

Medical records: practicalities and principles of patient possession

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Authors' abstract

This review of issues and research is in two parts: 1) practical problems surrounding patient-held records and 2) ethical arguments for and against patient-held records. We argue that research on patient-held records indicates that there are no substantial practical drawbacks and considerable ethical benefits to be derived from giving patients custody of their medical records.

Introduction

Currently patients in the United Kingdom have no legal right to see the information in their medical records, let alone the right to have possession of the records, even temporarily. Patients can ask for information and doctors are obliged to give enough information to ensure adequate health care and valid consent to treatment. While it is true that patients have some rights to access to data held on computerised medical records, as the Data Protection Act currently stands doctors are allowed, under certain circumstances, to withhold computerised information (1,2). With the passage of the Access to Health Records Act 1990, patients will, from November 1991, be entitled to access to information in their records which was added after the passage of the Act. However, as with the Data Protection Act, record-holders can deny access if they are of the opinion that disclosure would cause harm to the physical or mental health of the patient, or any other individual. Furthermore, access may be partially excluded when it would lead to disclosure of information relating to or provided by an individual other than the patient, who could be identified from that information. Patients can also obtain access to their records if they are contemplating, or have already commenced, litigation. Thus, the circumstances under which patients can have access to the information in their medical records are quite restricted.

The issue at the centre of legal arguments about access to medical records is 'ownership' (3,4,5). Does

the patient or the doctor own the record or the information contained in it? In law, the private doctor owns the paper on which the information is written. National Health Service general practitioners put information on forms supplied by the Primary Care Unit in Scotland and by the Family Practitioner Committee in England: hence, the records are considered to be the property of those bodies. Records kept by hospital doctors are made on National Health Service (NHS) property. Furthermore, hospital doctors are employees of health authorities and records made by them while in the employment of the health authority are, in law, the property of the health authority (6). Thus patients appear not to own their records, or at least not the paper they are written on.

But, what about the information contained in the records? It has been argued that patients supply the information that goes in the records and thus they 'own' the information and should, therefore, have rights of access. Unfortunately, the law on ownership of information is unclear (6). Furthermore, the argument itself is rather weak in that a high proportion of the information in medical records is supplied by doctors and not patients. Much of the information is the results of tests, information passed from one doctor to another (for example from a consultant to a general practitioner) and notes made by the doctor. Thus, even if it could be argued that because patients give information that goes into records they should have access to it, a counterargument would be that they could only have access to the information they give, but not to the information put into the records by doctors.

This then is the legal position. Nevertheless, many doctors now allow patients to read their medical records and there have been a number of studies which have experimented with patient-held records.

Aims

The aim of this paper is to examine the issues surrounding *patient-held* records. We shall argue that many of the standard arguments of medical ethics – the desirability of doctor-patient communication, the patient's right to know and confidentiality – all point to a policy of patient-held records.

The review has been divided into two areas:

Key words

Professional-patient relationship; patient-held records; confidentiality; doctor-patient communication; autonomy.

- 1) Practical problems surrounding patient-held records.
- 2) Ethical arguments in favour of patient-held records.

Although our main concern is with patient-held records, many of the studies cited are concerned mainly with patient *access* to records. The arguments for and against patient-held records are similar to those for patient access to records. The differences lie largely in the practical aspects of patient-held records and in the issue of confidentiality.

When considering problems that might arise with patient-held records, one must first consider what exactly is meant by patient-held records. Do we mean that the patient has custody of the only copy, or should there be a back-up copy held by the doctor or hospital? Should the copy held by the patient be a full version or a censored or modified version? How one views the arguments for and against patient-held records depends, of course, on what type of record is being considered. We shall attempt to take into account the various types of patient-held record in this review.

Arguments for and against patient-held records

1) Practical

The first argument that usually comes to mind when considering patient-held records is that it is impractical because patients would lose their records. This would be especially problematic if the patient held the only copy. However, research has shown that while up to 10 per cent of hospital records are 'missing' at the time of a consultation, patients rarely lose records. For example, a study at St Thomas's Hospital, London, in which pregnant women received their full records, found that women rarely lost their records, but that hospital staff were frequently unable to find notes (7). In a study in Oxford not one of 500 parents given their children's medical records lost them (8). In another study women in Portsmouth kept their maternity notes. Records were kept in good condition and few were lost (9). Thus, the argument that patients should not hold their case records because they will lose them is not very compelling.

