

Confidentiality of medical records: the patient's perspective

DAVID CARMAN

NICKY BRITTEN

SUMMARY

Background. The development of modern information technology and the increasing amount of multidisciplinary teamwork in primary health care mean that the principle of patient confidentiality is becoming difficult to uphold. The debate about confidentiality so far has paid little attention to patients' views.

Aim. A qualitative study was undertaken to explore patients' expectations and attitudes concerning confidentiality of patients' medical records in general practice.

Method. Semi-structured interviews were carried out with 39 patients from one general practice.

Results. Patients' expectations diverged considerably from actual practice. The majority of interviewees felt that administrative and secretarial staff should not have access to medical records. Some patients had reservations about a doctor not directly involved in their care having access to their records. They were unaware of the fact that practice staff had ready access to their medical records. Interviewees had particular concerns about recording of non-medical information in their records, and the confidentiality of computerized records.

Conclusion. Assumptions of shared doctor-patient definitions of confidentiality, at least in this practice, would be misplaced. It is suggested that explicit negotiations about what is recorded in patients' records would go some way to addressing the discrepancies identified in this study.

Keywords: medical records; confidentiality; access to patient records; patient attitudes.

Introduction

CONFIDENTIALITY in medicine serves two purposes. The first is to respect patients' privacy, so that they feel no shame or vulnerability. The second is to create an environment for honest communication between doctor and patient. Confidentiality is difficult to maintain in modern, high-technology health care provided by multidisciplinary teams.¹ In general practice, various members of the primary health care team, for example general practitioners, nurses, receptionists and secretaries, have a legitimate need to access patient medical records. Other people such as family health services authority employees and researchers may also have some need for access. Guidelines have focused on when confidentiality, both of medical records and generally, may be ignored.^{2,3}

A study was undertaken to explore the opinions of patients. As Sieghart implied, statutes will inevitably define the rules,⁴ and the access to medical records act 1990 has focused attention on patients' views. It has been suggested that an appropriate interpreta-

tion of the doctor-patient relationship 'pre-supposes a measure of agreement as to what should be kept secret and what should be disclosed [to others]'.⁵ Such a negotiated solution forming part of the ongoing doctor-patient relationship has also been advocated by Markus.⁶

Studies have dealt specifically with the issue of patient access to medical records⁷⁻¹⁰ but few have looked at patients' expectations and attitudes to confidentiality of medical records in more general terms, beyond the issue of access.¹¹ Rather than assuming what is best for patients, doctors should be aware of the 'rules' set by the patients themselves in order that they may have a shared understanding over what constitutes confidentiality. Patients' expectations of confidentiality may be raised by *The patient's charter* which states that 'every citizen has the right of access to their health records and that those working for the NHS [National Health Service] are under a legal duty to keep their contents confidential'.¹²

The aim of the study was to identify patients' attitudes to and expectations of confidentiality of medical records so that doctors are aware of any rules set by the patients themselves. This may help doctors and patients towards a shared understanding, rather than doctors assuming that they know what is best for patients.

Method

A qualitative design was chosen for this preliminary study as sensitive issues were likely to arise. The study took place in 1991 and the setting was a semi-rural, six general practitioner practice with 12 000 patients from four distinct villages. To reduce bias, interviewees were chosen from a village in which the general practitioner interviewer, D C, does not practise. This village is in the more affluent part of the practice area, containing many London commuters and owner occupiers. Seventy people aged 16 years and older were randomly selected for the study from the practice's age-sex register, there being no exclusions apart from age. As nine people had moved away, 61 patients were invited by letter to be interviewed in their own homes.

Interviews were semi-structured and covered opinions about who should and should not have access to patients' medical records and why, expectations of what information should and should not be recorded in the records, and attitudes to personal control over access to and content of patients' records. Interviewees were asked if there were sensitive items recorded in their records and whether they were concerned about what was recorded in their records. Interviewees were encouraged to raise other areas of concern as the interview proceeded. It was stressed that D C had had no prior access to interviewees' medical records.

After the interviews had been completed the medical records (both computerized and written) of respondents and non-respondents were compared with respect to four variables: age, sex, years registered with the practice, and sensitivity score. It was thought that those with highly sensitive issues recorded in their records might be reluctant to discuss patient control over access to and content of patients' medical records. Areas considered to be sensitive were those relating to: psychological or emotional problems; marital or relationship problems; sexual problems; and chronic disease or disability. All new episodes recorded in each category were counted to give a sensitivity score.

D Carman, BSc, MSc, MRCP, general practitioner, Rochester. N Britten, MA, MSc, lecturer in medical sociology, Department of General Practice, United Medical and Dental Schools of Guy's and St Thomas' Hospitals, London.

