FOR DISCUSSION

# Can patients influence health decisions?*

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INCREASINGLY in recent times it seems that patients have sought to influence the decisions which doctors make about their care. Some of them have undoubtedly done so by joining pressure groups like the Patients' Association and acting as representatives on policy-making bodies such as Community Health Councils. The question which arises is to what extent ordinary people as individuals influence such decisions in their transactions with doctors.

This article attempts to show that, in general practice at any rate, patients can influence decisions about the care they receive, but that many do not try to. I also maintain that passivity is a manifestation of the kind of relationship most patients want with their doctor.

The data on which the arguments are based come from a study of five general practices in an Inner London borough in the 1970s. There were 16 doctors in these practices and the material used in this paper was obtained in interviews with them and with samples of their patients. Just under a thousand patients were interviewed at the doctors' surgeries before and after a consultation and a further five hundred at home. Interviews with the former group were relatively brief and were conducted with a short, structured questionnaire. Those in the home were wide-ranging, patients being invited to comment on many health-related issues as well as on their relationships with their doctors. Additional data sources were records maintained by the doctors and 216 consultations tape-recorded with the consent of the participants.

The study was exploratory. It was designed to examine the relationships between the participants in a primary health service, that is between the providers and recipients of care, as well as among different providers (doctors, social workers and so on). Both qualitative and quantitative data were obtained and both kinds have been used. For instance, the data on what doctors thought about patient participation in the care process are qualitative in nature; those on patient activity in the doctor–patient relationship stem from quantitative measures.

I recognize that the conclusion drawn from the data, namely that many patients elect to leave decision-making to the doctor, is not the only one possible. I cannot rule out another, that the relationship is so deeply ritualized, and patients so strongly socialized into viewing doctors as in charge, that they cannot act other than in a subordinate way. Arguing for the former explanation, views of the doctors in the study sample are dealt with first, then some findings from patient studies are presented.

## The doctors' views

A century ago at any rate, it would seem that patients, at least those of lower social status than the doctors themselves, were expected to be wholly passive. John Pickles, a doctor practising in the last quarter of the nineteenth century and father of Will Pickles, first President of the College, is supposed to have said (Pemberton, 1972) of patients who asked questions:

> "I can always bluff them . . . If they ask me what's wrong with them, I say to them, 'That's my business. Do as I tell you and take your medicine and you'll get better.' "

As seen by John Pickles, the doctor–patient relationship was essentially hierarchical and authoritarian, the doctor in the dominant role and the patient in the subordinate and submissive one; the doctor giving direction and instruction, the patient expected to follow unquestioningly. In 1977, a hundred years later, only two in our sample of 16 doctors favoured such a paternalistic relationship. These two doctors thought it still potentially more therapeutic than other types of relationships. The other 14 viewed the ideal doctor–patient relationship as a friendly and open one, the patients neither afraid of the doctors nor putting them on a pedestal, but recognizing them as fellow human beings—neither omniscient nor omnipotent. Within this relationship the patients would feel free to discuss their problems and to express their views on their treatment and management. The ultimate goal of the relationship, according to these

*Revised version of a paper given to the Conference on Patient Participation at the King's Fund, 8 April 1980.

doctors, was patient autonomy, the patients perceiving the doctor as only one of several resources in their—the patients'—decision-making.

Whether favouring such a view or not, all the doctors believed that relationships between patients and doctors had, particularly in the last decade, become more egalitarian and that patients were participating in the consultation much more than ever before. Most attributed this to the changing social climate and to the spread of medical information through the media. As a result of increased knowledge, one doctor said, at least 10 per cent of his patients were now prepared to argue with him, something which never used to happen before. Another thought that, because patients were now better informed, the doctor did not have the magic he used to have and, he added, "that suits me".

A sense of feeling "more comfortable" or "more free off the pedestal than on it" came from most of the doctors and, once having had that experience, it seemed that the doctors themselves became agents for change. As one put it:

> "One tries to face patients with the truth of one's own limitations—to create an honest relationship. It matters to yourself. If you are not pretending to be something you are not, you can handle patients' problems so much better."

Nevertheless, at least half the doctors considered that, despite the changing social climate and the spread of knowledge, the doctor–patient relationship, although considerably more egalitarian than it used to be, was still basically an unequal one. Doctors still had knowledge and expertise patients did not have and, for this reason, the impetus for more patient participation had to come mainly from them. They also recognized that as agents of change, they had to be discriminating and not push patients too rapidly towards greater participation and autonomy. A doctor who said she enjoyed collaborating with patients—admitting that she did not know everything and inviting them to join with her in looking for causes and explanations for symptoms or problems—felt, nevertheless, that she had to be selective; for many patients such an admission could be unsettling.

