
The Lichfield Lecture

Quality assurance in health care: consumers' role

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I hope that what I shall have to say would have pleased Lord Lichfield, under whose colours I speak. Reputed to have been "a most humane and agreeable man," he would have approved, I believe, of the larger role I shall accord consumers in assuring the quality of health care. And, quite possibly, the squire so solicitous of his horses as to provide for them in his will ("so long as life can be made agreeable to them") would not have minded if a little of his generosity should touch an Armenian professor recently put to pasture.

But before I advance my main arguments, I need to define my terms and reveal my method.

Definitions and presentation

I shall conceive of "quality assurance" rather narrowly, as an activity aiming to elicit information about clinical performance, and, based on that information, to readjust the circumstances and processes of health care. "Consumers" I shall take to mean patients, as well as those who may legitimately speak on their behalf. "Quality" I shall not define but shall allow its meaning to emerge as my story unfolds.

As to my method, I shall assign consumers three major roles: firstly, as "contributors;" secondly, as "targets;" and, thirdly, as "reformers;" with subsidiary roles under each. I do so, aiming for an orderly progression, even though, as will soon appear, the several roles are interdependent and difficult to separate.

Consumers as contributors to quality assurance

I shall take consumers to contribute to quality assurance in three ways: by defining what quality is, by evaluating quality, and by providing information that permits others to evaluate it.

CONSUMERS AS DEFINERS OF QUALITY

Fundamental to any quality assurance activity is the concept of quality that animates the activity, giving it purpose and direction. Consumers make an indispensable contribution to defining quality and setting the standards by which it is to be judged. That contribution encompasses considerations close to the heart of quality itself, as well as others nearer the surface, but important none the less.

To explore this domain, I shall conceive of health care as consisting mainly of two parts: a technical task and an interpersonal exchange. Consumers have a great deal to say about both, and also about the circumstances under which the task is performed and the exchange occurs. I shall call this, third, element "the amenities of care," hoping the term will not lead any to believe that the subject is trivial.

In defining what is desirable or undesirable in the interpersonal exchange or the amenities of care, it is consumers, I believe, who should make the decisive contribution. It is their expectations that should set the standard for what is accessible, convenient, comfortable, or timely. It is they who tell us to what extent they have been listened to, informed, allowed to decide, and treated with respect. In doing so, consumers express their personal preferences; but they also voice the expectations that particular positions, in particular segments, of particular societies have implanted and nurtured.

About the conduct of technical care, consumers would seem to have almost nothing to say. "What do they know," we are asked, "of the arcane complexities of the technical task or of the resources and skills necessary to perform it?" There is reason to believe that consumers are not that ignorant of the processes of good technical care when the situation is familiar and, particularly, if prior experience of good care has adequately prepared the patient. But, in a more fundamental way, the quality of technical care is defined not by what is done, but by what is accomplished. And consumers are uniquely able to say what outcomes are to be pursued, what risks to be accepted in return for what prospects of amelioration, and at what cost. Individual patients value differently the relative importance of longevity, self image, self worth, and function – whether that function by physical, marital, familial, economic, or social.^{1 2} It can be argued that technical care not congruent with patient preferences has failed in quality. If one accepts this viewpoint, it follows that consumers define (or participate in defining) the quality of technical care by the simple expedient of specifying the goals it must serve. Only the technical means, and the skill by which they are implemented, remain for the clinical expert to govern.

CONSUMERS AS EVALUATORS OF QUALITY

It is a small step from saying what quality is, to judging how fully it has been attained. Thus defining quality and evaluating it are a related pair, scarcely separable. Consequently, obtaining information about consumer satisfaction or dissatisfaction, and the reasons for either, is a necessary component of any quality assurance enterprise.

Consumer satisfaction plays a tripartite role in health care. It is, firstly, as I have said, a judgment on the quality of health care, embodying the patient's expectations and perceptions. Secondly, it is an "outcome" of care: one aspect of the patient's psychological wellbeing and also a consequence that health care systems may strive for as a mark of their success. And, thirdly, patient satisfaction is a contribution to further care, motivating patients to seek care and to collaborate in enhancing its success. Thus by a subtle transmutation, patient satisfaction, having been an outcome of care, becomes also a structural feature of the health care enterprise itself.

CONSUMERS AS INFORMANTS

In addition to defining and evaluating the quality of care, consumers can contribute to the quality assurance effort by providing information concerning their own experiences in health care. They are not asked to express a judgment on care but merely to report, so others may judge.

There are certain kinds of information that only patients can provide – for example, about what happened when they sought care, about their hopes and fears, about being well or unwell, and about function and dysfunction. Other information, mainly concerning the technical process of care, which should have been in the medical record but may have been omitted, can be provided by the patient.

