

Patient access to records: expectations of hospital doctors and experiences of cancer patients

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SUMMARY. *The aim of this study was to examine cancer patients' reactions to the offer of access to their medical records, hospital doctors' preconceptions of patient access to medical records and the reality of access to records for both parties. Semistructured interviews were conducted with 32 patients and 21 hospital doctors. Hospital doctors were also shown letters from their department to the general practitioner and asked about any changes they would have made as a result of knowing about patient access to records. The results showed that most patients were able to judge for themselves if they wanted access or not and that patients who chose to look at their records found access to their records helpful and reassuring even if the news was bad. Doctors expected access to records to be harmful to patients but would not have wished to amend many of the letters they had written. Patient access to records can be a safe and useful adjunct to good patient care.*

Keywords: *patient access to medical records; patients' attitude; doctors' attitude; cancer; doctor-patient relationship.*

Introduction

IN November 1991, the access to health records act 1990 became law, thus allowing patients access to medical information held in manual form, primarily from November 1991 onwards. Although a number of advantages have been seen by the profession, such as a realignment of power between doctor and patient,¹ and an improvement in doctor-patient relationships,² reservations about the safety of record access have been expressed,³ particularly the feeling that patients with serious illnesses would be distressed by record access,⁴ that communication between hospitals and general practitioners would suffer,⁵ and that litigation would be encouraged.⁶ In general, speculation has not taken account of national and international evidence on patient access to records.

There is good evidence that patients welcome access to their records,⁷ and in neither Denmark, where record access has been introduced into the whole hospital system,⁸ nor the United States of America, where some states have introduced record access and others have not,⁹ has there been any sign of an increase in litigation above the general background rate. There have been a number of controlled and uncontrolled trials of record access in various settings.¹⁰⁻¹⁷ In addition, some hospital doctors give patients a copy of their letters to general practitioners.¹⁸ The conclusions all point in the same direction: access to records appears safe when handled sensibly, patients appreciate the extra information and the process strongly enhances doctor-patient communication.

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There have, however, been few studies that look at the effects of such a change in the National Health Service. A recent study reported that 28% of NHS psychiatric outpatients had been upset by seeing written summaries of their records.¹⁹ Given the worries expressed above, it is possible that doctors will see patients' requests for access as symptomatic of mistrust and likely to lead to problems for both doctors and patients. If in doubt, doctors may censor records rather than risk litigation or patient harm, as they perceive it. There is evidence that doctors, when censoring records, have bizarre notions of what is appropriate for patients to read.²⁰

A related aspect is the issue of disclosure, about which there is a body of literature. In summary, it appears that doctors are reluctant to tell patients about their illnesses,²¹ despite the fact that the vast majority of patients want to know.^{22,23} Doctors' reluctance is based on individual, often unconscious motivations,²⁴ including the need to protect themselves from the stress of delivering bad news.²⁵ Patients, after an initial shock, appear to adapt well to bad news²⁶ and appear to understand more than doctors think they will.^{27,28} It appears unlikely that information, given sensitively, will harm patients.²⁹ The effect of information withheld, however, is more unpredictable: it sometimes makes patients feel anxious³⁰ and sometimes calmer.³¹

The debate about access to records thus touches on both the personal and the public face of medicine. The design of this study attempted to capture these aspects. The aim of the study was to examine cancer patients' reactions to the offer of access to their records, hospital doctors' preconceptions of such access and the reality of record access for both parties. The study focused on the effects of access to records in a serious illness and on doctor-patient and doctor-doctor communication.

Method

The study was conducted in a four partner practice in south London. It has been practice policy for several years to hand patients their notes to read in the waiting room.¹⁷ Exclusions to this policy are third party information which is filed separately, and potentially disturbing letters which are presented to the patient in the consultation. Letters from the practice to consultants are routinely stamped, to inform them of this policy.

The patient sample consisted of all patients identified as having invasive cancer and being under active hospital review on 1 September 1990. Patients with severe cervical intraepithelial neoplasia, carcinoma in situ and dyskaryosis and those who had been discharged from hospital follow up were excluded. Patients were identified by searching their notes for hospital letters filed over the previous year and by a computer drug search for tamoxifen and other chemotherapeutic agents. This yielded 34 patients with a wide range of cancers. Patients whose consultant had not written to the practice during the year may have been missed, but it is likely that any such patients would have been healthier than those identified.

The doctor sample consisted of those consultants who were seeing the study patients. If a patient was seeing several doctors, the consultant with most contact (as reported by the patient) was chosen.

