



PROJECT MUSE®

Why We Need a Patients' Bill of Rights

Richard Sorian, Judith M. Feder

Journal of Health Politics, Policy and Law, Volume 24, Number 5, October 1999, pp. 1137-1144 (Article)

Published by Duke University Press



➔ For additional information about this article

<https://muse.jhu.edu/article/15425>

Why We Need a Patients' Bill of Rights

Richard Sorian and Judith Feder
Georgetown University

Background

Over the last ten years, Americans have experienced a substantial change in the way they receive health care. Not surprisingly, that shift has generated popular discontent. Also not surprisingly, that discontent has generated heated political debate about the need for greater consumer protections in the health care marketplace. The nature of that debate—particularly its partisanship at the national level—has called into question its basis in policy.

Some argue that there really is no problem in terms of the quality of care; that change, while disruptive, is constructive in bringing cost concerns into play in decisions about the delivery of medical care. From this perspective, the only significant threat managed care poses is to provider incomes. If that's the case, then action to mitigate that threat represents at best political pandering and at worst a costly caving to the interests of a well-paid few. In other words, the market is working and politicians should leave it alone.

Although pandering and caving are undoubtedly a part of the political process, this argument ignores the fundamental problem that underlies the current debate: a lack of accountability in the health care market. Since the demise of the Clinton health plan, the United States has followed a market-based approach to health care cost containment. The more we rely on market forces in health care, the more important it is that the market is held to the kind of accountability provided in other

markets. In fact, considering the potential impact of poor quality health care on people's lives, it is even more important. While we certainly agree that intervention can go overboard, to fail to balance market forces with accountability is to leave people at unacceptable risk and undermine the basic trust that is essential to a well-working system of care.

Too Much Change, Too Little Choice

The roots of the consumer protection debate can be found in the rapid transformation of the health insurance market from fee-for-service coverage to managed care. Between 1988 and 1998, the percentage of privately insured Americans in managed care plans skyrocketed from 14 percent to 71 percent (KFF: 18). For most Americans, the decision to move from fee-for-service coverage to managed care was made by their employer. Such an involuntary shift was bound to breed distrust among consumers, and it has. A series of public opinion polls indicates a strong and abiding discontent with many of the common traits of managed care plans:

- a July 1997 ABC News/*Washington Post* survey¹ found that 52 percent of Americans had an “unfavorable” opinion of managed care plans compared with 30 percent who had a “favorable” view;
- a September 1998 poll by the Kaiser Family Foundation (KFF) and the Harvard School of Public Health (KFF and Harvard 1998) found that 64 percent of Americans blamed managed care for allowing them less time with their doctors while 62 percent said plans made it harder for sick patients to see specialists; and,
- a February 1999 Associated Press poll² found that 34 percent of Americans believe the quality of their care was “worse” than it was five years ago.

Who Put the Bash into Managed Care?

A central question is whether this opinion is based on personal experience or is simply a reflection of the intense media coverage of the political debate. Certainly consumers are hearing much more negative news

1. The poll was conducted 9–12 July 1998. It surveyed 1,515 adults and had a margin of error of plus or minus 3.1 percent.

2. The poll was conducted 29 January–2 February 1999. It surveyed 1,008 adults and margin of error of plus or minus 3 percent.

about managed care and not all of it is based on hard evidence. Between 1990 and 1997, news coverage of the managed care industry took a turn for the worse. While earlier coverage tended to portray HMOs as the health system's "savior," later coverage was significantly more negative, often featuring vivid examples of consumers injured by health plans (Brodie, Brady, and Altman 1998). The question is, Did consumer unhappiness drive news coverage or did the media foment the discontent?

In the Kaiser/Harvard poll, 77 percent of those who disliked HMOs said they were influenced by their personal experiences or the experiences of their friends and families; only 17 percent cited negative media coverage. While news editors and reporters admit there often is a "pack approach" to covering national news, they argue strongly that the public's interest drove the coverage. As one national news editor put it, "If we didn't think people would read it, we wouldn't publish it."

Consumer discontent alone is unlikely to drive a national debate. In the case of managed care reform, consumer dissatisfaction was effectively harnessed to one of the nation's more influential lobbies—the medical profession. Physicians who saw their income and their autonomy reduced by the growing power of such plans were among the first to complain about managed care and seek reform.

The States Respond: From Pandering to Due Process

Public and professional unrest with managed care was bound to create a governmental response. As is usually the case, this response began first in the states and later spread to the national scene. State lawmakers were clearly torn about what to do about managed care. On the one hand, they recognized that health plans were serving an important role in controlling the rate of growth in health costs—a job that government had abandoned in the wake of the 1994 defeat of the Clinton health reform plan. Legislators were loathe to interfere with what seemed to be a welcome respite in health care inflation. At the same time, there was a clear feeling that many HMOs had gone too far in their zeal to cut costs and compete for market share.

