Patient Accountability and Quality of Care: Lessons From Medical Consumerism and the Patients' Rights, Women's Health and Disability Rights Movements

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I. THE QUALITY OF CARE PARADIGM

This article contrasts the prevailing model for assessing and improving medical care—the *quality of care paradigm*—with an alternative approach—the *patient accountability paradigm.* The first approach is technocratic: it measures and promotes the quality of medical care through technical and objective means. It relies on outside experts, analysis of data and protocols, and impersonal judgements of professionals to guide decisions. The second approach guides physicians and providers and subjects them to patient control. It enlists the participation of patients and consumers to evaluate and change the medical care system and to promote the rights and choices of patients and consumers. The strengths and limitations of the patient accountability approach are illustrated by four movements: 1) the patients' rights movement; 2) medical consumerism; 3) the women's health movement; and 4) the disability rights movement.

Our medical care system still pays homage to the ideals of accountability to patients and consumers. However, it often treats this goal as an old-fashioned idea — one that can be safely dispensed with in favor of fostering quality assurance by improved design of medical systems, professional and peer review and decision-making by experts. This is a flaw: for despite the importance of technical measures of quality, it slights the considerable complementary contributions of the accountability approach. The challenge for the future is to incorporate accountability to patients and consumers of health care into an assessment system that is currently technocratic.

Over the past quarter century the U.S. has made great strides in improving the practice of medicine and developing ways to assess and promote quality of medical care.[1] Quality assurance is now a growth industry and an academic specialization

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[1] For an historical overview see K.N. Williams & Robert H. Brook, *Quality Measurement and Assurance: A Literature Review,* HEALTH & MED. CARE SERVICES REV., May/June 1978, 3-15; Kathleen N. Lohr & Robert H. Brook, *Quality Assurance in Medicine,* AM. BEHAV. SCI., May-June 1984, at 583-607; John J. Williamson,

with its own journals.[2] The wide variety of methods to assure the quality of medical care range from formal monitoring of conduct, review of medical records, and regulatory sanctions to the promotion of continuing education, recertification, and a philosophy of continuous quality improvement.[3] More specific methods include accreditation, licensure or certification of professionals and medical care institutions; patient care guidelines and protocols for medical treatment; systems that prompt physicians and other medical care providers to check for certain problems or justify decisions; analysis of physician and institution performance by assessing how frequently particular services are used and the mortality, morbidity and complication rates for various kinds of medical procedures; patient assessment of medical care received; measures of patient health status; and clinical indicators for quality problems.[4]

Avedis Donabedian has summed up the three main ways to assess quality of care; these examine: 1) *medical structures*, characteristics of the medical resources and the training of medical personnel; 2) *medical processes*, which include the activities and services performed for patients; and 3) *medical outcomes*, the resulting health status of patients.[5] In the past, quality assurance programs emphasized structures; the push today is to assess health outcomes and to develop processes that promote professional learning and ongoing improvements.[6]

Most quality assurance programs attempt to assess the performance of hospitals, doctors and other medical care providers by detecting poor technical quality or over- or under- use of services. Reviewers assess performance by analyzing medical records or data on patient care from hospital discharge statements or bills.[7]

There are several ways for institutions to promote quality of care. They can sanction providers of poor quality of care, deny payment for services performed unnecessarily, or avoid using the providers' services in the future. They can also target poor quality providers for education or training or use financial incentives to reward improvements in performance.[8]

Future Directions for Quality Assurance: Lessons from the Health Accounting Experience, INQUIRY, Spring 1988, at 67-77.

[2] *See, e.g.*, QUALITY REVIEW BULLETIN and QUALITY PROGRESS. Quality assurance is also widely reported on in health, policy, and medical journals with a broader or different focus.

[3] For a general discussion of continuous quality improvement, see WILLIAM E. DEMING, OUT OF CRISIS (1986); D.A. GARVIN, MANAGING QUALITY: THE STRATEGIC AND COMPETITIVE EDGE (1988); J.M. JURAN ET AL., QUALITY CONTROL HANDBOOK (4th ed. 1988). For a discussion of continuous quality improvement in health care see B. Batalden & E.D. Buchanan, *Industrial Models of Quality Improvements*, *in* PROVIDING QUALITY CARE: THE CHALLENGE TO CLINICIANS. PHILADELPHIA: THE AMERICAN COLLEGE OF PHYSICIANS (N. GOLDFIELD & D.B. NASH EDS., 1989); Donald M. Berwick, *Continuous Improvement as an Ideal in Health Care*, 320 NEW ENG. J. MED. 53 (1989).

[4] *See* Bruce C. Vladeck, *Quality Assurance Through External Controls*, INQUIRY, Spring 1988, 100-07.

[5] Avedis Donabedian, Explorations of Quality Assessment and Monitoring Vol I-III; AVEDIS DONABEDIAN, THE DEFINITION OF QUALITY AND APPROACHES TO ITS ASSESSMENT (1988); AVEDIS DONABEDIAN, METHODS AND FINDING OF QUALITY ASSESSMENT AND MEASUREMENT: AN ILLUSTRATED ANALYSIS (1985); Avedis Donabedian, *Criteria and Standards for Quality Assessment and Monitoring*, QUALITY REV. BULL., March 1986, at 99-108; Avedis Donabedian, *The Quality of Care: How Can it Be Assessed?*, 260 JAMA 1743 (1988).

[6] John E. Wennberg, *On Patient Need, Equity, Supplier-Induced Demand, and the Need to Assess the Outcome of Common Medical Practices*, 25 MED. CARE 512 (1985).

[7] *See* MEDICARE: A STRATEGY FOR QUALITY ASSURANCE 45-68 (Kathleen N. Lohr ed., 1990) [hereinafter MEDICARE: A STRATEGY FOR QUALITY ASSURANCE]; Stephen S. Jencks & Gail Wilinsky, *The Health Care Quality Improvement Initiative: A New Approach to Quality Assurance in Medicare*, 268 JAMA 900 (1992).

[8] Incentives can also be used to encourage adequate or good providers to seek superior performance. MEDICARE: A STRATEGY FOR QUALITY ASSURANCE, *supra* note 7, at 16, 47.

Although quality assessors and reviewers are nominally outsiders, they have the perspective of medical professionals. They work in organizations using standards and approaches that have grown out of medical peer review. Judgements about what constitutes quality are drawn from existing professional knowledge and opinion as well as studies measuring outcomes.

Most quality assurance measures are tools used to benefit patients; tools typically under the control of health care professionals, third-party payers, or institutional providers. Though these measures of quality are important, they are narrow. Quality assurance programs have typically drawn on the perspectives and points of view of professionals rather than the people who receive the medical care.

Even with the more recent efforts to use patient surveys and other approaches that incorporate the perspectives of patients, professional values nevertheless largely drive quality assurance programs. The recommendations of an Institute of Medicine task force illustrate the tension between perspectives of patients and professionals. The recommendations say that:

> a successful [quality assurance] program must be accepted by the professionals and organizations in which it is embedded or to which it is directed. . . This implies that judgements about care and recommendations about change in practice are made by peers.[9]

The predominance of professional control is underscored in another passage, which states that: "no quality assurance program should jeopardize the relationship of trust or the ability of the practitioner to use his or her best judgement to guide the care of the patient."[10]

Viable quality assurance programs clearly need the active education and involvement of doctors and other professionals, for changes resisted by doctors may not be implemented. However, the perceptions of patients may differ from that of professionals.[11] Moreover, physicians and other providers have conflicts of interest.[12] Limitations therefore exist in the likely changes expected from quality assurance programs. With this in mind, let us examine another paradigm for improving medical care.

II. THE PATIENT ACCOUNTABILITY PARADIGM

By tradition and medical ethics, doctors are expected to work in the interest of their patients. This commitment is so fundamental that it is rarely questioned. Indeed, codes of medical ethics often remind doctors to place the interest of their patients before any other interests.[13] Physicians' proclaimed responsibilities to patients are appropriate, given that the roles doctors perform are similar to those of traditional fiduciaries, individuals the law requires to be loyal to designated parties and holds to the highest standards of ethical conduct. Doctors advise patients as to what

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[9] *Id.* at 50.

[10] *Id.*

[11] *See* Marie R. Haug & Marvin B. Sussman, *Professional Autonomy and the Revolt of the Client*, 17 SOC. PROBS. 153 (1969).

[12] *See generally* MARC A. RODWIN, MEDICINE, MONEY AND MORALS: PHYSICIANS' CONFLICTS OF INTEREST (1993) [hereinafter RODWIN: MEDICINE, MONEY AND MORALS]. For a discussion of conflicts of interest in the peer review of medical and scientific journals which can affect the perceptions of professionals, see Marc A. Rodwin, *Inside Information and Peer Review: A Legal and Ethical Analysis*, 3 ETHICS & BEHAV. 138 (1993).

