GrantWatch

I. ESSAY

The Consumer Movement Takes Hold In Medical Care

by Thomas W. Moloney and Barbara Paul

Most Americans encounter the medical system only occasionally, through routine check-ups and maintenance, processes usually provoking no more anxiety than general dental care. But when serious illness strikes, patients often experience it as an assault on identity and sense of self. Both seriously ill and seriously worried patients crave information. They can experience powerful sensations and dire fears, but they often do not know how to interpret them. They want to know what medicine can do and what they can do for themselves to make the best of whatever their new reality is to be.

Meanwhile, modern medicine too often behaves as if caring for such human needs is beyond its purpose. Medical education stresses pathophysiologic process to the exclusion of the social, personal, and even functional dimensions of health and illness. Residency training teaches diagnosis by biotechnological methods, rendering interpersonal skills and human performance measures anachronistic. Medical financing has followed suit: it so favors the biotechnological aspects of care that its implicit message to professionals is, "Deal with your patients' concerns on your own time."

This disjuncture between the patient's realities and the pursuits of modern medicine is moving toward a new alignment. This essay examines forces for change that are recognizable, formidable, and hard at work. Change will come because millions more aging American families will experience serious illness and insist on it, because researchers are facilitating it, and because medical practitioners and organization leaders are beginning to see the rewards of providing it. But the driving force for change is competition in medical care delivery.

Competition is leading to a redefinition of business purpose and quality

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in industries from automobiles to banking to airlines. Businesses that are winning the loyalty of customers these days define quality as meeting the needs of the customer, a concern that includes but is well beyond manufacturing a reliable product. Companies losing customers are those driven by the traditional producer's preoccupation with product improvement while ignoring service enhancement. Back in favor is Peter Drucker's thirty-year-old conclusion that the only valid business purpose is to create satisfied customers. The buyer's pursuit of better services has been so influential that *Business Week* has labeled the 1990s the "Decade of the Customer."

Changes in customers' expectations are moving into medical care services, as patients begin to take matters more into their own hands. Patients may well mobilize an expanded definition of quality in medical care, one calling on practitioners to attend to the full range of problems that patients present.

Why Change Is Inevitable

Substantial change will take place in consumers' expectations and interactions with the medical community for the following reasons.

With the growing burden of chronic care in an aging society, families are increasingly seeking practitioners skilled in addressing functional loss, pain, and anxiety.

"Baby Boomers" want far more information, involvement, control, and choice regarding the services they buy, including medical care, than do previous generations. The first real changes in hospital care have come in the services they have used first: far greater family accessibility and participation in birthing and pediatric units. The pressures of this most educated, consumer-oriented generation will soon be felt in internal medicine and geriatrics as they age and also begin to manage care on behalf of their parents.

Vast improvements in information-processing technology are making it feasible to publish patients' ratings of competing health care providers. J.D. Power changed the nature of the automobile marketplace by making consumer ratings of new cars widely available to the public. New surveys show that patients look forward to using their neighbors' ratings in deciding where to seek care in the future. Can the day be far ahead when employers, insurers, or consumer groups publish surveys of patients' experiences with competing medical plans, hospitals, or group practices? A beginning effort in Pennsylvania was reported in *The Wall Street Journal*: "[F]or the first time, consumers... can compare hospitals on price and performance, much as people compare mileage ratings, service rec-

ords, and sticker prices when they shop for cars. The implications for the nation's medical care system are huge."

Many patients are now actively involved in choosing their own medical services, often selecting a health plan or hospital first, then choosing a doctor from among those affiliated. Loyalty to a single provider is not common; many patients report they have switched hospitals or doctors recently or are considering doing so.⁵

Finally, patients are choosing providers on factors other than technical expertise, given the high quality level of equipment and personnel now readily available throughout the country and the difficulty in distinguishing among practitioners' ability to provide complex technical care. Patients are far more likely to focus on differences in providers' willingness to address the range of problems that accompany serious illness than on differences in technical skills.

The Potential

The groundwork for a major evolution in American medical care is being laid as researchers and practitioners respond to patients' mounting insistence on a more responsive system. A new era of consumerism on the part of patients could bring profound benefits over time.