An open-ended qualitative approach was used because this subject area is highly personal and relatively unexplored. Semistructured interviewing schedules were devised. The patient

schedule covered doctor–patient communication, reactions to reading the notes or the reasons for not reading notes, attitude to the truth, and control over illness. The doctor schedule covered doctor–patient communication, opinions of record access, and attitudes to the truth. Doctors were shown letters from their own department to the patients' general practitioner and asked about any changes that they would have made as a result of knowing about patient access to records. The respondents were encouraged to talk freely.

The doctors and patients were telephoned personally by B F and invited to take part. The interviews were conducted by B F and took place between September 1990 and July 1991; those with patients were conducted in their homes and those with doctors in hospital. In the case of one patient who was a child both parents were interviewed. The interviews were tape recorded with the interviewees' permission and full transcriptions obtained which were checked against the tape recordings for accuracy.

Content analysis was performed on the transcripts.³² A 'progressive focusing' method was used:³³ as the interviews were analysed, new themes were raised which were incorporated into the following interviews. One consequence of this method is that not all topics have been discussed with all respondents. It is inappropriate to compare figures with different denominators and therefore only figures where the denominator refers to all the relevant population (for example, all the patients who looked at their notes, or all the doctors interviewed) are given. For other results, those issues of relevance to the respondents have been discussed.

If patients had ever looked at the inside of their records, they were classified as having read their notes. The results presented are the main themes arising from the interviews, substantiated by verbatim quotations from the transcripts.

Results

Of the 34 patients identified 32 participated in the study (nine male and 23 female patients) — one patient could not be contacted and one had had a laryngectomy. Of the 23 doctors identified 21 took part — one did not respond and one refused to be interviewed. Two interviews with doctors were recorded in writing and included in the analysis. The nature of these interviews and the quality of their data were poorer than those that were tape recorded. Three patients were identified late in the survey, after their consultants had been interviewed about other patients for whom they had had responsibility. The relevant letters were sent to the consultants and their comments on the letters were gathered by questionnaire.

Doctors' expectations and patients' experiences of patient access to records

All 21 doctors expressed negative opinions about patient access to records. They identified a large number of problems which fell into four main categories. In the first category were worries that patients would be harmed by record access (21 doctors): they would be frightened and upset by 'information being shoved down their throats'. Hope would be destroyed:

'In order to sort of face life, face their relations and so forth they have got to perhaps have a grain of optimism about getting out and so forth. I find it difficult, but I think hope is the one thing that we have all got that enables us to ride the rough things that happen in life that we all have. We always hope that they are going to come to an end or we will overcome them and so forth and I think that if you have too much battering without hope you will cave in so I think people do need that to stand these sort of unpleasantnesses that go on.' (Doctor 14)

In the second category were worries that patients would misinterpret material and about the time that would need to be spent explaining technical terms. The third category comprised worries that the timing of the release of information would be sabotaged: doctors felt that they usually release information in a calculated and gradual way, to suit the needs of the individual patient, as seen by the doctors. If patients had access to their records, they could cut across this process and see information that might frighten and hurt them. In the fourth category were concerns that access to records might 'strip away the veneer of medicine' exposing doctors as uncertain and prone to error.

The majority of the patients (20/32; six males and 14 females) had looked at their notes. There were no apparent sex or age differences between those who had seen their records and those who had not. Neither were there any apparent differences in the type, length or seriousness of the cancers experienced. There were two aspects of patients' experiences that gave rise to concern. First, there were examples of the system of access to records breaking down — while in the waiting room two of the 20 patients had seen information in their notes that should have been presented to them with the support of a doctor or nurse. The patients were shocked and angry but nonetheless, they had both adjusted to the situation and were able to discuss the information with their general practitioner during the consultation, and with their hospital doctor. Secondly, one of the 20 patients had had a bad reaction to seeing her records despite the usual safeguards. She had not expected to see so much detail; the technical terms mystified and scared her, and she suspected that doctors communicated in a code that deliberately obscured information.

The doctors anticipated a number of advantages to patient access to their records. They felt that patients could see that doctors were telling the truth; that patients would be helped to make decisions and would gain information; and that it would improve the quality of the notes because doctors would be constrained to write more clearly and focus on the facts. Three doctors mentioned that patients might find access to their records reassuring.

Seventeen of the 20 patients who chose to look at their records were very enthusiastic about patient access to records. They found access to their records informative and it enhanced their understanding of the processes they were undergoing. For example, one patient mentioned the fact that polycystic kidneys led to high blood pressure. Patients described access to their records as reassuring and adding to their confidence, despite the risks involved. They felt that access to their records helped calm them and allowed them to plan for the future, both emotionally and practically. A large part of this reassurance was the elimination of worse fears and a reduction in uncertainty. Many patients mentioned that it gave them confidence in dealing more effectively with doctors, including being able to extract information from those reluctant to part with it. Patients used record access selectively: they made clear choices about whether to see their records or not. All those who chose to see their records took into account the risk of seeing unpalatable information. In all cases but one, they judged the situation correctly, finding the extra information generally neutral or helpful. All 12 patients who chose not to see their records also felt they had made the right choice.

