

ROLE FOR THE CONSUMER

- Peter Rogatz and Marge Rogatz

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Until recent years, the hospital with the most prestige and the greatest ability to confer prestige upon those associated with it (administrators, physicians, trustees) was the hospital offering the largest number of beds, the most elaborate radiologic facilities, and the most spectacular surgical procedures. With this prestige comes power--power within professional organizations and within the political environment of the community--and, more often than not, monetary rewards.

In the past few years we have seen some modest changes in the system of rewards and approvals, so that the most elaborate hospital is not always viewed as "the best"; and often the administrators, physicians, and trustees of the very elaborate hospitals bear the onus of explaining whether the hospital has been overnourished at the expense of sound community planning, whether it has become a source of ego gratification for its leaders at the expense of self-restraint and interinstitutional cooperation that might better serve the interests of its community.

Although the new trend has not been dramatic, we can perceive today that some of the rewards of professional prestige, community approval, and federal funding are beginning to go to those administrators, physicians, and trustees who have committed their institutions to a more balanced program, one more cognizant of, and responsive to, community needs. There is a slowly dawning awareness, for example, that a comprehensive mental health center may be more valuable than a unit for open-heart surgery, a neighborhood outreach program more worthwhile than a supervoltage radio-therapy unit or a hyperbaric chamber. But these new values need to be incorporated into an incentives system. Accrediting bodies and third-party payers, along with public information media, have the power to reward those institutions and programs that enable middle- and low-income consumers to participate actively in policy-making.

Clearly, this will not happen merely because consumers say it should. It can, and should, happen as a consequence of a dialogue among consumers, professionals, and trustees. If such a dialogue does not develop, or if it fails to produce a working consensus on involvement of consumers in an effective way, then consumers must take their case to third-party payers, accrediting bodies, and public information media, which represent the most effective points of leverage.

PLANNING AND POLICY-MAKING

Until recently, opportunities for consumers to play a meaningful role in the development of national policy for health care have been distinctly limited. Except for occasional "blue ribbon" advisory panels and occasional testimony before Congressional committees and at other public hearings, there are no channels for consumer input at the national level. Some believe that the recent establishment of statewide and regional comprehensive health planning agencies, with no less than 51 percent consumer membership mandated, will represent a new channel for affecting national policy. This view may be prematurely optimistic. We do not know yet whether such regional and state groups will be genuinely representative or how much power they will acquire; nor do we have any indication thus far that the chaotic and fragmented process by which national health policies are developed in the executive branch and in Congress will be responsive to inputs from these groups.

Simply mandating a technical majority of consumers offers no assurance that the decision-making processes will not continue to be dominated, directly or indirectly, by professionals. First, many individual consumers are unconsciously under the spell of the Professional. Second, professionals have both an economic and an emotional stake in the decisions of these agencies and usually are able to attend meetings with greater regularity than the lay person. Third, there is always the possibility that even a majority of consumers at a given meeting may be outmaneuvered by the professionals who, after all, are operating on their own turf. In recent years, consumers have dealt with this by using the tactics of confrontation, boycott, and packing of meetings. Such tactics may spread, but must sooner or later be replaced by ongoing, effective interaction if adequate care is to be regularly provided and received.

This interaction is most necessary at the local level, and it is locally that the greatest opportunities exist for consumers to assume a directive role in planning. Organization to obtain representation, accountability, and responsiveness is more feasible at the local level than at higher echelons. The financial and time commitment required to attend even local meetings regularly is difficult for many consumers, but it is less of an obstacle when the meetings are near home. Once the local planning agencies and boards of trustees have been altered to reflect the economic, ethnic, and age composition of the communities they serve, comparable action at regional and national levels may be facilitated.

