as clearly and unmistakably as possible."⁹

Lobbying by MMS resulted in the deletion of several provisions of the proposal and the addition of the word "reasonable" in front of almost every operational word in the statute (amendments offered by Senator David Locke). Most commentators, myself included, suggested that the amended version was worse than no statute at all; and no one seemed disappointed when the measure died in the Senate in 1976.

Funeral announcements were, however, premature; the bill continued to re-surface during the next two legislative sessions. Representative John G. King took the lead in shepherding and shaping the final legislation as passed in May 1979. While fundamentally similar to the 1975 proposals, enforcement provisions were gone, and a new provision on breast cancer (added by Senator Carol Amick at the last minute) was added.

Reaction to Passage

Many were surprised when Governor Edward King signed the bill into law. Efforts against it continued in his

office almost up to the moment of signing. Many assumed the addition of the breast cancer amendment would defeat the entire proposal. They were mistaken.

Consumer advocate Connie Williams, who lobbied hard for a bill, commented: "These rights begin to humanize you again; as a patient 'you're treated like a child and you tend to react like a child . . . it's an important first tiny little step."¹⁰ The Director of Boston's Beth Israel Hospital, Dr. Mitchell Rabkin, commented that their hospital's seven year experience with a patient bill of rights indicated that most patient complaints were "justified," that the hospital's "incidence of malpractice actions has, if anything, declined, and that the ratio of praise to blame has improved considerably."¹¹ Both the MHA and MMS have publically expressed the belief that the legislation is "a reasonable adjustment of the interests of all par-

The statute is primarily an educational one, designed to tell patients and providers alike what rights patients have under the law.

ties"¹² and that "the earlier versions were far more stringent, less workable, and imposed a greater restraint on both hospital and physician."¹³ Nevertheless, each organization has chosen one provision on which to concentrate its wrath: MHA has picked the notice provision, and MMS the breast cancer provision.

On June 5, MHA's *Bulletin* was devoted exclusively to the Association's interpretation of the law. While General Counsel Patrick R. Carroll noted that "The act is straightforward and easily understood," he went on to interpret the notice provision in a tortured, anti-patient manner. The provision requires that: "Every patient or resident shall receive written notice of the rights established herein upon admittance into such facility. . . ." To suggest that this language does not require distributing copies of the actual bill of rights as passed by the legislature, but only notice that such a bill of rights exists (somewhere) is not only a strained interpretation, but one that aims at undermining the educational thrust of the legislation by withholding the specific rights from patients. The MHA's comment: "Written notice need not include making available the entire document to the incoming patient, but rather a notice to the effect of its availability in

written form and to the posting."¹⁴ No comment at all is made about the provision requiring "conspicuous" posting of the rights, although it would seem that hospital patients should at least have the same rights of notice that hotel guests have: the bill of rights should be posted on the door of every patient room.

The Medical Society saved all of its indignation for the breast cancer patient's right "to complete information on all alternative treatments which are medically viable." The Society's rhetoric on this question, as set forth by President Grant Rodkey before the Health Care Committee of the Massachusetts legislature on September 24, 1979, can be charitably described as illogical, and uncharitably, as hysterical. He asks, for example, whether doctors have to read "entire libraries of information" to their patients; whether no treatment at all is an "alternative treatment;" and if an 85 percent five-year survival rate denotes a "medically viable" treatment. He thinks the law is mandatory, and that there is a "grave question" about whether patients can knowingly waive their right to this information. He equates informed consent with total recall at a later date, thinks informed consent will add three extra pre-operative days in the hospital for breast cancer patients, and that their hospital bills for consultants "will triple." He makes no suggestion as to how the law could be amended to meet these "objections," but instead calls for its total deletion from the statute.¹⁵

While I agree that the language could have been better drafted, and would not have included it in the bill in the first place, it has at least had the beneficial effect of bringing the views of physicians concerning what it is appropriate to tell cancer patients about alternatives into the open. Informed consent in this area seems to have been the exception rather than the rule. Regulations by the Massachusetts Board of Registration in Medicine might clarify the language for the medical community, but a better course would be to amend the cancer provision to include *all* cancer patients (why just breast cancer?) and use more traditional informed consent language:

For example: "Patients diagnosed as having cancer must be informed of all alternative treatments, including surgical, radiological, chemotherapeutic, and combinations thereof, and the likely risks, survival rates, and problems of recuperation of each."

Cancer is singled out for special

treatment because it is the disease most feared by patients, and the one that physicians have traditionally failed to discuss openly with patients. The provision also underlines the legislature's intention that the cancer patient not be seen as an exception to the general applicability of the doctrine of informed consent.

Regulations

Everyone agrees that to be effective, rights must be clearly understood. Since a number of the specific provisions — such as those on informed consent¹⁶ and refusal to be observed by students "or other facility staff" — have caused problems, it seems appropriate that regulations be promulgated to clarify these provisions. While there is no explicit language in the statute calling for regulations, the Department of Public Health seems the logical organization to write regulations on the provisions applicable to the institutions which the Department licenses, and the Board of Registration in Medicine seems the logical organization to write regulations on those provisions applicable to physicians. Extremely helpful as well would be a central state office to receive, catalog, and respond to specific written and telephoned complaints.

