

**THE AUTONOMOUS PATIENT**  
**Ending paternalism in medical care**  
**(Angela Coulter, Nuffield Trust, 2002)**

**Introduction: the problem**

Untested assumptions about what the patient wants can lead to unnecessary treatment.

Patients are frequently given a biased and highly optimistic picture of the benefits of medical care.

Too often the way in which clinicians and patients interact tends to promote passivity and dependence instead of self-reliance, sapping self-confidence and undermining people's ability to cope.

Instead of providing patients with new knowledge, self-help and coping skills, the effect of many medical consultations is to encourage them to rely on health professionals to solve their problems, even when this is unrealistic.

If doctors are unable or unwilling to tell their patients when medical care can do little to help, it is hardly surprising that patients keep coming back search for explanations and cures. This leads to frustration among doctors and dissatisfaction among patients.

In 1992 the Patient's Charter informed British patients that they have the right "to be given a clear explanation of any treatment proposed, including any risks and any alternatives, before you decide whether you will agree to the treatment." Yet it is still the case that many patients say they are not given full information about their treatments or a real opportunity to have a say in decisions about their care.

If health professionals act in a way which undermines people's coping skills, they can expect to see patients calling on their services with increasing frequency. On the other hand, if they could help their patients to help themselves they might be rewarded by fewer unnecessary consultations.

Medical education still operates under the shadow of the earlier paternalistic era and many doctors have not been trained to listen to patients and take account of their preferences.

Paternalism is harmful to health because it fosters passivity, sapping self-confidence and undermining people's ability to cope. Paternalistic relationships create and reinforce dependence on health professionals.

**What is needed**

In the 21<sup>st</sup> century the patient should be a decision-maker, care manager and co-producer of health, an evaluator, a potential change agent, a taxpayer and an active citizen whose voice must be heard by decision-makers.

Much more fundamental change is required in the way in which patients and professionals interact. Managers and clinicians will have to be prepared to cede some power and patients must be willing to take greater responsibility for their own health. These changes are necessary to ensure the sustainability of collective health care provision. Discharging the obligation to respect patients' autonomy requires equipping them to overcome their sense of dependence and achieve as much control as possible as they desire.

The clinician has an obligation to build up or maintain the patient's capacity for autonomous choice, to disclose information, to probe for and ensure understanding and voluntariness, and to foster adequate decision making.

The changes that are needed are more than cosmetic. What is required is a change in the way clinicians and patients think about their roles, in other words a culture change. Patients' rights to make autonomous decisions need to be better understood, encouraged and supported. This is necessary to restore confidence in the system, to facilitate appropriate treatment choices, to manage care effectively, to ensure patient safety, to raise quality standards and to promote accountability. The patient needs to be seen as an active participant and the clinician as a facilitator. They should be equal partners in the process of dealing with illness. Old habits which promote dependence and passivity in patients must be cast aside, along with the paternalistic attitudes which underpin these behaviours. Clinicians will need to develop expertise in information retrieval, preference elicitation, interpretation of evidence and risk, and education for self-reliance, alongside their more traditional clinical skills.

Doctors and their patients must be persuaded to acknowledge the limits of medical care.

The skills in critical appraisal that most trainee doctors now learn need to be transmitted to their patients. If doctors are encouraged to rethink traditional approaches but patients are left in ignorance, the result will be conflict and dissatisfaction.

Empathy and reassurance may be even more important when scientific medicine has little to offer.

Doctors should ensure that their patients are supplied with honest information if medicine has nothing to offer. There is no merit in perpetuating false hopes.

Patients will need help to enable them to become more discriminating consumers of health care and doctors will need help if they are to facilitate this process.

Patients require time to come to terms with the choices facing them and seek a sympathetic hearing from the clinician.

## **How this can be achieved**

Doctors should provide full information to enable the patient to make a choice. They should elicit patients' views and preferences, answer their questions honestly, use written material and visual aids where appropriate, and allow sufficient time for patients to absorb the information and discuss it with others if they wish. For this to be feasible, doctors need training in how to impart information about risk and probability and how to answer patients' questions.

An American group, the Centre for Information Therapy, has been established to promote the idea that information can have a therapeutic role in helping patients to manage their symptoms or health problems.

Educational initiatives are a good idea, but unless they are accompanied by a change in the way health professionals respond to patients they are unlikely to have a sustained impact.

If patients were encouraged to review their notes and provided with clear explanations of the meaning of the clinical terms used, it could be very empowering.