Patient-centered care could put the medical care system more squarely in the business of serving the needs of patients with chronic and serious illness. This could change the nature of medical inquiry, leading to vast improvements in patient functioning, the reduction of pain, and the relief of anxieties that accompany illness.

It could expand the business of medical care and the pursuits of its practitioners. It could lead to a discernibly different role for the generalist practitioner, one in which the patient's reports are crucial diagnostic information and the physician's counsel is a crucial therapeutic tool. An expanded concept of the purpose and value of the practitioner/patient interaction could in turn force the medical payment system to revalue the time practitioners spend with patients.

It could spawn a generation of patient-interactive technologies, including educational material on treatment options and on self-management of chronic disease, as well as survey information on patients' assessments of competing medical groups, hospitals, and medical care plans. Patient-administered and -monitored treatments should also become common-place: self-administered pain medication in hospitals is only the start.

It could change how medical care is valued by ushering in a system in which patients' values regarding risks and rewards are central to determining the appropriate course of treatment. This would lead to a vast

change in the type of information collected and analyzed to assess value. It could limit the use of protocols as standards of appropriate treatment.

It could even alter the scope of medical education and the mix of applicants. Medical education for general practitioners of tomorrow may entail far more integration of knowledge from disciplines such as physical therapy, psychology, and sociology.

Finally, the sum of these changes could increase public esteem for the medical care system. The root of today's discontent with the medical system is more than financial. It is also deeply personal. Witness the frustration of a patient writing in a recent "My Turn" column of Newsweek: "I wanted to be treated as a human being, not just the owner of a defective breast." Public esteem for any industry is the best predictor of the level of public investment in it and freedom from regulation over it. Thus, the nation's future investment in the medical care system may depend more on public confidence and trust, built through a better response to the needs of its patients, than on any other factor.

The Breakthroughs

An enduring principle of biomedical science is that the only relevant phenomena are those that can be observed, described, and measured in an objective manner. Phenomena have to be describable with quantifiable precision by independent observers at different times (otherwise, how can scientists be sure they're talking about the same thing?).8 But the problems that most concern patients often lack such precision. For instance, how does a scientific practitioner respond to the "severity" of a patient's pain, the "extent" of social functioning, or the "degree" of anxiety? So despite growing pressure from patients, physicians have held to their narrow ground in the name of science-based medical practice, even when it puts them in quite vulnerable territory. Witness the hesitancy expressed about the quantification of kindness in this recent article: "Any new chemotherapeutic drug that tripled the survival of patients with incurable cancer would cause great excitement, but we do not know quite how to handle the fact that kindness, emotional support, and optimism have quantitative therapeutic activity."

Expanding the scope of medical science requires breakthroughs in the measurement of these "soft" phenomena. Recent research efforts can claim breakthroughs in a number of areas, including patients' perceptions of their own well-being, the effects of patient control over treatment choices, the role of physician encouragement in the healing process, and the aspects of hospitalization that help and hinder recovery. We outline next some of the major research breakthroughs and discuss the potential

for greater involvement by foundations in supporting such efforts.

Medical outcomes. The first major breakthrough came recently, the result of years of tenacious efforts by a team headed by John Ware, of New England Medical Center, under a project titled the Medical Outcomes Study. Ware's team has developed methods for classifying patients' statements about how well they function and how well they feel, and for translating those classifications into objective measurements. The study group developed the first assessment tools to provide valid, reliable measures of a range of the problems patients care most about, including their functional status, degree of disability, cognitive functioning, emotional health, and social interaction. For the first time, the patient becomes both the recorder and the reporter of information that now is crucial to the diagnosis and treatment processes.

Ware's innovations could ultimately transform the ways in which chronic and fatal illnesses are managed. They should expand the boundaries of the scientific approach to the management of chronic and fatal illnesses, to include how well patients function and how well they feel. Once Ware's measures are widely available, remaining a "scientific" practitioner will entail addressing these broader aspects of the patient's experience of illness. Ware's approach also could change the way in which medical care is valued. Measuring "quality" will no longer rest exclusively on traditional physiological and clinical indexes of how various body organs respond to treatment but will entail determining the effects of various treatments on the quality of patients' lives.

Foundation support could help put these powerful new outcome measures to work in a variety of actual settings. For example, such assistance would help Ware's team examine variations in the quality of care among different health plans in a medical market area and determine how employers and employees could use this information to help choose among competing plans.