The Patient Rights Advocate

Sick hospitalized patients are generally in no condition to exercise their rights, even if they know what they are. Thus any effective program of patients rights requires some accessible method by which patients can be helped when they want to be to exercise their rights. No effective mechanisms currently exist. A civil lawsuit, for example, comes only after the damage has been done, and is often too costly to pursue. Current "patient representative" programs are usually little more than public relations ploys with job descriptions restricting representatives to non-medical and non-nursing requests made by patients.¹⁷

In order to re-focus patients' concerns on their own health care and permit them to exercise the rights outlined in the new Massachusetts statute, hospitals should adopt a system of patient advocates whose powers are the same as the legal powers of the patient, and who can exercise the patients' rights upon request of the patient. The advocate should be able to exercise at least the following rights on behalf of individual patients and at their direction:

- access to all medical records;
- the ability to call qualified consultants;
- the power to lodge complaints directly with the hospital's director and executive committee;
- immediate access to all chiefs of staff;
- access to all patient support services; and
- the ability to delay discharges.¹⁸

While outside funding and hiring is preferable, experimentation with advocates hired by the institutions themselves deserves a fair trial.

The Massachusetts law is a step forward in the long march to assure that patients are dealt with fairly and equitably. It is an important step, but must be viewed as the beginning of a journey rather than a homecoming. More detailed regulations are required to explicate the statute in parts, and an enforcement mechanism that enables patients to actually exercise their rights in institutional settings is needed.

Like Poe's Arthur Gordon Pym, The Massachusetts Patients' Rights Bill survived days of darkness, isolation, and starvation. It is now law, and it is up to patients and providers alike to see to it that the rights it espouses in theory are made a reality for every patient in the Commonwealth.

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2. E.g., Margolis, *Conceptual Aspects of a Patients' Bill of Rights*, CONNECTICUT MEDICINE SUPPLEMENT 43: 9 (Oct. 1979). Also see Ladd, *Legalism and Medical Ethics* in DAVIS, HOFFMASTER AND SHORTEN, editors, *CONTEMPORARY ISSUES IN BIOMEDICAL ETHICS* (Humana Press, New Jersey, 1978).
3. Examples of patient abuse based on provider misunderstanding of the law after the *Saikewicz* case in Massachusetts are cited in Annas, G.J., *Reconciling Quinlan and Saikewicz: Decision-Making for the Terminally Ill Incompetent*, AMERICAN JOURNAL OF LAW & MEDICINE 4(4): 367, 387 (1979).
4. RAWLS, J., *A THEORY OF JUSTICE* (Harvard University Press, Cambridge, MA, 1971).
5. DWORKIN, R., *TAKING RIGHTS SERIOUSLY* (Harvard University Press, Cambridge, MA, 1977).
6. *Id.* at 205.
7. Reprinted in Annas, note 1 *Supra*, at 25-27.

(continued on page 31)

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8. MASS. GEN. LAW c. 111, § 70E.
9. *Patients' Rights*, MASSACHUSETTS MEDICAL SOCIETY NEWSLETTER (September 1975) at 7-8, reprinted in NEW ENGLAND JOURNAL OF MEDICINE 293: 828 (1975).
10. Knox, R., *A Bill of Rights for Patients*, BOSTON GLOBE, August 20, 1979, at 10.
11. *Id.*
12. Statement of Grant Rodkey to Massachusetts Health Care Committee; reprinted in MASSACHUSETTS MEDICAL SOCIETY NEWSLETTER (October/November 1979) at 4-5.
13. MASSACHUSETTS HOSPITAL ASSOCIATION BULLETIN, no. 15 (June 5, 1979) at 4.
14. *Id.* at 1. This policy was restated at a conference on the law sponsored by the MHA on October 24, 1979.
15. Rodkey, note 12 *supra*. Physicians wondering what to tell patients might consult a two part "Medical Progress" article on *Cancer of the Breast* by Henderson and Canellos in the January 3 and 10, 1980, issues of the NEW ENGLAND JOURNAL OF MEDICINE. Among their conclusions: "The routine use of the classical radical mastectomy or of adjuvant radiotherapy, both standard practices a decade ago, should now be

abandoned . . ." (at 87) and, "It is no longer acceptable for one specialist to treat a patient without early consultation with the other specialties involved. With so many treatments available, the possibilities for cures are real, and there is no justification for a nihilistic approach to the treatment of breast cancer" (at 88).

16. While there has been no Massachusetts case formally recognizing informed consent as a common law basis for a civil action against a physician, in *Belchertown v. Saikewicz*, 370 N. E. 2d 417 (Mass. 1977), the doctrine was described as one with origins in the constitutional right of privacy and self-determination, and a federal judge, applying Massachusetts law, has implicitly accepted the informed consent doctrine. See *Rogers v. Okin*, 478 F. Supp. 1342 (D.C. Mass. 1979).

17. See Annas, G.J., *The Hospital: A Human Rights Wasteland*, 7 CIVIL LIBERTIES REVIEW 1: (Fall 1974).

18. For a detailed discussion of this proposal, see Annas, G.J., and Healey Jr., J.M., *The Patient Rights Advocate: Redefining the Doctor-Patient Relationship in the Hospital Context*, VANDERBILT LAW REVIEW 27: 243 (1974).

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