Patients are in a good position to evaluate the quality of their care and it is increasingly being recognised that patient feedback ought to be a central part of any quality improvement programme. Feedback can help refocus the attention of clinicians and managers on the patient's experience and can galvanise them into action to improve quality standards. One approach is to ask patients to report in detail on their experiences by asking them specific questions about whether or not certain processes and events occurred during the course of a specific episode of care.

Measures of patient experience may prove easier for patients to interpret than other measures of performance such as mortality rates. Awareness that these data are publicly available may prove to be an effective incentive for providers to ensure that their services are truly patient-centred.

Public education is required to encourage people to appraise health information critically and to help them understand the concepts of probability and risk and how to cope with uncertainty. Ideally this should start in schools, but it could also be incorporated into occupational training schemes and public education via the media.

## **Patient's involvement in decision making**

There is plenty of evidence that most patients want more information than they are currently given, but this does not necessarily mean they want to participate in decision-making.

Patients often prefer more conservative and cheaper treatments than their doctors are inclined to recommend. Shared decision-making could be one of the best ways to ensure

more appropriate use of health care resources, yet professional training programmes have been slow to incorporate it or to inculcate the necessary skills. Investment in decision aids has been confined to a few relatively small-scale initiatives. What is needed is a commitment to develop and disseminate good quality information and decision aids, coupled with staff training and organisational support. The effort and resources required are relatively modest, but the rewards for patient, clinicians and the health system as a whole could be considerable.

When patient participation is facilitated by using specially designed aids, their knowledge and satisfaction with the decision process is increased.

Decision aids help people make specific deliberative decisions about disease management and treatment options, prevention or screening. They use a variety of media to present the information in an accessible form to patient, including leaflets, audiotapes, workbooks, decision boards, computer programmes, interaction videos, web sites, structured interviews, and group presentations.

They are very different from standard health education materials because they are not didactic or prescriptive – they do not tell people what to do. Instead they help patients clarify their own values and preferences and weigh up the potential benefits and harms of alternative courses of actions.

Good decision aids include evidence-based statements of benefits and risks derived from credible sources, refer to the quality and consistency of empirical studies and are explicit about uncertainties and controversies, present all options (including doing nothing) in a balanced way, and are well designed, clearly structured and concise. Many decision aids use interactive methods to help patients clarify their values.

### **Suggested action plan**

#### *Sharing treatment decisions*

Give detailed information on local health services, including quality standards and maximum waiting times.

When you don't know the best course of action, be willing to admit it.

If there's no effective treatment for a patient's problem, say so.

Use graphics, computer programmes and other techniques to explain risk and outcome probabilities.

Give patients non-alarmist information about medicine side-effects.

Provide information on what patients can do to help themselves.

Educate patients about how to prevent illness and prevent recurrence.

Establish a library of good quality patient information materials.

Research information sources on the web so you can advise patients about where to look for relevant information.

Publicise reliable information sources such as the National Electronic Library for health, NHS Direct, etc.

Keep a collection of paper-based decision aids and/or a list of internet addresses for web-based decision aids and refer patients to these.

Give patients copies of clinical guidelines – for example, the National Institute for Clinical Excellence publishes patient version of its guidelines.

Put patients in touch with self-help groups and other sources of information about chronic disease.

Where appropriate refer patients to self-management training programmes.

Involve carers and inform them about support services.

Patients could be encouraged to append their own comments to the records and to draw attention to any errors or omissions.

#### *Patient feedback and quality assessment*

Ask patients about their experience of illness and how it and the treatment affects their lives.

Offer opportunities for patients to ask questions and check their understanding of the answers.

Encourage patients with long-term conditions to keep records or diaries of their experiences of treatment and review these with them.

Organise focus groups with specific groups of patients or carers (eg those with chronic diseases, those caring for people recovering from stroke, patients from ethnic minorities, asylum seekers, etc) to learn more about their experiences and how the practice or Primary Care Trust can meet their specific needs.

Learn about the needs, values and illness perceptions of people from minority ethnic groups (cultural competence training).

Learn more about the needs of people with disabilities (disability awareness training).

Use videos of patients talking about their experience of illness and treatment in educational programmes for staff and trainees.

Organise regular patient surveys and use the findings to set priorities for quality improvement.

Use brief questionnaires after consultations to elicit patients' views on communication and interpersonal skills.

Organise a patient participation group and enlist their help in reviewing practice organisation and suggesting improvements.

Review disabled access – involve disabled people.

Publicise and review the complaints procedure.

Give patients feedback on any changes made.

Arrange consultation skills training for all staff, not just doctors, and use patient feedback to monitor the outcome.

Make time available during the day for telephone or email consultations.