In this way patients serve as primary sources of information. At other times they serve what could be called a secondary, or confirmatory, function. This happens when a monitoring agency wishes to verify what has been reported to it, often accompanied by a claim for payment. By confirming, or failing to confirm, a claim, patients become, in effect, part of the regulatory mechanism by which the monitoring agency tries to keep the system in line.

By having this role, and also in the other ways I have described, consumers can contribute mightily to the quality assurance enterprise. But now I must ask whether or not it is proper that they should and what difficulties may arise when they do.

JUSTIFYING CONSUMERS' CONTRIBUTORY ROLE

The first of these two questions is, I believe, mainly rhetorical. No one would argue that the pursuit of each patient's welfare is not the chief purpose, and primary obligation, of every health care practitioner. And it is difficult to hold that the patient's views of what constitutes that welfare are of little relevance to that purpose and obligation. There could be, however, differences of opinion concerning the merits of according so large a place to the

quality of the interpersonal exchange, compared with the execution of the technical task itself. But it is a mistake, I believe, to put these two components of care in opposition when, in fact, they are mutually reinforcing.

The interpersonal exchange is, after all, the vehicle by which technical care is dispensed and acquired. Often, it is itself technical care, or so close as to be hardly distinguishable. Patients are justified, I believe, in suspecting that the practitioner who has been cursory, inattentive, uninformative, or even rude has not marshalled the full potential of technical skills on their behalf.

In a more mercenary vein, the properties of the interpersonal exchange mightily influence patient satisfaction; and satisfaction is necessary to competitive success when there is choice and to political viability in all circumstances, but especially if choice is restricted.³ The interpersonal exchange also stands on its own, independently of what other uses it may have. For it is the measure of the humanity and dignity of us all, in every form of intercourse. How it is conducted can either ennoble or debase both practitioner and patient to an equal degree.

But it is one thing to affirm the right and duty of every patient to define and evaluate the quality of care and quite another to give legitimate, practical expression to that belief. Regretfully, I must now lead you into more troubled waters by describing the obstacles that might be encountered and the dangers to be avoided.

PROBLEMS OF CONSUMERS' CONTRIBUTORY ROLE

Problem of goals

One must guard against the perils of "goal displacement" when consumers are accorded a large role in defining and evaluating the quality of care. I mean by that the manipulative substitution of aspects of care more readily visible to patients for those less easily perceived or assessed. Particularly when competition is rampant, it is easy to see how more pleasant circumstances and more ingratiating manners might distract consumers and cloud their judgment, at least for a while. Similarly, concentration on short term, visible results might replace the attention from some that are immediate, but less noticeable and others that are long delayed. It is important, by simultaneously assessing the quality of all aspects of care, to guard against these artificial disjunctions.

Problem of validity

It is necessary to assess carefully the validity of information obtained from consumers. Evaluations of quality can be based on erroneous assumptions and faulty expectations. Often patients are, in fact, overly patient; they put up with unnecessary discomforts and grant their doctors the benefit of every doubt, until deficiencies in care are too manifest to be overlooked. Generally speaking, one can assume that the quality of care is, actually, worse than surveys of patient satisfaction

would seem to show. Patients need to be taught to be less patient, more critical, more assertive. However, in some cases, the reverse is true: patients are disappointed and unhappy because they had an unrealistically high opinion of what contemporary medicine could accomplish. But in such cases one can argue that the doctor may have failed, by not properly preparing the patient. More factual information obtained from patients may also be faulty and incomplete. But, I believe that the repeated solicitation of such information is itself salutary; it suggests to the patient what should have been noted and remembered, perhaps sharpening the capacity to observe and fostering a more assertive stance as well.

Problem of particularisation

The problems of particularisation are the paradoxical consequence of a virtue: that each person receive care precisely tailored to individual preferences and circumstances. In part, the undesirable consequences are only operational; in part, they are ethical. Ethical ambiguities arise in several ways. Sometimes, a patient's preferences would seem contrary to what a reasonable person would conclude the patient's own best interests to be. At other times, patient preferences challenge the practitioner's social obligations or personal convictions. Not infrequently, patient preferences reflect privilege or disadvantage in the circumstances of life itself – circumstances that one might regard as legitimate or otherwise. To equip patients to cope successfully with deep rooted injustices in the social order is a worthy goal, greatly to be cherished. But is it enough? Besides raising such fundamental questions about the nature of quality itself, the need to take account of the individual expectations of particular patients calls for a correspondingly flexible method for assessing the quality of care. The criteria and standards that usually govern assessment procedures are pitched to the average case, in the more ordinary circumstances of life. They are useful, at least as an initial rough screen, because despite individual differences much common ground remains. It is possible, of course, to design criteria and standards that are adjusted to a large number of prespecified patient characteristics, but some patient attributes we do not know how to measure or allow for; and it is always with averages that we must deal, even though these are the averages of progressively smaller, more finely demarcated, groups. Ultimately, in matters of great moment, nothing less than a case by case evaluation will do – an evaluation that is nothing other than a replay of clinical care itself. And it is here that we need most urgently the detailed knowledge of individual experiences and preferences that only patients can provide.