What of the frequent argument that the poor are "not ready" for major roles on boards of trustees because they lack experience in such matters as financial management? In fact, lack of such experience is less of a handicap than that faced by an affluent white banker who is knowledgeable in the preparation of budgets but has no experience with deficiencies in the delivery of health care to the poor. Members of the upper middle class, of course, have been serving on the boards of health agencies and boards of education for generations. Not surprisingly, the question of "readiness" was raised only when low-income Blacks and Puerto Ricans began to assert their determination to direct the institutions in their own communities. The question is prejudiced and self-serving.

Since consumers, directly or indirectly, must foot the bill for abuse of hospital facilities, are they not entitled to information about the deliberations

of the utilization committees charged with preventing unnecessary use of hospital beds and/or ambulatory facilities? Should this not extend beyond mere information to actual participation in the deliberations of such committees? Although this raises questions of confidentiality and technical competence, the former issue can be resolved, and the latter is probably not a valid concern. There is no reason why a lay person cannot understand the matters dealt with by a hospital utilization committee and contribute constructively to its deliberations. There is no reason, for that matter, why consumer-established standards should not be included as criteria in every aspect of health program evaluation.

MEDICAL EDUCATION

One further area that might, at first glance, seem totally outside the purview of the consumer is professional education. Yet herein lies one of the most critical keys to a reorientation of the health-care system in this country if it is to attain greater responsiveness to the needs of users. Consumers must be included in decisions affecting this crucial element of the macrosystem. Criteria for the selection and evaluation of students, staff, and faculties of professional schools must be reexamined in the light of consumer needs and experiences. The same is true for the design and content of curricula and materials. Traditional models--such as the goal of "scientist-practitioner"--need fresh scrutiny, with active participation by consumer spokesmen. New models being developed at a few schools, such as Case Western Reserve (Cleveland, Ohio), stress early relationships with patients. These models need encouragement and support.

Until recently, the idea that a patient might have some useful ideas about the education of a doctor, nurse, or social worker would have been inconceivable. The patient has always been utilized essentially as an inanimate object in the teaching process. He is a subject for examination; and if he is invited to speak at all, it is only for the purpose of reciting his symptoms so that the student can evaluate his illness.

However, students can also learn much from patients about provider-user relationships. It is time for the consumer--the patient--to become a teacher as well. Some police departments, recognizing the need for policemen to better understand those with whom they are so often in confrontation, have asked students and representatives of the poor to participate in training seminars. Why shouldn't professionals in the health field show at least as much enlightened self-interest in exposing themselves, in their own education, to those who are, or will be, their clients?

Implicit in the preceding discussion is the unsettling thought that there may actually be something inherent in the training of the professional that helps to build a barrier between him and his patients, blurring communication, making him resistant (perhaps subconsciously) to certain of his patients' demands, and making the patient suspicious of the professional's ability or willingness to provide the care that is needed. Often when a member of the indigenous poor secures access to a provider role--even as an aide or a paraprofessional--he is subject to many of the same symptoms of professionalism that afflict physicians, nurses, and social workers. Can we learn how best to encourage the nurse's aide, as well as the physician, to resist adopting the mystique of the professional? This would involve both behavioral scientists and community groups in designing and implementing new patterns of training. Neighborhood health centers, from Mississippi to New York, have used such training and have established promising models.

References here to the consumer's need to speak for himself and confront the professional establishment should not obscure the fact that the consumer does have allies in the professional world who are addressing themselves seriously to his needs and concerns. Far more active than established professionals are the students. Increasing numbers of medical students, for example, are telling their deans and professors that, although they are confident of being well educated scientifically and technologically, they want their schools to be concerned with the application of science and technology in the day-to-day delivery of personal health care.

Students learn at least as much by example as by precept, and role models are of great importance in forming future attitudes. It does little good to tell students about a hospital's responsibilities to its community if they observe in the emergency room of their university hospital that patients with conditions that do not satisfy the intellectual interest of their staff or faculty are shunted away to other hospitals. Nor is there much value in lecturing about the dignity of the individual when students observe the predisposition of doctors and nurses to patronize patients from minority groups and those of low income by addressing them by first name (while the patient, of course, is expected to use formal terms of address when speaking to a doctor or nurse). These examples have a fundamental impact upon the attitudes of students in medicine and nursing.