[13] For a selection of codes of medical ethics including the Hippocratic Oath, see ETHICS IN MEDICINE: HISTORICAL PERSPECTIVES AND CONTEMPORARY CONCERNS (Stanley Joel Reiser et al. eds., 1977).

medical care they need. They make decisions on behalf of patients. And through their decisions and advice, they control, in effect, the use of patients' money.[14]

Despite the strong tradition of medical ethics which encourages doctors to act in the interest of patients (or perhaps because of it), institutional and legal means to hold doctors accountable to patients have been relatively weak. Physicians, like other professionals, have conflicts of interest and sometimes breach their fiduciary-like obligations.[15] Moreover, many institutions hold doctors accountable to third-party payers, medical providers and medical suppliers. There has been very little, however, in the way of regulatory or other institutional mechanisms to hold doctors accountable to patients.[16]

However, there are at least two ways in which political movements have helped to redress this imbalance. These are promoting the use of *voice* — that is, consumers and patients voicing their complaints, grievances, and protests, and forming associations to promote their interests — and *exit*, that is, consumers exiting from the organization or purchasing medical services elsewhere.[17]

Four examples are the movements involving: 1) patients' rights; 2) medical consumerism; 3) women's health; and 4) disability rights. Each of these efforts have fostered the ideal of serving patients, promoting autonomy, and promoting a more responsible and humane health care system. And each of them has had limited success.

A. The Patients' Rights Movement

Until very recently, medical professionals interpreted the ethical injunction to work in the interest of patients to mean that they should make decisions *for* patients. Physicians generally assumed that medicine was primarily a science, that doctors were experts who would know better than patients what was in their interest, and that

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[14] For a discussion of fiduciary law applicable to physicians, see Rodwin, *supra* note 12, at ch. 7, 8. *See also* Frances H. Miller, *Secondary Income from Recommended Treatment: Should Fiduciary Principles Constrain Physician Behavior?*, *in* The New Health Care for Profit: Doctors and Hospitals in a Competitive Environment 153 (Bradford H. Gray ed., 1983). For a discussion of fiduciary law in general, see Robert Cooter & Bradley J. Freedman, *The Fiduciary Relationship, its Economic Character and Legal Consequences*, 66 N.Y.U.L. Rev. 1045 (1991); Tamar Frankel, *Fiduciary Law*, 71 Cal. L. Rev. 795 (1983); Austin W. Scott, *The Fiduciary Principle*, 37 Cal. L. Rev. 539 (1949); L.S. Sealy, *Fiduciary Relationships*, 1962 Cambridge L.J. 69 (1962); L.S. Sealy, *Some Principles of Fiduciary Obligation*, 1963 Cambridge L.J. 119 (1963); Ernest J. Weinrib, *The Fiduciary Obligation*, 25 U. Toronto L.J. 1 (1975).

[15] *See* Rodwin, Medicine, Money and Morals, *supra* note 12.

[16] For a review of existing laws and institutions that are used to hold physicians accountable, see Rodwin, Medicine, Money and Morals, *supra* note 12, at 11-34, 162-75.

[17] For a discussion of the use of the concepts of exit, voice and loyalty see Albert O. Hirschman, Exit, Voice, and Loyalty: Responses to Decline in Firms, Organizations, and States (1970); Albert O. Hirschman, *Exit and Voice: An Expanding Sphere of Influence*, *in* Rival Views of Market Society and Other Recent Essays 77-101 (1986); Brian Barry, *Review Article: "Exit, Voice, and Loyalty"*, 4 Brit. J. Pol. Sci. 79 (1974); A.H. Birch, *Economic Models in Political Science: The Case of "Exit, Voice, and Loyalty'*, 5 Brit. J. Pol. Sci. 69 (1975); Albert O. Hirschman, *"Exit, Voice, and Loyalty": Further Reflections and a Survey of Recent Contributions*, Soc. Sci. Info., Feb. 1974, at 7-26, *reprinted in* Milbank Q., Summer 1980, at 430-53; Rudolph Klein, *Models of Man and Models of Policy: Reflections on Exit, Voice, and Loyalty Ten Years Later*, Milbank Q., Summer 1980, at 416-29.

In recent years there have been many efforts to increase the use of citizen and consumer voice as a way to improve the governmental process. For a discussion of representing consumers as a way to improve the quality of federal regulations, see Marc A. Rodwin, *Can Bargaining and Negotiation Change the Administrative Process?*, 3 Environmental Impact Assessment Rev. 373 (1982); *see also* Lawrence Susskind & G. McMahon, *The Theory and Practice of Negotiated Rulemaking*, 3 Yale J. on Reg. 133 (1985).

patients had neither the interest in becoming involved in medical decision-making nor the ability to do so. Doctors promoted benign paternalism.

But practice did not always live up to ideals and patients were often denied basic human rights. The hospital, in the words of George Annas, was "a human rights waste land."[18] The most shocking abuses involved dangerous medical experimentation on human subjects, without their consent, experimentation that offered no possible therapeutic benefit.[19] But even in the course of ordinary medical treatment, physicians frequently did not consult with patients about important choices concerning their medical treatment.[20]

Most hospitals still do not let patients see their records, or they make it difficult for them to do so.[21] They are also reluctant to explain the records' contents. Without this information, patients are less able to participate in medical decision-making, and errors that patients can correct may creep into records. In addition, many hospitals have not respected the confidentiality of patient information and have widely allowed access to personal information.[22] Also, doctors often do not inform patients of their prognosis especially when the chance of survival is bleak.[23] And only after years of litigation have the physicians come to respect the right of patients to refuse life-sustaining medical treatment.[24] Many patients still are not told that medical students are examining them or that residents and interns will perform their surgery under the supervision of a doctor. And patients are still often subject to exams, tests and procedures for the benefit of teaching medical students.

The organization of hospitals also undermines important patient interests.[25] Patients lose control over their time, sleep schedule, choice of clothes, privacy, food selection, and contact with family and friends. They share rooms with strangers and may have to listen to their conversation or television; they also have their own conversations with families and doctors overheard by other patients and medical personnel.

Starting in the 1950s, patients used the courts to seriously challenge medical paternalism.[26] The first inroads came in cases that developed the law of informed

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[18] GEORGE J. ANNAS, JUDGING MEDICINE 4-26 (1988).

[19] The two earliest and most influential accounts of such dangerous experimentation without consent are by Beecher and Pappworth. Henry E. Beecher, *Ethics in Clinical Research*, 274 NEW ENG. J. MED. 1354 (1966); M.H. PAPPWORTH, HUMAN GUINEA PIGS: EXPERIMENTATION ON MAN (1967).

[20] Individuals do not have a general right to health care regardless of ability to pay, except to receive emergency care from hospitals. *See* The Emergency Medical Treatment and Labor Act, 42 U.S.C. § 1395dd; *see also* JOAN STEIBER & SIDNEY WOLFE, PUBLIC CITIZEN HEALTH RESEARCH GROUP, PATIENT DUMPING CONTINUES IN HOSPITAL EMERGENCY ROOMS: AN UPDATED REPORT ON THE DEPARTMENT OF HEALTH AND HUMAN SERVICES' ENFORCEMENT OF THE FEDERAL PATIENT DUMPING LAW (1993) [hereinafter STEIBER & WOLFE, PATIENT DUMPING CONTINUES].

[21] Some consumer guides have been designed to help patients get their medical records. *See* BRUCE SAMUELS & SIDNEY M. WOLFE, PUBLIC CITIZEN'S HEALTH RESEARCH GROUP, MEDICAL RECORDS: GETTING YOURS: A CONSUMER'S GUIDE TO OBTAINING AND UNDERSTANDING THE MEDICAL RECORD (1992).

[22] One physician has even concluded that medical information is disseminated so widely the idea of confidentiality has lost its meaning. *See* Mark Siegler, *Confidentiality in Medicine: A Decrepit Concept*, 307 NEW ENG. J. MED. 1518 (1982).

[23] Naoko T. Miyaji, *The Power of Compassion: Truth-Telling Among American Doctors in the Care of Dying Patients*, 36 SOC. SCI. & MED. 249 (1993).

[24] *See, e.g.*, Cruzan v. Director, Missouri Dep't of Health, 497 U.S. 261 (1990); Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417 (Mass. 1977); *In re* Quinlan, 355 A.2d 647 (N.J.), *cert. denied*, 429 U.S. 922 (1976).

[25] *See generally* GEORGE J. ANNAS, THE RIGHTS OF PATIENTS (1992); GEORGE J. ANNAS, THE RIGHTS OF HOSPITAL PATIENTS: THE BASIC ACLU GUIDE TO A HOSPITAL PATIENT'S RIGHTS (1975).

[26] For a history of this process, see David J. Rothman, *Human Experimentation and the Origins of Bioethics in the United States*, *in* SOCIAL SCIENCE PERSPECTIVES ON MEDICAL ETHICS 185-200 (George Weisz ed., 1990);

consent.[27] The early cases appear shocking to us now. One physician told a woman he would only repair a few cervical and rectal tears but instead removed her ovaries and uterus.[28] Another surgeon removed a woman's fibroid tumor after she had insisted that there be no operation but had given him permission to examine her under ether.[29] Still another surgeon, when asked about the risks in proposed surgery, had told the patient that it was simple and there was "nothing to it." The patient's left hand became paralyzed.[30]

In three celebrated cases the courts developed the principle that doctors must inform patients of the risk and benefits of medical care.[31] Traditional medical malpractice suits were premised on doctors negligently performing medical diagnosis or treatment. Informed consent suits, on the other hand, looked only to whether doctors had informed patients of the risks and benefits of treatments and alternatives, and received the consent of patients to undertake medical treatment. The legal premise was that patients were the ultimate decision-makers and that doctors acted as their agents. This assumption clashed with much of common medical practice as well as the traditions of medicine.