Problem of documentation

The degree of our dependence on patients as sources of information reflects the woeful inadequacies of medical recording; and it is possible that attention to patient preferences

will eventuate in more accurate, more complete records, in formats better suited to quality assessment. It is debatable whether or not some way can be found to include patients' unbiased opinions about the care received. But, it should be possible, whenever sharply different alternatives of care are in contention, to find in the record evidence that the alternatives have been considered jointly by patient and doctor and that the course of action taken is justified. The problems of eliciting information about patient satisfaction are too well known to require repetition. It may be enough to say that the questioning should be done at the proper time; be conducted without jeopardising the patient-practitioner relationship; include questions about specific aspects of care, in specific episodes; and allow for a free commentary on matters unforeseen by the questions. Collateral questions about behaviours that might indicate dissatisfaction should also be included: such behaviours as breaking appointments, ignoring instructions, changing doctors, and so on. A cursory question about whether a patient is satisfied or not is likely to elicit an equally perfunctory response, especially when the respondent does not expect the answer to make a difference. The pre-eminent condition to successful solicitation of consumer opinions and suggestions, it seems to me, is absolute assurance that the respondent's reports will be acted upon. Every suggestion should be individually acknowledged and its consequences reported back.

Problem of implementation

The final, and most important step, in any quality assurance effort is that of readjusting the system so it responds to the problems that prior assessment has revealed. But an adequate response to the considerations I have raised might require almost a revolution in our thinking about the model practitioner-patient relationship, a change that some may not only deem impractical but, more fundamentally, undesirable. We can cherish the time hallowed tradition that the good doctor always acts on behalf of the patient. In simpler times it served us well; it is defensible in caring for most illnesses, when doctors, by long association, intimately know their patients. In decisions of great moment it is less defensible; and it is precisely in momentous, often ambiguous, conditions that medical attendant and patient meet virtually as strangers. From "paternalism" to "informed consent" has not been a difficult step, especially when the elicitation of consent becomes an impersonal litany, whose main purpose is anticipatory self exoneration.

"Collaborative consent" is the mode of interaction I envisage. I see practitioner and patient together, actively engaged in a search for the most appropriate solutions. Once we recognise the need, we shall find the means. On the one hand, we shall advance the science of health care, so that the consequences of alternative strategies of care are more completely understood, and, on the other, we shall develop more effective ways of conveying

the information patients need to make informed decisions about their own care.^{4,6} Perhaps, having assumed this more responsible role, consumers could more justifiably be called upon to make their second contribution to quality assurance, that of serving as its target.

Consumers as targets of quality assurance

There are two ways in which consumers can become targets of quality assurance: as coproducers of care and as vehicles of control.

CONSUMERS AS COPRODUCERS OF CARE

I do not believe it is true that practitioners provide care and patients receive it. Rather, we should conceive of practitioners and patients as jointly engaged in the production of care. Consequently, it is not sufficient to determine how practitioners perform. It is also necessary to know how patients acquit themselves.

In part, the performance of patients depends on what practitioners have permitted them to do and how well they have prepared them for the task. To that extent assessing patient performance affords indirect evidence of the practitioner's contribution to that performance. But, patients are autonomous beings as well – persons who can, and do, govern their own care. They are therefore necessary and legitimate targets of the quality assurance enterprise.

The consequences of this broadening of scope are easy to see. It calls for information about patient behaviour. It also requires efforts to modify that behaviour, partly through education, and partly through ameliorating the circumstances that affect adversely the ability of patients to act in their own best interests. And, incidentally, the assessment of outcomes gains in cogency, because outcomes reflect the contributions of all participants in care, including those of the patients themselves.

CONSUMERS AS VEHICLES OF CONTROL

Consumers can become targets of quality assurance in still another way: when they are used as a means to regulate practitioners' behaviour. Many certification procedures (such as those that require approval of hospitalisation or of elective surgery) appear, by threatening to deny payment, to ask patients to control their own doctors. Often these expectations impose a burden consumers have not, as yet, been adequately prepared to assume. Perhaps consumers could be more effective agents of control if their capacity to reform the system of health care were to be materially enhanced, as I shall describe next.

Consumers as reformers of health care

I think consumers can change the health care system in at least four ways: by direct participation, through administrative support, through markets, and through political action.

