Editorials

Should patients read their own medical records?

More data than ever are now recorded in patients' records, mostly in written form. A variable number of general practitioner and hospital versions exist in different places of any one patient's past history, present management and future prognosis. A small but an increasing amount is now being recorded on computers; the amended Data Protection Act (1984) will soon allow this information to be available to individuals. It may be expected that not long after this, they will also have access to written notes, but this may not help them much. Few doctors have the art of clear calligraphy. All use abbreviations far too much, and even when these barriers to clear note-keeping are overcome, there is still the technical language of medicine to be interpreted. Doctors tend to write in a short, coded form an interpretation of what they hear, see, feel and discuss with the patient. In addition, the increasing fear of litigation may encourage doctors to use their own private shorthand systems arranged to confound lawyers but also making casualties of their patients' understanding.

Perhaps some parts of the records are suitable for patient consumption while others are not. All those outside the medical profession, from the Department of Health to the daily newspapers, lump all specialties in medicine into one homogeneous group called Medicine. We know this is not so inside the profession; the activists at the sharp end are different from the philosophers whose medical practice allows a little more time to contemplate. Medical records reflect this. As examples of this spectrum, at one end is obstetrics and at the other psychiatry.

The idea of pregnant women looking after their own antenatal records is attractive. The obvious advantage is that, should an emergency arise whilst away from their home area, they may be admitted to another hospital and up-to-date records would be with them. A parallel important advantage is that they can read their records and from it derive questions they can ask at their antenatal visit. Disadvantages might be that the woman would be worried by what was in the records or that she may lose them. A recent study by Lovell *et al.*[1] showed that most women comprehended the content of their obstetrical records but there were some parts they did not follow; the four areas most cited were medical terms, information about tests, abbreviations and handwriting. The same study also showed a greater involvement of the partner who also read the notes; this seemed to be associated with a more positive attitude to his baby afterwards. Occasionally there might be sensitive information in the notes which the doctor might not wish the woman to see or, further, which the woman might not wish to divulge to her partner. Examples might be details of previous pregnancies or termination of pregnancy. These instances are rare and can be overcome by keeping a full set of notes in the hospital, with some colour-coded flagging attached to the abbreviated set carried by the woman indicating that further information is available at the hospital.

Obstetrics is a subject which lends itself well to records being read by the woman. Most of the information can be expressed in numerical terms or visually on graphs. Growth of the baby, weight, blood pressure, and descent of the head in the pelvis, are all capable of expression in terms the woman understands, and these details are encouraging for her in following the progress of her own pregnancy. The fears that women's notes might be lost seem unfounded. It is probably the antenatal component of the notes that is most useful for a woman to carry. The events of delivery and the puerperium are a matter of a few days only and, when the woman leaves hospital, the records may as well stay there after her delivery. In consequence, a system could be devised early using NCR paper, which would allow the woman to carry her records and a perfect copy to be kept in the hospital.

At the other end of the spectrum are the notes of psychiatric patients. Sargent[2] reviewed 100 psychiatric case notes of patients admitted under his care to a day hospital. He found in 29 that medical terminology confused the patient and in 79 there were comments that would be alarming or worrying to the patient. Thirty-three cases apparently had insulting or objectionable statements and in 54 some of the comments might have caused distress, such as 'she is intensely dependent and more than a little manipulative'. There were 31 cases with sensitive information from other people than the patient, such as wife or professionals, and another 32 with sensitive information about other people. Because of this, Sargent concluded it might be wise to limit the disclosure of medical information to psychiatric patients to the administrative details only, rather than the full tapestry of psychiatric notes. Stein *et al.*[3], in an American study in 1979, found that the majority of patients had a better understanding of their problems after reading their medical records, but a substantial minority (32%) were upset by some of what they had read. From this Stein concluded that the benefits seemed to outweigh the costs.

Perhaps a compromise to this is the proposed legislation on Access to Personal Files. This will not be retrospective (in contrast to the Data Protection Act) and so comments made in the past need not be considered. Similarly, personal information about others would also be excluded. Further, doctors would retain some control over the timing of access.