Submitted: 9 May 1994; accepted: 8 February 1995.

© British Journal of General Practice, 1995, 45, 485-488.

Interviews were audiotape recorded and transcribed, and the data were analysed using the methods advocated by Riley.¹³

Results

A total of 39 patients agreed to be interviewed and the other 22 patients either refused or failed to respond after two invitations. The ages of the 20 women and 19 men interviewed ranged from 22 to 84 years (mean age 50.3 years). None of the interviewees was D C's own patient and none had previously consulted him. There were no significant differences between respondents and non-respondents in terms of age, sex or number of years registered with the practice. Non-respondents were not found to have a higher sensitivity score compared with respondents.

Staff access to medical records

Interviewees seemed unaware of any basic principles that might be used by practices to determine who should or should not have access to medical records. Interviewees had their own ideas regarding the degree of access that should be allowed for different members of staff.

All 39 interviewees felt that all six doctors in the practice should have some degree of access to medical records. Not all of the patients, however, accepted the idea of completely free access. Some reinforced the idea that discussion of a patient's medical history between doctors would be beneficial.

'I would expect that [the medical record] to be shared, especially in difficult cases or situations.' (Patient 3)

Others had reservations about doctors not directly involved in a patient's care having access to records.

'If they are to deal with my health that would be okay, not just "Oh, that's interesting isn't it?" from one doctor to another.' (Patient 4)

Interviewees' opinions were divided between those who expected other members of the primary health care team (for example nurses and midwives) to have no access whatsoever to medical records and those who expected such members to have some access. The former were a small minority of six interviewees who justified their stance on the grounds that either such access was unnecessary since the work of these staff members was under the direction of the doctor or the staff members' code of conduct was under suspicion.

'No, definitely not, as far as I'm concerned, those people [nurses and midwives] could inadvertently pass information on to someone else outside the medical profession, and it could distort the facts.' (Patient 36)

The majority of interviewees (33) were happy for nurses to have some access to medical records, the degree of access depending on the perceived extent to which nurses were bound by principles of confidentiality. Some interviewees felt quite confident that nurses would use access responsibly while others felt that the decision about whether or not nurses could have access still rested with the doctor.

'Yes if the doctor deems that they [nurses] are responsible people... I presume that the doctor is employing responsible people?' (Patient 32)

Confidentiality applied to nurses seemed to relate to how much people felt that nurse training had instilled this principle.

Interviewees' opinions were divided regarding administrative

and secretarial staff's access to medical records. Twenty three interviewees felt that no member of this group should have access to medical records. The concept of 'need to know' seemed to be the major determinant of the degree of access considered appropriate by the other 16 interviewees. Of these, six felt that only secretaries should have access, justified on the grounds that they had special qualifications as well as being bound by the same rules of conduct as other professionals.

'Access would be limited to people who have a similar responsibility to a doctor. I am thinking specifically of the medical secretary, who I would want to believe had a greater degree of responsibility because of their training.' (Patient 35)

The other 10 interviewees felt that some administrative duties necessitated receptionists having access to medical records, for example, when relaying information between doctor and patient. Any qualms about maintenance of confidentiality were settled by seven people in terms of the practicalities of the situation where, for example, access by receptionists was inevitable because of the need to undertake filing of patients' medical records.

'One would expect that the receptionists would see them [medical records] but I wouldn't have thought that they would be terribly interested... so yes, filing access, but I don't think I would like them to be able to sit in their coffee area or somewhere, reading them.' (Patient 2)

Only three of the 16 interviewees who would allow administrative and secretarial staff to have access to medical records gave any thought to the question of standards of training and contractual obligations.

Interviewees held strikingly different attitudes to the way in which confidential information should be managed in hospitals compared with in general practices. Of the 23 interviewees who did not expect non-medical staff, and in some cases nursing staff, to have access to records in general practice, only three felt strongly that similar restrictions should be placed on their records in hospital. The change in context from general practice to hospital seemed to be solely responsible for this.

'You don't really know who is looking at them in hospital... but then usually in a hospital it is more anonymous... so it wouldn't bother me really... not so in the surgery, the difference is that in the area everybody knows you.' (Patient 18)

This principle of anonymity was a determinant of attitudes to access to records in the practice. Twelve interviewees felt strongly that people working in the surgery should not live locally and it became clear that personal acquaintance was an issue.