Patient education. John Wennberg of Dartmouth Medical School and Albert Mulley of Massachusetts General Hospital have moved the valuation of "quality" even more toward the concerns of the individual patient. They find that for a number of medical conditions, no amount of objective clinical or physiologic data is adequate to make an appropriate clinical choice among competing therapies. For conditions such as an enlarged prostate or breast cancer, the decision can be made only by careful reference to a particular patient's unique perceptions and valuations of the likely risks and benefits of alternative therapies. "

The implications of Mulley and Wennberg's observation are immense. It suggests a need to better inform patients about their illness and the benefits and risks of alternative therapies and a need to develop better

methods of such patient education. Office-based physicians cannot provide such detailed information regarding alternative treatments. The harried physician, rotating a closed fist to illustrate the location of heart ventricles and valves—just before introducing the choice between angioplasty or bypass surgery—should soon be an anachronism.

Mulley and Wennberg's team is developing interactive video disks as the patient education technology of the future.¹² The disks use scripts and graphics to convey the nature of an illness and the effects of alternative treatments. They are based on the best clinical research and tested for patient understanding. If the method proves successful, video stores throughout the country may one day stock illness-specific educational films, dramatically changing patients' literacy about their conditions and the caliber and frequency of participation by patients in their treatment.¹³

Foundation support would help these researchers broaden their work to include additional clinical conditions. Such assistance could help establish the probabilities that alternative treatments provide the outcomes that matter to patients; help this promising work address various issues of patient comprehension; and devise new communications methods, such as the interactive video films, to help patients become fully informed about the potential benefits and risks of various treatments.¹⁴

Physicians' coaching skills. The practitioner's skills as coach will take on greater importance as care for chronic illness renders the patient's behavior itself—diet, exercise, lifestyle, medications—a more crucial part of treatment. Sherrie Kaplan and Sheldon Greenfield of New England Medical Center have demonstrated that coaching patients with chronic illness to become more involved in their care can result in better physical functioning, speedier recovery from illness, and greater ability to tolerate pain and handle stress. They urge the medical system to teach and reward practitioners who coach patients to think positively, teach self-help skills to aid recovery and coping techniques for pain and disability, and give patients a greater sense of control over their functioning.

This approach is the least well funded type of outcomes research, so evidence of its potential benefits remains thin. Foundation support would enable researchers to address several limitations of existing studies. Foundation support could also illuminate how well various practitioners' coaching styles work. The first major opportunity to examine the relationship between physicians' coaching styles and improved patient functioning and well-being is now available through the Ware team's work. Their research should give important clues about which physician styles lead to improved functioning and well-being in various types of patients. It could open a "scientific" era of research and education on how to improve physician coaching and patient motivation and compliance.

Valuing time with patients. Patients' most common complaint about their physicians is that the physician won't make time to talk with them. Stingier physician reimbursement is the usual culprit; it squeezes time with patients out of the doctor's ever busier day. Physicians wind up spending incrementally less time each year with each patient to maintain their incomes. Yet the lack of time spent with patients is also a problem in prepaid group practices, where the reimbursement pinch is not so specific. There may be more than sheer economic determinism to this disjuncture. Perhaps the lack of time made available is further evidence of the difference between the practitioner's focus on the treatment of disease and the patient's longing to discuss the illness. If so, time together may soon become more important. Under an expanded view of the role of medicine, the patient's observations become crucial in recording and reporting functioning and well-being, in choosing the appropriate course of treatment, and in carrying through any prescribed lifestyle changes.

To increase time spent with patients, practitioners could form new provider teams. These teams might include nurses, psychologists, educators, nutritionists, and physical therapists, as well as generalist physicians. Insurers could place greater relative monetary value on time spent with patients. After decades of a technology-dominated Medicare physician payment system, the Physician Payment Review Commission (PPRC) is pushing the rewards in the direction of more time with patients.