Probably more than any other doctrine, informed consent spurred the idea that doctors should promote patient autonomy and that they should share medical decision-making with patients.[32] With courts expanding the requirement that doctors obtain patients' informed consent, it was not long until the emerging field of bioethics spawned a vast literature debating the ethics of patient autonomy and informed consent.[33]

Informed consent was the most visible manifestation of what might be called the *legalization* of medicine.[34] But other legal doctrines also helped redefine the contours of the patient-physician relationship. By tradition, doctors decided when to terminate medical treatment for dying patients. A series of celebrated cases gave patients the legal right to refuse treatment, even if this refusal resulted in their death.[35] Although the Supreme Court in *Cruzan* stated that the state has an interest in preserving life when the wishes of patients are not known, it also held that when patients write durable powers of attorney or living wills which specify what kind of treatment they want to refuse, doctors must honor these wishes.[36] Recent federal legislation

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see also DAVID ROTHMAN, STRANGERS AT THE BEDSIDE; A HISTORY OF HOW LAW AND BIOETHICS TRANSFORMED MEDICAL DECISION MAKING (1991).

[27] JAY KATZ, THE SILENT WORLD OF DOCTOR AND PATIENT 59-84 (1984). For a review of the law and history of informed consent see RUTH R. FADEN & TOM L. BEAUCHAMP, A HISTORY AND THEORY OF INFORMED CONSENT (1987); PAUL S. APPLEBAUM ET AL., INFORMED CONSENT: LEGAL THEORY AND CLINICAL PRACTICE (1984).

[28] Pratt v. Davis, 79 N.E. 562, 563-64 (Ill. 1906).

[29] Schloendorff v. Society of New York Hosp., 105 N.E. 92 (N.Y. 1914).

[30] Hunt v. Bradshaw, 88 S.E.2d 762 (N.C. 1955).

[31] Canterbury v. Spence, 464 F.2d 772 (D.C. Cir. 1972), *cert. denied*, 409 U.S. 1064 (1972); Salgo v. Leland Stanford Jr. Univ. Bd. of Trustees, 317 P.2d 1093 (Cal. Dist. Ct. App. 1960); Natanson v. Kline, 350 P.2d 1093 (Kan. 1960).

[32] *See generally* ROBERT M. VEATCH, A THEORY OF MEDICAL ETHICS (1981).

[33] For an overview of this field, see WARREN T. REICH, ENCYCLOPEDIA OF BIOETHICS (1987). A second edition of the encyclopedia is forthcoming. *See also supra* note 27.

[34] I follow Lawrence M. Friedman in using the term "legalization" to describe the process by which law brings increasing numbers of issues into court and spreads its influence to places it has not penetrated before. LAWRENCE M. FRIEDMAN, AMERICAN LAW: AN INTRODUCTION 78 (1984).

[35] *See* Cruzan v. Director, Missouri Dept. of Health, 497 U.S. 261 (1990); Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417 (Mass. 1977); *In re* Karen Quinlan, 355 A.2d 647 (N.J.), *cert. denied*, 429 U.S. 922 (1976).

[36] *Cruzan*, 497 U.S. at 261.

now requires that hospitals receiving funding for Medicare must inform patients they have a right to make an advance directive stating their intentions for medical treatment if they become incompetent.[37] This statute is the fruit of two decades of patients and their advocates using courts to promote the rights of patients to refuse treatment.

Statutes and court cases have also specified other patients' rights.[38] These include the right to be offered experimental treatment only if there is a reasonable prospect of its being safe; to be informed of any risks of participation in medical experimentation, and to refuse to participate in medical experimentation; to receive *emergency* medical care, regardless of ability to pay if one goes to a hospital which has an emergency room;[39] to receive copies of one's medical records; to have medical records and other information about one's medical treatment kept confidential. Certain patients—such as women and children—have also been accorded special rights concerning medical treatment.

In response to the demands and lawsuits of patients, courts expanded patients' rights. They had several aims: to protect patients, to provide legal remedies in the case of mistreatment, and to curb the paternalism of the medical profession.[40] The movement expanded legal rights of patients, changed the attitudes of doctors, and altered many undesirable practices. Despite these changes, vindication of patients' legal rights through lawsuits has proved slow and costly. It often proves more effective at eliminating gross abuses than at promoting quality of life on a daily basis.[41] Patients' transient status further limits the ability of patients to organize and makes it difficult to sustain political pressures to hold providers accountable.

B. Medical Consumerism

The reining metaphor of medical consumerism is that medical care is a service, like any other, and that patients are consumers who can choose who should provide medical services and even what kind of services to purchase.[42] When market competition thrives, proponents say that goods and services are distributed more efficiently and quality is higher. Their prescription for good medicine: increase the amount of information available about providers to consumers, allow a greater range of choices in health insurance plans, medical care providers, and even therapies, and promote market competition between medical care providers. The medical care delivery system will, they say, respond to patient demand, and patients and the public will be

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[37] The Patient Self-Determination Act, 42 U.S.C. 1395cc (f)(1)(A)(i) (1993); *see also* Susan M. Wolfe et al., *Sources of Concern About the Patient Self-Determination Act*, 325 New Eng. J. Med. 1666 (1991).

[38] For an overview, see George J. Annas, The Rights of Hospital Patients (1975).

[39] *See* The Emergency Medical Treatment and Labor Act, 42 U.S.C. § 1395dd(a)-(b) (1988); *see also* Steiber & Wolfe, Patient Dumping Continues, *supra* note 20.

[40] For a summary of some of these developments, see George J. Annas, Standard of Care: The Law of American Bioethics (1993).

[41] Sidney H. Croog & Sol Levine, *Quality of Life and Health Care Interventions*, *in* Handbook of Medical Sociology (Howard E. Freedman & Sol Levine eds., 1989); Dan Brock, *Quality of Life Measures in Health Care and Medical Ethics*, *in* The Quality of Life (Martha Nussbaum & Amartya Sen. eds., 1993).

[42] Much of the discussion of medical consumerism assumes that patients are motivated by self-interest. For a discussion of alternative motivations in health care, particularly prevention, see Marc A. Rodwin, *Preventing AIDS: Self-Interest and Public Spirit*, 4 AIDS & Pub. Pol'y J. 131 (1989) ; For a general discussion of medical consumerism, see Judith Hibbard & Edward Weeks, *Consumerism in Health Care: Prevalence and Predictors*, *in* 25 Med. Care 1019 (1989).

better off even if there is also an increase in the commercialization of medicine and entrepreneurial activity that benefits providers.[43]

Medical consumerism challenges the expert model of medicine. It has great appeal—and plausibility—when the services provided are simple, when patients can plan the medical service they receive or are more likely to use it frequently, and when the choices patients make involve value issues or matters of taste rather than technical medical judgements.[44]

Antitrust law has promoted market competition in medical care.[45] Until mid-century, professional codes of ethics restricted many aspects of medical markets including advertising and other competitive practices. But elimination of the professional exemption from anti-trust in *Goldfarb v. Virginia Board of Bar Examiners* paved the way for more competition.[46] And following antitrust suits against the American Medical Association initiated in the 1970s and settled in the 1980s, the AMA dropped code provisions that prohibited advertising.[47] Since then the Federal Trade Commission, courts, and aggrieved firms have used anti-trust law to limit or eliminate medical care arrangements that fix prices, tie the sale of one service to another, and other anti-competitive practices.

The effect of anti-trust law, however significant, has been limited. Kenneth Arrow notes that several inherent factors create uncertainty, increase the cost of obtaining information and thereby preclude fully competitive markets.[48] The presence of health care insurance also limits competition. Providers have little incentive to economize when they know the bill will be paid in full, and patients have a diminished incentive to be frugal when insurance eliminates their out-of-pocket costs, except for deductibles and co-payments. Furthermore, some health care regulation also inhibits market competition. Despite the increased use of market incentives in recent years, medical care is characterized by "half-way competitive markets" which do not meet our expectations of well-functioning markets.[49]

Various approaches have been used to make more information about alternative providers available to the public. The Health Care Financing Administration, until 1994, published statistics on hospital mortality and infection rates. Pennsylvania state agencies rated cardiac hospital programs and surgeons in terms of outcome and cost.[50] Some popular magazines have also rated medical programs. *U.S. News and World Report* rates hospitals periodically.[51] *Boston Magazine* published nurses' ratings

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[43] For a discussion of the consumer movement see Thomas W. Maloney & Barbara Paul, *The Consumer Movement Takes Hold in Medical Care*, HEALTH AFF., Winter 1991, at 268. *See also* MARIE HAUG & BEBE LAVIN, CONSUMERISM IN MEDICINE: CHALLENGING PHYSICIAN AUTHORITY 83 (1983).

