The Bill for Rights

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by Carl E. Schneider

Where today is legislative ingenuity lavished more bountifully than on the titles of statutes? And where has that ingenuity been better exercised than in the name “patients’ bill of rights”? Do not our dearest liberties flow from the Bill of Rights? And who more deserves similar protection than patients in the hands of an angry Managed Care Organization? And behold, both Democrats and Republicans, both President Clinton and President Bush, have summoned us to arms. The patients’ bill of rights is an idea whose time has seemed to have come for several years, and only conflicts among the numerous proposals and 11 September have postponed the apparently inevitable.

The impetus for legislation is irresistible. Its name is managed care. American medicine has moved from cottage industry to bureaucratic behemoth with imposing and implacable speed. Ought not combinations of great size—malefactors of great wealth—be regulated, especially when their services can literally be vital? What is more, cost containment with bite, once a fantasy, is becoming a reality. When medical bureaucracies are commanded to conserve resources, they in turn drive physicians into an ethically tense position—serving both the god of patients’ welfare and the Mammon of MCO profits. Ought not government police that conflict of interest?

And where are the police when we need them? Preempted. Our federal system confides governmental supervision of medicine to the states. However, most people obtain medical insurance from their employers’ benefits plans. In 1974, the federal government, concerned about the safety of employers’ pensions, enacted the Employee Retirement Income Security Act to safeguard them. To protect ERISA’s strictures, that statute “supersedes any and all State laws insofar as they may now or hereafter relate to any employee benefit plan.” Although ERISA was primarily aimed at pensions, it covers employee benefits generally, including medical benefits. Thus while states may continue to make individual doctors liable for medical wrongs like malpractice, various other kinds of MCO activities—and not least their cost-control programs—may escape the states’ regulation, at least insofar as those programs are part of an employee benefit plan. (I say “may” because the extent to which ERISA preempts state regulation of MCOs remains grossly uncertain even after the Supreme Court’s recent encounter with that question in Pegram v. Herdrich.) And while the federal government has not been inactive, neither has it acted systematically.

The case I have so far sketched for a patients’ bill of rights is circumstantial: MCOs must want to economize, they must pressure doctors to do so, doctors must acquiesce, this must injure patients, and thus patients must be endowed with rights. Arguments for regulating managed care are not, however, solely circumstantial; they are also anecdotal. What journalist trying to make the dull vivid, what politician trying to make duty plain, could resist the anecdotes lobbyists luridly spread before them? In their canonical form, these anecdotes tell of someone dying of a dreadful disease, someone without hope unless a bureaucracy will let doctors do their jobs and will pay for a “cutting-edge” treatment. These anecdotes are supplemented by stories that resonate with us all about bureaucratic intrigue, incompetence, and insolence.

So there is a circumstantial and anecdotal case for regulation. And that case has become the case for a patients’ bill of rights. Versions of that device throng like leaves in Västombrosa and change about as frequently, so generalization is hazardous. Politically prominent versions, however, have attempted—often in ambitious and elaborate ways—to establish procedures MCOs must use in utilization reviews, to require appeals outside the MCO of denials of treatment, to specify what services MCOs must provide, to state what information MCOs must and must not furnish, to restrict MCOs from using incentive systems to influence doctors’ decisions, to extend patients’ ability to sue their MCOs, and on and on.

Well, who could object to any of this? In a later column I will examine specific provisions that are actually enacted or seem about to be. Here I will suggest seven questions we should ask before succumbing to the conventional wisdom about “the need for a strong patients’ bill of rights,” as conventional wisdom’s fount, the New York Times editorial page, put it.2

First, how convincing is the evidence that legislation is necessary? Circumstantial evidence and anecdotes are pitiful bases for public policy, but they may be irresistible when they confirm what seems obvious. Nevertheless, it is wise to doubt the obvious, and there are especially provoking reasons to do so here. For example, it is widely assumed that MCOs’ efforts to economize must mean that they offer worse care than their alternatives. Yet “[o]verall, the evidence . . . does not support the premise that managed care has lowered the effectiveness of care.”3 It is also widely assumed, and doctors widely insist, that MCOs rob physicians of time with patients. Yet during the period in which MCOs have proliferated, the time doc-
itors spend with patients has actually increased.4

Second, what are the goals of a patients’ bill of rights? To make health care more efficient? More accountable? Fairer? Cheaper? Better? These are only a few of the possible goals. And they are all worthy goals, but a statute that serves one often disserves others. If we simply ask whether a bill of rights promotes one desirable end, we may overlook the ways it interferes with others.