Many medical schools reserve their highest rewards (in terms of promotion, tenure, and salary) for those faculty members who are concerned primarily with research, rather than for those concerned with patient care. Students can hardly fail to be influenced by such practices. This is not to say that medical schools should stop doing research or that they should admit to the hospital any patient who presents himself to the emergency room and demands admission regardless of valid clinical indications. It is to say, however, that many of the practices and procedures followed in our professional schools and university hospitals offer an example of indifference to patient care that belies the stated purposes of these institutions. Consumers and their allies among students and professionals must be listened to and heeded in these respects.

PROGRAMS AND SERVICES

This nation is just beginning to give lip service to the point of view that the delivery of health care is sufficiently important and complex to require the development of a carefully designed network of coordinated programs. Such programs must range from health promotion and maintenance, through prevention, screening, and early detection, to an integrated network of primary, secondary, and tertiary centers for diagnostic and treatment services.

Well-informed professionals, with good intentions, have persistently and self-righteously resisted the obvious fact that consumers must have a significant role in the design, implementation, and evaluation of health-care services. Indeed, some programs (for example, those for the prevention of venereal disease or lead poisoning) can be successful only insofar as residents of the community participate in their development, in disseminating information about them, and in their staffing.

The more local the focus of a particular program, the more critical it is that consumers participate actively in it. A graphic example is the recent "hijacking" by the Young Lords of a mobile tuberculosis screening unit operated by the New York City Department of Health. The Young Lords believed that a change in the location of the unit would produce a substantial increase in utilization and, through the dramatic "hijacking," they effectively demonstrated this point.

The problem is not that professionals are trying to put something over on their patients, but that the perceptions of providers differ substantially from those of consumers. More importantly, underlying assumptions of providers and consumers differ significantly.

The professional sees himself as the central or pivotal figure in the provider-user equation: it is he who possesses the vital knowledge and who must perform numerous tasks within a limited period of time in order to care for a large number of patients. They, after all, are the ones in need; and if they wish to have their needs met, they must make themselves available to him at the times and places and under circumstances that make it possible for him to function with the greatest economy of effort.

The consumer, on the other hand, sees it differently: he needs relief from pain, disability, or anxiety; and he sees it as the provider's responsibility to help him obtain that relief. Poor consumers are beginning to come to the point of view that affluent consumers have long held--that optimum health care can be provided only under conditions that protect the dignity and convenience of the patient as well as of the physician and the nurse.

This latter view is gradually coming into vogue among professionals; but, here again, it is one thing to give lip service to this point of view and quite another to function under conditions that are determined by this premise. Professionals will find it difficult and irksome to function under consumer surveillance and will be quick to charge that this will result in unwarranted and dangerous interference with medical practice. Consumers and professionals will have to confront a host of questions, ranging from minor procedures to fundamental policy.

Shall the outpatient department be organized primarily along departmental lines, or shall each clinic be oriented toward comprehensive health services, with consultants on call at every clinic? Many physicians believe that conversion to comprehensive clinics will make it more difficult and time-consuming to treat patients with common specialty problems. Consumers seem to feel that a patient's total needs are more likely to be met by a comprehensive clinic than by a series of isolated specialty clinics. Professionals argue that if specialists do not have ongoing involvement with concentrated pools of patients, their specialized skills will atrophy and will no longer be adequate to serve the needs of consumers. Consumers counter that the main advantage of specialty clinics is to serve the academic curiosity and ego needs of the specialist.

Consumers assert that nursing procedures, such as waking patients at early hours for temperature-taking and baths, are designed for the convenience of the nursing personnel. Nurses and hospital administrators respond that the realities of staffing patterns and the multiplicity of the essential procedures to be carried out throughout the day make it impractical to allow each patient to wake at his own convenience. Consumers complain that mealtimes are set for the convenience of the staff; the professionals counter with arguments relating to the demands of personnel schedules and the complexity of overall hospital operations.