Hospital care. Researchers and practitioners, determined to become more sensitive to the way patients experience illness, have singled out hospitalization to receive special attention because of its unique trauma-provoking potential. Upon entering a hospital, patients must surrender control over their time, privacy, activities, comfort, and clothes. They forgo the reassurance, intimacy, and diversions from worry that companionship of family and friends can provide. Patients are interviewed, wheeled, scoped, poked, and processed on whatever shifting schedules they can be slotted into, alongside hundreds of others who are hurriedly "worked up" in similar ways. These events usually precede far more bewildering treatment and recovery phases. Hospitalization amounts to the gravest form of incarceration most noncriminals ever experience.

This hospitalization process was never designed with the patient/customer in mind. It is, instead, the residual of thousands of continuous accommodations to new technology and competing demands of the various practitioners who command those technologies. Hospitals are recognizing that tomorrow's patients will seek out hospitals that provide excellent patient care as well as top-notch technical services. Researchers and practitioners are calling for far more than a public relations campaign or a refurbishing of the hotel-like services hospitals provide. They point

out, by way of analogy, that companies that are serious about satisfying the customer are reorganizing their businesses throughout—from research to manufacturing, from information systems to pay incentives.

Researchers and practitioners aim to establish continuous improvement of hospital care systems, based upon careful examination of patients' experiences. They seek to identify and revise practices that contribute to inappropriately high rates of unacceptable patient experiences. Their longer-term goal is to enable hospital staffs to incorporate the systematic improvement of patients' experience into their institutions' systems for monitoring and improving care and, finally, into their professional concept of what good practice requires.

Systematic efforts to understand how today's hospital practices collide with patients' needs have just begun. Only recently have survey techniques, applied in other fields for years, been called into service to dissect how patients actually experience hospitalization. Doing so was previously considered an impossible task: different patients need different things and their needs are constantly changing. To circumvent an infinite diversity in preferences, surveyers target patients' actual experiences. They learn the frequency and intensity with which undesirable events occur to various types of patients and positive events are neglected.

A team led by Thomas L. Delbanco of Boston's Beth Israel Hospital has used focus groups to find out whether certain common hospital practices impede the recovery process. The team devised a questionnaire for patients about their experiences with a range of practices and surveyed recently hospitalized patients across the nation (see P.D. Cleary et al., "Patients Evaluate Their Hospital Care," in this volume of *Health Affairs*). A book describing the team's findings and observations about how to improve patient care practice is in preparation.¹⁸

Valid, reliable scorecards of hospitalized patients' experiences could eventually transform hospital staffing and practices, just as the medical outcomes study promises to transform the management of chronic illness. Foundation support could hasten the process. For example, far more needs to be known about how accurately hospitalized patients can recall events that took place, often amidst considerable stress, uncertainty, or distraction, or how factors such as the patient's age, educational level, or severity of illness affect the accuracy of their recall under stress.

The real work begins after surveys pinpoint the nature and severity of problems patients encounter. Developing a continuous monitoring capacity to deliver relevant, timely feedback from patients to staff members will require ingenuity and effort. A hospital must then determine which staff groups have the opportunity to improve specific problems, make them aware of the problems, involve them in devising solutions, enlist

their cooperation in carrying out new approaches, and provide incentives to help assure that new behavior becomes part of a new standard practice. This may entail implementing changes in work priorities, attentiveness to requests and potential problems, and interpersonal styles.

More serious or pervasive problems require more fundamental reconsideration of staffing responsibilities. For example, many patients crave information at times when no one authorized to give it is available. Delegating authority to provide more information on the spot is called for, even though this will challenge long traditions of tight hierarchical control over who can provide certain information. Other serious problems, such as long waiting times for pain medication, are amenable to technological solutions: providing self-administered analgesics is an easier solution than paying for extra staff or changing staff priorities.

Two groups of hospital directors, led by Mitchell T. Rabkin of Beth Israel Hospital in Boston and Ronald Anderson of Parkland Memorial Hospital in Dallas are pioneering efforts to rebuild practice systems for their hospitals that are far more patient-responsive. Participating hospitals intend to share patient reports with staff and alert them to unacceptable frequencies of unwanted experiences. Then, staff will help identify ways to eliminate inappropriate error rates, emphasizing practices that limit pain, reduce anxiety, provide information that patients seek, enhance patients' sense of control, and teach them coping and self-help skills. Information systems also being developed will measure the extent to which the changes lead to better experiences for subsequent patients.

