

Incorporating patients' voices in the audit process

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Abstract

Obtaining patients' views about their experiences of care should be an integral part of clinical audit. The importance of listening to patients as an aspect of quality can be attributed, in part, to the growth of consumerism in health care, and this in turn has led to the widespread use of satisfaction surveys to obtain patients' views. This paper raises some doubts about current methods for assessing patient satisfaction, and recommends the use of qualitative methods to capture patients' voices in audit.

(*Quality in Health Care* 1997;6:86-91)

Keywords: audit; patients' views

Introduction

Audit in health care has been defined as "a systematic critical analysis of the quality of medical care, including the procedures used for diagnosis and treatment, the use of resources, and the resulting outcome for the patient".¹ Audit is currently conceptualised as a cyclical activity requiring formulation of a set of performance standards; monitoring actual performance against those standards; identifying aspects of performance that fall short of expectations; introducing changes to improve matters; and reviewing standards before moving on round the cycle again.

However, it is not always clear who should set the standards, who should participate in the process, and most importantly, what should be done with the results.² There is also the implication that audit should include some notion of accountability. In the context of health care this can obscure deeper complexities. Should audit involve accountability to patients, professionals, or managers whereby they can be reassured that the best possible care is being provided for the resources available? Or should audit entail accountability to those who ultimately pay for health care, taxpayers and the treasury, so that those who pay the piper can at least hear the tune being played. This paper concentrates on patients' involvement in the audit cycle; it briefly considers users' involvement in health care, and provides a critique of the current use of patient satisfaction as the main method for obtaining patients' participation.

Who sets the standards?

It is usual for professionals to define healthcare standards according to their own perceptions of a quality service.³ Some approaches use standards that have been predefined by researchers and experts; such "off the shelf"

nursing packages including Monitor⁴ and Qualpac.⁵ An alternative approach is to use locally determined, nurse led standards, exemplified by the dynamic standard setting system (DySSSy) described by Kitson.⁶ However, both approaches tend to favour professional exclusiveness. Indeed, some have argued that audit is a rigorous science.⁷ As a consequence, the process and results of clinical audit are as much a contribution to professional self education as they are part of quality assurance. Such benign paternalism shows ingrained differences in power and status between health service users and professionals, and reflects the serious doubts that professionals have about the ability of lay people to know what is good for them.⁸ Although it is essential that standards of patient care, wherever possible, should be based on replicated and valid research as well as professional expertise, we also need to listen very carefully to patients' ideas of benefit and harm (fig 1). It can easily be forgotten that health practices can compromise patient autonomy or inflict psychosocial harm in the course of providing medical benefit. We can harm patients by failing to meet their individual needs for information, reassurance, or involvement in decision making.⁹ Treatment can also overlook the spiritual and holistic aspects of individuality that mean much to patients.¹⁰ If we do not consider these issues we may find that what might be effective in treating disease may also give rise to disabling anxiety or depression. When we evaluate the evidence about the most effective forms of care we must listen to the patients' view.

Listening to what the patients have to say about the health care they receive is a surprisingly new phenomenon, at least it is in the United Kingdom. Some pioneering work was carried out in the 1960s by people such as Cartwright¹¹ and Raphael¹² when they surveyed people's views of their doctors and health care. However, it was not until the reforms

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Accepted for publication
7 April 1997

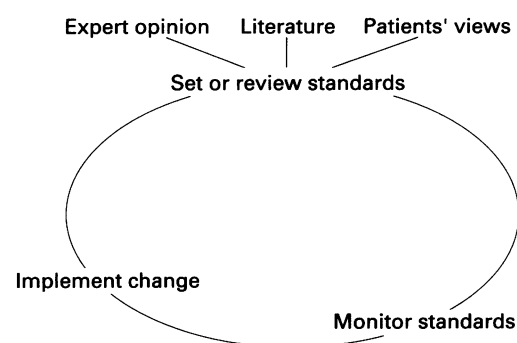


Figure 1 Integrating patients' views in a standard way during the audit cycle.