[44] *See* Eliot Friedson, *Prepaid Group Practice and the New "Demanding Patient"*, 51 MILBANK Q. 473 (1973) [hereinafter Friedson, *Prepaid Group Practice*]; Eliot Friedson, *Client Control and Medical Practice*, 65 AM. J. SOC. 374 (1959) [hereinafter Friedson, *Client Control*].

[45] *See generally* BARRY FURROW ET AL., HEALTH LAW (1994).

[46] Goldfarb v. Virginia State Bar, 421 U.S. 773, 788 (1975).

[47] *But see* American Medical Ass'n v. FTC, 638 F.2d 443, 448 (2d Cir. 1980), *aff'd*, 455 U.S. 676 (1982) (per curiam) (holding that the AMA's effort at dropping provisions that prohibited advertising was insufficient).

[48] *See* Kenneth J. Arrow, *Uncertainty and the Welfare Economics of Medical Care*, 53 AM. ECON. REV. 941, 964-65 (1963).

[49] Stuart H. Altman & Marc A. Rodwin, *Half-Way Competitive Markets and Ineffective Regulation: The American Health Care System*, 13 J. HEALTH POL., POL'Y & L. 323, 324 (1988); *see also* Judith H. Hibbard & Edward C. Week, *Consumers in a Competition-Based Cost Containment Environment*, 9 J. OF PUB. HEALTH POL'Y 233 (1988).

[50] Ron Winslow, *Data Spur Debate on Hospital Quality*, WALL ST. J., May 24, 1990, at B1.

[51] *See, e.g., America's Best Hospitals*, U.S. NEWS & WORLD REP., Apr. 30, 1990, at 51-60.

of hospitals and physicians.[52] *Consumer Reports* has rated various health maintenance organizations (HMOs), offered advice on purchasing long term care insurance, and published articles on health reform from a consumer perspective.[53] *The Public Citizen Health Research Group* publishes a directory of practicing doctors that have been disciplined by states and the federal government.[54] The states of California, New York, and a collaborative venture between providers and businesses in Cleveland now publish statistics on surgical outcomes for both hospitals and doctors.[55] And the Clinton administration says it will promote this trend, if Congress enacts the *Health Security Act*, by providing information on health plans to the public.[56] All these groups hope that when patients have access to more information they will be better able to choose, and medical care providers will improve their performance as a result.[57]

Still, there is no equivalent of *Consumer Reports* to assess the competence and integrity of physicians and their advice, and patients have difficulty assessing physicians or choosing ancillary medical care facilities. In a 1989 survey conducted by the Consumer Federation of America, more than half of the persons interviewed indicated that they found it somewhat difficult or very hard to shop for doctors and hospitals, and nearly three-quarters found it somewhat difficult or very hard to shop for medical services.[58] Consumers even have a hard time determining physicians' specialties and training, whether they are board certified, and other basic information about their qualifications.[59] Moreover, physicians are in a position to control information and access to services and learn to manage demanding patients.[60]

Nevertheless, health care providers do try to cater to consumer wants. Responding to the demand for convenient services for affluent households, some physician groups now make home visits and walk-in medical centers provide medical care without an appointment.[61] Some of these practices are located in shopping centers and will provide pagers to patients who can shop and return only when they are beeped.

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[52] Art Jahnke, *The Doctors the Nurses Go To*, BOSTON MAG., Oct. 1990, at 77.

[53] A collection of these articles has been published as a book. CONSUMER REPORTS, HOW TO RESOLVE THE HEALTH CARE CRISIS: AFFORDABLE PROTECTION FOR ALL AMERICANS (1992).

[54] SIDNEY WOLFE ET AL., PUBLIC CITIZEN'S HEALTH RESEARCH GROUP, 10,289 QUESTIONABLE DOCTORS (1993).

[55] Linda Oberman, *Data Measuring Quality Advances*, AM. MED. NEWS, Jan. 17, 1993, at 2.

[56] Health Security Act, (V)(B)(1). The Health Security Act was introduced November 20, 1993 by Congressman Gephardt in the House of Representatives as H.R. 3600 and by Senator Mitchell in the Senate as S. 1757. The Clinton health care legislation has spurred interest in promoting mechanisms to make health care organizations responsive to consumers. For a discussion of these issues, see Shoshana Sofaer, *Informing and Protecting Consumers Under Managed Competition*, HEALTH AFF., Supp. 1993, at 76; Walter Zelman, *Who Should Govern Purchasing Cooperatives?*, HEALTH AFF., Supp. 1993, at 49.

[57] For a discussion of the limitation of using disclosure to promote the interests of patients that draws on the experience of consumers in other contexts, see Marc. A. Rodwin, *Physicians' Conflicts of Interest: The Limitations of Disclosure*, 321 NEW ENG. J. MED. 1405 (1989). Nonetheless, many commentators advocate the disclosure of physician economic incentives as a way to promote the interests of consumers. *See, e.g.*, Douglas F. Levinson, *Toward Full Disclosure of Referral Restrictions and Financial Incentives by Prepaid Health Plans*, 317 NEW ENG. J. MED. 1729 (1987).

[58] CONSUMER FEDERATION OF AMERICA, PUBLIC OPINION ABOUT HEALTH CARE PURCHASES: COSTS, EASE OF SHOPPING AND AVAILABILITY (1989).

[59] *See* Julia M. Reade & Richard M. Ratzan, *Access to Information—Physicians' Credentials and Where You Can't Find Them*, 321 NEW ENG. J. MED. 466 (1989).

[60] *See* Friedson, *Prepaid Group Practice*, *supra* note 44, at 473.

[61] These walk-in centers, dubbed "doc in a box" in the trade have spread to many parts of the country. Some, such as *Health Stop* are national chains. For a discussion of a private practice built on home care/house calls, see Arthur J. Samuels, A New Concept for Health Care Reform: Comprehensive Managed Medical Care in Patients' Home By Internists (paper presented at the 1994 Annual Meeting of the American Geriatrics Society and the Association for Aging Research, Los Angeles, May 19-22 1994) (on file with

Some HMOs have used patient surveys to judge consumer attitudes and rate the performance of physicians on such matters as the amount of time patients have to wait for an appointment, how patients perceive their manner, and other measures of patient satisfaction.[62]

Several efforts show imaginative ways to facilitate decision making by users of medical services. Often the choice between treatments requires weighing competing values: informing patients of the risks and benefits in quantitative terms may not enable patients to make informed decisions. John Wennberg and his colleagues therefore developed an interactive video disc to help patients with breast or prostate cancer understand the implications of treatment choices.[63] The disc includes interviews with patients who have used different therapies indicating how it has affected them along with explanations and graphics explaining the medical aspects of the treatment.

In a similar vein, John Ware headed a team that developed survey instruments to assess medical care.[64] However, rather than using measures of quality based on technical assessments by third parties, Ware uses statements by patients concerning how well they function and feel.[65] And several other researchers are assessing pharmaceutical products, medical procedures and therapies, and other medical care based on how it affects the quality of the patients' lives.[66]

Paul Cleary, Thomas Delbanco and their collaborators also developed surveys to assess quality of hospital care from the patient's perspective. These surveys elicited the views of patients on several dimensions of their hospital care.[67] These included the communication between doctors, nurses and patients; the response of medical personnel to patients' needs and desires; the role patients played in decision-making; the manner in which medical personnel treated patients; pain management; patient education; and discharge preparation. Hospitals can use such surveys to systematically assess the perceptions of patients and thus alter hospital practices. If the results of the survey are publicized, the risk of losing patients to competitors will provide hospitals with an even greater incentive to respond to patients' concerns.

Another approach is to give patients a greater role in their treatment while in the hospital. Some hospitals allow patients to administer pain medications themselves. *New York University Medical Center* developed a "cooperative unit" in which patients and a care partner take charge of daily tasks. Patients administer their medicines, choose

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author). *See also* J. Portnow & A. Samuels, *Home Care, in* THE PRACTICE OF GERIATRICS (E. Calkins et al. eds., 1992).

[62] U.S. Health Care is one of the first HMOs to make this a standard feature of their management. *See* Neil Schlackman, *Integrating Quality Assessment and Physician Incentive Payment,* QUALITY REV. BULL., Aug. 1989, at 234, 236.

[63] For a discussion of his work, see Thomas W. Maloney & Barbara Paul, *The Consumer Movement Takes Hold in Medical Care,* HEALTH AFF., 1991, at 272.

[64] *See* Anita L. Stewart, *Functional Status and Well-Being of Patients with Chronic Conditions: Results from the Medical Outcomes Study,* 262 JAMA 907 (1989); Alvin R. Tarlov et al., *The Medical Outcomes Study: An Application of Methods for Monitoring Results of Medical Care,* 262 JAMA 925 (1989).

[65] *See* Maloney & Paul, *supra* note 63, at 272-73. The work of Professors Ware and Wennberg are part of the Picker/Commonwealth Fund Patient Centered Care Program.

[66] For a review of the literature, see Croog & Levine, *supra* note 41, at 508-528; *see also* KAREN DUNNELL & ANN CARTWRIGHT, MEDICINE TAKERS, PRESCRIBERS, AND HOARDERS (1972).