Most doctors would probably not object to the patient's scrutiny of factual data, which may be expressed in numbers or simple facts, such as haemoglobin levels, size of uterus or results of ultrasound measurements. The problem comes when they see the opinions expressed by the doctors about such information. Opinions are personal to the doctor, and it might be that these would be best kept so, when data and facts might become more public possessions.

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Patients seem to want this. The Campaign for the Freedom of Information commissioned a MORI poll late in 1986 which showed that three-quarters of the sample of almost 2000 members of the public believe they should have a right to see their personal medical records. At the BMA Annual Meeting the same year, doctors voted against this, 183 votes being cast against patient access compared with 169 in favour. This is a very small majority, and if 8 doctors had voted the other way, the decision would have gone otherwise. It would seem as though public opinion, both medical and professional, is moving toward the patient reading certain factual medical records; this will probably start in the comparatively easier field of notes such as antenatal records.

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References

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3 Stein EJ, Furedy R, Simonton M, Neuffer C. Patient access to medical records on a psychiatric inpatient unit. *Am J Psychiatry* 1979;136:327–9

Negation of responsibility: a heavy price to pay?

Like it or not, surgeons are going to be assessed with respect to their productivity, efficiency, economy and maybe even their current knowledge, availability and usefulness/need. Hard on the heels of financial constraints have come performance indicators, clinical budgets and further manpower assessments. No one would argue that we have neglected to address these problems, and too often in the past we have hidden behind the excuse of our heavy clinical commitment. In truth, we have never really wanted to know and certainly up until now have never confronted these problems. Griffiths, Körner, Short and the Joint Planning Advisory Committee have made us aware we are being looked at in every way.

Personally, I welcome it, because I have always considered it somewhat unhealthy that an appointment lasting 25 to 30 years should be so safe that only alcoholism, drug abuse, the breaking of professional codes with patients, and occasionally madness can lead to dismissal. There are many of our colleagues who, once appointed, never again put pen to paper; who do not attend conferences; and who end up 30 years later performing the same procedures that they learned as surgeons in training.

However, although I welcome some form of assessment, I would abhor this to be undertaken by non-medical administrators. But unless we act and opt for peer review, that is the obvious action that will be taken by the DHSS.

Who are one's peers? Why should anyone of a similar status take it upon themselves to assess a colleague? These are difficult questions, but they need to be answered and soon.

It is my feeling that the Royal Colleges and the specialty associations must take this on board. I should like to see the Royal Colleges coordinating review boards set up by the specialist associations. The Specialist Advisory Committee has looked at senior registrar positions in the past; now similar bodies must look at incumbents of the consultant class. It may be said that this is merely copying the American system. In part this is true, and that is not a bad move as there is no doubt that continual assessment keeps people on their toes, productive and up-to-date. On the other hand, I have never thought that the attendance at courses and the credit point system used by our colleagues across the Atlantic is a good system. One can take a horse to water but not make him drink. Courses and conferences can end up being mere jamborees (not all of course) with a substantial number of people merely attending to sign on for their credits.

So what form will assessment take? It must, of necessity, be different for the various types of hospitals and institutions. In some, teaching and research will play as important a role as the surgery performed. In others, throughput, quality control and clinical research will be the major role.

I ask, would you rather be questioned by colleagues or by administrators? The choice is still there, but if we procrastinate for much longer and shirk our responsibilities, we may have to pay the heavy price of non-clinical assessors investigating us.

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Alcohol, seizures and epilepsy

Although the disastrous physical and psychosocial consequences of excessive alcohol are well known, attention is most frequently focused on damage to liver (cirrhosis) and peripheral nerves (peripheral neuropathy). If a patient presents with either of these, the possibility of alcohol being the cause is not likely to be forgotten or missed, but the same cannot be said for the effects of alcohol on the brain, even though these may be equally dramatic. Such terms as Wernicke's encephalopathy, Korsakoff's psychosis and, less commonly, central pontine myelinolysis and the Marchiafava-Bignami syndrome may roll off the tongue, but cases are often still not diagnosed until autopsy[1]. Alcoholism is also a cause of global dementia and ataxia due to cerebral and cerebellar degeneration. In addition to thiamine deficiency, there are several possible mechanisms, often acting together, whereby alcohol produces brain damage, but in many cases the pathogenesis remains undetermined. The effects of alcohol may be insidious and

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