'I think if I knew someone in the surgery, I would be a bit wary of going in there... but I don't mind really because I'm anonymous to them.' (Patient 6)

Content of medical records

It seemed reasonable to assume that the content of an individual's medical record would determine the individual's attitudes towards confidentiality. The sensitivity scores computed from the records, however, were not correlated with the views expressed in the interviews: what seemed more important was the individual's perception of what was in his or her record. Interviewees were asked directly if they felt that there might be areas of sensitive information recorded in their own medical

records. Fifteen people expressed specific concerns and there were variations in the nature of their concern. Of these 15 patients, six felt that what was recorded was part of their life experience and they were happy that it should remain in the records in whatever form.

'Otherwise you are just trying to hide from yourself... that perhaps something was wrong in your life and yet you can't turn the clock back, so I mean if it happened... it happened.' (Patient 20)

The other nine interviewees wanted to know whether such information had actually been recorded and in what form; they had felt vulnerable at the time the problem had arisen. Their attitudes seemed to be determined by their actual experience of the problem and not by what might be thought to be socially acceptable to the interviewer.

'I started thinking perhaps I shouldn't have told the doctor things... or it's just that you get a feeling that perhaps I was stupid, I could have sorted it out myself, but I couldn't have done it at the time... it was just the panic.' (Patient 15)

Of this group of 15 interviewees expressing concern over the content of their medical records there were only four who did not expect non-medical staff or nursing staff to have access to medical records. It seemed that many of those who were anxious about the content of their records were not concerned about who might be able to see them, or had not considered the possibility.

Interviewees were asked about what sort of information they would expect to be recorded in patients' medical records. Two major themes emerged. First was the belief, expressed by 28 interviewees, that compared with hospital records general practice records include more personal information, such as social circumstances, relationships, and judgemental comments, all going back over a long period. Secondly, all the interviewees expected every contact with the doctor to be recorded. The reasons given for such a complete record related to diagnosis and safety (35 interviewees) and to continuity of care (25 interviewees).

All the interviewees expressed concern about the sort of non-medical information that might be recorded in their medical records. Although factual information about social circumstances was thought to be acceptable by most (34 interviewees), particularly when related to a medical problem, some felt that subjective opinions or judgements were not appropriate (23 interviewees).

'I wouldn't like something wrong with your moral or social standards recorded, but that's very difficult to quantify really isn't it?' (Patient 2)

Patient control over access to and content of medical records

Control over the content of medical records was linked with how the decision was made as to what should be recorded. All interviewees, whether concerned or not about the content of their medical records, seemed to feel that this decision rested with the doctor. There was, however, a perceived need for negotiation over this process of recording, particularly with sensitive issues.

'It should be a true and complete record but with a bit more openness about what the doctor is putting on your record to make a sort of agreement between doctor and patient and both have their input to the records there.' (Patient 36)

Many interviewees felt, however, that questioning by the patient

might upset the doctor-patient relationship. Another form of control was for the patient to conceal the information from the doctor, but the majority felt that this would be counterproductive to their need for help.

Personal control over access to and content of medical records was not considered to be a replacement for a good doctor-patient relationship.

'No, I think I would rather make an appointment to go along and see the doctor and say "Now look, I don't understand and I want you to explain it to me" rather than look at my records and be faced with a lot of words.' (Patient 27)

Another patient commented:

'I would like the situation where you can ask questions and leave the surgery understanding what was said, rather than the other way round... perhaps?' (Patient 32)

Personal access to medical records was only considered useful where: an explanation was forthcoming; there were concerns about what judgements the doctor may have been making; there was a fear that the whole truth was being withheld; or there was concern about a lack of communication between general practitioner and hospital. Access was considered by most as an appropriate 'civil right', whatever the circumstances.

'I don't think I would particularly want to see them [medical records] at present but if anything happened in the future and I felt as though I really wanted to get access then I feel as though I should have that right.' (Patient 7)

Computerized medical records

Although not specifically mentioned by the interviewer, each respondent spontaneously raised concerns about computer-stored records. Computerized records seemed to present a much greater threat to privacy and confidentiality than the written word.

'On paper it's okay... on computer, it's very difficult, I mean... you're in the lap of the gods really.' (Patient 22)

Interviewees were concerned about perceived control over access to and content of electronically stored information. Interviewees knew little about the type and amount of information stored on the practice computer. Twenty two respondents considered that a national network of computerized health records might provide speedy access to notes in a crisis but this concept gave rise to concern about people gaining unauthorized access to medical records.

Twenty two interviewees suggested that computer records be restricted to specific kinds of non-sensitive information, such as blood groups. They emphasized the need for negotiation with their doctors about what would and would not be appropriate for their computer record. This eagerness to negotiate over the content of computerized records contrasted with their approach to written records.

