Giving patients a copy of their computer medical record

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SUMMARY. Medical summaries were prepared by a general practitioner for inclusion in a computer system. Both the medical records and a patient-filled questionnaire were used. A representative sample of the practice population were then sent their summaries. In creating the summaries the general practitioner felt the need to exclude 11 diagnoses whenever they appeared (5 per cent of the patients), and to suppress one or more diagnoses in a further 14 per cent of patients. In 2 per cent of summaries the general practitioner felt unable to give a copy to the patient because he was afraid of an adverse reaction by the patient or immediate relatives.

The patients' views of the usefulness of the summaries, and of their accuracy and completeness, were sought by a questionnaire. Replies were received from 71 per cent; of these, 91 per cent reported that they thought the summary useful. However, in 18 per cent of cases, the patients requested additions, corrections or deletions. Only 1 per cent of patients replied that they definitely did not like the idea of a computer containing their medical information.

Some of the benefits and difficulties both of using a computer to store medical information, and of giving the patient a copy of the medical summary, are discussed.

Introduction

OVER the last few years there has been increasing awareness of the problems associated with storing confidential medical information on computers (Hewitt, 1977; Jones and Richards, 1978; Rector *et al.*, 1979). There have been demands from Community Health Councils and similar organizations for patients to have free access to their medical records (Osman, 1980). It has been stated that one of the most useful consequences of patients seeing their own records would be the patients' satisfaction that they contained no inaccurate or subjective elements (Hewitt, 1977).

As our practice was already storing confidential medical information with the computer used by the Oxford Community Health Project (OCHP), we felt that it would be worth while exploring both the general practitioner's and the patient's attitudes towards some of these problems by providing patients with a statement of their medical problems as held on the computer, and then assessing their reactions.

Aims

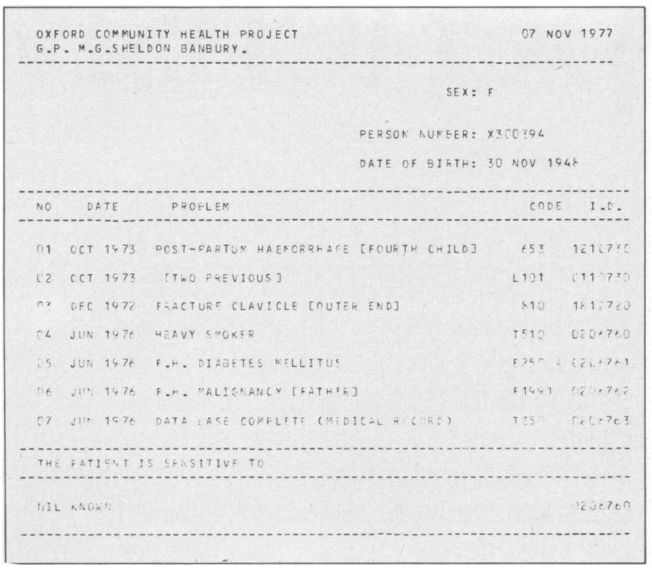
The objectives of the study were:

1. To document the doctor's actions when preparing a medical summary knowing that it would both be stored in a computer and also given to the patient.
2. To explore some of the practical difficulties associated with giving the patient a medical summary.
3. To find out whether the patients thought the summaries were accurate and complete.
4. To find out how the patients felt about placing this information in a computer.

Methods

The practice is semi-rural, is in North Oxfordshire and has 2,500 patients. The system of record-keeping and data collection and the use of the facilities of the OCHP have been described elsewhere (Sheldon, 1979; Sheldon and Tulloch, 1979).

Background information on all patients in the practice is routinely collected by patient-filled questionnaires (Sheldon, 1976) and is subsequently checked by the general practitioner at the next consultation. This information is compared with the medical record when it arrives, and summary forms are completed by the practice secretary. These are then sent to the OCHP secretary in Oxford for entry into the computer system. A computer print-out of the medical summary is returned to the practice and filed in the patient's records (see Figure).



OXFORD COMMUNITY HEALTH PROJECT 07 NOV 1977
G.P. M.G.SHELDON BANBURY.

SEX: F

PERSON NUMBER: X3C0?94

DATE OF BIRTH: 30 NOV 194?

