

THE EXPECTATIONS OF THE MODERN PATIENT*

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It gives me great pleasure to come back to my home town to give this paper on the expectations of the modern patient. To the best of my knowledge, there has been no authoritative research into this subject. But what I have to say is of no less importance because there is no such evidence. I have where possible, substantiated my comments from a variety of published sources.

There are now two generations of patients who have become accustomed to what the National Health Service (NHS) has been able to provide since 1948; access to treatment, free at the point of delivery. I suggest that we, as patients, base our assumptions about health services on what we have become accustomed to as well as what we learn may be available. Therefore, we assume that we can have: access to treatment, free at the point of delivery; care, free at the point of delivery, from the cradle to the grave; skilled and professional staff to treat us; effective treatment for most illnesses. Some patients also assume that they can have access to a doctor at any time i.e. out of hours.

I use the word assumption. An assumption is defined as 'something taken for granted' (Collins). But in discussing patient attitudes to health care, assumptions are often referred to as rights, with the word right taking on an almost challenging tone. 'Patients see it as their right to be seen in clinic within 30 minutes and send in abusive letters of complaint if they are not', reported one Chief Executive recently. Many suggest that a result of the Patients Charter¹ has been a rise in the patients view that they have a right to a particular service. An objective of the Patients Charter was to put the Citizens Charter into practice in the NHS. The Patients Charter, and I quote, is helping the NHS to: Listen and act on peoples views and needs; set clear standards of service; provide services which meet those standards. Many Health Authorities and Trusts are trying to involve patient representatives in aspects of planning, purchasing and contract monitoring. Patients representatives may be members of voluntary organisations and or Community Health Councils. And when patients are dissatisfied new complaints procedures have been introduced to make the process of making a complaint easier. Patient charter standards such as waiting times for an outpatient appointment have also been introduced and these have given patients an idea of what can be expected.

However my talk focusses on patient expectations and not specifically on assumptions and rights although there is some overlap. Expectations are forward looking, anticipatory and hopeful. And it is concepts that fit into this definition that I am now going to examine. I believe that certain expectations have developed which have arguably arisen from the Patients Charter. Patients expect to have access to the health services that they need. They expect to receive timely, appropriate and quality health care on the basis of clinical need and regardless of the ability to pay; to be treated with consideration, respect and

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courtesy regardless of age, gender and race; to receive immediate emergency medical care at any time, through GP or the emergency ambulance service and hospital accident departments; to be registered with a GP of their choice; to be referred to a consultant and for a second opinion when appropriate.

These expectations are well described and have been adopted by Trusts and Health Authorities in their own Charters.

Patients have increasing expectations about access to information. They expect to receive information about the treatment available and about the treatment options. When patients enter a research project they normally receive and certainly ought to receive a great deal of information about the underlying problem and the treatments being offered in the study. Indeed it is not considered ethical for patients to be entered into such studies or drug trials without first giving consent based on considerable information. This is surely good practice and should be part of normal clinical practice.

Julia Neuberger² writing in *Controversies in Health Care* suggests that what the patient will be considering is: information about the aims of the available treatments; what would be the likely outcome without treatments; what is the objective effectiveness of each treatment; what are the alternative treatments; what treatment targets will be set; what are the most common side effects or interactions; when should one stop, change or switch treatment; is it cheaper to prescribe privately or buy over the counter; where did the doctor get his information about the medicine; would the doctor use the same information for his family.

If we look at one aspect of treatment, drug treatment, patients are now expecting to have information about both prescribed and over the counter (OTC) medicines. Recent European Union regulations stipulate that all prescribed medicines must contain a patient insert leaflet (PIL) and this is welcomed. Unfortunately most patients do not have an opportunity to read this information until after they have collected the medicines from the pharmacist. We are all aware of the difficulty in absorbing and retaining complex information given in a relatively short consultation. So even if the prescribing doctor had given information about the drug, not all patients would remember the information. The information available in the PILs is available in the ABPI Compendium of PILs.³ I recommend that this book is made available in pharmacies, clinics and surgeries for patients to consult. It can also be used for doctors and patients to discuss proposed drug therapy.