Consumer participation in the planning process is likely to result in services' being brought to neighborhoods where consumers work and live, rather than the construction of facilities that require people to travel unreasonable distances to obtain primary health care. When communities have been permitted to join in planning for their own services, many have proposed such measures as greater use of mobile health units and the placing of facilities in stores, housing developments, and other outreach sites. In addition to improved physical access for users (leading to improved utilization and, one hopes, improved health), such outreach arrangements increase the likelihood that professionals will become better acquainted with the living and working conditions of those they serve.

Hospitals and other agencies that establish outreach facilities may find that staffing advantages result. The chronic shortage of personnel that afflicts large, centralized facilities may be substantially ameliorated when facilities are decentralized and thus are accessible to potential pools of employees. This assumption, of course, rests on the premise that hospitals and health-care agencies are prepared to draw upon indigenous groups as sources of manpower for jobs beyond the menial ones to which they have been traditionally confined.

The combination of readiness to train and employ indigenous persons for semiprofessional and professional jobs and decentralization of formerly centralized facilities offers the promise of very significant improvement in the nation's ability to meet its health manpower needs. This solution can be effective only if there is cooperative planning among provider agencies, professional schools, and communities. There must be arrangements that assure that a steady supply of indigenous applicants will be accepted by the professional schools and that, when they subsequently return to their own local communities, they will be reasonably sure of employment by the provider agencies.

PATIENT-ADVOCATES

In the final analysis, there are few unassailably "right" answers; and differences of opinion will be resolved in favor of whichever side holds an edge in terms of power. What must be sought is a reasonable balance of power between providers and consumers--a balance that will persuade each to listen to the other with some degree of restraint, respect, and attention and that will, in the long run, enable both points of view to be worked into a series of compromises that will best serve the needs of the community of which the professional, too, is a part.

Special arrangements will have to be made if consumers are to participate to the extent proposed here. Daycare programs, which should be provided for employees who need them, should be available also for those consumers who, as patients, as visitors, or as members of boards and committees, require such services. Additional assistance may also be necessary for travel subsidies, for example, to enable consumers to attend meetings.

Until programs and services receive enough consumer input to be reasonably responsive to consumer demand, there will be a continuing need in almost every program for a patient-advocate, or ombudsman. Such a person, selected by the community, should be particularly sensitive to, and have the ability to intervene on behalf of, consumers whose needs are not being met.

Introduction of a patient-advocate raises complex and sensitive issues. If the advocate is to function effectively, he must be able to report his findings to the community--that is, to a body representing the community. Neither the administrator nor any group made up exclusively of professionals--no matter how well motivated--can serve as his sole channel of reporting. Although it is vital that the professional (including administrative) staff be aware of what the ombudsman learns, his authority must derive from the community, or he will be essentially impotent to effect change. If the board of trustees is broadened to include low-income consumers, it may be able to serve as the ombudsman's line of reporting. A community advisory board can serve this function, but its effectiveness will depend on the extent to which it (the advisory board) has access to, and influence upon, the board of trustees.

The matters that will concern a patient-advocate range from mundane to fundamental. Is there a faulty air conditioner in a patient's room that has not been repaired? Are outpatient clinic hours set without regard for patient needs? Are patients who seek abortions subject to unreasonable delays? Because of the wide range of problems with which he must deal, the ombudsman must have access to lines of communication that will assure prompt repair of the air conditioner as well as lines of communication that will affect long-range policy issues.

Consumers in policy roles and nonprofessionals in service roles represent a long-overdue invasion of the health field on two fronts. This invasion may ultimately produce important changes in the attitudes of providers and users, rich and poor. In the process, there will undoubtedly be innumerable confrontations and severe upheaval. But health services will not become consumer-responsive until consumers in all economic groups are accepted as full partners in directing basic reform of the total health system.