NO	DATE	PROBLEM	CODE	I.D.
01	OCT 1973	POST-PARTUM HAEMORRHAGE [FOURTH CHILD]	653	121L7?C
02	OCT 1973	[TWO PREVIOUS]	L101	[11??70
03	DEC 1972	FRACTURE CLAVICLE [OUTER END]	810	1A1?7C0
04	JUN 1976	HEAVY SMOKER	T510	020?7A0
05	JUN 1976	F.H. DIABETES MELLITUS	F260	[2L?7A1
06	JUN 1976	F.H. MALIGNANCY [FATHER]	F1941	[20?7A2
07	JUN 1976	DATA BASE COMPLETE (MEDICAL RECORD)	T251	[4C?7E3

THE PATIENT IS SENSITIVE TO

NIL KNOWN 020?7A0

A medical summary produced by the Oxford Community Health Project computer and given to the patient.

As a study population, we chose the first 100 families identified in alphabetical order from the practice register (surnames A to C). This is a representative sample of 10 per cent of the whole population, as the practice contains no ethnic groups or preponderance of one surname over any other. This method produced a total of 244 patients. No differences were identified in age, sex, social class or family size between this sample and the whole practice population.

For each of the patients in the study a duplicate of the medical summary prepared in the above manner was examined by the general practitioner and amended if necessary in the knowledge that a copy was to be given to the patient. All alterations and omissions were recorded, and with each summary one of the following courses of action was decided upon:

1. Include all known problems in full.
2. Include all known problems, but suppress the print-out of one or more problems by the use of L codes (see below).
3. Omit one or more problems altogether.
4. Remove the patient from the study and not send them a copy of their summary.

When each medical summary was corrected or amended by the doctor, it was posted to the patient in the sample. The summaries for each family were sent in one envelope addressed to the head of the household, except for those of children over 16 years of age, which were sent separately. Included in each envelope was a short questionnaire designed to gauge the accuracy and acceptability of the summary. A covering letter was also sent to each patient.

L codes

This facility, enabling each doctor to create his own confidential codes, has been included in the Oxmis system (Perry, 1977, 1978). An arbitary numerical code may be used with the L prefix, in which case no-one but the general practitioner originating the summary knows what the code represents. The computer print-out will record the code number, but no interpretation will be printed. This system leaves an unexplained blank on the summary sheet.

Table 1. Information included in the patient's copy of the summary.

Category	Number of patients	Per cent
1. Include all known problems in full	200	*82*
2. Use one or more L codes	34	*14*
3. Omit one or more problems	10	*4*
4. Exclude from study	0	*0*
Total	244	*100*

Table 2. Problems for which a confidential L code was always given in the 244 patients in the study.

Problem	Number of patients with diagnosis
Inadequate personality	1
Attempted suicide	3
Low IQ	2
Abortion	4
Illegitimate child	3
Impotence	1
Adopted child	5
At risk battered baby	1
On probation	1
Alcoholic	2
Total	23

Results

Of the 244 patients included in the study, the general practitioner entered the full details on the summary in a total of 200 patients (82 per cent). A further 34 patients (14 per cent) had the print-out of one or more problems suppressed by the use of L codes, and 10 patients (4 per cent) had one or more problems omitted altogether from the summary (Table 1). Although no patient was excluded from the study at this stage, a total of 19 patients were eventually not given their summary for a variety of reasons outlined below.

The use of L codes was confined to 42 problem statements in 34 patients. The 10 problems detailed in Table 2 were always given an L code, as it was felt inappropriate to store these diagnoses in any computer which was outside the practice premises. Certain other diagnoses, such as the venereal diseases, would also have been given an L code on every occasion, but there was no patient with these diagnoses in this sample.

For all sensitive diagnoses, the doctor decided what

Table 3. Problems which were either omitted altogether, given an L code or entered in full in the patient summary.

	Number of times problem omitted altogether	Number of times an L code was used	Number of times problem entered in full
Malignant disease	1	2	4
Anxiety and depression	5	7	16
Marital discord	1	7	1
Family problems	1	2	1
Bereavement	1	1	1
Illegitimate child	1	0	0

action to take on the basis of his opinion as to how the patient would react. Thus, in some cases a diagnosis of malignant disease would be omitted altogether from the summary; in certain others it would be suppressed using an L code (thus implying that the doctor and patient both knew the diagnosis but did not want others to know); and in other cases it was entered in full. All the diagnoses treated in this way are detailed in Table 3.

