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PRACTICE OBSERVED

Medical Records

Our patients have access to their medical records

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Introduction

The advent of the 1984 Data Protection Act and the Campaign for Freedom of Information's promotion of an Access to Personal Files Bill highlight whether patients should be given access to their medical records. Doctors will have to formulate their response as a profession and as individuals. What is lacking is any experience in Britain of how or whether giving patients access to their records works. We describe how open access has worked in our practice for nine years.

Background

Patients of an inner city general practice, which was set up in 1977, have always had the opportunity of reading their records. The intentions of those who founded this general practice were to make patients aware of health issues and of the choices available to patients as part of an overall approach to provide a humane style of primary care.[1] Implicit in this approach is the assumption that the patient is trustworthy and a prime agent with the practitioner in the search for health. When a patient consults a doctor he or she places a confidence in the doctor. Central to the doctor's response is a proper reciprocation of this confidence, which is the basis of a confidentiality instigated by the patient and exercised on behalf of the patient by the general practitioner and those hospital doctors whom the patient chooses to include within it. Excluding the patient from this confidentiality is a potential breach of the patient's initial confidence and inimical to the patient's awareness and responsibility. Giving a patient access to information in the records may provide a natural and useful tool for the patient to understand his or her own health. We assumed that, in the absence of evidence to the contrary and subject to safeguards, it was unnecessary to consult medical colleagues who contributed to the records since they too must regard patients as being central to the confidentiality and confidence in the exchange of information.

We also have an open style of reception in homely surroundings. Receptionists are trained to welcome and sit with patients, sometimes offering a cup of tea, without losing professionalism in the more formal aspects of reception work. This atmosphere of professional openness in the waiting room promotes the patient's sense of concern in health matters and also suggests that the question is not whether patients should be allowed but whether they ought ever to be disallowed access to their records.

In this practice of 4000 patients a small percentage only is highly articulate. The polyethnic majority is by comparison disadvantaged in communicating with doctors and other professionals. It is reasonable to infer that if open access can work in such a population it can work more generally—and especially where written English is a familiar medium of communication.

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The system at work

Patient records are kept in the standard FP5/6 envelopes. Since the practice was set up patients who have come to see the doctor or nurse practitioner have been handed their records by the receptionist when they enter the reception area, eventually taking them into the consulting room. Sometimes, but not always, they are reminded that they are free to inspect the record. Consequently, though a great many patients appreciate that they have this freedom and commonly use it, some patients, such as those who have recently registered with the practice, are not aware of this, and the receptionists make a special effort to acquaint them with the policy of open access. The fact remains that patients are often seen scrutinising their records, and if there is no opportunity to do this before the consultation some examine the records afterwards or visit the surgery again to do so.

Records of new patients are scrutinised by the doctors when they are received from the family practitioner committee. Incoming letters are opened only by the doctors. Thus material that might be disturbing for the patient or which the writer clearly intended as confidential to the addressee may be identified. Such instances are rare. A judgment is then made whether to withhold access to such information and for how long.

Access is withheld from a few patients, and a marker attached to the envelope indicates to the receptionist that the document is to be handed directly to the practitioner. Twelve patients are thus affected, roughly 0·3% of the practice population. There are four categories of embargo:

(1) Bad news. Personal communication is essential here. Once the news has been disclosed to the patient and the letter containing it discussed the records are made available to the patient thereafter. This category does not represent in principle withholding of the record.

(2) Patient choice. Occasionally a person asks not to be given the record for fear that its contents may be seen by another. For example, a young Asian woman who was taking the contraceptive pill without her husband's knowledge was usually accompanied by him to the surgery, and she feared

that he might insist on reading her records. Records are handed only to the patient concerned except for children under 16 accompanied by a parent.

(3) An explicit or clearly implied request by a professional colleague that information is withheld from a patient. Such requests are respected, though not to the extent that the general practitioner colludes with another doctor in forever denying a patient truths or opinions which the general practitioner believes ought to be passed on. Here, of course, communication between the doctors concerned is highly desirable.

(4) The severely disturbed patient. The occasional patient is so unwell psychologically that any information may exacerbate the illness. Fine judgment is called for, and in our experience such instances are rare and do not include every case of mental illness. We have sometimes found that the extremely anxious patient is helped by access to and frank discussion of all that is in the medical record.

Other difficulties have occurred. For example, we are often asked about the 14 year old girl who seeks advice on contraception without the consent of her parents. A parent may subsequently accompany her to surgery and discover the facts in her records. Our policy is to protect the confidence of the consultation and to ensure that its recording is kept securely and separately from possible scrutiny, that may be unwelcome to the patient, until she is 16. Such cases may be administratively untidy but are not fatal to the policy. We believe that the trust expressed by the open access policy has been instrumental in defusing potentially explosive issues.

