Asking patients about their treatment

Why their answers should not always be taken at face value

Patients’ views on health care are sought for various reasons. They form a crucial component of research into the outcome of clinical interventions and help improve our understanding of how people cope with being ill or strive to remain well. Recently, patients’ views have received growing acknowledgment in the planning and delivery of health care, most notably in Working for Patients and the patient’s charter. Developing methods for involving patients in the evaluation of health care is regarded as a priority in clinical audit.

In eliciting the views of patients two assumptions are crucial: firstly, that patients want their views taken into account and, secondly, that such views are trustworthy indicators of a patient’s health or health care. The first assumption implies that patients’ views should be balanced and well informed. This in turn requires that patients should have access to all the information they require and should participate as actively as possible in the management of their illnesses. Although a sound principle to follow, this cannot be applied fully under all circumstances to all patients. For example, older people express a weaker preference for personal involvement in decisions about their medical care than younger people.2 Patients’ expressed wishes for involvement decline with increasing severity of their illness,3 4 although this probably relates more to their perception of the severity of their disease than to objective, “disease” variables.5 Ethnic group and cultural background are also likely to be important.6 Other factors may operate—for example, some patients adopt denial to cope with their illness,7 and they commonly find detailed inquiry about their illness intrusive or even distressing.

How trustworthy are patients’ accounts of their health or illness? For example, how do they compare with other variables, particularly those defined by the patients’ professional carers? Where disease related variables are available they do not necessarily accord with patients’ views. For example, in arthritis, patients’ assessments of their disability and functional status correlate only weakly with objectively obtained measures of these. They are more strongly linked with psychological factors such as patients’ perceptions of how controllable their symptoms will be.9 Similar observations have been made in other illnesses, including cancer and chronic renal failure.10 This is hardly surprising—to a patient an illness is an experience, not easily reduced to a list of variables measured in the laboratory or clinic. Attempting to define and understand such experiences forms a major focus of the work of general hospital psychiatrists and health psychologists, who have much to contribute to the assessment of patients’ views from their research and clinical work.

If patients’ views are not always reliable is it possible to predict when they should be interpreted with caution? Denial is likely to be important in only a few cases. Of greater importance quantitatively is the presence of affective disturbance. Symptoms of depression or anxiety occur in up to 60% of people with serious physical illnesses.11 These rates overestimate the prevalence of clinically important affective disorder as such symptoms in physically ill people are often transient. Even such transient symptoms, however, are associated with the distorted patterns of thinking that are characteristic of depression or anxiety.12-14 Symptoms of depression influence patients’ perception of disability and pain, and their coping strategies,15 which in turn can affect overall adjustment to illness.16 Depression and anxiety can also affect patients’ perceptions of their medical care17 and are therefore likely to affect their desire for involvement in decisions affecting their management. Affective disturbance leads to a systematic bias in patients’ perceptions and beliefs, which is likely to distort all types of self ratings, including reported symptoms, functional status, overall health, and satisfaction.

Some measures of global satisfaction for assessing the outcome of intervention were developed for use in (healthy) community samples.18 In such populations affective symptoms, particularly transient ones, are far less common than they are among physically ill people. Such scales, whose ratings correlate significantly with measures of depression,19 have yet to be properly validated in samples of patients to whom they have been applied. Other scales intended to provide global outcome ratings in the physically ill, such as the SF-36 questionnaire,20 include items that are likely to elicit different answers if depression is present. Again, invalid results are more likely from patients with serious physical illness than from patients drawn from general practice lists.21 For people with HIV infection, overall self ratings on the SF-36 questionnaire correlate strongly with physical symptoms, suggesting that this questionnaire may be a valid measure of outcome.22 All scores from the SF-36 questionnaire, however, correlate significantly with self ratings of depression, and scores on the scales assessing psychological aspects of quality of life do not correlate with disease progression (M Dayer et al, unpublished observations). Wells et al have argued that patients make similar demands for health care whether they are physically ill or depressed and that the basis of these demands can therefore be ignored.23 In this instance, demands are very different from needs. Patients with physical illnesses who are anxious or depressed may ask for more frequent review in the outpatient clinic and may even be satisfied with their care if this can be arranged. Such management fails, however, to meet one of their needs—namely, the management of their affective disorder.

Although the growing interest in patients’ views should be welcomed, comments and questionnaire ratings may not necessarily be adequate end points in themselves. In clinical audit, doctors rightly insist that managers, politicians, and others must understand how data are collected to judge their professional involvement with hereditary Alzheimer’s disease. Science 1991;253:717-19.


meaning accurately. This principle applies equally to data gathered from patients. The difficulties of interpreting information from patients should not detract from the aim of involving patients as fully as possible in their health care. Rather, this should act as an even greater incentive to research into communications between patients and health professionals.

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Department of Health reports on tobacco advertising

A ban would significantly cut consumption

The European Community directive to ban tobacco advertising was proposed over a year ago. Strongly supported by the British health and medical establishment, the ban has been consistently opposed by the British government. The long awaited report on the effects of tobacco advertising by the Department of Health's chief economic adviser is now issued as a discussion document. It includes a wide ranging assessment of worldwide evidence and presents its own new empirical analysis. Its aim is to assess whether tobacco advertising affects aggregate demand for tobacco products and not simply the share of the market taken by individual products, as is argued by the tobacco industry.

The report's main and strongest evidence comes from studies of tobacco consumption analysed by price, income, advertising, and publicity about tobacco's harmful effects. Advertising is notoriously difficult to model because it takes time to reach its full effect, which may then last for many years. Three main types of analyses were studied: analyses of year by year fluctuations in cigarette consumption, cross sectional comparisons between countries, and analyses of cigarette consumption in countries before and after they banned tobacco advertising.

The report concludes, with reason, that the studies of bans are the most satisfactory. These present a direct measure of the total impact of tobacco advertising, controlling for price and other factors, and avoid the problem of direction of causation present in cross sectional studies. There have been bans in New Zealand (1990), estimated to have reduced consumption by 5-5%; Canada (1989), a rather confused situation but estimated to have reduced consumption by 4%; and Finland (1977), estimated at 7%. Because the effect of the ban in Norway (1975) had not been formally evaluated the Department of Health's economists analysed its effects themselves. They estimated that the average consumption of tobacco per adult fell by 16% due to the ban; a double hurdle model, simultaneously estimating the effect on prevalence and amount smoked, suggested a long term reduction of 9%. All these studies suggest sizeable and significant effects of tobacco advertising bans.

A cross sectional study of 22 countries belonging to the Organisation for Economic Cooperation and Development reported a significant effect of different levels of advertising restrictions. Countries were scored from 0 to 10 according to severity (Britain scored 6 in 1986), and the study suggested that each point was associated with a 1-5% decrease in consumption. This would imply that an advertising ban would cut consumption in Britain by 6%. The report points out the difficulty of interpreting the direction of causation—negative social attitudes to smoking may be related to both low tobacco consumption and stricter advertising controls.

The third and most numerous group comprise time series. The report notes that 13 reported only positive effects of tobacco advertising on consumption, one reported a negative effect, and five reported both (in different equations). The authors note that "the preponderance of positive results points to the conclusion that advertising does have a positive effect on consumption." British researchers work within the limitation that published data on tobacco advertising omits spending on billboard advertising (estimated as 30-40% of total advertising spend^2) or sponsorship. The leading studies in this category were published some years ago, and the first implied that a ban would reduce consumption by about 7-5%, which would take some time to show its full effect.

The report emphasised that analyses of time series are likely seriously to underestimate the real effects of a ban: annual...