A second argument against patient-held records is that patients would not be able to understand the content of records and hence doctors would need extra time to explain the contents of the records to patients. Melville, in a study of access to records found that it took on average only ten seconds more for a consultation where the record was discussed (10). Although other studies have found that increased time was often required to discuss records with patients, this was felt to be outweighed by the benefits accruing (11).

The third argument against patient-held records is that it would be too costly to produce and update double copies. While this might be true if a copy had to be made of the whole record, it would not necessarily

be the case if a modified form of the record were to be provided. For example, Jones and his colleagues produced diabetic, patient-held records from a computerised data-base easily and cheaply (12). Another study found that costs were small and time minimal in producing four types of patient-carried records: (a) full case notes, (b) shortened case notes, (c) pocket-sized notes and (d) wallet-sized summaries (13).

Arguments about the cost of producing records for patients tend to assume that the records will be written or will be some form of computerised records. However, developments in new technology could force the pace of change in the use of patient-held records. In particular, the smart-card, a credit-card-sized plastic card with an embedded thin computer-chip is becoming cheaper and its use more widespread. In France, patient-held smart-card medical records are already used by well over 100,000 patients in four separate schemes (14). Trials of a smart-card in Cardiff between 1984 and 1987 concluded that the card was acceptable to patients and general practice staff and would be acceptable to general practitioners (GPs) if it contained clinical as well as medication data (15). New trials are now underway in Devon involving a card holding medical and prescription details (16). We conclude that there are no compelling practical arguments against patient-held records.

On the other hand, there are a number of practical arguments in favour of patient-held records. Firstly, locums and deputies would have access to records when making house calls. To be really effective case notes need to be available at the time of consultation. Secondly, there would be no delay in transferring records when patients moved or changed general practitioners. Lengthy delays in the transfer of notes can occur when a patient changes general practitioner (17). Thirdly, if patients were to hold their records, storage of records in general practice surgeries and hospitals would cease to be problematic. Time would, of course, be saved in pulling notes in clinics. The savings in salaries for medical-records staff could perhaps be used to hire more nurses.

A fourth, and one of the most compelling practical arguments for both patient-held records and patient access to records, is that patients could correct inaccuracies in records; in other words, patients could 'audit' their records. It is now fairly well established that there are unacceptably high levels of inaccuracies in case notes. For example, Baldry and her colleagues found that 12 per cent of their GP records contained inaccuracies (18). Tomson found that 35 additions, deletions or amendments were needed in the problem lists of 100 patients (11). Sheldon found that 10 per cent of patients in his general practice had items missing from their practice records; these included pregnancies, previous operations and drug sensitivities (19). Concern over inaccurate drug information in traditional medical records has also been expressed (20,21). If patients had custody of their records they

could check the accuracy of personal information, dates of tests, etc. They could also ensure that screening was carried out at regular intervals.

2) Ethical

Although it would be an advantage if patients could check the accuracy of records if they possessed a copy, it might be argued that a disadvantage, from the doctor's point of view, would be that he or she might feel restricted in what could be written in the record or might feel compelled to keep separate sets of notes (22,23). On the other hand, there are ethical advantages in this. Patient-held records would certainly put an end to the common practice of surgical witticism such as 'GRT' (Guardian-reading teacher) or 'NLM' (nice-looking mum) and 'FLK' (funny-looking kid) (7). Although gratuitous and (from the patients' view) offensive remarks often say more about the doctor than the patient, some doctors argue that personal comments round out the picture of the patient for other colleagues. Whether or not one doctor's opinion should be allowed to influence another's in such a way is, of course, debatable.