associated with the Griffiths' Report in the early 1980s that the NHS became aware of the importance of taking users' views seriously.¹³ His report left a deep impression about the importance of listening to patients. He emphasised that a quality service involves "getting close to the consumer".¹⁴ A series of Department of Health publications have subsequently stressed the importance of consumer choice, consultation, and feedback.¹⁵⁻¹⁸ Although some have embraced this emphasis on consumerism as compatible with a drive to create a new type of nursing practice based on partnership with patients, others have been critical of whether it represents a genuine attempt to empower service users.¹⁹ It has been noted that the consumerist rhetoric has accompanied an attempt to wrest the control of health service provision and spending from the professional elites,²⁰ and as yet there has been little evidence of the development of a consumer oriented management culture in the National Health Service (NHS).²¹ However, there does seem to be greater emphasis on consulting patients at all levels of the service.²² The genie of consumerism, once conjured up, cannot easily be controlled or put back in the bottle. It remains a potent force for change in health services because it reminds us that the more we listen to patients the less we can assume that we know what is best for them, and this is the best insurance against paternalism.

The method for obtaining patients' involvement in the audit cycle

During the past decade surveys of patients' satisfaction have become the most common method for obtaining the views of patients.²³ Managers, professionals, and purchasers have recommended the use of satisfaction surveys in audit.^{24,25} Donabedian,²⁶ well known for his writings on quality, has argued that "satisfaction is a measure of the quality of care because it gives information on the provider's success at meeting those client values and expectations which are matters on which the client is the ultimate authority".

There are now several "off the peg" patient satisfaction questionnaires for use. These have been designed to measure satisfaction with medical consultations,²⁷ hospital care,²⁸ and nursing.²⁹ However, many of these questionnaires lack a well developed conceptual model of patient satisfaction.^{30,31} Apart from the few standardised and replicated instruments there have been many local, ad hoc satisfaction questionnaires developed by staff to collect the views of their patients. Unfortunately, many of these surveys are carried out in a haphazard manner with "little attempt to learn from experience or refine the methodology".³² Perhaps it is not surprising that so much of the activity to obtain the views of patients has been associated with the measurement of satisfaction. Patient satisfaction surveys provide a relatively cheap, efficient, and reliable method of obtaining consumer views. The results are readily comparable and we can monitor changes in satisfaction as part of an ongoing

audit cycle. Calnan has argued that surveys of patient satisfaction offer three ideological attractions that have enhanced their ubiquity.³³ Firstly, measuring satisfaction is seen as a way of making health services democratic and counteracting vested interests in health care which fit with a consumer model of influence. Secondly, satisfaction is based on meeting patients' expectations, which are viewed as central to encouraging patient centred practice. Thirdly, satisfaction is a relevant patient outcome. It is related to a patient's sense of wellbeing, and a satisfied patient may be more inclined to use health services and comply with treatment.²⁵

Does the idea of satisfaction really promote consumer influence?

Consumerism encompasses different, and perhaps incompatible, approaches to promoting user influence in health care.³⁴ In a public health service based on meeting clinical need through equity in the availability and provision of services, consumer power can be channelled through means whereby users can exercise their "voice". At the other end of the scale there are those who think that consumer power rests on choice in a healthcare market place, having the opportunity to leave the service and take one's custom elsewhere.³⁵ These views represent differing conceptions of consumer participation and of the relative importance of choice and equity in health care (fig 2). Although current management seems to regard the NHS as moving towards a "mixed economy" approach, it is not apparent that surveying satisfaction can amount to either "voice" or "choice". It is not voice because patients' views are channelled through the distorting medium of a satisfaction survey. It is not choice because the opportunity to take custom elsewhere on the basis of that feedback remains severely limited. Satisfaction surveys rarely consider questions of patients' rights such as access, information, choice, redress, safety, value for money, fairness, and participation.³⁰ They encourage the patient to respond to his or her own health care on an individualistic basis without reference to the wider collective of healthcare users.

Should we base health care on patients' demands?

On the face of it, helping to meet people's wants and expectations would seem to be one of the basic duties of health care. In helping people to get what they want we are respecting their autonomy.³⁶ However, in the context of health care, satisfying people's wants may not necessarily be a justified way of promoting autonomy. A smoker may want or crave a cigarette but it will not necessarily meet his long term health goals to be given one. A local community may demand more high technology acute medical facilities but that may not best meet the health needs of the community. The American healthcare experience suggests that a demand led healthcare system can result in increased spending and more treatments without making the population any healthier.³⁷

