activities must be weighed against potential disadvantages such as increased exposure to ultraviolet.

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Patients' prerogatives and perceptions of benefit

Frank Kee

Patients today demand more information about their treatment. Doctors, however, seem reluctant to cast aside ingrained habits of paternalism, believing they can best interpret therapeutic choices for their patients. Whether doctors can be more objective and effective than patients in interpreting the "probabilities" of medical evidence is open to question. On the other hand, the exercise of choice by patients may itself have a bearing on the probabilities of outcome. Involving patients more in making therapeutic choices is justified if doctors can present options in an unbiased and effective manner and if the process improves the outcome of the care delivered.

A prominent medical educator reputedly once told a group of students: "Half of what we teach you is wrong; our problem is to determine which half." However, exposing the scientific frailties of current medical practice is still a relatively novel pursuit in British medical schools. Whether in response to a rising current of consumerism or litigation, patients have begun to question their doctors' "certainties," demanding more and better information about their care. Despite this, reports of the demise of paternalism are premature. While there are those who hold the view that medical "power" rests as much on uncertainty as on technical expertise, it would seem that physicians "must strike a balance between submerging their patients in information, thereby diminishing their patients' ability to make rational choices, and restricting that information to simplify decision making."¹

Such views presuppose the ability of doctors to make entirely rational choices based on new therapeutic information and reflect a rather limited view of the value of the information and dialogue that is shared with patients. Perhaps it is time to question some of the apparent underlying assumptions.

Do doctors give sound and unbiased information about therapeutic choices?

In an intriguing study Cassileth *et al* asked patients and members of the public what would prompt them to participate in a clinical trial.² Over half of all respondents selected "getting the best medical care" as their primary reason for potential participation in medical research. However, when asked which patients receive superior care, respondents chose treatment recommended by doctors over treatment given in clinical trials. Clearly, therefore, many patients have faith in their doctor's judgment. However, professional

complacency would be misplaced. Antman *et al* have elegantly highlighted the divergence between the publication of research findings and recommendations made by experts for routine medical care,³ a finding that echoed Sackett's earlier definition of what constituted a clinically important difference in the effects of treatments—namely, one that brought about a change in clinical practice.⁴ The substantial variation in clinical practice that has been demonstrated in various clinical domains would hardly be credible if valid evidence about the benefits of treatments were being more uniformly assimilated.

While this variation has been assumed to reflect professional uncertainty about the best forms of care, this hypothesis has been difficult to test directly. An alternative hypothesis that has recently gained credence states that geographical variation in the use of procedures depends more on the variation in the prevalence of enthusiasts for particular forms of care.⁵ Enthusiasts are seldom uncertain. They are believers. Support for this alternative explanation has come from a recent study of an intervention to improve doctors' knowledge of probabilities in making diagnoses and recommending treatment. Teaching doctors to make better judgments of the probability of a disease developing neither affected the extent of variation in practice nor had any real impact on treatment decisions.⁶

Corollaries are not difficult to find, and three examples from cardiovascular medicine merit mention. In one study doctors' estimates of haemodynamic function (such as ejection fraction) before right heart catheterisation were found to correspond only modestly with the true values.⁷ More importantly, there was no relation between a doctor's experience or confidence in the estimates and their accuracy.⁷ In the multicentre bypass angioplasty revascularisation investigation (BARI), agreement could not be reached for objective angiographic criteria for patients' eligibility.⁸ Instead, comparisons among readers showed that the most important factor determining eligibility was the angiographer's degree of confidence in the efficacy of angioplasty (this was despite the fact that readers agreed in their assessments in only 28% of cases and that, when blindly re-reading patients' films, the operators agreed with their earlier assessments only 73% of the time).⁸ Furthermore, cardiologists undertaking angioplasty systematically overestimate pretreatment luminal stenosis and underestimate the residual stenosis, tending to produce a biased view of treatment "success."⁹ It is therefore not surprising that few patients appreciate the real chances of re-stenosis after angioplasty¹⁰ and that half of

People's perceptions affect outcome

patients who have had bypass surgery and perceived a benefit believe that the operation was lifesaving.¹¹

While cognitive biases among clinicians are becoming more widely appreciated,¹² it has also become clear that doctors may make different therapeutic choices according to whether the effects of a treatment have been reported in the literature in terms of relative or absolute reduction in risk¹³ and whether they are reported on an averaged as opposed to a stratified basis (for example, mean life expectancy versus the proportion surviving five years).¹⁴ General practitioners, for example, were much more likely to prescribe a cholesterol lowering drug when shown data suggesting that it could lower the cardiac event rate by 34% than when given information about the same drug which suggested that it could reduce the event rate from 4.1% to 2.7%.¹³ Small wonder then that patients are more inclined to accept treatments when their efficacy is framed in terms of relative rather than absolute reduction in risk.¹⁵ If it is true that efforts to improve in the practice of medicine and the health of our patients depend as much on the interplay between doctor and patient as on the results of research, then some collective humility might be in order and we must not assume that our interpretation of research is necessarily free from bias.

Do doctors communicate effectively with patients?