Several patients (12/20) described problems in understanding or reading the notes. There was one obvious misunderstanding picked up during the interview. In general, although patients had problems in understanding some terms, this did not appear to cause any major difficulties. Patients mentioned that they could, or would, ask for clarification if necessary, usually from their general practitioner. On occasion record access made patients

question the meaning of their diagnosis in a searching and useful manner.

As regards litigation, for five patients a mistake of some type could have been thought to have been made. Four of these patients had chosen to see their records. One of the four was involved in litigation before seeing the records. For two patients, access to their records confirmed their feelings, but did not suggest to them that a mistake had been made. The remaining patient found that the records made her less critical of the consultant's approach and more understanding. None of the patients were induced by access to their records to proceed any further.

Motivation of patients choosing to see their records

The most important reason for patients using record access, mentioned by almost everyone (19 of the 20 patients), was that patients wanted the truth in order to clear their minds, to aid their control and to assist them in coping with the stresses of cancer.

'I feel that I will be able to cope better. I think I would go to pieces if I didn't know ... well I am an orderly sort of person. I get things into perspective then I can cope, but if I got bits here and bits there and not know the full picture then I tend to go around worrying about things. Until I have got myself sorted out into these little sections I will worry about things.' (Patient 4)

They also felt they had a moral right to the information: it was their body after all. Many also reported that they were 'plain curious' to see what was in their records. In addition, there was a strong feeling among those who chose to see their records (but not among those who did not) that doctors may have been hiding important information from them and that record access gave patients the opportunity to check on what they had been told.

'I am checking really that they are telling the truth. This is one of my things I do like to know the truth. I am not squeamish and I like to know what is going on. I don't like being left in the dark.' (Patient 20)

Motivation of patients avoiding access to their records

Two of the 12 patients who chose not to see their records could not read English. There were three main reasons for the remaining 10 patients choosing to avoid access to their records. The first of these was fear. Patients felt they would get too worried; access to their records might reveal news that was worse than what they already knew or could cope with.

The second reason was that what was in the notes would be too black and white. A few patients felt that reading their notes was very different to being told by a doctor: they felt there was a finality about reading information in their notes, and no longer a possibility of negotiation. In general, these patients seemed clear about their boundaries of tolerance. It was not clear whether they could tolerate more uncertainty than those who used record access.

The third reason was lack of curiosity. One quarter of those who avoided record access (three patients) described themselves as lacking curiosity.

Doctors and the truth

In the course of the interviews, it became clear that doctors had contradictory views on telling patients the truth. A number said that they would lie to patients, particularly about hidden tumours, such as those of the pancreas or bowel. The commonest reason given for telling the truth was that telling lies meant that you might get found out and that that would result in a loss of trust.

'It's easier to have a patient that's informed because I don't have to remember a fairy tale to tell the patient. Because I'd get it wrong sometimes. I would have been inconsistent and this I think would lead to increased suspicion and decreased trust on the part of the patient.' (Doctor 3)

These feelings contrasted with doctors' protective feelings towards patients and a strong belief that truth-telling needed to be tailored to patients and their needs, as perceived by the doctor.

Effect of record access on doctor-doctor communication

Doctors felt that patient access to medical records would reduce their ability to communicate frankly with general practitioners. Some felt they would bypass the system by using the telephone instead of letters for negative news. Letters would have to be more bland and would have to avoid snide comments. Specific aspects of letter writing that were expected to cause problems were mentioned. Comments about personal aspects of patients — home circumstances, or attitude of the spouse — were seen as a problem. Exposure of false optimism was mentioned. Although doctors had found it necessary to give patients bad news, they often put the information in the best possible light, so as to maintain hope. Patient access to records might destroy that facility. Doctors were surprisingly sanguine about record access and litigation: they expected record access to have a neutral or beneficial effect.

Review of letters to general practitioners

There were 442 letters in all, sent from the hospital department to the patients' general practitioner, including 88 hospital discharge letters — a mean of 14 letters per patient and three discharge letters per patient. Most consultants and their juniors said that they had forgotten that these patients had access to their notes.

Substantial changes were suggested in the letters for two of the 32 patients. One was because the term 'in-situ ductal carcinoma' was felt likely to cause confusion. In the event, this was indeed the case, although it did not cause distress. This seems not unreasonable, in view of the fact that debate still continues about this new disease, the characteristics of which are still unclear.