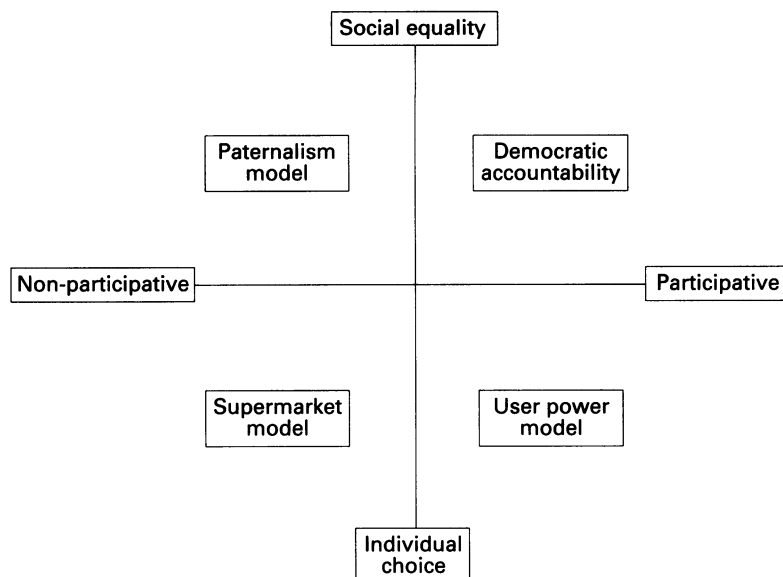


Figure 2 Different models of patients' involvement based on individual choice, social equity, and participation.

The idea of a relation between patients and professionals based on consumer demand is also misleading in the context of health care. Consumer relations rely on a consumer who has decided what his or her wants are, and chooses a certain provider to purchase the product or service that is desired. This requires a balance of information and knowledge between purchaser and provider that is difficult to achieve in health care. Furthermore, consumer relations are based on an underlying competitive tension between the purchaser and provider as both are trying to maximise their own interests at the expense of the other.³⁸ Stacey³⁹ has argued that this type of relation is not appropriate for health work. Patients are best seen as partners and co-producers of their own health outcomes. She argues that to conceptualise patients as consumers of a service is, in fact, to disempower them, as it obscures the structural reasons, knowledge, power and status that allow health professionals to remain paternalistic and resist partnership models of health care. The understanding and skills that support partnership between patients and professionals are not likely to be promoted through consumer relations. Surveys of consumer satisfaction encourage patients to engage passively and superficially in their care, rather than to take a more participative approach to health care which could genuinely challenge dominant interests.

Is satisfaction a valid outcome measure for healthcare interventions?

There remain several doubts about the validity of measures of patient satisfaction. Firstly, there are temporal difficulties with the measurement of satisfaction. People's contact with health services can be thought of as a story. It starts when the patient decides to seek help, and develops through the processes of investigation, diagnosis, treatment and evaluation. Along the way the patient learns more about his or her condition, forms judgements about the helpfulness and competence of staff,

and considers the meaning and value of each health encounter.⁴⁰ The story concludes when the patient thinks that the problem has been resolved, or when the patient becomes reconciled to the fact that medical intervention will achieve no further benefit. In this process patients experience moments of expectation, disappointment, frustration, hope, pessimism, and relief. Attempts to measure satisfaction are usually one off attempts to capture the patients' feelings at one moment in this narrative. Patients' views, therefore, can become divorced from the background narrative of their own healthcare story.⁴¹

Secondly, the underlying model of satisfaction is based on fulfilment of expectations. This model suggests that people are satisfied when their care meets their expectations. In fact, there is little empirical evidence that satisfaction is linked to fulfilment of expectations.⁴² Patients do not always have clear expectations of their care,⁴³ and there is some evidence that negative expectations may be important; patients who fear the worst in their contacts with health care can, paradoxically, be satisfied when their care has not confirmed their worst expectations.⁴¹ Demographic variables, orientation to care, and sociopolitical beliefs about the NHS may all function as intermediary and confounding factors in patients' assessments of their care.³³ We simply do not know enough about how patients make judgements about health care when asked by researchers. Williams⁴² argues that: "Patient satisfaction questionnaires do not access an independent phenomenon but, in a sense, actively construct it by forcing users to express themselves in alien terms". Furthermore, questionnaires that measure satisfaction with specific aspects of care—for example, nursing—risk fragmenting the patients' views of their care and diverting attention from the multidisciplinary aspects of quality.