Nearly 40 years ago Pratt *et al* tested patients' comprehension of the information that they were routinely given about their treatment.¹⁶ Doctors significantly overestimated the amount of information understood by the patients, and, moreover, the authors found that the less the doctor thought the patient knew, the less information that was given. Later studies have shown broadly similar results, and, though it might be thought that the ethos of the 1990s is more enlightened, there is still clearly a need to improve the comprehensiveness, relevance, and intelligibility of the information given to patients.¹⁷

One reason often given for a more paternalistic approach is that open discussion of the benefits and risks of treatment might cause undue anxiety and may make the reporting of side effects more likely. This was elegantly shown to be unlikely in a recent randomised controlled trial.¹⁸ A further reason is that patients may not be best placed to understand the probabilistic nature of the relevant outcome data. However, the now large literature on the use of probability trade offs suggests that we should not assume that patients will have any more difficulty than their doctors.¹⁹ In one well known study the attractiveness to patients of one treatment over another was substantially greater when the information provided consisted of life expectancy rather than cumulative survival probability and when the choices were framed in terms of probability of living rather than of dying.²⁰ However, the preferences

expressed by the doctors, which are likely to play an important part in the advice they give to patients, were subject to the same biases.²⁰

On the other hand, giving explicit information on clinical trials in terms of probability trade offs fosters more fully informed consent without adversely affecting trial participation.²¹ Indeed, a recent study has shown that it is not an increase in data given to patients *per se* that affects their preferences but rather the level of explanation of the data.²² For instance, when more extensive explanation about the effects of treatment on survival was provided, patients reported being more influenced by medium range data (the area under the survival curves) or the average life expectancy than by endpoint data (the proportions alive or dead after, say, five years).²² Therefore, when patients express complex contingencies relevant to their treatment decisions, health care professionals should avoid simplifying those complexities into a list of pros and cons.

Can more effective communication improve health care outcomes?

Chalmers argues cogently that greater involvement of patients in setting research agenda might lead to a more open minded approach to which questions are worth addressing, which forms of health care merit further study, and which treatment outcomes matter.²³ Several randomised controlled trials have already shown that interventions designed to increase patients' involvement in medical decision making can lead to improved outcomes. In one study the degree to which hypertensive patients perceived that they had participated in planning their medical management correlated with the success of controlling hypertension.²⁴ In a more recent study, subjects with lower perceived control over decisions about their health had higher blood pressure.²⁵ A recent systematic review of 10 analytical studies and 11 randomised controlled trials indicated that, in 16 studies, more effective communication was significantly related to improved health outcomes.²⁶

Doctors and researchers now realise that they cannot assume that their own values and priorities apply to their patients, and thus the incorporation of patient preferences is seen as the next frontier in attempts to devise valid practice guidelines. Although several aids to consumer decision making are being developed—including video disks,²⁷ decision boards,²⁸ and audio-tape booklets²⁹—the development of flexible guidelines may incur greater costs because of the extra work needed to assess patients' preferences. However, the available evidence, though limited, suggests that the marginal cost effectiveness ratio for incorporating individual patients' preferences into treatment decisions compares favourably with other health interventions.³⁰ This is a growing area of research, which has now been recognised by a recent commission from the Research and Development Directorate of the NHS and the establishment of a Cochrane Collaboration group on effective professional practice.

From current research, it is not clear whether interventions in health care are more effective in informed patients who are involved in decision making about their care or whether the exercise of choice itself is therapeutic. For example, in the coronary drug project³¹ and the β blocker heart attack trial³² it seemed that the subjects who chose to take their medication (the compliers) had significantly lower mortality irrespective of whether they were taking the active drug or the placebo. This effect has also been observed for well informed subjects in the physicians' health study.³³

Key messages

- No information, even that on efficacy of treatment, is without value
- Doctors and patients often share optimistic views about new treatments, but, since they may be equally prone to cognitive biases, paternalism in sharing information is seldom justified
- Patients' expectations are likely to modify their perceptions of the benefit of treatment
- Doctor-patient communication is a central clinical function, and future research must help disclose its largely untapped therapeutic potential

IMPORTANCE OF PATIENTS' EXPECTATIONS

Although health beliefs may predict compliance,³⁴ several studies suggest that patients' beliefs and expectancy have more general effects that might determine the outcome of treatment. Sox *et al* found that, when patients complaining of non-specific chest pain were randomised either to having routine electrocardiographs or to having all tests withheld, significantly fewer patients who underwent the tests had disability after the index visit.³⁵ They concluded that the content of care could modify patients' expectations of care and the perceptions of benefit.

In a prospective study of 348 men undergoing elective surgery for benign prostatic hyperplasia, the men who had positive expectations of surgery were most likely to report feeling better after surgery, even after changes in symptoms were controlled for.³⁶ In another study, patients with cancer who were due to receive chemotherapy were asked about their expectations of their health and quality of life after treatment. These expectations were significantly predictive of the patient's perceived health at follow up, even after their actual health states before and after treatment were controlled for.³⁷ Scheir *et al* examined the effects of dispositional optimism on recovery from coronary artery bypass.³⁸ Optimists, despite having somewhat more adverse risk factors, were significantly less likely than pessimists to have developed new Q waves at electrocardiography after surgery or to have shown a clinically important rise in cardiac enzymes. In addition the optimists had a speedier recovery.³⁸ It is arguable whether these effects are properly described as placebo responses, but it should be only a matter of time before attributable biological pathways are clear.³⁹

Conclusion

It seems that the case for more effective sharing of information with patients is more than a leap of faith.⁴⁰ It would seem sensible however to ensure that future research on evaluating standards for patient decision supports must also assess the impact of expectancy on health care outcomes. It is unclear, for instance, whether patients with positive but unrealistic expectations of their therapy (as in the case of coronary artery bypass surgery) ultimately do better or worse than those holding a more realistic view, but the implications for patient support and education might be different. Patients' health state perceptions and preferences are conditioned by the difference between what is and what they consider might have been.

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