[67] MARGARET GERTEIS ET AL., THROUGH THE PATIENT'S EYES: UNDERSTANDING AND PROMOTING PATIENT-CENTERED CARE (1993); Thomas Delbanco, *Enriching the Doctor-Patient Relationship by Inviting the Patient's Perspective,* 116 ANNALS OF INTERNAL MED. 1414, 1414-18 (1992); Paul D. Cleary et al., *Patients Evaluate Their Hospital Care: A National Survey,* HEALTH AFF., Winter 1991, at 255.

For discussion of related approaches, see NANCY MOORE & HENRIETTA KOMRAS, PATIENT-FOCUSED HEALING; INTEGRATING CARING AND CURING IN HEALTH CARE (1993).

their own meals at a dining facility and perform other tasks. Drawing on such approaches, proponents of medical consumerism suggest that patients can self-administer and monitor other treatments, particularly for many chronic illnesses.

Medical consumerism shows that market forces and patient perspectives can serve as powerful and constructive tools to make medical care institutions more responsive to the needs and wishes of patients. The challenge lies in finding ways to promote consumer consciousness in the public and to make it easier for medical consumers to organize and communicate their wishes.[68] Without the free use of "voice," providers will have a poorer sense of why patients are leaving and consumers will feel more limited in their choice of alternative providers.

Here there are lessons to be drawn from some of the successful consumer oriented changes that have occurred as a result of the women's and disability rights movements. Both of these political movements challenged the excessive reliance on medical expertise and paternalism and made use of market forces to promote their respective agendas.

C. The Women's Health Movement

Starting in the mid-1960s, women's groups started to criticize medical care institutions.[69] They believed that the way medicine was practiced was often sexist and denied women autonomy and control over their bodies. The result, they said, was poor quality care, provided in a demeaning manner, which often reduced rather than improved the quality of women's lives. The medical profession, these groups also said, inappropriately medicalized social problems; they therefore sought to change medical practice and to increase lay women's control over their health outside of traditional medical care institutions.[70] They underlined four main areas of concern.[71]

1. Doctors and Medical Institutions Lacked Women's Perspectives and Therefore Did Not Adequately Protect their Health.

The medical profession ignored many medical problems that pertain exclusively or primarily to women. For example, Diethylstilbestrol (DES) was widely prescribed to over 3 million women from World War II until 1970 to prevent miscarriages, even though several studies suggested it was ineffective for this use. Starting in the 1970s, many daughters of women who had taken DES developed a rare form of vaginal cancer during puberty. Despite these findings, the National Institutes of Health funded studies of DES as a post-coital contraceptive and DES was promoted as a post-coital contraceptive by doctors and pharmaceutical firms. The Food and Drug Administra-

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[68] James A. Morone, The Democratic Wish 253-321 (1990); Friedson, *Client Control, supra* note 44.

[69] For an early book length history, see Sheryl B. Ruzek, The Women's Health Movement: Feminist Alternatives to Medical Control (1978); *see also* Helen Marieskind, *The Women's Health Movement*, 5 Int'l J. Health Services 217 (1975). For a more recent analysis, see Mary K. Zimmerman, *The Women's Health Movement: A Critique of Medical Enterprise and the Position of Women, in* Analyzing Gender: A Handbook of Social Science Research 442 (Bess B. Hess & Myra Marx Ferree eds., 1983); Lesley Doyal, *Women, Health and the Sexual Division of Labor: A Case Study of the Women's Health Movement in Britain*, 13 Int'l J. Health Services 373 (1983); Judy Norsigian, *The Women's Health Movement in the United States* (1991) (Paper presented at the Symposium *Our Bodies, Our Medicine: Autonomy in Medical Care*); Sandra Morgan, Into Our Own Hands: The Women's Health Movement: 1970-1990 (forthcoming).

[70] Catherine Kohler Riessman, *Women and Medicalization: A New Perspective*, 14 Soc. Pol'y 3, 6 (Summer 1983).

[71] *See generally id.*; The Boston Women's Health Book Collective, *The Politics of Women and Medical Care, in* The New Our Bodies, Our Selves (1992); Beatrice S. Levin, Women and Medicine (1980).

tion (FDA) was slow to place restrictions on its use, which prompted women's groups to argue that regulatory officials would have acted more promptly had the risks fallen on men.[72]

The response of government regulators to the risks of Thalidomide is another case in point. Thalidomide was kept on the market in Britain long after there was evidence that it caused serious birth defects. Women at the FDA were on the forefront of efforts to regulate its use in the United States.[73]

Over-medicalization also presents risks for women. Today doctors often are quick to operate on women when less radical approaches may be preferable. Studies show that doctors perform hysterectomies and cesarean-sections more often than necessary or desirable.[74] Cesarean births usually present greater risk than vaginal births for women, cost more and often leave women far less satisfied.[75]

2. Doctors and Medical Institutions Delivered Medical Care in a Demeaning and Derogatory Manner.

When providing medical care, many doctors talked down to women, treating them as incapable of understanding information or participating in medical care.[76] Gynecological and obstetric care was often delivered in a manner that suited the convenience of medical professionals (mostly men) rather than their patients. Doctors often did not provide information on what they were doing, and often they did not listen to the concerns of their patients or consult women on significant medical choices.

In the 1950s, women were expected to be passive in child birth. Birth took place in a cold medicalized surrounding and the mothers were often denied information, restrained while in labor, and sometimes drugged and strapped. To fit the schedules of doctors, births were often induced when not necessary; other times they were delayed by holding patients' legs together. Babies were pulled out with forceps. Mothers and fathers were frequently denied any contact with their newborns for several hours. And, as noted *supra*, Cesarian-sections were performed more often than necessary.[77].

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[72] Zimmerman, *supra* note 69.

[73] *Id.* at 445.

[74] PAMELA S. EAKINS, THE AMERICAN WAY OF BIRTH (1986); BEATRICE S. LEVIN, WOMEN AND MEDICINE 162 (1980); JUDITH W. LEAVITT, BROUGHT TO BED: CHILDBEARING IN AMERICA: 1750 TO 1950 65 (1986); INGRID VAN TUINEN & SIDNEY M. WOLFE, UNNECESSARY CESARIAN SECTIONS: HALTING A NATIONAL EPIDEMIC (1992); Noralou P. Roos, *Hysterectomy: Variations in Rates Across Small Areas and Across Physicians' Practices*, 74 AM. J. PUB. HEALTH 327 (1984); Carol Sakala, *Medically Unnecessary Cesarean Births: Introduction to a Symposium*, 37 SOC. SCI. & MED. 1177 (1993) [hereinafter Sakala, *Medically Unnecessary Cesarean Births*]; Carol Sakala, *Midwifery Care and Out-of-Hospital Birth Settings: How Do They Reduce Unnecessary Cesarean Section Births?*, 37 SOC. SCI. & MED. 1233 (1993) [hereinafter Sakala, *Midwifery Care*]; Centers for Disease Control, *Rates of Cesarian Delivery — United States*, 42 MORBIDITY & MORTALITY WKLY. REP. 286 (1991); *Too Many Cesarians*, CONSUMER REPS., Feb. 1991, at 120.

[75] Cynthia S. Mutryn, *Psychosocial Impact of Cesarean Section on the Family: A Literature Review*, 37 SOC. SCI. & MED. 1271 (1993); E.L. Shearer, *Cesarean Section: Medical Benefits and Costs*, 37 SOC. SCI. & MED. 1223 (1993).

[76] Mary Lynn M. Luy, *What's Behind Women's Wrath Toward Gynecologists*, MODERN MED., Oct. 14, 1974, at 17.

[77] *See supra* note 74.

3. Medical Institutions Reinforced Disparaging Social Roles and Stereotypes of Women.

Many doctors defined women's health problems primarily in terms of their reproductive functions. According to this technical view, "[a] woman is a uterus surrounded by a supporting organism . . ."[78] Such views linked common illnesses to women's reproductive systems and were used to preclude women from entering into many social roles on a par with men.

Gynecologists proclaimed expertise on women's psychology and other areas that went beyond any medical competence.[79] Many statements of doctors, supposedly made on the basis of expertise, were little more than social mores dressed up as science. In short, medical lore and medical education had built-in stereotypes and prejudices which reinforced myths and prevailing patterns of discrimination.[80]

One leading gynecology textbook published in 1981 states:

> The frequency of intercourse should depend primarily upon the male sex drive, for the male physiology involved requires active physical stress. . . . The female should be advised to allow her male partner's sex drive to set their pace and she should attempt to gear hers satisfactorily to his.[81]

An obstetrics and gynecology textbook published in 1979 states:

> The evaluation of the patient's personality need not be a lengthy matter. It begins as she enters the consultation room and sits down. Character traits are expressed in her walk, her dress, her makeup. . . . The observant physician can quickly make a judgment as to whether she is overcomplaining, overdemanding, aggressive, passive, erotic or infantile. . . .[82]

4. Medicalization of Women's Lives Removed Women's Control of Their Bodies and Lives.

Medicine can and has been used as an institution of social control over women.[83] Doctors label and certify medical conditions and proclaim how such conditions can or should limit a patient's activities.[84] They also act as gatekeepers for many health care resources. Women's health activists say that medicine has been used to control their reproductive and sexual choices, foster stereotypes, and keep women in their place.[85]

The women's movement responded to these problems in several related ways. Women's groups offered critiques of conventional medical practices and medicalization of social issues. They also attacked the idea that women's health issues were the exclusive province of doctors. In articles and books they showed that medicalization forced women to adopt a sick role whereas many health care concerns could be addressed by women themselves with the support of nurses, midwives, and lay person-

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[78] I. Gladstone, *Other Aspects of the Abortion Problem: Psychological Aspects*, *in* ABORTION IN THE UNITED STATES (M. Calderone ed., 1958).