Reactions and comment

The two medical and two nurse practitioners whom patients are free to consult are in full accord with the policy, which features prominently in interviews for staff vacancies. A common impression among us is that the recording of consultations is not materially affected by the knowledge that patients may subsequently read what has been written about them. It has not been necessary to maintain secret additional records from the patient except when the professional protocol of other agencies requires this—for example, the case conference report of the social services.

Patients not infrequently ask questions about the records that they have read. A pilot study that was carried out in 1984 among 100 randomly selected patients showed appreciable patient satisfaction with access to records.[2] The policy is being further evaluated as part of a project funded by the Department of Health and Social Security.

Since 1981 open access has been recognised as an aspect of our work by the Birmingham University department of general practice, which places final year medical students on clinical attachment with our practice. Speaking on radio recently, a BMA spokesman commented favourably on our procedures (Radio WM BBC, 25 September 1985). But reaction from medical colleagues has been varied. We have made no secret of our policy, which was proposed as early as 1976.[1] The local medical committee, having been approached in 1984 by consultants, sought the views of the General Medical Council, which confirmed that by allowing patients access to their records "we were not breaking professional discipline," but they pointed out that there might be circumstances in which it would be appropriate first to obtain the consent of the authors of letters or clinical notes. We had already suggested meeting the local medical committee to discuss matters but had no response. In 1985 the district medical officer requested a written statement of our policy on behalf of a group of consultant psychiatrists, and our offer to meet the group to explain our procedures, which is our policy, rather than provide written accounts has not been taken up.

Finally, we welcome the safeguards for the patient that are implicit in open access. Derogatory statements made by doctors in the records are rare in our experience, but the damage that such statements may do to a patient's reputation may be offset by frank discussion or removal when the writers know that they may have to answer for their opinions. Such accountability can only improve the standard of record keeping and so promote confidence that achieving health is the responsibility of both the patient and the doctor.

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Giving patients their own records in general practice: experience of patients and staff

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Abstract

Patients have reacted positively to seeing their medical records in a general practice which has a predominantly working class population in south east London. Most patients were familiar with the information in their records. Older people tended to avoid reading their notes. There have been few inaccuracies and unpleasant reactions reported, and few problems have arisen.

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Introduction

Since the autumn of 1983 we have allowed patients to see their records while they sit in the waiting room. Our motives are: to reduce the doctor's inappropriate power by sharing information in the consultation; to foster health education by encouraging patients to ask questions; and to enhance trust and communication between doctor and patient. We believe that patients should be refused information about their own health only in unusual circumstances.

The waiting room wall has a message which reads: "We have decided to allow you to read your notes because: it's your body and your health. We want to share our decision making with you. We want to break down barriers between the surgery and you. But be careful: there may be things in the notes you are not happy about. We are always available, doctors and receptionists, to discuss any comments and queries you may have about the notes. Only your own notes and those of your children under 14. No editing, no defacing. No removal from surgery." The doctor usually opens the consultation by asking if there are any queries about the notes.

All letters to hospitals are stamped: "In this practice patients have access to their records." All communications from hospital are read from both the doctor's and the patient's point of view. If any letters

TABLE I—*Characteristics of patients who read their notes*

	No (%) of women	No (%) of men	Total No (%)
Social class			
I-III	27 (28)	14 (15)	41 (43)
IV, V	28 (29)	26 (27)	54 (57)
Age (years)			
>65	11 (12)	5 (5)	16 (17)
<65	44 (60)	35 (36)	79 (83)

Note: There is a higher proportion of patients in social classes IV and V in our practice than in the UK as a whole (p<0·001).

TABLE II—*Characteristics of patients who did not read their notes*

	No (%) of patients who read notes	No (%) of patients who did not read notes
Social class		
I-III	34 (35·8)	8 (8·4)
IV, V	39 (41)	15 (15·8)
Sex		
Male	33 (34·7)	8 (8·4)
Female	40 (42)	15 (15·8)
Age		
>65	68 (71·5)	12 (12·6)
<65	5 (5·3)	11 (11·6)

Note: Only age was significantly different (χ^2, p<0·001).