Some information in case notes, for example, 'suspected child abuse', falls in between personal comments and medically relevant 'fact'. It is argued that this type of information is essential for doctor-doctor communication. Furthermore, it is argued that the notes are for the benefit of the doctor and hence doctors should not be restricted in what they can write in the notes. Psychiatrists in particular might be affected if they felt they could not write their speculations in the case notes. It is frequently argued that psychiatric record-keeping is qualitatively different from medical-record development in general because of the more diffuse nature of symptomology; this is said to render the recording of such data as more vulnerable to subjective interpretation and the interposition of value judgements by various members of the treatment team. In recognition of the differences between mental and physical disorders, many US states which have statutes allowing access to records also include provision to exclude all or part of psychiatric records from direct patient review under certain circumstances. Nevertheless we think it is ethically difficult to argue that all patients, except psychiatric patients, could keep their records or have access to their notes. Like Showalter (24), we believe that psychiatric patients should be given access to their records, and that the need to invoke the 'therapeutic exception' probably reflects a deterioration in the psychiatrist-patient relationship.

Quite apart from ending the practice of surgical witticisms and the addition of mere speculation to medical records, allowing patients to hold their own records might mean that doctors would keep separate notes or would 'censor' information. Research, however, has shown that this is rarely the case. Jones and Hedley, in their study of diabetic follow-up systems using computerised summary cards, found

that doctors initially censored 13 per cent of all problems and 41 per cent of patients had at least one censored problem (25). In a follow-up audit they found that 69 per cent of censored problems were re-instated with doctors eventually censoring only one per cent of problems. Interestingly, the types of disorders that doctors censored were not always what one might have expected. For example, diagnoses like 'obesity' were more likely to be censored than cancer or terminal illness. Jones and Hedley did not find any apparent pattern in doctors' censoring of sensitive items. Sheldon excluded diagnoses in 19 per cent of cases and did not issue a summary to two per cent of patients (19). Bronson and colleagues found that as sensitive issues were regularly discussed with patients, doctors became more comfortable with the process and restricted information for less than one per cent of patients (26). In a study in Birmingham 0.3 per cent of patients were denied access to full GP notes; however, the GPs sometimes kept separate sets of notes for the benefit of other professionals (27). A study in Fyfe, in Scotland revealed that no patients were denied access to the full notes (10). Although allowing doctors to censor records might make them more likely to agree to patients holding their own records, if records are censored then they will always be, for the patient, incomplete. Knowing that records are incomplete might even provoke more concern about what has been missed out than concern about what is in the record.

It is said that detailed information makes many patients anxious, that many patients do not want to know about their illnesses or access to records, and that non-disclosure is, for some patients, good management (22,23). Such arguments are usually used in relation to terminally ill patients and psychiatric patients. For example, it is argued that patients with cancers with a poor prognosis will 'give up' and die 'prematurely' if they are not given hope. Information in records about the terminal nature of a cancer would destroy this hope. Another example has to do with noted placebo effects with treatments. Knowing that one's doctor was unsure of the diagnosis and the benefits of a prescribed treatment might destroy the faith that the patient had in the doctor and, hence, do away with the benefits of placebo effects. In the case of psychiatric patients it is argued that access to information in notes might make patients especially despondent. How compelling are these arguments?

There is little evidence to support the view that access to records makes patients unduly anxious. Baldry *et al* allowed access to records in London and found that 10 per cent reported being upset by their notes; however, although they had been upset about particular issues, they felt that record sharing was reassuring, informative and helpful (18). Bronson *et al* in Vermont found that shared records reduced anxiety in a study of over 7,000 patients (26). Altman *et al*, in another American study found that access to hospital case notes upset some patients; there were, however, only 11 cases in this study (28). In a more recent study

in Nottingham on patient attitudes to patient-held records, Jones *et al* found that only nine per cent of patients reported being worried about something in their record (29). An Australian study by Stevens *et al* found no effect on anxiety when patients were given access to hospital records (30). On the whole, studies on access to records and patient-held records indicate that access and possession of records reassures patients.

The evidence also does not support the prevalent view that patients do not want access to medical records and that they would be unwilling to have custody of full or even partial records. In Massachusetts, Giglio and Papazian found that 55 per cent of primary care patients accepted a patient-held record (13). In the Jones *et al* study cited above only three per cent of patients said they did not like having a record; 71 per cent reported liking having the record (29). In Scotland, Melville reported that 91 per cent of 150 patients given medical records said they thought it was a good idea to see the complete record; 96 per cent said that it was a good idea to see a summary record. Eighty-eight per cent of Melville's sample reported wanting continuing access to records of some type (10). Michael and Bordley found that 80 per cent of patients attending an American hospital felt that they should be able to see their own medical records (31). The American experience also indicates that non-disclosure may increase malpractice suits as patients institute legal proceedings simply to gain access to records (32).