[79] Zimmerman, *supra* note 60, at 451-52.

[80] *See* Barbara Bernstein & Robert Kane, *Physicians' Attitudes Toward Female Patients*, 19 MED. CARE 600 (1981); Mary C. Howell, *What Medical Schools Teach About Women*, 291 NEW ENG. J. MED. 304, 304-307 (1974).

[81] EDMUND R. NOVAK, NOVAK'S TEXTBOOK OF GYNECOLOGY 847, 849, 851 (1981).

[82] J. ROBERT WILLSON ET AL., OBSTETRICS AND GYNECOLOGY 51 (6th ed. 1979).

[83] *See generally* Irving K. Zola, *Medicine as an Institution of Social Control*, 20 SOC. REV. 487 (1972).

[84] *See* Reissman, *supra* note 70, at 4-5.

[85] LINDA GORDON, WOMAN'S BODY, WOMAN'S RIGHT: A SOCIAL HISTORY OF BIRTH CONTROL IN AMERICA 160-65 (1976).

nel. They showed that many "routine" medical procedures were unnecessary or even harmful and that promoting women's health could be achieved with less complex and intrusive technology.[86]

Some critiques attacked the underlying values and approaches of medicine. A few analyzed medical textbooks showing sexist images and statements about women. Others focused on specific clinical choices. They suggested alternative ways to care for women and children in birth, fought for more choice in the treatment of breast cancer, showed that pelvic exams could be performed in a sensitive manner, and promoted better communication between doctor and patient.

Women also formed self-help groups.[87] Many of these groups met only to discuss particular concerns. Others became long-standing institutions such as the Boston Women's Health Book Collective and the Los Angeles Feminist Women's Health Center. These groups served many functions. They provided mutual sharing and emotional support as well as information about women's health to participants and to the general public. They showed women how to examine themselves. A few groups showed women how to perform menstrual extractions, which could be used to avoid cramping pain, and if performed at the right time could also serve as early stage abortions.[88] These groups served as patient advocates and helped train medical personnel in a more sensitive approach to providing health care. Many self-help groups also encouraged women to have an advocate with them when they received medical care, and, if this was not acceptable to their physician, to choose another doctor.

Women's groups challenged medical education as well as popular views.[89] They also sought to change doctors' behavior. The Boston Women's Health Book Collective, for example, worked with medical schools to modify their gynecological training.[90] They provided paid subjects for students to learn how to perform pelvic exams, and the women provided feedback to medical students on how they performed. As part of this program, medical students also received the Collective's book *Our Bodies, Ourselves.*[91] Women's groups also sought to change public perceptions through research and publications and active use of the media, particularly popular women's magazines. The result was wide-scale questioning of many established medical practices in such mainstream publications such as *McCall's.*[92]

Women's groups even offered competing services and institutions. Some evaluated doctors and health care providers in the region and made up lists of recommended physicians and doctors to avoid. Others created a series of alternative

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[86] Levin, *supra* note 74; Mary Ann Elston, *Medicine as 'Old Husbands' Tales': The Impact of Feminism, in* MEN'S STUDIES MODIFIED: THE IMPACT OF FEMINISM ON THE ACADEMIC DISCIPLINES (Dale Spender ed., 1981); BARBARA EHRENREICH & DEIRDRE ENGLISH, FOR HER OWN GOOD: 150 YEARS OF THE EXPERTS' ADVICE TO WOMEN (1978); Riessman, *supra* note 70.

[87] Audrey Gartner, *A Typology of Women's Self-Help Groups,* SOC. POL'Y, Winter 1985, at 25. For a more general discussion of the role of self-help groups in social movements see ALFRED H. KATZ, SELF-HELP IN AMERICA: A SOCIAL MOVEMENT PERSPECTIVE (1992); *see also* Alfred H. Katz, & Eugene I. Bender, *Self-Help Groups in Western Society: History and Prospects,* 12 J. APPLIED BEHAV. SCI. 265-82 (1976).

However, some commentators have argued that the self-care movement is not a social movement and has pacified activists. *See, e.g.,* Gordon H. DeFriese et al., *From Activated Patient to Pacified Activist: A Study of the Self-Care Movement in the United States,* 29 SOC. SCI. & MED. 195 (1989).

[88] Laura Punnet, *The Politics of Menstrual Extraction, in* FROM ABORTION TO REPRODUCTIVE FREEDOM: TRANSFORMING A MOVEMENT (Marlene Gerber Fried ed., 1990); *see also* RUZEK, *supra* note 69.

[89] Howell, *supra* note 80.

[90] Susan Bell, *Political Gynecology: Gynecological Imperialism and the Politics of Self-Help,* SCI. FOR THE PEOPLE, Sept.-Oct. 1979, at 8.

[91] The Boston Women's Health Collective, *supra* note 71.

[92] Judy Klemesrud, *Why Women are Losing Faith in Their Doctors,* MCCALL'S, June 1973, at 76-77, 116.

providers. By 1981 there were over 100 women's health centers in the U.S.[93] Until 1973, when the Supreme Court declared that access to abortion services was a constitutional right, one group called *Jane* provided underground abortion services to women in the Chicago region.[94] Women's groups helped spawn classes and services on alternative approaches to birth, including home birth and midwifery.

Women's groups organized politically and formed interest groups that monitored public actions and lobbied political representatives. For example, the National Women's Health Network monitors Congress and governmental agencies. The California Coalition for the Medical Rights of Women pushed California to adopt standards for regulation and labeling of medical devices for pregnant women. This eventually led to national manufacturers adding warning labels on over-the-counter drugs for pregnant women. These groups and others also pushed for stronger regulation of intra-uterine devices and other contraceptives. Other groups such as the Women's Legal Defense Fund and the National Association for the Repeal of Abortion Laws (now the National Abortion and Reproductive Rights Action League, NARAL) pushed women's health issues onto the political agenda.[95]

As the effect of the women's health movement became more pronounced, women's groups expanded their concerns to include menopause, eating disorders, issues of weight, osteoporosis, heart disease, diabetes, and many other issues. They found that most studies of health and safety for the general public were based on clinical studies that most often used men rather than women and thereby ignored differences between women and men.[96]

The Congressional Caucus for Women's Issues and other Women's groups pushed for greater federal funding for research on women's health. In response, the National Institutes for Health (N.I.H.) established an Office of Research on Women's Health in 1990. Criticism of the N.I.H. by the General Accounting Office and wo-

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[93] Zimmerman, *supra* note 69, at 460; J. BRUCE, WOMEN-ORIENTED HEALTH CARE, NEW HAMPSHIRE FEMINIST HEALTH CENTER, STUDIES IN FAMILY PLANNING 12(10) (1981).

[94] *See* RUZEK, *supra* note 69, at 25, 199. For a discussion of the abortion and the women's movement see GORDON, *supra* note 85; *see also* KRISTIN LUKER, ABORTION AND THE POLITICS OF MOTHERHOOD (1984); *Just Call 'Jane"*, *in* FROM ABORTION TO REPRODUCTIVE FREEDOM: TRANSFORMING A MOVEMENT (Marlene Fried ed., 1990); Lindsy Van Gelder, *The Jane Collective: Seizing Control*, Ms., Sept./Oct., 1991, at 83; Melinda Bart Schlesinger & Pauline B. Bart, Collective Work and Self-Identity: The Effect of Working in a Feminist Illegal Abortion Collective (1979) (Paper presented at the Meetings of the Society for the Study of Social Problems), *reprinted in*, WORKPLACE DEMOCRACY AND SOCIAL CHANGE (Frank Lindenfeld & Joyce Rothschild-Whitt eds, 1982).

[95] Ruzek, *supra* note 69; Zimmerman, *supra* note 69. For a review of the recent political activities of the NARAL on health care reform and women's health, see Eliza Newlin Carney, *The Morning After*, NAT'L J., Mar. 5, 1994, at 521.