The Role For Foundations

The breakthroughs discussed above are ushering in a new era of consumerism on the part of patients. Change is irrepressibly under way; yet the task ahead is herculean. It consists of nothing less than introducing a new paradigm for medical care delivery—one true to the principles of William Osler, yet uniquely adapted to the opportunities of today.

Foundations have an enormous opportunity to contribute. Their support could help enable medical professionals, medical institutions, and community associations to establish, as part of the fabric of their quality assurance programs, systems for the continuous monitoring and improvement of practice, based upon the scrupulous examination of patients' experiences. Foundations' goals should include helping participating professional groups to incorporate the systematic improvement of patients' experiences into their professional concept of good practice.

Foundations can start by investing in any one of the promising pursuits described in this essay or in efforts to spark synergies among various health

services researchers. Such investment would complement that of the federal government, which to date has concentrated its support in this field primarily on the study of clinical outcomes. By accelerating movement toward a more patient-valued paradigm of medical care, foundations could help restore public trust and confidence in the medical professions and improve the healing process.

One foundation's activities. The Commonwealth Fund directs its work on this subject through the Picker/Commonwealth Patient-Centered Care Program. Begun in 1986, the program has three interlocking pursuits: (1) improving methods for examining patients' experiences and how various practices affect patients; (2) enabling a wide range of medical professionals and institutions to devise and implement ways to improve practice in their own settings; and (3) helping medical providers and community associations to put patient reports to practical use in communities. Funding under this program has totaled \$4.85 million to date.

The Commonwealth Fund is investigating three initiatives under the first pursuit. One is a fellowship program to support the postgraduate training and career development of young professionals who are particularly interested in improving the methods for examining patient experiences. Second, the fund supports research to improve methodological techniques fundamental to diagnosing and categorizing patients' experiences. The third initiative will seek to convene forums of interested investigators to facilitate the exchange of theories, methods, instruments, and information.

Within its second pursuit, The Commonwealth Fund is continuing its sponsorship of work by a task force of private hospitals under the direction of Rabkin and a task force of public hospitals under the direction of Anderson, on behalf of the National Public Health and Hospital Institute. Work toward a system for monitoring how office-based practices can be more responsive to patients continues under the leadership of John R. Ball and Frank Davidoff of the American College of Physicians. A major research study of the effects of various staffing levels and patterns on patients' experience is intended to provide the nation's nursing leadership with important information. This study is being conducted by Ann Minnick at Rush-Presbyterian-St. Luke's Medical Center in Chicago. The fund is also investigating ways to help prepaid group practices and neighborhood health centers devise ways to use patients' experience reports for continuous improvement.

Under the Picker/Commonwealth program's third pursuit, the fund is investigating ways to incorporate patients' experience reports into communitywide systems for monitoring quality of care. This includes various systems adaptations under consideration by community associations of

employers, insurers, and providers, as well as communitywide monitoring systems devised by any one of these groups, consumer associations, or national periodicals. The fund is discussing initiatives with many of these different groups. It has also been following the path-breaking efforts of the Hartford Foundation's Community Health Management Initiative to include patients' experience reports in community-based quality-monitoring systems.

In Conclusion

A major evolution in the purpose and practice of medical care toward the greater accommodation of the needs and experiences of patients is now under way. If it flourishes, it will improve the health of the American people, expand the business of clinical care, alter the training and pursuits of medical practitioners, change the nature of patient education, change the care process of hospitals, and revise the way patient care is measured and rewarded.

While the nation's attention is riveted on access to medical care and how that care is to be financed, these two issues cannot be resolved satisfactorily without a sensible accommodation to the consumer movement now under way. This will entail, at a minimum, a payment system that gives patients choice among plans, physicians, and hospitals; that gives them ready access to the kind of patient information and education that enables informed choice; and that rewards the practitioners and facilities that provide the type of care they choose, within whatever system of fiscal constraints is devised.