Denying patients access to records when it is requested is certainly unlikely to increase rapport with patients. But, would patient-held records or access to records actually destroy rapport as suggested by Burrows (33)? If this were so it would be a strong ethical argument against patient-held records. Certainly, sharing of records might reduce the imbalance of information between patient and doctor and hence change the nature of the relationship between doctors and patients. In support of this argument it is worth noting that Bronson *et al* found that sharing records *improved communication* between patients and doctors and helped patients to deal with their condition (26). Moreover, Tomson feels that allowing patients access to information on their records *increases the trust* between patients and doctors (11). In a practice in East London, patients felt that access to their records increased their confidence in their doctors (18). A study in West Berkshire found that women who held their obstetric records were more likely to feel in control of their antenatal care and to feel it was easier to talk to their doctors (34,35).

Improved communication and increased confidence via patient-held records may also increase compliance. In Oxfordshire, uptake of cervical cytology, blood-pressure recording and tetanus immunisation increased with the use of summary records which displayed dates on which review was due (36). The process of creating a shared record can clarify treatment goals which will lead to increased

compliance (26,37). Apart from any increased verbal communication that may result from patient-held records, the very fact that the patient would have written information could increase compliance. There are many studies showing that providing written information improves adherence to medical advice (38).

The ethical arguments so far are, therefore, that patient-held records improve communication and increase trust, both of which involve patient autonomy, and that in increasing compliance they facilitate the discharge of the doctor's therapeutic obligation.

The final issue that we want to consider is confidentiality. Confidentiality is clearly ethically central to any discussion of patient-held records. The debate about confidentiality is often about who has a right to know, though, as pointed out by McLean and Maher, confidentiality and right to know are by no means identical concepts (39). Confidentiality is described as a 'duty', whereas the right to know is clearly a 'right'. Doctors have a professional duty to maintain confidentiality; patients have a right to expect that the information disclosed in confidence is maintained in confidence. The patient's right to know also imposes a duty on the doctor to make disclosures to the patient.

There is no law of privacy in Scotland or England and confidentiality is not an absolute obligation. There are so many exceptions to the duty of confidentiality in Britain that critics have argued that the whole concept has little value. It has been suggested that it is best to think of 'extended confidentiality' in the UK (40). Thus, quite large numbers of people may be informed of the details of a patient's medical history, for example nurses, health visitors, social workers, researchers, etc (9). These people are, of course, expected to treat the information as confidential. In other words, those to whom confidentiality is extended are expected to keep silent about the information disclosed about the patient.

Unfortunately, it is often the case that confidentiality is confused with secrecy. Thus, the records of a patient may be seen by a number of people, but there is a general reluctance to concede that the patient has a right to see the information in his or her case notes. Maintaining the duty of confidentiality does not preclude patient access to records or patients having possession of their own records.

If patients were to have custody of their records then they, rather than doctors, would control access to the records. It could, therefore, be argued that the patient's right to confidentiality would be enhanced through patient-held records. Patients, not doctors, would decide, for example, if their records could be made available for research purposes, to social workers, health visitors, etc.

Nevertheless, giving patients their records might mean that family members or even friends might see the records and, hence, confidentiality might be

reduced. Of course, it could be argued that if patients want their notes to remain secret then they would have to ensure that no one in the household had access to them. In many cases patients might find that having their notes at home would improve communication about illness within the family. The presence of notes would provide a focal point around which difficult topics could be broached, for example terminal illness.

Conclusion

The notion of patient-held records is still somewhat novel. We believe that research on patient-held records shows there are no substantial drawbacks and considerable benefits, both practical and ethical, to be derived from giving patients their records. Although medical opinion is inclining towards greater involvement of patients in their medical care, the line is often drawn at patients having custody of their records. While we acknowledge that allowing patients to have possession of the only copy of case notes might be impractical, and that there might be problems when dealing with psychiatric patients, the practical arguments against patient-held records are not, in light of the research evidence, very compelling. They certainly do not outweigh the ethical arguments in favour.

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