TABLE III—*Answers to questions about the doctor-patient relationship*

	No of patients who:				
	Strongly agree	Agree	Disagree	Strongly disagree	No opinion
(A) Helps break down barriers between doctor and patient	55	35			1
(B) Gave you medical information about yourself which you were not sure about	22	29	5		1
(C) Helped you to understand more about how doctors think	19	36	6		5
(D) Gave you more confidence in doctors	23	33	7		6
(E) Gave you less confidence in doctors	1	2	30	14	6
(F) Made you feel that doctors understand you	18	29	4	2	8
(G) Made you feel doctors don't understand you	1	1	29	14	7

or results are grave we keep the paper from the notes and contact the patient. We then discuss these with the patient, and often with the consultant as well, and the paper is then included in the records. All incoming notes from the family practitioner committee are scrutinised for third party information and for minutes of case conferences. Both of these are filed separately and the medical records envelope clearly marked so that patients and doctors understand. Records that arrive from the family practitioner committee with potentially upsetting but not third party information (information given by, or about, someone other than the patient and doctor) are considered individually. We often hold them back and discuss them with the patient before allowing the patient to read them. We have censored notes on rare occasions, as described later. Notes are filed in date order.

There are examples of patient access to records in various countries. The legal background varies. In the United Kingdom the BMA supports "the right of patients and clients to have access to all information held about them on their behalf." The BMA working group recommended "access to the extent and in the manner judged most helpful by the responsible clinician." The Data Protection Act will allow patients access to computerised information.

In the United States the right to obtain one's own record in federal institutions has been established by law.[1] By 1981, 18 states had legally defined access, and legislation was pending in another 27.[2] There is evidence that patients want access to their records.[3] Both inpatients and outpatients have been given access. Patients have found it educational, and no problems have arisen.[4,5]

Outpatients at a health centre in Vermont were allowed to read their notes: 97% felt less worried about their health, 85% said that they would be more compliant with physicians' recommendations, and 80% had altered their eating or drinking habits. Doctors reported that records can be shared without provoking undue fear in patients. They have restricted information to fewer than 1% of patients. The frequency of home visits declined for patients who had participated.[6]

At the cardiology centre in Lisieux, France, 8000 inpatients took home information on admission and discharge to give to their family doctors. Greater confidence and efficiency were reported.[7] In Warwick a child development centre has given written reports to parents, which has proved useful and popular. Numerical results were not misinterpreted, but 7·8% of parents reacted unfavourably, which seemed to be related to their initial acceptance of the need for assessment. Record sharing was a valuable asset to the consultation.[8]

In a psychiatric ward where patients were not told of their right of access requests for notes seemed to be made in a spirit of mistrust. Access reassured some patients and precipitated problems in a few others.[9]

In four other practices in the UK which give patients access to records there have been few problems and the patients seem to show more trust and ask more questions.[10] The main difficulties seem to be with patients with psychiatric problems (B Jacobs, personal communication, 1985). In an Oxfordshire community hospital where patients have access the notes have become more relevant and there is more discussion.[11]

On the whole the experiences have been similar. Doctors and patients have either reacted undramatically or been extremely positive and excited by giving patients access to records.

We present the results of a questionnaire which assessed the patients' reactions to this experience in our practice.

Method and results

For one week in July 1984 patients who said that they had read their notes were given a questionnaire. Those who denied reading their notes were given a different questionnaire. They were helped if there were problems because of language or literacy. A pilot study was carried out first. Copies of the questionnaire are available on request.

Ninety five patients filled in the questionnaire, two of them incompletely. The doctor forgot to give the questionnaire to four (5%) patients. Table I gives the characteristics of the patients who read their notes and table II the characteristics of those who did not.

Of the patients who had read their notes 43 (60%) said that they understood all or most of the hospital letters; 32 (44%) said that they could read all or most of the general practitioner's handwriting; 19 (20%) said that they could understand the general practitioner's notes; and 49 (67%) said that they were familiar with the contents anyway. In addition, nine (12%) found things in the notes that they wanted to clarify, three (3%) asked someone in the practice about this, nine (12%) found incorrect information in the notes, and four (4%) told someone in the practice about this. Table III gives the answers to questions about the relationship between doctor and patient.

All the comments by patients were positive. They "felt more in control." It "helped discussions of problems." They were "being given responsibility by being allowed to see" their notes. It was "helpful," a "very good idea," it generated "more trust."

The reactions to seeing their notes were as follows: helpful, 46 patients; confusing, one; interesting, 54; reassuring, 28; made me angry, three; lots of feelings, four; unhelpful, one; informative, 32; boring, three; alarming,

TABLE IV—*Reactions to questions about the doctor-patient relationship by the eight patients who had been upset by seeing their notes*

	No of patients who:				
	Strongly agree	Agree	Disagree	Strongly disagree	No opinion
(A) Helps break down barriers between doctor and patient	6	2			
(B) Gave you medical information about yourself which you were not sure about	4	3			
(C) Helped you to understand more about how doctors think	2	4	2		
(D) Gave you more confidence in doctors	1	3	1	1	
(E) Gave you less confidence in doctors		1	1	1	
(F) Made you feel that doctors understand you	1	4		2	
(G) Made you feel doctors don't understand you	1		2	2	1

three; made me sad, three; and no feelings at all, four. Upsetting feelings, which were specifically asked for, were experienced by two men and six women (11%) (table IV). Two men and one woman had seen an opinion about them that had upset them. No one had seen any information about family members. Five women and one man said that it reminded them of bad times in the past. Three comments were made: "the comments in the notes were untrue and made a long time ago"; one comment showed a lack of insight and made the person feel unfairly criticised; one comment made the person feel sad; but the principle of seeing one's own notes was a good one.