Thirdly, there are well known measurement problems with satisfaction surveys. The almost uniformly high levels of patient satisfaction shown by most surveys casts doubt on their ability to detect real differences in patients' opinions.³⁰ We know, for example, that there are "halo" effects, patients who experience one favourable aspect of care tend to rate all aspects of their care very highly; and it has been argued that patients are reluctant to criticise out of gratitude, or fear that they may jeopardise future care.⁴³ The wording, ambiguity, and superficiality of patient satisfaction questionnaires have also been criticised.⁴⁴ Surveys often have poor response rates, require a certain standard of literacy, and tend to exclude those with visual impairments or who do not use English as a first language.³²

None of which should take away from the fact that there is a central place for satisfaction surveys in monitoring standards of quality in health care. However, they must be sensitively performed. We need to learn from experience and improve the methodology, and make progress toward meeting some of the reservations already mentioned. Although satisfaction surveys are easy to use, they are

blunt instruments. As an old adage reminds us, "to someone who has a hammer everything begins to look like a nail". Measuring patient satisfaction can give us the comforting illusion that we are listening to patients. But satisfaction surveys do not, by themselves, promote a listening service, in which staff attend to the views of patients and their relatives, are willing to make changes in the service, and reflect on their own attitudes in response to what they hear.

Using qualitative methods

A qualitative approach to obtaining patients' views about health care remains essential to maintain a critical perspective on the quality of care. Qualitative methods concentrate on obtaining narrative information from less structured and more detailed interview and observation techniques. They are based on an interpretative and naturalistic approach to enquiry rather than control and measurement. Qualitative methods aim to discover how people talk about their experiences, attitudes, and behaviour without fitting them into predetermined categories, and to place these descriptions within a detailed cultural context.⁴⁵ Qualitative research asks why and how questions rather than how many and how much, and it gives patients a chance to say what they think in their own words. The idea that qualitative research can be used to capture users' views is relatively new. In the 1970s Mayer and Timms⁴⁶ published a book entitled *The Client Speaks* in which working class clients spoke about their responses to the social work practice of the day. The authors were prepared for the criticism which would ensue when they wrote in their introduction that "an investigation of clients' perceptions may be threatening to the professional to the extent that it is construed as a challenge to his competence". Further studies have applied this qualitative approach to medicine^{47, 48} and nursing.⁴⁹ The impact of hearing patients' views in this way is often unsettling and disturbing for professionals because it exposes the frame of reference that patients use to judge them, and can challenge the cosy comforts of benign paternalism.

Qualitative techniques are likely to involve patients more fully in the research as they depend upon an exchange of views. Patients are seen as research partners rather than subjects.⁹ Roberts⁵⁰ argues that: "the active contribution of citizens to research is a necessary way of ensuring that policies which arise from that research can, in a meaningful and effective way, be connected with the lives of those towards whom they are directed". Use of participative and qualitative approaches to audit avoids treating service users as sources of data, and can lead to improvements in care which are fully grounded in patients' expressed values and aspirations. For example, Redfern and Norman have used qualitative methods to understand what quality nursing meant for both patients and nurses.⁵¹ Integrating qualitative research into the audit cycle requires a change in the timing of patient involvement.

Instead of asking patients how far they are satisfied with a range of standards chosen for them. It is to involve patients, through the use of qualitative research methods, in the setting of quality standards.⁵²

With this model, standards are set with the available research literature, canvassing professional opinion, and finding out through qualitative research what patients think about the service. Patients' views can be elicited in several ways: complaints monitoring; patients' associations; suggestion boxes, etc. However, the richest, and most detailed sources of information can come from individual interviews and focus groups. Monitoring standards will involve a range of activities including studying outcome by reviewing records, and some form of systematic evaluation by patients, possibly to include satisfaction surveys (fig 3).³

Carrying out qualitative studies

WHO TO ASK TO PARTICIPATE?

Qualitative studies do not aim to obtain a representative cross section of a particular patient population. Instead the researcher selects people to participate on the basis of their having something to contribute to the research question. This approach has been termed "theoretical sampling".⁵³ In research designed to obtain patients' feedback about health care it is essential to recruit people who have both positive and negative experiences of care to relate. Identifying such respondents can present a problem, and some authors have recommended following up patients who write in to complain or praise.³⁰ Advertising within the hospital or clinic, or contacting patients associations or self help groups, can also yield participants. Hospital or community staff can also identify people with something to contribute. Once you have located the people you wish to include there is usually no problem in getting them to participate.⁵⁴ In a local study of cancer services the researchers were anxious about whether people would want to take part, due to the nature of the subject, instead they found that people were "falling over themselves to participate". In terms of the number of patients to include, between 10 and 30 participants is usually adequate depending on the context and the duration of the interviews.