With these views, it is not surprising that most doctors in the sample accepted, condoned or justified patient non-compliance with their advice or instructions. "I think", said one, "patients have always disregarded our advice, we just didn't realize it and assumed they were doing what we told them. Now we know that half of it won't be carried out, and that is not a bad thing." Another perceived two divergent trends in patient compliance. On the one hand, patients were coming increasingly for reassurance only, and once they had that they hardly bothered with anything else: "It's the immediate relief after the panic." On the other hand, she said, chronically ill patients, or patients with clearly established disease, were more likely now than formerly to respond to the doctor's advice and adhere to treatments prescribed. A third saw her role as purely advisory. When a patient came with a problem she gave her view, and often, she stressed, her view was no more than an opinion. She might even offer more than one view, her own and that of others, and leave it to the patient to choose.

While the doctors could speak of the changes they perceived, they could not, understandably, quantify them. They also knew that many patients remained passive recipients of their care, depending on them to make the important decisions, and they regarded it as their job to respond to a patient's need to be dependent. If they could cure the patient of this need, that was excellent. In fact many patients needed only short-term support, and a positive response to a cry for help often made the patient aware of the true nature of his or her need. This realization could well be a first step towards cure or adjustment and decreased dependency on the doctor or on anyone else. For others, cure was not always possible, and for some who were lonely and bereft, the doctor was often their mainstay.

However, as nearly all the doctors pointed out, not all consultations lead to a decision, other than the doctor's decision to listen, to allow patients to ventilate distress, anxiety or grief. At times the consultation was a batting wall: one doctor said it was almost as if as the patient talked, the words went to the wall and came back looking different, enabling the patient to see things afresh.

These views are those of a selected group of doctors. It is not known how far they might be general within the profession or whether they reflect those of a minority only. It is clear, however, that some doctors at least are aware of and welcome change in the customary hierarchical relationship with patients.

## Patient behaviour

Theoretically at least, patients, in the context of the one-to-one relationship, can influence decisions about their care in a number of ways. They can do so by their initial decision to consult; then by the way in which they present or formulate their problems; by what they ask the doctor to do for them; and, lastly, by the extent to which they follow advice or instructions.

The doctors' records and interviews with patients at the surgeries just prior to a consultation suggested that nine tenths of all the consultations were initiated by the patient. Even second or subsequent visits in an episode of illness were mainly patient initiated (60 per cent). In short, patients still play a major role in the initiation of the transaction.

The taped consultations showed that patients rarely offered a diagnosis to the doctor. In only 29 (13 per cent) of the 216 consultations in this sample did this happen. In all the others, the patient presented a symptom: "I have a sore throat", "It feels as though there is a lump here", or, in a more diffuse way: "I am a bit run down."

Having told the doctor their problem, in fewer than half the consultations (45 per cent) did patients make requests for specific items of service, such as a prescription, a certificate, treatment, advice, reassurance or information (requests averaged 0.96 per consultation). The tapes showed that virtually all such requests were met. Only four (three for prescriptions and one for reassurance) were coded by the research team as "not met". From this finding it might be concluded that the influence of those patients who tried to specify their care was considerable. The conclusion, however, might not be quite so simple. It is possible that patient requirements, as formulated in requests, may be the outcome of the patients' past experience of what they think is or is not possible in general practice as a whole, in their doctor's practice or with individual doctors if there is more than one doctor in the practice.

We wanted to see whether there were differences in the number or kind of requests made by patients which could be associated either with patient characteristics, such as their age, sex and social class, or with the characteristics or behaviour of their doctors. Although not marked, there was a tendency for the number of requests to increase with the patients' age. Differences between social classes were not so much in the number as in the kind of request: middle-class patients were more likely to request information and advice, manual workers for reassurance. There were virtually no differences between the sexes.

We had thought that premature closure of discussion by the doctor, that is terminating a consultation before the patient had the opportunity to say all he or she appeared to want to say, might determine the number of requests made. This was found not to be so, since only nine of the 216 consultations were defined as ending in this way. A slight association was found between the number of enquiries the doctor made to clarify the patient's needs and the number of patient requests. However, the most significant association to emerge was with the duration of the consultation. In general, the longer the consultation, the more requests; in other words, time would seem to be the enabling factor. So it may be that if patients are to be encouraged to contribute to request- and decision-making in the consultation, they must be given the time to do so.