The first wave of state efforts in 1994–1995 was driven primarily by providers. Unhappy with the strictures imposed by tight provider networks, the American Medical Association and state medical societies pressed for legislation to force open those networks and require plans to accept "any willing provider" into their midst. While most states rejected

that approach, fearing that it would destroy the basic tenets of managed care, many did adopt laws requiring plans to provide direct access to specific types of providers (e.g., chiropractors, acupuncturists, optometrists, and dermatologists).

The second wave of state legislation, in 1995–1996, focused more on consumer concerns but still tended to address the symptoms (e.g., drive-through deliveries and mastectomies) rather than the underlying causes. States enacted 245 managed care laws in that period, most taking a “body-part” approach. For example, thirty states mandated minimum maternity hospital stays and fourteen states took the same approach to care after a mastectomy. Others mandated coverage of specific procedures (e.g., infertility services, bone mass measurement, and bone marrow transplants).

State policy makers grew uncomfortable with the body-part approach to managed care reform and began searching for a more traditional consumer protection approach. In most other markets, government tends to establish basic ground rules that outlaw egregious practices, mandate information disclosure, and establish due process standards for accountability. In 1996, New York became the first state to take this approach to managed care reform.

The New York law included minimum standards for the adequacy of provider networks, greater access to specialists for the severely ill, direct access to pediatricians and obstetrician/gynecologists, utilization review standards, easier access to emergency care, internal quality assurance standards, information disclosure, and standards for appeals (PPEFNY 1995).

New York’s success shifted the state debate away from micromanagement and toward accountability and due process. In 1997–1998, states passed another four hundred managed care laws, including twenty-eight comprehensive packages. Two states—Texas and Missouri—took the debate further by voting to allow consumers to sue their health plans in state courts for damages caused by a denial or delay in coverage of needed care.

While final figures aren’t in yet for 1999, it appears certain that the number of state laws will continue to rise. A survey of state legislators at the beginning of the year found that every state was planning to debate managed care reform with twenty-two states planning to consider adopting external appeal systems (Dixon, Rothouse, and Stauffer 1998). It is likely that by the end of this year, states will have enacted upward of one thousand managed care laws in only six years, a remarkable record.

A surprising element of the state debate has been the minimal level of

partisanship. Most state laws were enacted with strong bipartisan support. In fact, many of the leading states (New York, New Jersey, and Connecticut) were run by Republican governors with Democratic legislatures. While the insurance industry was active in opposing provisions that it felt went too far, it did not run the kind of high-priced lobbying and ad campaigns for which it has become famous. The industry's quiescence may have lulled national policy makers into a false sense of confidence.

The Feds Respond: Politics and Partisanship

Policy makers in Washington had stayed on the sidelines for most of the initial phase of debate over managed care reform. In 1996, however, with a presidential and congressional election looming, federal lawmakers looked for ways to jump on the anti-managed care bandwagon. In August, Congress enacted modest legislation requiring all plans to provide a minimum of forty-eight hours of hospitalization for women and their newborns—the same body-part approach that many states had followed.

Perhaps more significant was the enactment of the Health Insurance Portability and Accountability Act (HIPAA) of 1996, which set federal rules for the sale and renewal of individual and group insurance. This expansion of federal regulation of insurance marked a sea change in the tradition of leaving insurance regulation to the states.

Beyond the political attractiveness of the issue, a significant factor in the passage of the maternity stay mandate and HIPAA was the inability of states to regulate much of the insurance market. The Employee Retirement Income Security Act (ERISA) of 1974 exempts self-funded health plans from all state regulations and protects fully insured plans from many state rules. ERISA also prohibits consumers from suing HMOs in state courts for damages associated with a plan's wrongful denial of coverage. Consumers who are injured must go to federal court and damages are effectively limited to the cost of the service denied. An estimated 124 million Americans are in ERISA-regulated plans, including about 48 million in self-funded plans.

There were some signs of bipartisan interest in HMO reform early in 1997 with major proposals by Representative Charlie Norwood (R-GA), Senator Alfonse D'Amato (R-NY), Representative John Dingell (D-MI), and Senator Edward Kennedy (D-MA). Ironically, it was the GOP plan that was the most invasive bill. Norwood's "Patients' Access to Responsible Care Act" (PARCA) would make sweeping changes in managed

care regulation, requiring plans to allow certain providers to participate in their networks and establishing due process protections for consumers. Norwood's bill also would allow consumers to sue their health plans in state courts. PARCA was surprisingly popular with House members of both parties, eventually garnering nearly two hundred cosponsors, a clear sign of the viability of managed care reform as a political issue.