I believe that patients will be expecting information about risk versus benefit concerning drugs as recommended for example by the International Medical Benefit/Risk Foundation RAD-AR.⁴ As more powerful drugs are being brought into use and as more older people are on multiple drug regimes information about risk versus benefit becomes increasingly important. Patients are expected to be informed about the side effects of medicines. The ABPI DATA Compendium Sheets are available in public libraries but this is not known by many people. And even if the majority of the public did, this source of information is not the most user friendly and unlikely to be useful to most patients.

Patients self medicate and modern patients want to take responsibility for their own health. There may be several different OTC preparations to treat the same problem. But how does the public decide which preparation is appropriate to purchase? Studies have shown that people use preparations recommended by

family and friends as well as what they have used themselves in the past. They also seek advice from the pharmacist or counter assistant. The Proprietary Association of Great Britain⁵ has published an excellent directory of OTC medicines. Why is this OTC directory not available in all pharmacies for the public to consult? It is still easier to obtain good information about cookers, cars and CDs than it is to find out about medicines!

Patients will be expecting to have information on evidence based medicine. Almost 20 years ago, in the late 1970s, the late Archie Cochrane drew attention, to the apparent ignorance by the medical profession of which treatments work effectively. The Cochrane Collaboration, set up in his memory, may be one way in which consumers are going to learn what works and what does not work. Patients want to know the results of evaluations of the effectiveness of particular health treatments. The Cochrane Collaboration has been running critical appraisal skills programmes⁶ for consumers and members of consumer groups. These enable people to weigh up the evidence of research to see how useful it is for decisions about health care. Patient illness groups are also assessing 'best practice' and disseminating such information to their members. However, it still remains difficult for individual patients who are not members of such organisations to acquire information about evidence based medicine.

Patients will be expecting to find out which unit, department or hospital has the best results for specific problems. To some extent this information is already available but it may not always reach the patient who has been informed of their need for a particular intervention. Furthermore although 'money is meant to follow the patient in the new NHS' the reality for most patients is that they will be referred to the unit where the contract is held. Commissioners are keen to limit the number of extra contractual referrals. This reduces choice for patients who need to be satisfied that the local service is providing the 'best' care. In addition patients will be expecting more general information about how health services work in their area, including information about waiting lists. They will also be expecting information about public expenditure policy, health economics and cost benefit ratios.

Many patients expect to share in the responsibility for their own treatment and health. Some patients have always done so; for example patients on maintenance dialysis, those with diabetes or other chronic disorders. But we have come through a period of paternalistic medicine which does not encourage the patient to think nor to be involved in decisions about their health. So there are still patients, particularly older people, who are not interested in sharing responsibility. There will always be some patients who simply want the doctor to decide for them. Success in sharing responsibility and being 'partners in care' will depend upon patients having access to information as I have already described.

The process of sharing responsibility between patient and doctor is not always a comfortable one. I think of apprehensive patients approaching end stage renal failure. They have been told of the need for dialysis and the choices available. They wish the security of maintenance dialysis in hospital. That is not acceptable. The choice is haemodialysis or CAPD at home. It takes a long time and a lot of encouragement to persuade such patients that they are very able to take on this responsibility. Once established such patients can become very independent often questioning professional and clinical judgements. Sharing responsibility is by definition a two way process. If, for example, patients want a smooth running

appointment system with minimum waiting time, they must then make sure that they cancel appointments which they are unable to keep. Medical staff must, on the other hand, ensure that there is not block booking with the majority of patients booked for 2 pm and the staff appearing later. Sharing responsibility also means listening to the patient. Modern patients are expecting to be listened to. And more and more patients are expecting to ask detailed questions and therefore receive answers.

Patients now expect to be involved in some of the decision making about their health services. They are expecting to be consulted by the commissioners to give an input into plans for their local services. They do not wish consultation to be merely a token, they expect their views to be taken seriously by providers and purchasers. Modern patients also expect that there will be patient involvement in the monitoring of health services through audit.