Discussion

The results of this qualitative study exploring patients' attitudes to confidentiality of medical records showed a divergence between patients' expectations and actual practice. Patients were unaware of the fact that practice staff other than doctors had ready access to their medical records. Some had concerns even about other doctors' access, and the majority felt that none of the administrative or secretarial staff should have access. Inter-

viewees also had concerns about non-medical information recorded in their medical records and about computer-held records. There seemed to be a hope that confidentiality would be maintained by indifference, in that the medical records of anonymous patients would be of no particular interest to those with access to the records. Personal control over access and content in general was not seen as a replacement for a good face-to-face explanation and most seemed to hope for a trusting relationship with their doctor to achieve such explanations.

The study was carried out in one semi-rural practice in south eastern England and it is not possible to say if the results are representative of practices in other parts of the United Kingdom. Interviewees may have been trying to please the interviewer who was a general practitioner, but they had been chosen from a village in which D C did not practise in order to reduce this kind of bias. The results suggest, however, that the situation is precarious and that assumptions of shared definitions of confidentiality may be misplaced. If *The patient's charter*¹² raises patients' expectations, the way forward may lie in explicit negotiations between doctor and patient about what is recorded in the medical records. Such negotiations may go some way towards addressing the lack of common agreement revealed by this study. If patients are more willing to negotiate about the content of computerized records than written records, this bodes well for the future.

References

1. Siegler M. Confidentiality in medicine — a decrepit concept. *N Engl J Med* 1982; **307**: 1518-1521.
2. General Medical Council. *Professional conduct and discipline: fitness to practise*. London: GMC, 1987.
3. British Medical Association. *Guidelines on the access to health records act. Guidance note — ethics 1*. London: BMA, 1990.
4. Sieghart P. Medical confidence, the law, and computers: discussion paper. *J R Soc Med* 1984; **77**: 656-662.
5. Anonymous. Briefings in medical ethics 7. Medical confidentiality [editorial]. *J Med Ethics* 1990; **7**: 1-4.
6. Markus AC. Medical confidentiality and records in general practice [editorial]. *Br J Gen Pract* 1991; **41**: 136-138.
7. Baldry M, Cheal C, Fisher B, *et al*. Giving patients their own records in general practice: experience of patients and staff. *BMJ* 1986; **292**: 596-598.
8. Strathdee G, Parrott J, Brown P. Patient access to psychiatric records: the patient's view. *J R Soc Med* 1988; **81**: 520-522.
9. Britten N, Bartholomew J, Morris R, Zander L. Consultants' and patients' views about patient access to their general practice records. *J R Soc Med* 1991; **84**: 284-287.
10. Fisher B, Britten N. Patient access to records: expectations of hospital doctors and experiences of cancer patients. *Br J Gen Pract* 1993; **43**: 52-56.
11. Weiss BD. Confidentiality expectations of patients, physicians and medical students. *JAMA* 1982; **247**: 2695-2697.
12. Department of Health. *The patient's charter*. London: HMSO, 1991.
13. Riley J. *Getting the most from your data: a handbook of practical ideas on how to analyse qualitative data*. Bristol: Technical and Educational Services Ltd, 1990.

Acknowledgements

This paper is based on a research project by D C presented in part requirement for the MSc in general practice at the United Medical and Dental Schools of Guy's and St Thomas' Hospitals, London.

Address for correspondence

Dr D Carman, The Marshlands Medical Practice, Cliffe Surgery, Millcroft Road, Cliffe, Rochester, Kent ME3 7UN.



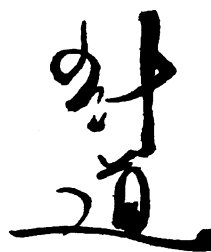
AcuMedic

101-105 Camden High Street NW1 7JN
Tel: 0171 388-6704 Fax: 0171 387-5766



Bridging East and West in medicine

Specialising in medical development with the emphasis on integrating Chinese Medicine and Acupuncture with Western Medicine. Manufacturers and distributors of Acupuncture Equipment and Chinese medical products.



The AcuMedic Centre in Camden is the largest Chinese Medical Centre in Europe providing medical products, publications and clinical services with a team of eight doctors and specialists. AcuMedic also operates several other branches in the UK.

The AcuMedic Foundation has organised two weekend foundation courses for doctors in Chinese Medicine and Acupuncture. The dates are: **Manchester** - October 21-22 and November 4-5 **Oxford** - October 28-29 and November 25-26 **London** - November 18-19 and December 9-10

PGEA approval is being sought. All the courses are run by Consultants from Beijing University of Chinese Medicine. Specialist subject modules to follow during 1996.

Course details from:

Mr B Mei, Acumedic Foundation, 101-105 Camden High Street, London NW1. Tel: 0171 388 6704. Fax: 0171-387-5766