After complètion of the medical summary, it was then decided not to send a copy to 19 of the 244 patients. The reasons were: elderly demented in a welfare home (three patients); Chinese family with a delicate relationship with the general practitioner and which involved many confidences (six patients); and five patients where the doctor was seriously concerned about the patient's reaction to diagnoses in the summary. The diagnoses involved were: paranoid delusions, multiple suicide attempts, previous pregnancy unknown to husband and malignant growths of which the patient was unaware (two patients). Summaries were also not sent to the immediate family of these patients, so avoiding the situation where some members of the family received a summary whilst others did not (a further five patients were excluded in this way). These concerns on the part of the doctor were not so much about including the details on a summary to be held in a computer, but about giving a copy to the patient.

Medical summaries were thus sent to 225 of the 244 patients, who came from 78 family units. Questionnaires were sent to each family, and a total of 161 patients (71 per cent) returned their questionnaires without prompting. It was not possible to sample the non-respondents, so the findings must be assessed with this in mind. The non-respondents did not differ from the responders in social class, family size or sensitivity of problems included in the summary. The responses to the questionnaire are analysed in Table 4. Just over 90 per cent of patients replied that they thought it was a good idea to have a copy of their medical summary. Only three patients of all those included in the study commented either in writing or verbally to the general practitioner that they did not wish their details to be entered in a computer. After explanation from the doctor, no one requested that their details should be removed.

A total of 21 patients (13 per cent of the respondents) replied that there was something in the summaries about which they were unhappy. However, on further examination of the reasons, in all but two of the replies this was due to missing, incomplete or inaccurate data needing correction.

In reply to the question asking if anything was missing from the summary, 16 patients (10 per cent of the respondents) replied that there was. The missing items were: family history (one patient); pregnancies (four patients); contraceptive details (one patient); previous operations (five patients); items of past medical history (five patients); and sensitivities (two patients). In three further patients, corrections were made to the dates of certain events in the summary.

Seven patients (4.4 per cent) requested that an item be removed from their summary. One patient wanted the details of his vasectomy removed, and another patient thought that threadworms were not worth including in her child's summary. A mother with epilepsy wanted the entry 'family history of epilepsy' removed from her children's summaries, and another patient pointed out that the diagnosis of asthma was incorrect. In this case a transcription error had arisen and the entry should have read 'family history of asthma'. The other three patients requested that diagnoses be removed which they thought incorrect, but which the doctor considered correct and should be included. These diagnoses were depression, menopausal syndrome and endometriosis.

A total of 28 patients (18 per cent) therefore requested that either additions, deletions or corrections be made to their summary.

In reply to the question asking what they intended doing with the summary, 2 per cent reported that they did not want it, 67 per cent intended carrying it with them and 40 per cent intended keeping it at home. Some respondents ticked both of these latter responses.

Discussion

The medical record has traditionally been the property of the doctor completing it, but over the last 30 years this situation has been challenged. With the creation of the NHS, the medical record has become the property of the Secretary of State and is now passed from one

Table 4. Replies to the questionnaire as a percentage of those replying. Three per cent of those replying to Question 5 ticked both a and b (n = 161).

	Yes	No	Don't know
1. Do you think it is a good idea to have in your possession a summary of your past illnesses, sensitivities and medications?	*91*	*5*	*4*
2. Is there anything about your medical history that you are unhappy about?	*13*	*87*	
3. Is there anything in your medical summary which you wish to be removed?	*3*	*97*	
4. Is there anything missing from your medical summary?	*10*	*90*	
5. What do you intend doing with your medical summary? (Please tick more than one if you wish.)			
a. Keep it in my wallet or handbag so that it can be shown to a doctor in an emergency.	*67*		
b. Not carry it with me, but keep it safe at home.	*40*		
c. Cut my name and address off so that it cannot be traced to me if I lose it, but keep it for my own future use.	*0*		
d. I do not want the summary at all.	*2*		
e. Some other use? Please explain.	*0*		

general practitioner to another by Family Practitioner Committees. This system has obvious advantages, the main one being a continuity in the record, acknowledged to be potentially of great benefit both for the advancement of knowledge and for the care of the patient. This does mean that opinions, possible diagnostic queries and inaccurate diagnoses assume different proportions when the notes are in the possession of someone other than the person who wrote them. Many doctors use the records knowing that they will not be seen by the patient, and if this situation is altered, many will feel that their note-keeping may become inhibited. Whether this will be to the advantage of the patients or to their detriment has not yet been agreed.