There were indications in the data, however, that some patients who may have wished to make requests did not do so. First, although not substantial in number, some implicit requests were detected in the consultations for which no requests were recorded. Second, from the interviews with patients at their doctors' surgeries immediately before and again immediately after a consultation, it seemed there were patients who wanted or hoped for specific items of service but who, when face to face with the doctor, did not say so. It was established, too, that such patients were somewhat more likely to be disappointed with their visit than those who were able to express their needs.

Data from wide-ranging interviews with patients in their homes, however, revealed that most patients were less concerned with whether or not specific items of service were performed by their doctor, that is with what could be viewed as the more negotiable aspects of care, than with what could be called the personal or empathic aspects of the relationship. For instance, asked to name the qualities which made a good doctor, four fifths of the patients in that sample spoke of a readiness or willingness to listen and of kindness, sympathy, patience, tolerance and understanding. Listening to the taped consultations, it seemed to us that, having decided to consult, the principal need of the majority of patients was to gain the doctor's ear and to be able to tell him or her whatever it was that was causing pain, concern or anxiety; this need seemed to be present irrespective of the type of problem about which they were consulting. For example, a woman in her early 30s, speaking in a strained voice, said: "I know this is going to sound very strange, but I've started eating obsessively and I can't stop and I don't know what to do." An old man said: "When I got up yesterday morning, the pain here was so bad that I could not put on my socks. It's all right once I am up, it's the getting up." Even relatively common, simple conditions were "handed over" in this manner to the doctor: "My throat is sore and gargling hasn't helped." For some, even this step, acquainting the doctor with the problem, seemed very difficult. When asked: "What can I do for you today?", an adolescent boy appeared not able to answer at all, until the doctor asked kindly: "Is it your spots?" In each instance the patient appeared to be relieved after conveying the problem to the doctor.

'Handing over' to the doctor did not mean, however, that patients did not participate in the consultation. Leaving aside extraneous chat, which occurred in a quarter of the consultations, there was what could be defined as considerable elaboration by patients of their symptoms and their significance in at least half the consultations. Without probing by the doctors, the patients in these consultations listed several symptoms and described many of them in detail, together with other information which they regarded as relevant to their condition. The aim of this elaboration appeared to be to ensure that the doctor fully grasped and understood their problem or difficulty rather than a desire to influence what was to be done about it.

Finally, having come to the doctor for help and, in the majority of consultations, leaving him or her to decide on appropriate help, how did the patients respond to the help offered? In three out of every four instances our observations suggest that the help offered was accepted. In the remainder only some of the doctor's advice or explanation was accepted, and in 10 instances it seemed to be rejected. Among patients interviewed in their homes, 70 per cent said they would complete courses of medicine prescribed by their doctor and 66 per cent said they would follow all his instruc-

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|---|---|---|
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tions. Between a quarter and a third of that sample were thus not prepared to commit themselves without question to complying with all that their doctor might suggest. A sizable minority appeared to perceive the doctor as the majority of doctors in our sample claimed they wished to be perceived—as providing one set of alternatives for health care amongst others. Younger patients and patients in social classes I and II were somewhat more likely to act autonomously than older patients or patients in other social classes.

## Conclusion

The information gathered in our study suggests that, at least in those practices where doctors favour egalitarian relationships and patient decision-making, patients can and do influence decisions, not only by presenting their problems, but by making requests which, in all probability, these doctors will meet. There is some indication too that, given more consultation time, more patients might articulate specific requirements. Overall, however, the indications are that in such practices patients do get what they want, and that what they want most is to be listened to by the doctor, to have their problem understood and for the doctor to take charge of it.

## Reference

Pemberton, J. (1972). *Will Pickles of Wensleydale: The Life of a Country Doctor,* p.29. Newton Abbot: Country Book Club.

**Acknowledgement**

The project which provided the material for this paper is financed by a grant from the DHSS. It will be published as: Jefferys, M. & Sachs, H. General practice in the 1970s: a case study in London.

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## Aminophylline and nocturnal asthma

Twelve asthmatic patients with nocturnal wheezing were given a single nocturnal oral dose of slow-release aminophylline or matched placebo in a double-blind crossover trial. A dose of slow-release aminophylline (mean 683 mg; 10.4 mg/kg) gave a therapeutic plasma-theophylline concentration 10 h later. This was not associated with any adverse effects. Mean peak expiratory flow on waking was significantly greater with aminophylline than placebo. There was a significant difference between morning and evening peak flow on placebo but not on aminophylline, indicating abolition of the morning fall in peak flow.

Source: Barnes, P. J., Nevills, L., Greening, A. P. *et al.* (1982) Single-dose slow-release aminophylline at night prevents nocturnal asthma, *Lancet,* **1**, 299-301.