

Patient-held records: censoring of information by doctors

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There are many reasons, legal, ethical and utilitarian for giving patients access to their own medical records. Perhaps the most topical of these are the legal requirements, under the Data Protection Act [1], to allow individuals access to any computer-held information about them. While this is being qualified for medical data so that access may be given at the discretion of the patient's doctor, the situation is only likely to be completely clarified after a test case. In the USA, after a long series of cases, the law is evolving towards allowing patients greater access to their own medical records [2,3], including psychiatric records [4], but patients may have reservations about asking to see their records [5]. In the UK, Zander [6] has recently argued that the Data Protection Act will in fact provide the impetus for many clinicians to provide greater access to information for patients.

The public view as expressed in the press [7], journals [8] and other publications [9] is for patients to be given free access to their own records. However, the caveat 'Not to be handled by the patient', now less often printed on the cover of case records, still influences general attitudes amongst doctors. Some clinicians are uncertain about the principle [10] and the number of experiments in giving patients their records are few.

There are four areas in which giving patients either their complete record or, perhaps better, an interpreted version may lead to important benefits:

1. *Education.* Ellis *et al.* [11] showed that the provision of brief, supplementary written information improved understanding and recall in patients discharged from an acute general medical and respiratory unit.

2. *Availability.* When patients have to see a locum or attend an accident and emergency department their full medical record may not always be available. If medical care is at all dependent on good records then the argument that there should always be access to it is compelling.

3. *Audit.* It has been shown that if patients use abstracts from their computer-held records to confirm their personal details, the quality of data in the records improves [12]. Bronson *et al.* [13] studied 3400 patients who were given their medical record and asked to audit it. Twenty per cent responded by returning the audit form; a third of

these made corrections and in 8 per cent of responses the patient audit led to changes in problem statements or plans.

4. *Improved doctor/patient relationship.* The time available for doctor-patient contact is often limited. Any mechanism that can improve the effective use of this time, for example by prompting the discussion or allowing the patient to consider the advice in more detail outside of the consultation, is likely to be beneficial.

We have developed a new clinical information system in a diabetic clinic which provides each patient with an edited version of their record [14]. In this article we have examined the tendency of doctors to withhold information from some patients by censoring the patient-held record.

Patients and methods

Clinical information system

The diabetic clinics at University Hospital Nottingham are supported by a register and information system which allows a wide range of clinical information to be collected and presented in structured medical records. Data are collected at full review consultations by doctors and nurses using standard clinical encounter forms. A questionnaire is used to collect information from new patients. The system generates printed records for hospitals, general practice and patients. The patient's version may be a facsimile of the hospital version or in an edited form. All patients are currently issued with a record and asked to check its contents. The computer prints prompts on the clinic forms at each patient visit to encourage the completion of missing information.

Patients

Medical records were issued to 2262 patients attending diabetic clinics. These records included identification details, family history, smoking and drinking habits, past and current treatment and a comprehensive problem list. The system allows certain problems to be deleted from the patient's copy at the discretion of the doctor or at the request of the patient. However, if the doctor has not indicated whether or not the problem may appear on the

patient's copy then the clerk will usually censor the problem.

Audit of records

Analysis has been made, using the computer-held record, of the frequency with which problems did not appear on the patient's copy and the characteristics of these patients. The computer records held information collected at previous reviews (average 3, range 1-6) during which censoring may have occurred. The patients were in the care of three consultants and eight junior doctors. This audit was made retrospectively and independently of the doctors working in the clinics. The results therefore represent routine clinical behaviour.

To estimate how many censored problems were actively censored as opposed to censoring by default, the last clinic contact form for a sample of 1005 consecutive patients was audited. The characteristics of this sample have been compared with the whole clinic population. There was no difference in the total number of problems on the problem list or the number of problems which were censored. There was also no difference in the proportion of males and females but there were more insulin treated patients ($X^2 = 50.1$; 2df; $p < 0.001$), fewer patients over the age of 70 ($X^2 = 48.8$; 6df; $p < 0.001$), and more patients from one firm rather than another ($X^2 = 24.3$; 2df; $p < 0.001$). This sample has been followed up one year later to see if censored entries on the problem list were now included on the patient's copy. Computer-held records for these patients were reviewed to identify possible reasons for the censoring of these problems.