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### **Other observations**

My contention is that they will not be achieved until those working in the NHS adopt a radically different view of the patients' role. There has been much talk of the need for a 'culture change' in the NHS, but little clarity about what needs changing and how to do it.

Their views on interpersonal care should be systematically monitored to establish whether they are receiving care of optimal quality.

Patients have a legitimate and important role as evaluators of health care, both in generating reports on their own experience and in analysing and using information on the quality of care to make comparisons between health care providers and to inform their own choices.

In health care we rely on health professionals to assess our needs and to decide whether or not we have a problem which requires their intervention. In this sense the doctor is the patient's agent. However, if the agent is also the supplier of services, the separation of demand from supply – one of the essential characteristics of a properly functioning market – no longer holds. The relationship depends on the patient's trust in the doctor and in the various regulatory systems.

Patients with life-threatening illnesses, such as cancer, may be less willing to accept shared responsibility than those with less serious conditions. In these cases it may be more important to allow patients an opportunity to express their concerns and preferences than to involve them in the decision itself.

Patients' information needs may change during the course of an illness.

It seems that patients are often more risk-averse than the clinicians they consult.

The authors concluded: “the culture into which the leaflets were introduced supported existing normative patterns of care and this ensured informed compliance rather than informed choice”.

If health professionals find it difficult to support shared decision-making and informed choice, they will need training and support to implement a patient-centred approach.

In essence, consultations are not units of consumption, but units of production.

About a third of those who continued to take the medication failed to take it in sufficient quantities to achieve a beneficial effect.

Stroke, depression, chronic pain, insomnia, sickle cell disease and multiple sclerosis. A number of these programmes have been independently evaluated.

The new enthusiasm for self-care risks disappointment and disillusion if it is assumed that it will automatically lead to a dramatic reduction in demand for health services. This certainly won't happen unless there is also a significant change in the way patients and professionals interact with each other.

Not told when to resume normal activities.

These results offer compelling evidence that, in general, patients have unacceptably high rates of problems with selected issues, such as emergency care, explanations of test results and treatment options, opportunity to discuss anxieties with doctors or nurses and to have a say in their treatment, and information about treatment outcomes and follow-up care (eg after surgery or discharge from hospital).

- down from 19% to 10% following staff training and reorganisation into smaller work groups – and in pain relief, where the proportion of patients reporting a problem was reduced from 15% to 6% following retraining, reorganisation and provision of self-medication facilities.

An evaluation of this approach to obtaining and using patient feedback with Australian GP registrars found that it led to significant improvements in specific aspects such as listening skills, ability to elicit concerns and fears, time given to patients and the provision of reassurance.

All mention of “rights” had been expunged, to be replaced by “commitments”, “responsibilities” and “expectations”.

It seems more designed to reassure staff than to empower patients and it smacks strongly of a return to paternalism.

The WHO declaration on patients' rights emphasised the importance of strong patient groups and called upon governments to support them financially.

The British government has announced its intention to “move away from a system of patients being on the outside, to one where the voices of patients, their carers and the public generally are heard and listened to through every level of the service, acting as a lever for change and improvement.

Since most patients are not members of organised groups, these groups cannot be said to represent the views of the majority.

It will be crucial to ensure that the Patients Forums have access to regular feedback from representative samples of patients and citizens to balance the views of the special interest groups.

The rationale for decisions to restrict access should be: clearly and publicly stated; it should be contestable and be acceptable to ‘fair minded’ people; there should be a mechanism for appeal; and the process should be enforceable and defensible.

The government is taking this tentative step into the dangerous waters of explicit rationing because the political risk of not keeping the public informed about the choices that are being made on their behalf is beginning to look more dangerous than the traditional alternative of muddling through implicitly.

Encourage the Primary Care Trust to employ specialist staff to act as information brokers.

Patients who are well-informed about prognosis and treatment options are more likely to adhere to treatments, leading to better health outcomes. They are also less likely to accept ineffective or risky procedures.

The principles of shared decision-making, concordance in medicine-taking and strategies to promote self-management should feature prominently in the curriculum, together with development of the skills to explain probability, risk and uncertainty.

Involving a few token patients on committees is relatively easy to do, but it does nothing to tackle the heart of the problem, which is that healthcare delivery is still steeped in paternalism. The really important changes need to occur at the level of individual interactions between patients and health professionals.

In this monograph I have tried to show that these objections miss the point altogether. Far from being peripheral, the development of a more active role for the patient and the citizen will be fundamental to securing the future of public healthcare. It is the only way to ensure its affordability, acceptability and sustainability over the long term.

Jw/gm/docs04/the autonomous patient angela coulter