The doctor looking at the other patient's letters concluded that it would be extremely unwise to show her the letters at all. This was because she had acted against doctors' advice in the past.

'I'm not sure this patient should be shown any letters would be my first observation ... Her response is irrational. If someone goes for a screening test and an abnormality is shown and then refuses to comply strikes me they haven't thought what the screening test's for ... She's a difficult patient she doesn't want a blood transfusion, she's calling the shots a bit ... I wouldn't offer them to her.' (Doctor 10)

It may be useful to contrast this with the patient's own assessment when she had seen the letters.

'Well it just says what he did when I first saw the 64 year old woman, which didn't sound very nice but what else are you going to say I suppose, and so on, and he did this and that and the other and it's a whole page, and her chances of prognosis are such and such — and something like one per cent chance of recurrence for a year or something I don't know how they calculate that ... Well

I know that there was a chance of recurrence and even that truth doesn't feel good but I know it anyway'.
(Patient 13)

Minor changes were suggested in the letters for five other patients. These included concern about the tone of 'doom and gloom' that was felt to have been expressed, and concerns over using the word 'cancer' where 'tumour' would be preferable. Explanation was felt to be necessary in letters of four patients. The letters about the one patient who was upset by what she read in her letters were passed without comment by the doctors.

Discussion

This study has used qualitative methods with a small sample of doctors and patients to investigate the issue of access to records from the participants' point of view. The advantages of these qualitative methods are that, by incorporating discussion with the respondents, and allowing the themes they generated to drive the direction of the study, a more intimate and accurate analysis of how people construct their world was possible. The method allowed respondents to raise issues of importance to themselves in contrast to issues of importance to the researcher. It would be difficult to identify salient issues by means of a questionnaire. The disadvantages centre on the individual bias inherent in the method. A different interviewer may have discovered different themes. However, the individual questionnaire designer may also select biased questions. B F is known to both patients and doctors. This has advantages and disadvantages. Although respondents may have been more revealing to someone they were familiar with, they may have been less likely to offer criticism. While it is difficult to generalize on the basis of a small study, it is likely that the issues raised would be of importance in other settings.

The results relate well to other studies in the field, both in terms of rates of take up of access to records, and also attitudes expressed by both patients and doctors.^{17,34,35} In fact the rate of take up of access to records in this study of cancer patients was similar to those in other studies that had looked at patients in general.^{17,34,35} However, it needs to be remembered that the method of access to records in the study practice is different from that recommended in the access to health records act, chiefly because retrospective access has been given and because patients have not had to request access.

The results of this study revealed a gulf between the views of hospital doctors and patients. The doctors saw truth as a potentially dangerous resource: it could harm patients, unless focused and channelled by the doctors, and it could harm doctors by undermining their credibility. However, most patients seemed to be able to judge whether they could deal with additional information or not. Those patients who chose access to their records felt that the truth was frequently being kept from them and that, when they got it, it was usually a reassuring and helpful experience, even if the news was bad. This was because it helped them plan the future, both in practical and emotional terms.

There also seemed to be inaccurate judgements on the part of the doctors. For the two patients where doctors had felt important changes in the letters to the patients' general practitioner needed to be made, the patients had already seen the information. For one patient, the doctors' assessment was quite inaccurate, for the other, although the doctor correctly predicted her confusion, it caused no harm and, in fact reflected the profession's confusion as well. The bad reaction experienced by one patient to her notes was not predicted by the doctors.

There was also a gap between doctors' expectations and experience. They predicted problems in the abstract but when look-

ing at the letters for particular patients that they knew, they found that, on the whole, they felt that they had already explained most of the key facts and decisions. Patient access to records seemed safe and appropriate.

The doctors were correct in believing that patients would find difficulties in understanding their records. However, few problems seemed to result as patients felt they could ask questions as necessary. This aspect of patient access to records needs further study.

A number of patients felt that doctors might be hiding important information from them, and this was an important reason for choosing access to their records. Some doctors were quite clear that there were indeed a number of situations where information was kept from patients, particularly when patients were unlikely to find out the information for themselves, such as when they were suffering from hidden tumours, such as those of the pancreas or bowel.

This study suggests that the new law is likely to be an asset to patients. In the study practice, where retrospective access has been available for several years, there has been no increase in litigation and the majority of patients choosing to see their notes have benefited from the experience. The results suggest that doctors do not need to have a low threshold for censoring records, even in patients with a serious disease such as cancer. Extra time has had to be spent in vetting the records and in explaining potentially disturbing letters to patients, but the benefits in communication, reassurance and patient autonomy have been very real.

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