This study lends some support to the view that the records contain many inaccuracies and should be seen by the patient for verification. We found that even after the use of patient-filled questionnaires, subsequent checking of these questionnaires at interview and then further correction when the previous records arrived, 18 per cent of medical summaries still required additions, corrections or deletions when checked by the patient. It is likely that this figure will be very much higher in practices not using patient questionnaires. It therefore seems very sensible to give patients the opportunity to check the information held in their medical record.

It is interesting to note that three patients (1 per cent) disagreed with the doctor over a diagnosis entered on the summary and wanted it removed. In these cases disagreement between doctor and patient could hazard the relationship between them. Who is to have the final word in such a disagreement? It is important to recognize that there could be serious consequences for the patient if the diagnosis is significant for employment or insurance purposes. In this study the patient in whom the doctor diagnosed depression would have been denied certain employment if that diagnosis had been entered on a medical summary seen by prospective employers. Likewise, some insurance companies could have loaded his life insurance policies. Would the patient have recourse to sue the doctor if such an event happened and the patient was convinced that the doctor was mistaken?

This study has also highlighted some of the problems which will be encountered if patients are allowed access to their records. With 2 per cent of patients the general practitioner felt that he could not allow them to see even the summary, let alone the whole record. The diagnoses represented were such that they are likely to be present in every practice and would seriously inhibit any attempt to throw the records open to all patients. The situation arose on several occasions when the doctor realized that a patient had conditions not known to other members of their family. Sending a summary to all family members (even in separate envelopes) may cause considerable difficulties if one family member refuses to allow the others to see their problem list, or if it is seen by others inadvertently.

It may be helpful to consider the medical record now kept by the general practitioner as consisting of three separate parts. Firstly, there is the summary information, being a distillation of important diagnoses, events and problems which, it may be argued, should be available to the patient to examine and comment upon. It is this part of the record which will be passed on to employers or insurance companies when they ask for a report with the patient's consent. However, how can the patient give informed consent if he has no knowledge of

that to which he is consenting?

Then we have the main body of the notes written by the patient's general practitioner, or letters to the general practitioner from other doctors. This may be considered to be the property of all doctors charged with looking after the patient, and must remain confidential to those doctors. Finally, there are the general practitioner's scribblings and *aide-mémoire* notes, which may be considered the sole property of the doctor writing them. It is probably best if these are not passed on to subsequent doctors when the patient moves, as they will mean very little to other doctors and may seriously affect future care if opinions and guesses are accorded greater weight than that intended by the writer.

The use of an external computer to store this confidential medical information added an extra dimension to the problems encountered. There are many diagnoses which the doctor did not wish to enter into such a system as a matter of policy, so they had to be suppressed by a confidential code number. With other diagnoses they either might or might not need suppressing or omitting, depending on the patient. One patient with marital problems may be far more concerned than another, and no hard and fast rules could be drawn to cover all eventualities. It was interesting to observe that the most frequent diagnoses suppressed by an L code were minor anxiety/depression and marital/family problems. On further examination the general practitioner was interested to note that nearly all of these patients had a social relationship with the doctor. It is often hardest to tell the truth to your friends!

With adequate explanation 91 per cent of the patients responding to the questionnaire were happy with the idea of having a computer-produced medical summary, and only three patients (1 per cent) approached the doctor with doubts about the use of the computer. The use of dedicated computers in the doctor's surgery will almost certainly lead to fewer worries about unauthorized access to confidential data, but the provision of computer-held records will highlight the problems of inaccurate and sensitive data being retained and available to other doctors long after the useful life of the information has passed.

Conclusion

Although there are strong arguments in favour of letting patients see a part of their records, there are many difficulties which will arise if this becomes commonplace. Perhaps we should devise a set of rules covering this eventuality, and the following suggestions are offered for the purposes of debate.

1. The patient should not have the right to see the whole record, but only the medical summary, which is that part of the record which may be passed on to an employer or life insurance company with the patient's consent.

2. This summary should be made available to the patient in the surgery so that the doctor can answer any queries raised.

3. A copy of the summary should be made available to the patient on request.

4. If entries on the summary are disputed, the doctor should have the final say, although a system of obtaining a second opinion may be necessary in a few cases.

5. The rest of the medical record should remain confidentiial to the general practitioner, unless required for legal purposes, and then only released after the due process of law has been carried out.

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