The reasons for not reading notes were: four (17%) were frightened by what they might read, two (9%) did not have their glasses, five (22%) did not think that they would be interesting, three (13%) did not feel that it was any of their business, seven (30%) did not think that it was a patient's place to read their notes, six (26%) did not know that they were allowed to read their notes, four (17%) could not read, and none of the patients said that they did not have time. Other reasons were that the person "didn't think about it" or "wasn't interested."

In the future 12 (52%) patients said that they would read their notes, and four (17%) said that they would not because they "prefer to remain in ignorance." They were "too anxious and wouldn't understand" and "terms not understood would lead to groundless fears."

Discussion

The most obvious conclusion is the high degree of acceptability of record sharing. Patients confirmed over and over that having access to their records broke down barriers between doctors and patients, enhanced their confidence in doctors, and was reassuring, interesting, helpful, and informative. People will avoid looking at their notes if they think that they are likely to be alarmed by what they might see. Older people tended not to read their notes, but if given the opportunity again over half said that they would try. The reasons seem to reflect two main feelings. Firstly, they felt that it was neither their place nor their business, suggesting that a hierarchical relationship with their doctors had developed. Secondly, they were not aware that they had permission. A smaller group were frightened by what they might see.

Unexpectedly, 67% of patients said that they were familiar with the contents, and nearly 60% felt that they understood all or most of the hospital letters. This challenges doctors' assumptions of "medical illiteracy" in working class patients.

Ten per cent had been upset by reading their notes, which is comparable to findings in other studies. These were mainly people who had had psychiatric troubles in the past. In general, although they were upset about particular issues, they felt that record sharing was reassuring, informative, and helpful.

Twelve per cent found inaccuracies, which ranged from a wrong address to a note that a termination had taken place, which in fact the patient had refused. We are concerned that two thirds of patients who found inaccuracies or issues to clarify informed no one at the practice.

We expected many difficulties at the outset. The contrary has been the case: patients have been very appreciative and, surprisingly, it has not affected our clinical work greatly. By now most patients have read their notes and are bored by them.

We have, however, made some contradictory decisions. Firstly, we occasionally censor notes. A relative insisted that we censor a frightening diagnosis; soon afterwards the patient asked for the diagnosis, was told it, and since then has denied the information despite seeing it monthly. An elderly paranoid patient was not given all her notes for fear of precipitating a crisis.

Secondly, only once has a patient been frightened by a diagnosis revealed in the old notes. She found that she was at risk of skin cancer but was reassured after discussing it, which would have more appropriately been done years before.

Thirdly, the opinion of our hospital colleagues is divided; some local consultants are highly critical, some have welcomed it. In general, after some initial concern there seem to have been no problems. Letters sent to us from local hospitals seem to be comprehensive, and letters from our practice conceal no relevant information.

Fourthly, we have not asked permission from patients' previous general practitioners to begin open access. We could not justify the complexity of doing so, particularly since we can put misinterpretations into their correct context by discussing them with patients.

There are three other major problems. Firstly, recording findings, such as the first episode of what could be multiple sclerosis. Although it might be wrong to communicate one's concern early, its occurrence and importance need to be noted for future reference. In most cases, however, it is the patient who is thinking the serious differential diagnosis. In general practice sharing notes is, for the vast majority of patients, very reassuring.

Secondly, what should we do when a third party gives us information but does not want the patient to know? The problem is analogous to a patient asking a doctor not to write notes on the consultation.

Lastly, will this procedure not encourage litigation? We think the opposite: the climate of trust militates against anger. The American Medical Association's Committee on Medical Services found no change in malpractice litigation in those states with laws on patient access to records.[2]

It seems, therefore, that sharing records is a safe procedure when carried out with simple precautions. The patients with psychiatric problems are most likely to experience difficulties. The process enhances trust, can be educational, and reassures and informs. It gives patients an extra degree of control in the consultation and can be helpful in eliminating administrative errors. It also discourages biased note taking. It puts a premium on clarity, is ethically sound, and encourages honesty.

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