
Family Practice Forum

Government Regulation of Patients' Rights

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We live in an era in which public concern for human rights is continually being expressed. Organized advocacy, professional and lay, on behalf of individual liberties and entitlements has become a major enterprise. One area in which this rights phenomenon is especially pronounced is in the health care delivery sphere, the largest single service industry in America today. For better or worse, the patients' rights movement has affected in a fundamental way both the perception and the reality of the professional relationship between health care provider and patient.

A number of health care provider organizations have voluntarily adopted statements announcing their commitment to specific patients' rights, such as the 1972 American Hospital Association's "Patient's Bill of Rights." Further, revealing the impressive political skills and power of the pro-consumer lobby, expressions regarding patients' rights are being found with increasing frequency embodied within the formal legal context of government-promulgated statutes and regulations.

Patients' rights laws appear in a variety of forms. On the federal level, laws in this area generally emanate from the role of government as a major purchaser, through the Medicare, Medicaid, and CHAMPUS programs, of health services for eligible beneficiaries. Patients' rights have been passed or proposed as conditions with which providers of nursing home¹ or hospital² services must comply in order to be eligible for financial reimbursement by the government for those services. These conditions may be included in statutes considered by Congress or promulgated as regulations by executive departments. On the state level, most jurisdictions have relied upon their inherent police power to promote the public health, safety, and welfare or their *parens patriae* power to protect

those who cannot or will not fend for themselves. States have enacted³ or are seriously considering⁴ legislation or regulations attempting to ensure patients' rights in hospital, long-term care, and outpatient settings. The main theme found in patients' rights laws, as well as in voluntarily adopted codes, is the notion of individual dignity and autonomy. This ethical underpinning is reflected in specific laws dealing with topics like informed consent, patient privacy, confidentiality, the refusal of treatment, and access to relevant medical information.

There is, however, a substantial problem. Merely announcing the existence of rights, even when they are inscribed in the law, does not by itself make them happen. Patients' rights are not self-executing. While the power of government to legislate noble sentiments of dignity and autonomy is virtually unbounded, its practical ability to enforce those pronouncements, to bring their content to reality in a way that exerts a positive impact upon the welfare of their intended beneficiaries, is only too limited.⁵

There are several serious obstacles to the effective enforcement of well-intentioned patients' rights laws. First, the government agency charged by law with the responsibility for enforcing specific patients' rights provisions may lack the political will, either in fact or at least in the perception of interested consumer groups, to mount and sustain an effective enforcement campaign.

Second, even where the official commitment to a patients' rights law is sincere, the very nature of the subject matter being regulated—human status or relationships—may encourage (and perhaps actually necessitate) regulatory language so broad and vague as to be unenforceable in the face of a legal challenge.⁶ How, for example, does a lawmaker define concepts like dignity and autonomy with sufficient precision to place affected citizens on notice, as required by the constitutional doctrine of due process and by ethical precepts of fairness, of what particular conduct is forbidden

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and what is required? In practice, statutes and regulations embodying fundamental ethical canons in all-encompassing terms generally invite successful litigation when enforcement is sought, an invitation that is all too frequently accepted by the party, such as a health care provider, who is charged with wrongdoing.

The third, and probably most prevalent, impediment to effective enforcement of patients' rights laws is a lack of available resources to properly do the job. This deficiency may exist because meaningful sanctions for noncompliance with requirements are not available. The lack of resources to effectively enforce patients' rights may also appear in the form of public funding shortages. When a legislature or agency purports to create rights entitling specified beneficiaries to make claims for certain goods or services, it is virtually implicit that public funds must be expended in order to provide those goods or services. Unfortunately, the commitment that inspires the declarations of entitlements in the first place is often not matched, particularly in this age of shrinking public resources, when it comes to adequately funding the programs essential to implementing the rights expressed.

Given the largely unenforceable nature of patients' rights statutes and regulations, particularly in undefinable areas such as dignity and autonomy, we are compelled to question whether it is prudent social policy for legislatures and executive agencies to continue to promulgate Patients' Bills of Rights. Do the costs involved in such pretentious and unenforceable pronouncements outweigh any benefits derived? Indeed, are there benefits? Is it really worth all the effort?

Promulgation of Patients' Bills of Rights in the context of formal laws, even where vigorous enforcement is not legally or politically practicable, does yield positive results that can exceed the detriments.

First, such laws put society squarely on public record in favor of respect for the dignity and autonomy of the individual as a consumer in the health care delivery system. Even in the absence of strict enforcement, it is important for society to formally clarify its moral position on a subject of this magnitude. Rights are moral as well as legal commodities,⁷ and in any tolerably just society many moral rights should and will be legal rights as well. As Ronald Dworkin has asserted, "It is part

of the job of governing to 'define' moral rights through statute and judicial decisions, that is, to declare officially the extent that moral rights will be taken to have in law."⁸

Second, Patients' Bills of Rights serve an educational function for health care providers, raising their individual and collective consciousness and forcing them to grapple seriously with complex and unpleasant issues.⁹ Even if unenforceable as a matter of law, these bills, by compelling providers to think about patients as autonomous human beings, can serve as the basis for altering provider attitudes and, not infrequently, their conduct as well.

Third, enactment of patients' rights laws raises the consciousness of consumers concerning their own worth as individuals. While unrealistic expectations of immediate tangible results should be assiduously avoided, consumers should be encouraged to recognize and assert their own legitimate claims to dignity and autonomy. Patients' Bills of Rights can be catalysts for accomplishing this transformation of attitude from patient as passive recipient of medical largess to patient as active consumer and participant, responsible for his or her own health care and well-being.¹⁰ The having of rights confers status as a person. It allows the patient to share in the provider-patient relationship with a sense of dignity. In the final analysis, laws remain an admittedly poor, but unfortunately necessary, substitute for a shared moral commitment to the dignity and autonomy of health care patients.

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