DIRECT PARTICIPATION

Perhaps consumers can bring about change

most directly by more effective participation in the patient-practitioner exchange, in ways I have already described. Practitioners are responsive, I believe, to overt and covert expressions of their patients' expectations. It is important, therefore, that these expectations be properly shaped by prior experience of good care and by continuing education.

ADMINISTRATIVE SUPPORT

Consumers can influence the conduct of care even more effectively if the quality assurance enterprise empowers them to participate. This can occur either indirectly or directly.

It occurs indirectly when the enterprise uses information provided by patients to judge and improve the circumstances and processes of care. The first step is receptiveness to spontaneous suggestions and complaints. Secondly, consumers can be encouraged to express their opinions by providing suggestion boxes and, more effectively, by holding regular meetings during which practitioners and their past or future clients can engage in a candid exchange of views, an exchange from which both patients and practitioners might emerge much the wiser.⁷ And, thirdly, there should be a systematic canvassing of the feelings, opinions, and suggestions of clients in ways I have already alluded to. But all these efforts, as I have already said, will come to naught, unless those in charge of the quality assurance enterprise use the information obtained and are able to demonstrate to patients, individually and collectively, that they indeed do so.

More direct participation of consumers in the machinery of the quality assurance enterprise itself seems more difficult to accomplish, but it should be tried. Certainly, consumer representatives should participate in formulating the objectives and policies that embody what quality is to mean. And I see no reason why such representation should not be part of the quality improvement teams charged with reviewing and reforming many components of the health care system, unless these are exceptionally technical in nature.

MARKETS

Markets are still another mechanism by which consumers can bring about change in the health care system. At least five conditions should be met if markets are to function effectively.

The first condition is that consumers have an opportunity to choose among alternative sources of care, and perhaps among alternative modalities of management as well. A corollary is that there be sources of care sufficiently different in quality. Paradoxically, too many potential providers can also hamper the efficacy of choice by rendering the process of discriminating choice excessively onerous. That is one argument in favour of organising doctors into groups. There would be, as a result, a smaller number of entities, with perhaps more information concerning each.⁸ The second condition to be met if markets are to regulate quality is that the providers of care

be responsive to choice. This happens if their own interests, whether financial or professional, are vitally affected by succeeding or failing to attract clients. If not, they could remain indifferent to how sought after they are. As a third condition, the grounds for consumer choice should be socially legitimate and individually rewarding, in ways I have already mentioned. Otherwise, the consequences of choice could be, paradoxically, a deterioration in at least some aspects of care. It follows, as a fourth condition to the efficacy of markets, that consumers be able to act on accurate information. It has been difficult to identify items of information that consumers could use to select sources of care that offer prospects of higher quality in care. It has proved even more difficult to provide timely, relevant, and trustworthy information that would help consumers decide where to go for particular types of care in specific instances, when this choice is available.

The difficulty individual consumers have had in finding and interpreting information about provider performance, suggests a fifth condition necessary for regulating health care through market mechanisms: that of intermediacy or agency. Ideally, each patient's doctor should have the role of informed guide. But, in the absence of that, or when the doctor's choices are themselves suspect, corporate purchasers can act on behalf of their members. Still, even then, a disproportionate emphasis on cutting costs, coupled with a paucity of information about quality, can vitiate the choice. Fortunately, as quality monitoring gains ground, its findings should provide the information needed for more intelligent choices.

That information is a prerequisite also to appropriate political action, my final observation on the means by which consumers can contribute to reforming the health care system.

POLITICAL ACTION

Consumers appear in many roles on the health care stage: often as patients, at other times as past or future clients, and at all times as citizens. As patients, they can influence the quality of health care, subtly and not so subtly, but always being constrained to maintain a friendly relationship with the doctors on whom so much of their welfare depends. As

consumers move further and further away from this position of relative dependency, they can become more outspoken, more assertive, even contentious; and it is proper that they should become so, provided the purpose is always constructive.

There is no need, I think, to detail all the many ways in which political action can be taken. Permit me, rather, to make a few concluding remarks.

I believe, with a passion, that, at heart, the best interests of health care practitioners and consumers are congruent and that the political system will be most responsive to quality enhancement when health care professionals and consumers present a united front. It is necessary, therefore, that individual practitioners be always completely open and truthful with their patients about the ways in which public policy shapes what they are able to do. How else could patients act intelligently in their other role: as citizens in a democracy?

Similarly, our professional associations must come to be regarded as the most truthful, most impartial sources of information on matters of public policy pertinent to health and health care. Moreover, we must, at all times, pursue not selfish, immediate advantage but whatever best serves patient welfare. That is our higher cause, our most sacred duty. It is also the most efficacious and enduring guarantor of our own best interests.

It is when we help consumers help us, that they can make their greatest contribution to enhancing the quality of care, even as we make ours.

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