Results

Censored problems

Forty-one per cent of all patients had at least one problem censored, 16 per cent had two or more. Out of 11,667 listed problems, 1,507 (13 per cent) were censored. There was no association between censoring and the sex, duration of diabetes, age of diagnosis or current treatment of patients. However, patients over 50 years of age were more likely to have a censored problem list ($X^2 = 6.8$; 1df; $p < 0.01$). Censoring showed marked variation between doctors. One consultant censored only 32 per cent of problem lists, while two other consultants and four juniors censored between 36 and 41 per cent. The other three juniors censored between 49 and 52 per cent.

Table 1 gives details of the audit of the data collection forms for the sample of 1005. This showed that most (85 per cent) censored problems were actively censored by the

Table 1. Audit of data collection forms for 1005 patients.

Censored problems	n
Problem censored on last clinic contact	231
actively censored by the doctor	197 (85%)
censored by default	34 (15%)
Problems censored at earlier review	441
Total	672

Table 2. Examples of the 197 actively censored problems among the sample of 1005 patients.

Actively censored problem	n
<i>Organic/medical</i>	
Impotence	21
Obesity	18
Retinopathy	35
Neuropathy	4
Nephropathy	7
Cataracts	6
Other organic/medical	34
Total 125 (63%)	
<i>Social/psychological</i>	
Compliance/understanding/motivation	13
Lives alone	6
Depression/overdose attempts	10
Other social/psychological/occupational	21
Total 50 (25%)	
<i>Family</i>	
Illness	9
Risk factors	2
Other problems	6
Total 17 (8%)	
<i>Other</i>	
Total 9 (5%)	

doctor and not by default through incomplete entries. Table 2 gives examples of the 197 actively censored problems which are considered below in more detail below; 63 per cent of these could be classified as organic/medical problems.

Reasons for censoring

To provide further insight into when and why problems might be censored, analysis was made of four particular problems; obesity, impotence, cancer and retinopathy. For example, 105 out of 1005 patients had 'obesity' or 'overweight' on the problem list and for 18 (17 per cent) it was actively censored. For this problem censoring varied by doctor, from none out of 12 entries to 7 out of 14 entries. There was no difference between males and females, but when ranked by body mass index females in the lightest third were more likely to have the entry censored ($X^2 = 7.5$; 1df; $p < 0.01$). Seventy-nine out of the 1005 had 'impotence' on the problem list and of these 21 (27 per cent) had this entry censored. No pattern, either by the age of the patient or by the doctor seen, was observed.

Only 17 out of 1005 had problems that included the terms cancer, carcinoma or tumour on the problem list. Eight out of 17 had the entry censored although only one of these was among the data collection forms audited. Six out of nine patients who had 'cancer' or 'tumour' included on their copy had other entries censored. For example, a sixty-year-old woman had 'left mastectomy: breast cancer' on her own record but 'constipation' and 'anxiety' were censored; a sixty-two-year-old woman had

'carcinoma sigmoid colon: hemicolectomy' on her version of the record but 'obesity' was censored.

Of the 1005 patients, 411 had retinopathy entered on the problem list and of these 35 (9 per cent) had the entry censored. For 17 of these 35 patients, the entry had been censored at the last review, while for 18 the entry had been made at an earlier visit. Four of the 17 had the entry censored by default, while for 13 it was a decision by the doctor seeing the patient that time. Most (24) of the censored entries were for 'background retinopathy' (Table 3). There was no association between the censor-

Table 3. Thirty-five entries concerning retinopathy which had been censored among the sample of 1005 patients.