[96] Vanessa Merton, *The Exclusion of Pregnant, Pregnable, and Once-Pregnable People (a.k.a. women) from Biomedical Research*, 19 AM. J.L. & MED. 369 (1994).

men's groups spurred renewed efforts.[97] Various provisions of The Women's Health Equity Act would further promote research.[98]

The women's movement has prompted providers to change their practices. In some communities women now have more choices available for birthing and gynecological care. However, in many parts of the country childbirth has become highly medicalized even though there have been changes to make the medical setting look more like a home (e.g., by adding rocking chairs and floral wallpaper to hospital rooms).[99] Some women health advocates believe that these changes are largely matters of style and marketing which do not affect the most important issues about childbirth; others believe the process has become more humanized, although there is still room for much progress.[100]

More doctors now allow women to participate in health care decisions. The attitudes of many women patients and doctors have changed. Government, too, has recognized women's health issues as a legitimate category of research and the academy has recognized women's health as a field of specialization. It has funded studies on women's health and developed policies that require N.I.H. grant recipients to include women or explain why this is not feasible.[101]

The women's health movement had political aims, but it also exemplifies a kind of medical consumerism; and the presence of market competition helped promote its goals. Medical providers have catered to women's groups in part because they risked losing income to competitors if they did not. In recent years hospitals and HMOs, for example, have marketed birthing centers to women (although in hospitals).[102] These centers range from those which provide more pleasant and home-like rooms for birthing in a hospital, to free-standing centers which offer women a less medicalized environment and often rely on midwives to supervise the process. Birthing represents an example of consumer choice working well. Women can compare notes

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[97] Hearings Before the Committee on Energy and Commerce, Subcommittee on Health and the Environment (June 18, 1990) (Testimony of Mark Nadel, General Accounting Office); UNITED STATES GENERAL ACCOUNTING OFFICE, GAO/HRD-93-17 WOMEN HEALTH: FDA NEEDS TO ENSURE MORE STUDY OF GENDER DIFFERENCES IN PRESCRIPTION DRUG TESTING (1992); NATIONAL INSTITUTES OF HEALTH, UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES, PUB. NO. 92-3457A REPORT OF THE NATIONAL INSTITUTES OF HEALTH: OPPORTUNITIES FOR RESEARCH ON WOMEN'S HEALTH (1992); ANNA C. MASTROIANNI ET AL., WOMEN AND HEALTH RESEARCH: ETHICAL AND LEGAL ISSUES OF INCLUDING WOMEN IN CLINICAL STUDIES (1994); Ruth L. Kirschstein, *Research on Women's Health*, 81 AM. J. PUB. HEALTH 291 (1991); Merton, *supra* note 96; Gina Kolata, *N.I.H. Neglects Women, Study Says*, N.Y. TIMES, June 19, 1990, at C6.

[98] The Act was introduced as multiple bills or amendments several times since 1990. The 1993 Women's Health Equity Act included 32 separate bills or amendments. *See* CONGRESSIONAL CAUCUS FOR WOMEN'S ISSUES, Sept. 14, 1993 (news release).

[99] *See* Sakala, *Medically Unnecessary Cesarean Births*, *supra* note 74, at 1183-84.

[100] For a skeptical view of the changes brought by consumerism and on childbirth, see Raymond G. DeVries, *The Alternative Birth Center: Option or Cooptation?*, WOMEN & HEALTH, Fall 1980, at 47; *see also* Sakala, *Midwifery Care*, *supra* note 74, at 1236.

[101] The N.I.H. announced this policy in February, 1991. For an overview of women's health research, see the JOURNAL OF WOMEN'S HEALTH RESEARCH, which was started in 1992 by the Society for the Advancement of Women's Health Research. See also *Institute of Medicine, Women in Health Research: Ethical & Legal Issues of Including Women in Clinical Trials* (1994).

[102] RUTHIE H. DEARING ET AL., MARKETING WOMEN'S HEALTH CARE 58 (1987) ("Data from national surveys conducted by market consultants and market researchers indicate that catering to the maternity market segment is critical to patient acquisition, not only for maternity department, but for other health services as well."); Nancy Worcester & Marianne H. Whatley, *The Response of the Health Care System to the Women's Health Movement: The Selling of Women's Health Centers*, *in* FEMINISM WITHIN THE SCIENCE AND HEALTH CARE PROFESSIONS: OVERCOMING RESISTANCE (1988); DeVries, *supra* note 100; *Providers Target Women with Full-Service Centers*, BUS. & HEALTH, November 1986, at 55 (noting that "this market is ripe for servicing").

with friends, learn from their experiences, educate themselves about the main choices and issues, and plan when and what services they will use.

While the women's health movement has had some positive effects on medicine, change has been slow and partial.[103] Professional power is still strong and often determines how health services are performed. Despite the women's movement's efforts to allow women greater control over childbirth, trends exist that counter such control. For example, births by cesarian section in the United States have increased steadily from 4.5% in 1965 to 24% in 1986 and stayed around this level until 1991.[104] Despite efforts by women's groups and consumers, women frequently have been forced to have cesarean sections against their will.[105] Although there may be some legitimate reasons for increased cesarian section births, such trends, one can argue, show that the women's movement has had only limited effects on changing practices. Yet neither have quality assurance programs successfully countered these practices.

D. The Disability Rights Movement

Society has long stigmatized people with disabilities by shunting them aside or warehousing them in quasi-medical institutions.[106] Professionals often stress the disability as the source of their client's "problem" and say that professional help or caretaking is needed. Frequently, professionals exercise control over important aspects of their client's lives.[107] When institutionalized, people depend on the schedules and goodwill of professionals who provide their care. When they live outside of institutions, their lives are frequently isolated because employers and institutions often discriminate against them. Often they cannot access public buildings and transportation although the recently enacted Americans with Disabilities Act seeks to prevent this kind of discrimination.[108]

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[103] Elston, *supra* note 86, at 189.

[104] *See* Centers for Disease Control, *supra* note 74. These rates are particularly high. To put these trends in perspective some hospitals report cesarean section rates of less than two percent with very good outcomes and there is no evidence that these hospitals have a biased selection. For a discussion of these trends, see Sakala, *Medically Unnecessary Cesarean Births, supra* note 74.

[105] Moving narratives are reported in the following two publications. *See, e.g.*, C/SEC Newsletter 1-16, 1975-90, Newsletter of Cesarean/Support Education and Concern; The Clarion (1982) (Newsletter of International Cesarean Awareness Network).

[106] This section often speaks about people with disabilities as a group. This kind of categorization generalizes. People with disabilities have different backgrounds and interests and great differences also exist in the kind of disabilities they may have. There are also many different groups organized around the interests of particular illnesses or disabilities. Nevertheless, important trends in recent years have been the formation of a disability rights movement and civil rights legislation to prevent discrimination against people with disabilities. I seek to learn from these common elements even though there are many differences. We should not forget that an important trend in the disabilities rights movement is that people are demanding to be treated as individuals. For an overview of the literature on disability as a category, see Michelle Fine & Adrienne Asch, *Disability Beyond Stigma: Social Interaction, Discrimination and Activism*, J. Soc. Issues, Volume 44, 1988, at 3. For a political perspective on American disability policy and the way society has defined disability, see Deborah A. Stone, The Disabled State (1984).

[107] For a review of disability policy in the United States see Edward D. Berkowitz, Disabled Policy: America's Programs for the Handicapped (1987); Stone, *supra* note 106. Disability Policy: Restoring Socioeconomic Independence, 67 Milbank Quarterly Supplements 1, and 2 (1989).

[108] The Americans with Disabilities Act, 42 U.S.C. § 1201 (1991). For a discussion of the statute see The Americans with Disabilities Act: From Policy to Practice (Jane West ed., 1991).

For a history of the disability rights movement see generally Gary Albrecht, The Disability Business: Rehabilitation in America (1992); Richard Scotch, From Goodwill to Civil Rights: Transforming Federal Disability Policy (1984); Joseph P. Shapiro, No Pity - People With Disabilities Forging A New Civil Rights Movement (1993); Richard B. Treanor, We Overcame: The Story of Civil Rights For Disabled People (1993); Richard K. Scotch, *Disability as the Basis for a Social Movement: Advocacy and the*

Not surprisingly, many people with disabilities object to the approach and attitudes of professionals who provide them with services. They resent being put in a position of dependence and being treated as sick or infantile. They object to the presumption that they are incapable of making choices themselves. Custodians and professionals, they feel, neglect their interests and concerns, particularly those involving quality of life rather than their medical treatment. And social service funding for disabled people often benefits the providers of care most directly and the people with disabilities only secondarily.

In response, disability rights activists have formed self-help groups and independent living centers to provide social support, have organized politically, and have formed a community.[109] The groups range in style and approach, but typically people with disabilities provide the organizational leadership and perform many of the services. They offer counseling, informal networks and information, and various forms of social support.

A variety of aims spurred the disability rights movement. One was to shift the burden of responsibility from the individual with a disability to the institutions or parties which create obstacles or do not make reasonable accommodations. For example, advocates argue that the absence of ramps and elevators, not disability, impedes access for people with wheelchairs. And the absence of braille or auditory signals impedes access by the blind, not their lack of sight alone. Disability, advocates argue, is often socially created. Disability rights advocates cast problems of public access and employment as issues of civil rights and discrimination. They have organized a political movement to pass legislation that made it illegal to discriminate on the basis of disabilities.[110]

The push for independent living is another important development within the disabilities rights movement. The aim is to enable people with disabilities to live outside of institutions: in communities, in families, or as individuals. Independent living lets people with disabilities control their lives rather than rely on professionals to provide services and supervision. It breaks relations of dependency and empowers individuals.[111]

Beyond the rehabilitative ideal of providing self-sufficiency in housing, there is an independent living *movement* that promotes the ideal of people with disabilities gaining control of their lives. The movement created a range of resource centers and social support networks.[112]

Politics of Definition, *in* MOVING DISABILITY BEYOND STIGMA (Adrienne Ash & Michelle Fine eds., 1987) [hereinafter Scotch, *Disability as the Basis for a Social Movement*].