More openness in the decision making process of research ethics committees and in the reporting of the results of trials is required. Most patients are willing to participate in a research project. If patients are genuinely regarded as partners in the process, this will result in them being informed of the results of the research.

Better informed patients are able to ask for and make choices. But we need to remember that these choices may not be the same as those made by the medical profession or by the government. For example the tendency is for GP's to practice in group practices and in health centres and with some of the doctors offering specialist services. Is this what the patients want? A recent study by Baker and Streatfield⁷ in the British Journal of General Practice concluded that 'patients in this study preferred smaller practices such as supported by members of the Small Practices Association (SPA), non-training practices and practices that had personal list systems. Practice organisation should be reviewed in order to ensure that the trend towards larger practices that provide a wide variety of services does not lead to a decline in patient satisfaction...'. Patients are increasingly expecting personal care which reflects a quality of relationship between doctors and their patients. This is a relationship that must surely be attractive and desirable to all doctors.

We live in a society where we are constantly making choices—choices in not only what we buy but in which manufacturer we purchase from. We make choices about which television programme to watch and what to listen to on the radio. So patients are accustomed to making choices. I understand that making choices about one's own care and treatment may be in some circumstances extremely difficult and indeed too difficult for some. Patients can make choices between different types of treatment, between radical or conservative treatment or even to have no treatment at all. There is considerable evidence that when patients are involved in the plans for their treatment they are much more likely to comply with that treatment. Patients certainly know about the type of ward that they would like to be nursed in. And yet only a few years ago mixing male and female patients in the same ward was introduced without ever consulting the patients.

To be able to make such choices, patients need information. Providing information does cost money. To be able to provide appropriate information and to work with patients as partners requires to be addressed in the medical curriculum. But such an investment can only bring increased satisfaction to both

patients and their doctors. Involving patients as partners in their health care can only be beneficial to the people, patients of this country.

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QUALITY OF CARE IN THE CHANGING NHS*

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I am honoured to be here giving the 1996 Sir Stanley Davidson Lecture. He was a generous benefactor of the Edinburgh Royal College and a distinguished physician. I hope that his ghost will not be baffled or upset by the fact that I, who am not a physician, pontificate on this supremely important topic. I apologise that my own experience is based in England but my ancestry is Scottish and my national service was in a Scottish regiment. It is for you to judge whether anything that follows is relevant north of the border.

From the title assigned to me, I have assumed you would like me to talk about both quality and change, and the interrelationships between the two, in the context of the NHS. What I want to say falls into four parts, namely: concepts of quality; evaluation of Mrs Thatcher's 1991 changes in the NHS; three initiatives to improve quality; some thoughts about the future.

CONCEPTS OF QUALITY

Doctors are most likely to define quality of patient care primarily in technical terms. Was the diagnosis right? Was the care appropriate? Were the results acceptable? Without doubt these are important questions and perhaps the most fundamentally important, but they are not all-important. There are other questions that can properly be asked about the care setting, the manner in which people are treated and what precedes and follows this particular episode of care (Fig 1).

I have argued elsewhere that quality in our field is complex, elusive and multi-dimensional.^{1,2} Besides the technical dimension already referred to, there are some five other dimensions (Table 1). It is not my contention that these are the only possible ones, but they seem to cover most of the ground, including the population aspects of health care (equity, relevance, public cost) as well as the individual.

Not surprisingly, these elements of quality sometimes pull in different direc-

TABLE 1

Questions that help to define and expand the quality label.	
Effectiveness	Is the treatment given the best available in a technical sense?
Acceptability	How humanely and considerately is this treatment/service delivered?
Efficiency	Is the output maximised for a given input, or (conversely) is the input minimised for a given level of output?
Access	Can people get this treatment/service when they need it?
Equity	Is this patient or group of patients being fairly treated relative to others?
Relevance	Is the overall pattern and balance of services the best that could be achieved taking account of the needs and wants of the population as a whole?

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