Democrats were less certain how to proceed. Burned by health reform, the White House was reluctant to take the lead on managed care reform. Instead, President Clinton created the thirty-four-member Advisory Commission on Consumer Protection and Quality in the Health Care Industry and asked it to advise him "on changes occurring in the health care system and recommend such measures as may be necessary to promote and assure health care quality and value, and protect consumers and workers in the health care system Executive Order # 13017, dated 5 September 1996." With its broad representation (including consumer advocates, physicians, nurses, HMO executives, large and small employers), the Commission also was an attempt to find a political middle ground. In November, the Commission recommended the Consumer Bill of Rights and Responsibilities, which hewed closely to the states' model of due process and accountability.

In early 1998, the Democratic leadership of both houses of Congress introduced a new managed care bill that added several provisions recommended by the Commission—most notably a requirement for external review of plans' decisions to deny or curtail coverage—and adopted Norwood's proposal to allow consumers to sue health plans in state courts.

While the Republican rank-in-file was embracing reform, Republican leaders were adamantly opposed. House Majority Leader Dick Armey (R-Texas) dubbed the various proposals "Clinton Care II," saying they were an incremental attempt to enact the defeated Clinton health reform plan of 1993–1994. Senate Majority Leader Trent Lott (R-MS) urged the insurance and employer lobbies to fight a "real war" against reform and the industry heeded that call with a campaign that would eventually cost more than \$60 million (Salant 1998).

In mid-1998, GOP leaders abruptly abandoned their "just say no" approach to reform when pollsters reported that public support for managed care reform was strong and growing and that the party risked losing its majority in the House of Representatives. In June, House and Senate Republicans introduced their own versions of a Patients' Bill of Rights, which resembled the Democratic bill in its broad outline, but differed dramatically in the details.

In the end, Congress failed to enact any meaningful managed care reform legislation in 1998. Ironically, the single piece of legislation to pass was a return to the body-part approach mandating plan coverage of breast reconstruction after a mastectomy.

What's at Stake?

Continuing public demand for change still makes it likely that Congress will eventually adopt a managed care reform package. The question remains: What form will it take? Will it pander to the medical profession and undermine the legitimate role of HMOs in containing health care costs? Will it promise consumers real protections but deliver only pabulum? Or will it provide patients with a system that makes decisions out in the open and is held accountable when it makes the wrong decision?

The answer is likely to be a combination of all three. Any political process demands trade-offs and managed care is no different. But some issues are more important than others. Take, for example, the question of medical necessity as a major sticking point in the current congressional debate. Health plan contracts typically include a list of covered services but condition that coverage on the service being "medically necessary." There is, however, a growing trend among health plans to define medical necessity arbitrarily as a means to control costs through claim denials. In a small number of cases, such denials lead to irreversible damage or even death. In a larger number of cases, it results in unnecessary delays in needed care.

Legislative action is needed to create a better balance between HMOs' desire to control costs and patients' desire to get appropriate medical care. External review is an effort to accomplish that balance but it can only reach that goal if external review panels can take a fresh look at each case and base their decision on the relevant evidence and expertise. State experience shows that such a process will result in better decisions by health plans at a modest cost.

A next step would be to allow consumers who are dissatisfied with the results to seek review in court as a means to assure that the process is honest. Use of the courts is highly controversial and vulnerable to misinterpretation. No one is advocating that courts should be used to make medical decisions. The legal system is far too costly and cumbersome for that. Rather, courts are needed to provide the entire system with legitimacy. By punishing the miscreants, courts are a powerful deterrent for bad behavior. In all other markets, the ultimate consumer protection is

the ability to go to court and be made whole. As long as health plans are shielded from liability, consumers will continue to believe that the deck is stacked against them.

Enactment of a federal Patients' Bill of Rights is a vital step toward restoring the appropriate balance between cost and access. And it is a crucial part of restoring public trust in a market-based health care system. Six years of debate have refined the approach to managed care reform to the point where we can confidently move forward and complete the job at hand.

References

- Brodie, M., L. A. Brady, and D. Altman. 1998. Media Coverage of Managed Care: Is There Negative Bias? *Health Affairs* 17(1):9–25.
- Dixon, L., M. Rothouse, and M. Stauffer. 1998. *1999 State Health Care Priorities: Health Policy Tracking Service*. Washington, DC: National Conference of State Legislatures, December.
- Kaiser Family Foundation (KFF). 1998. *Trends and Indicators in the Changing Health Care Marketplace*. Menlo Park, CA: Kaiser Family Foundation.
- Kaiser Family Foundation (KFF) and Harvard University School of Public Health. 1998. *Survey of Americans' Views on the Consumer Protection Debate*. Storrs, CT: Roper Center, 17 September.
- Public Policy and Education Fund of New York (PPEFNY). 1995. *The Managed Care Consumers' Bill of Rights: A Health Policy Guide for Consumer Advocates*. 1995. New York: PPEFNY, October.
- Salant, J. 1998. Foes of New HMO Rules Spent \$60 Million for Lobbying in Six Months. *Philadelphia Inquirer*, 28 November, A10.