[109] NANCY CREWE & IRVING K. ZOLA, INDEPENDENT LIVING FOR PHYSICALLY DISABLED PEOPLE (1983); Irving K. Zola, *The Evolution of the Boston Self-Help Center*, *in* A WAY OF LIFE FOR THE HANDICAPPED (Glenys Jones & Norman Tutt eds., 1987) [hereinafter Zola, *Evolution*]; Irving K. Zola, *The Politicization of the Self-Help Movement*, SOC. POL'Y, Fall 1987, at 32-33; Irving K. Zola, *Helping One Another: A Speculative History of the Self-Help Movement*, 60 ARCHIVES PHYSICAL MED. & REHABILITATION 452-56 (1979).

For a discussion of self-help groups in general, see KATZ & BENDER, *supra* note 87.

[110] Americans with Disabilities Act, 42 U.S.C. §§ 1201 (1991). For a discussion of the statute see EQUAL EMPLOYMENT OPPORTUNITY COMMISSION & U.S. DEP'T OF JUSTICE, AMERICANS WITH DISABILITIES ACT HANDBOOK (1991).

[111] GARY WOODILL, INDEPENDENT LIVING AND PARTICIPATION IN RESEARCH (1992); Andrea G. Zetlin et al., *Socialization Effects on the Community Adaptation of Adults Who Have Mental Retardation*, *in* LIVING ENVIRONMENTS AND MENTAL RETARDATION 293 (Sharon Landesman & Peter Vietze eds., 1987).

[112] Gerben DeJong, *Independent Living: From Social Movement to Analytic Paradigm*, 60 ARCHIVES PHYSICAL MED. & REHAB. 435(1979); Scotch, *Disability as the Basis for a Social Movement*, *supra* note 108; Zola, *Toward Inclusion*, *supra* note 108.

Several approaches are now used to promote independent living: furnishing housing that is fully accessible, providing attendants to help with various tasks of daily living, and offering other resources under the control of the individuals with disabilities. Many independent living centers function as self-help groups and are staffed in large part by people with disabilities.[113]

One illustration is a pilot project planned in Ontario, Canada. The Center for Independent Living in Toronto (CILT) and affiliated groups have proposed a way of funding personal care services for people with disabilities.[114] Rather than having health or social service agency officials provide services, the government will provide direct funds in lieu of services to beneficiaries, who will become the managers. Each beneficiary will be responsible for hiring, training, supervising and firing their attendant and accounting for their use of funds. The pilot program (for approximately 80 people), will start in 1994, and will free beneficiaries from institutional, bureaucratic and professional controls.[115]

The independent living movement helped to change the way we think about disabilities. In the past, the medical community assumed that professionals, because of their expertise, would decide what services disabled people needed and the best way in which to provide them. In contrast, independent living advocates say that it is important to treat people with disabilities as normal people and that the way to do this is let them make their own decisions and give them the "dignity of risk."[116] They say that professionals, like personal care attendants, should work under the direction of disabled people and allow them to set their goals and agenda.

Another feature of the disabilities rights movement is the change in self-image. In the past many people with disabilities felt inadequate; they blamed themselves for their difficulties and sought to quietly accept, and adapt to, the status quo. To the extent they sought to integrate themselves in the larger community, their models were what some disability rights activists call "super-crips": people who overcome, ignore or deny they have a disability in their struggle to become like "normal" people.

More recently, there has been a shift in attitude characterized by pride. Rather than apologize for their differences and try to change, many people with disabilities have celebrated their differences and sought to have others change their attitudes and responses.[117] Thus increasingly many of the deaf, for example, increasingly speak of a deaf community and culture and rejoice in their own language.[118] Some have resisted efforts to have deaf people speak or lip read and favor American Sign Language over Sign English, which follows the syntax of English.

This awakening engendered a new voice. People with disabilities sought to explain their lives, aspirations, and problems, rather than depend on professionals to

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[113] Zola, *Evolution*, *supra* note 108.

[114] ATTENDANT CARE ACTION COALITION, DIRECT INDIVIDUALIZED FUNDING FOR ATTENDANT SERVICES: A PROPOSED MODEL (1991); CENTER FOR RESEARCH AND EDUCATION, SELF-DIRECTED ATTENDANT SERVICES: TOWARD A CONSUMER ORIENTED POLICY AND PERSPECTIVE ON PERSONAL SUPPORT SERVICES (1990); Letter from Ross Robinson, Vic Willi, and Ian Parker, Canadian Association of Independent Living Centers, to the Hon. Francis Lankin, Ontario Minister of Health (Feb. 14, 1992) (on file with author).

[115] Interview with Victor Willi, Executive Director, Center for Independent Living of Toronto (Mar. 22, 1984).

[116] Irving K. Zola, *Toward the Necessary Universalizing of a Disability Policy*, 67 MILBANK Q. 1401 (1989).

[117] This pride may be a characteristic stage of social movements. Similar trends have occurred in the civil rights movement for African Americans, Gays, and other groups.

[118] An example of this can be seen in the movement to appoint a deaf person as president of Gauledette College, a College for deaf people. This movement from the perspective of a sympathetic person who hears is recounted in OLIVER W. SACHS, SEEING VOICES: A JOURNEY INTO THE WORLD OF THE DEAF (1989).

speak for them. This expressive aspect of the movement was partly geared toward political change and partly an effort to assert humanity, individuality and community that had long been dormant. This new attitude has also manifested itself in people who demand that employers and institutions make accommodations to meet their needs rather than by trying to adapt on their own to institutions.

III. PATIENT ACCOUNTABILITY: COMMON ELEMENTS AND LESSONS

What can be learned from these four movements? Each identified deficiencies in our health care system that quality assurance programs would not be likely to identify as problems. And each movement pushed for changes which quality assurance programs would not be likely to encourage. These movements pressed for large-scale changes in health care. They used a combination of political, market and legal approaches to encourage physician and organizational accountability to patients and the public.

The disability rights and women's health movements were social movements that had natural constituencies, easily identifiable and organized. These groups had common concerns and specific grievances. Because they organized for a host of issues, they had the political organization in place to promote their health care agenda.

In contrast, the patients' rights movement and medical consumerism lacked a clear, continuous, or concentrated constituency. Being a patient is a transient phenomenon for most people. Most people who are well do not identify themselves primarily as consumers of medical care, so organizing patients or medical consumers is more difficult. And without political organization the market may be insufficient to encourage medical institutions to respond.

Yet, both the patients' rights movement and medical consumerism also promoted change. The idea of patients having civil and other rights provided a framework and approach that the women's health and disability rights movement used. Both the women's and disability rights movements used legal approaches, including lawsuits and legislation. Indeed, they exemplified the patients' rights agenda for specific groups.

Furthermore, both the women's and disability rights movements used consumer-oriented strategies as complements to their political organizing. The women's health movement was effective in part because doctors and hospitals responded to their concerns as a way to compete and increase their business. Women's groups used markets by providing information on medical care to women, by rating and referring to selected doctors, and by providing alternatives to traditional medical care. The disabilities rights movement promoted the idea that people with disabilities should not have to rely on the judgements and choices of professionals but instead should make decisions on their own. This approach often drew on market and consumer approaches. For example, activists in Toronto lobbied for direct funding of disability benefits for personal care attendants, a change which will use markets and give people with disabilities greater choice.

One common element informs all of these movements: the idea that professionals—be they doctors or quality assurance specialists—are not always the only or the best judges of what is in the interest of the groups they serve. The people who receive the service can and often do identify quite significant problems that the experts overlook.

IV. CLASHING OR COMPLEMENTARY PARADIGMS?

Political controls and market, alone are an insufficient way to promote quality of care. There are many instances where consumers and patients alone will not be able to assess quality because differences will only be apparent through expert knowledge and analysis. On certain technical issues, the lay person may be uninformed or misinformed and so consumer satisfaction may not be a meaningful measure of good care. On the other hand, many consumer concerns and quality problems are not identified by existing quality assurance programs.

The quality of care paradigm and the patient accountability paradigm provide different yet complementary ways to improve medical care. Each approach fulfills distinct functions not easily performed by the other. Both approaches are necessary. Today, however, to promote patient accountability, our health care system and health policy emphasize technical quality assurance first, then use consumer exit second, and consumer voice last.

A danger exists that as managed care grows and we reform our health care system, we will neglect or even discourage the use of consumer voice and exit as means to promote quality and accountability. For those physicians and medical providers are forced to change, such approaches are unwieldy and often irritating, unpleasant, and cumbersome. Consumer voice and exit may challenge the authority of professionals and medical institutions.

Yet we must not overlook the past contributions and future potential of consumer voice and exit to promote desirable change. We should not wait until dissatisfied patients and the public form political movements and demand change. Rather, society should encourage the use of voice and accountability. The challenge we face is to devise ways to build institutions incorporating voice and accountability within our health care system.