NOTES

- 1. C. E. Silberman, "From the Patient's Bed," Health Management Quarterly 13, no. 2 (1991): 12–15.
- 2. "King Customer: At Companies That Listen Hard and Respond Fast, Bottom Lines Thrive," Business Week (12 March 1990).
- 3. Louis Harris and Associates, The Picker/Commonwealth Patient-Centered Care Survey, Study no. 884027 (November 1989).
- 4. R. Winslow, "Data Spur Debate on Hospital Quality," The Wall Street Journal, 24 May
- 5. "Former Patients May Not Be as Loyal, Study Shows," Modern Healthcare (7 May 1990): 39; and N. Cousins, "How Patients Appraise Physicians," The New England Journal of Medicine 313 (1985): 1422-1424.
- 6. Louis Harris and Associates, "Americans and Their Doctors" (Survey conducted for Pfizer Pharmaceuticals, January 1985); and P.D. Cleary and B.J. McNeil, "Patient Satisfaction as an Indicator of Quality Care," Inquiry (Spring 1988): 25–36.
- 7. M. Kaufman, "Cancer: Facts vs. Feelings," Newsweek (24 April 1989).
- 8. A.R. Feinstein, Clinical Judgment (Huntington, N.Y.: Robert E. Krieger, 1967).

- 9. H.B. Wheeler, "Shattuck Lecture—Healing and Heroism," The New England Journal of Medicine 322 (24 May 1990): 1546.
- 10. A.R. Tarlov et al., "The Medical Outcomes Study: An Application of Methods for Monitoring the Results of Medical Care," Journal of the American Medical Association 262 (1989): 925–930; A.L. Stewart et al., "Functional Status and Well-Being of Patients with Chronic Conditions: Results from the Medical Outcomes Study," Journal of the American Medical Association 262 (1989): 907–913; and K.B. Wells et al., "The Functioning and Well-Being of Depressed Patients," Journal of the American Medical Association 262 (1989): 914–919. Initial support for the medical outcomes study was provided by The Henry J. Kaiser Family Foundation. Efforts have been sustained by The Robert Wood Johnson Foundation, The Pew Charitable Trusts, federal agencies, and the research funds of the participating institutions, The RAND Corporation and the New England Medical Center.
- 11. J.E. Wennberg et al., "An Assessment of Prostatectomy for Benign Urinary Tract Obstruction: Geographic Variations and the Evaluation of Medical Care Outcomes," Journal of the American Medical Association 259 (1988): 3027–3030; M.J. Barry et al., "Watchful Waiting vs. Immediate Transurethral Resection for Symptomatic Prostatism: The Importance of Patients' Preferences," Journal of the American Medical Association 259 (1988): 3010–3017; and F.J. Fowler et al., "Symptom Status and Quality of Life Following Prostatectomy," Journal of the American Medical Association 259 (1988): 3018–3022.
- 12. Support for Wennberg and Mulley's work has been provided by The John A. Hartford Foundation, The Robert Wood Johnson Foundation, The Commonwealth Fund, and federal agencies. Development of interactive videos was first supported by The John A. Hartford Foundation and recently by The Commonwealth Fund.
- 13. See grant announcements in GrantWatch in this volume of Health Affairs.
- 14. Earlier research found that even among patients who are excellent assessors, variations in the way information is presented can decisively influence a patient's preference for one therapy over another. Average assessors can tend to miss the overall message, focusing instead on specific pieces of information or holding onto their preconceptions.
- 15. S. Greenfield et al., "Patient Participation in Medical Care: Effects on Blood Sugar Control and Quality of Life in Diabetes," *Journal of General Internal Medicine* 3 (1988): 448–457; and S.H. Kaplan, S. Greenfield, and J.E. Ware, "Assessing the Effects of Physician-Patient Interactions on the Outcomes of Chronic Disease," *Medical Care* 27 (1989): S110–S127. To date, support for this work has been provided primarily by federal agencies.
- 16. First, strategies for involving patients tend to focus on a single intervention (for example, presurgical information), used only at one discrete point (for example, choice of therapy) rather than throughout an episode of illness. Second, the content of teaching sessions needs refinement; many are too long to be feasible in busy patient care settings. Third, projects have been conducted in special research settings; they need to be tried in a variety of actual clinical settings. Fourth, whether patients not actively involved on their own should be activated by a medical team is controversial. Would patients who now manage reasonably well through denial or more passive patient roles cope better or worse if they were coached into more active roles?
- 17. L.K. Harvey and S.C. Shubat, Physician and Public Opinion on Health Care Issues (Chicago: American Medical Association, April 1991).
- 18. Through the Patient's Eyes (Jossey-Bass, forthcoming.).