Third, will a patients’ bill of rights accomplish its goals? Law often frustrates its makers, and the history of bioethical legal reform has been the history of humiliation. Why expect a bill of rights to do better? For example, bills of rights unimaginatively attempt to bring “due process” to the MCO. In other areas, due process solutions repeatedly go unutilized by the people they intend to benefit. A recent survey of research on the effects of MCOs finds that “sick enrollees who are poor or elderly fare worse in HMOs.” But such patients are exactly the people least likely to be aggressive enough to wring results from due process rights. Put it this way: is the only cure for the ills of bureaucracy more bureaucracy?

Fourth, cui bono—who benefits? Patients’ bills of rights are piously described as serving patients. But doctors’ groups have been instrumental in framing and promoting many of them. “The voice is Jacob’s voice, but the hands are the hands of Esau.” Have doctors’ groups again succumbed to the temptation of advocating legislation that benefits the profession more than the patient? Bioethicists have written for years about the “abject” relationship of patient to doctor. MCOs are the only countervailing force on the horizon. In short, if medical costs are to be cabined and medical care to be improved, doctors’ power will need to be constrained, not institutionalized under the banner of patients’ rights.

Fifth, in a medical world in turbulent change, are these the rules we want to enact into legislation that will be hard to alter? Managed care has gone from marginal to predominant in hardly more than a decade, and it continues to develop tumultuously. A bill of rights attempts to enshrine timeless principles. Are these they? For instance, even as Congress debates mandating cumbersome procedures for utilization reviews, at least one prominent MCO has “decided to abandon utilization review mechanisms due to their cost and the relatively small number of recommended treatments that were found to be inappropriate.”

Sixth, is the legislation so harmless that nothing can be lost by enacting it? If bills of rights simply ask MCOs to do what is plainly right, why not pass one here, we must remember what brought us to MCOs—namely, the struggle to subdue health care costs. Governmental efforts were feeble and failed. Employers acted by promoting MCOs. They seem to have won a battle, but the war remains perilously in doubt. Patients’ bills of rights are largely directed against the aspects of managed care that have helped tame costs. Few argue that we should devote more of our GDP to health care. Employers yearn to control health care costs. Employees, when given a choice about whether to buy more extensive health insurance or to spend their money elsewhere, repeatedly choose the latter, so that patients’ bills of rights seem likely to impose on people insurance more expensive than they would choose to buy for themselves. Small wonder, then, that support for bills of rights plummets when their costs are described. And small wonder that while Congress congratulates itself for imposing a bill of rights on private MCOs, it hesitates to inflict one on federal programs.

Seventh, is a patients’ bill of rights where we should spend scarce reformist energies? Congress has repeatedly failed to formulate cogent health policy, and it has tried only sporadically. Such moments ought not be wasted. Let me make the point a challenge: Should a country in which more than 40 million people lack health insurance expend limited human and legislative resources to make medical care more expensive—but not necessarily better—for those who already have it?

These seven questions about patients’ bills of rights have been skeptical. But they are the same questions we should ask about any health care legislation. And one reasonable inference from them is that many kinds of proposals ought to be considered. Law’s arsenal enjoys various weapons. One, for example, is the law of contract. It might seek to build on the market’s energy and creativity in devising managed care but to structure the market to better reflect what patients want. Another weapon is the law of tort. Perhaps much can be gained by shifting malpractice liability from individual doctors to MCOs and hospitals. Yet another weapon is to assign government agencies regulatory authority, an approach that seems most successful when the agency seeks less to write and enforce its own rules than to stimulate an industry to intelligent and aggressive self-regulation. But, surely, before seizing any weapon, systematic inquiry into its costs and its benefits is essential.