Background retinopathy (24 times)

(Once each):

Choroido-retinal scarring from toxoplasmosis
Retinal vein occlusion
L. superior temporal retinal artery occlusion and gliosis
Extensive retinal ablation for proliferative retinopathy
Background retinopathy; early maculopathy
Severe macular retinopathy
Proliferative retinopathy; photocoagulation
Diabetic retinopathy with hypertensive changes
Exudative retinopathy
Early background retinopathy with hard exudates
Diabetic retinopathy and maculopathy

ing of retinopathy and the patient's age, sex, duration of diabetes or treatment type. A review of these records one year later showed that eight of the 35 previously censored records had had the problem included on the patient's version. Five patients had been discharged and three had died; the remaining 19 attenders still had the entry for retinopathy censored. A review of other entries on the problem lists showed no obvious reasons as to why retinopathy might have been censored on the patient's copy, except in the case of two patients, one of whom had the entry 'Lots of odd ideas and feelings', and the other 'Very anxious and talkative lady'.

Discussion

Most reported experience with patient-held records has been favourable. In a department of obstetrics and gynaecology in Portsmouth, the staff chose to give the complete obstetric hospital record to the patient [15]. A total of 10,000 records were carried by patients and only two were irretrievably lost. In Oxfordshire [16], 500 parents had been given their children's medical records and not one had been lost. The use of treatment cards to provide both doctors and pharmacists with a list of current drugs is widespread both in the USA [17,18] and the UK, and shared-care records are routinely used for hypertension [19] and obstetric care [20]. Similarly, the use of diaries [21,22] by patients for recording the results of self-monitoring is widespread for patients with diabetes. Hetzel [23] reports the successful self-monitoring and recording of the peak expiratory-flow rate by

inpatients while Koscel [24] describes the successful use of patient-completed log-books amongst alcoholics.

The involvement of patients in drawing up a 'health-care plan' (an extension to the problem-orientated system) improved compliance [25], and a patient-held record acted as a prompt for patients to discuss problems not normally taken to the GP [26]. Simonton *et al.* [27] found that over 80 per cent of psychiatric inpatients who were given their complete medical record to read daily believed it allowed them to take a more active part in making decisions about their treatment.

Neither strikingly harmful nor beneficial effects were observed by three groups of investigators from the issue of records to inpatients [28-30], but only 11 out of 2500 psychiatric inpatients actually *requested* their records [28]. The report states 'all record requests were symptomatic of mistrust . . .' However, as Lipsitt [5] argues, very few patients will request their record for fear of being labelled 'deviant' or 'troublemaker'. 'Attitudes and traditions in medical care are more likely to be modified by an awareness of patients and their feelings than by an incantation of laws that bestow on patients such self-evident 'rights' as the right to obtain the name of the physician responsible for his care or the right to inspect his medical records' [5].

Recent editorials have argued the case for [31] and against [10] giving patients access to their records. Three reports [32-34] discussed patients' reactions, which were generally favourable to greater access to their own records. However, very little is known about the attitudes of individual doctors to the disclosure of information. The computer system used in this study has allowed the easy audit of doctors' censoring behaviour. Some censored problems may have been discussed with the patient, but there are obviously occasions when some doctors have found it difficult to disclose information. Consultants tended to censor fewer problem lists than their juniors. The majority of censored problems were not psychological or social problems but organic medical conditions, many of which were directly related to the patient's diabetes, particularly retinopathy. Short [35] has recently discussed the sort of information which he would not wish patients to see and perhaps the doctors in this study had similar reasons for censoring entries but, as yet, there is little information about attitudes to disclosure in routine clinical practice.

Despite the stated advantages, the use of patient-held records is not widespread. One of the practical problems encountered with manually maintained records is the associated workload in recording information twice. Furthermore, the unstructured handwritten material in conventional manila folders is quite unsuitable as a method of communicating with patients. However, if information is recorded on a computer, as in this system, the production of a paper copy designed for the patient's use is easy and practical. On the other hand information in such a medical record might still be either meaningless to the patient or worse, might be misunderstood. In this study no attempt has been made to print explanatory or advisory text but this could be developed. The computer system has also allowed the easy audit of doctor's censor-

ing behaviour. The recent evidence [36] that young doctors provide incomplete information to patients about investigation, treatment and prognosis strengthens the argument for the development of a comprehensive patient-held record for the purposes of both explanation and reinforcement.

Patients increasingly have rights of access to their records and further study is needed to find out why doctors do not disclose information and what effects disclosure of information has on patients' understanding of their medical problems. The problem deserves closer attention and should be given more emphasis in both undergraduate and postgraduate teaching.

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