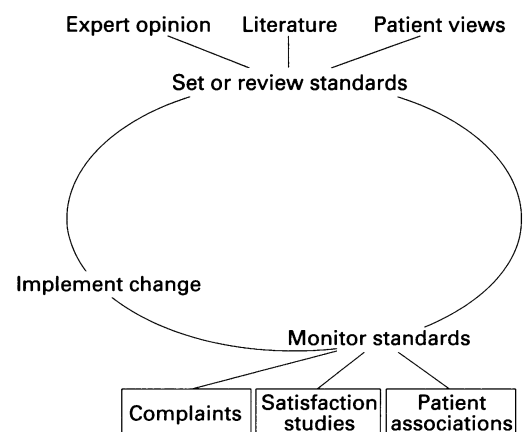


Figure 3 Capturing patients' voices during the audit cycle.

WHAT QUESTIONS TO ASK?

Qualitative researchers use open, flexible questions. The aim is to encourage patients to provide a narrative of their experience and to discover their understanding of events without imposing the interviewer's own ideas.⁵⁵ Issues for discussion could include patients' perceptions of the approachability of staff, whether they thought that they were treated as an individual person, the efficiency and fairness of the service, the amount, clarity, and usefulness of the information they were given at each stage of their care, their views about choice and involvement with care and treatment decisions, and whether they considered their use of the service to be worthwhile.⁵⁴ It is best to use a semistructured interview guide, this allows for a core of prepared questions that consider these topics but leaves considerable flexibility and freedom to pursue matters of importance to the patient. Semistructured interviews do not use standardised wording, and depend on the use of supplementary and clarifying questions phrased in participants' own vocabulary to clarify the meaning that they attach to their experiences. The general intention is to prompt patients to give examples of their experiences that illustrate their views.

How to present and use the findings?

Qualitative interviews produce data in the form of interview notes or transcripts of tape recordings. The purpose in analysis is to give voice to the diversity of patients' experiences of care rather than to summarise them into a typical point of view. The usual method is to distil out the important issues for the interviewees by a meticulous process of classifying and coding the data.⁵³ Analysis aims to identify themes, based on the classification, which capture the range of patients' views. As the results of qualitative studies cannot be neatly summarised in tables or graphs, it is common practice to use quotes from the interview data to illustrate the tenor and diversity of the patients' views. The validity of the findings of qualitative research depends on detailed descriptions of the methods and context of the study, so that researchers' interpretations can be judged against their methods and the social location of the study. Claims for the generalisability of qualitative studies are made with great caution, and only where there is a background of social theory which would allow wider application of the findings.⁵⁶

It can be uncomfortable, and sometimes even painful, to hear how patients think about professional help. Those used to scientific studies tend to deny the value of a report based on a non-representative sample that does not rely on a reliable measurement. But it is important to remember that qualitative studies are about listening to what people say on their own terms, before they get homogenised through the process of statistical analysis into a mean and standard deviation.

A qualitative study can be more time consuming for both staff and patients than simply using an off the peg satisfaction survey.

However, with appropriately trained staff this is not a prohibitively expensive option, and the quality of information is worth the extra effort. It is especially suited to people who are vulnerable or have poor communication skills, and who find it easier to express their views in a manner of their choosing.⁵² The findings of studies carried out by consultants or external researchers who used off the peg questionnaires can be difficult to incorporate into local policy because of lack of staff commitment and local relevance.³² Qualitative methods, on the other hand, require greater levels of involvement and more attention to the context of the study. It has been suggested that the two central issues in making any quality initiative worthwhile are staff ownership and clear actions for improvement.⁵⁷ Powell *et al*⁵² argue that it can be easier to get staff to take ownership of a qualitative study as it provides a better understanding of patients and their carers' concerns, and the findings of qualitative studies can give more direct impetus for change as they relate directly to local practice and context.

Conclusion

Capturing patients' voices is essential if we are to promote quality services, challenge paternalism, and provide effective health care. Measuring satisfaction, although widely practised, does not capture the full richness and diversity of patients' views. If we really want to have standards focused on patients, then we should use qualitative techniques, for it is these methods that genuinely encourage a listening service.

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