

Privacy for patients

Patients at present are protected by their general practitioners whose referral letter now only gives information relevant to the current complaint. Are psychiatric and sexual histories to be printed out every time a patient goes to hospital for a bunion?

DOCTORS can only do their work properly if they know all the relevant facts—but patients often want to keep some of these facts secret. Confidential information is what the patient does not want the neighbour to know. In recent years it has become more difficult to keep things quiet: in the future it is going to be harder still.

General practice has changed. In the last 40 years there have been great advances in the understanding of human development and behaviour. Emotional factors are significant in at least a third of all consultations, so generalists are constantly dealing with patients' fears and feelings. The kind of information handled has become more sensitive and this will continue.

Records are becoming fuller and more detailed, and are now documenting behaviour. In the past single-handed practitioners could afford not to record many intimate details: nowadays it all goes down in the notes. Diagnosing alcoholism, for example, may involve detailing aberrations of behaviour or conflicts with the police or other authorities.

Furthermore, in the National Health Service these notes are all marked government property, and have to be passed through at least two health service offices every time a patient moves from one executive-council area to another.

The 1974 reorganization of the NHS brought together for the first time the three branches of the British NHS and more exchanges of medical information will follow. Similarly, the Seebomh social service departments, although somewhat unsteady at present, will find their feet eventually. Many social workers regard the medical tradition of confidentiality as unreasonably restrictive—if not anachronistic. They will seek more access to medical records in the future.

As society becomes inevitably more complex, so the rules requiring statutory notification will be expanded. Yesterday the problem was the epileptic train driver, today there is concern about mentally-ill doctors, and tomorrow there will be more demands from the community for information about individuals.

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Computers are coming and this *Journal* has already published several papers from practitioners already using them. The British Medical Association Planning Unit (1969) wrote, "We do not consider that computer-based medical record systems give an inherently lower degree of confidentiality than manual systems, rather the reverse". We disagree.

Reassuring statements like this arise because computer experts stress that they can build security locks into the system and can limit access to graded information to authorized users. This may be true, but the problems in practice will be not only of access but of guarding output.

Computers produce information either through television-like visual display units, which are expensive, or on print-outs of various kinds. Will the houseman read and destroy the print-out every time? Or will it be kept to be read by the consultant, the registrar, and the nursing staff? Will these highly detailed records be any more secure than the present ward notes? If parity is basic obstetric information, how will a woman going into hospital to have a baby conceal a previously adopted child or an abortion?

Computers, regardless of safety keys or restrictions on access, will disseminate personal information much more widely. If general-practice records are computerized, as is already happening in several centres, a major step is taken towards a medical data bank. The next step is record linkage, and if this becomes widespread the information known to the personal doctor may be provided for hospital and perhaps clinic doctors.

Patients at present are protected by their general practitioners whose referral letter now only gives information relevant to the current complaint. Are psychiatric and sexual histories to be printed out every time a patient goes to hospital for a bunion? Is it likely that general surgeons and orthopaedic consultants are going to accept exclusion from these areas of the records? If they are allowed access, how far will they delegate this right?"

From theory to practice

The above words are taken from an editorial which was published in the *Journal* in 1973. What was then a theoretical problem has in 1978 appeared in practice. In this issue Kumpel reports how hospital consultants were given access for the first time to the full computerized records of general practitioners in one health centre in Devon. The remarkable technical achievements of this

system are already well known (Bradshaw-Smith, 1976), and this study gives food for further thought.

It also brings into the open the smouldering problem of the confidentiality of the patient's record. Here for the first time practitioners are actually sending total records instead of or with letters of referral to hospitals.

This issue has never before been faced, because in the past relative privacy was provided for patients through their general practitioners being highly selective in using information in their referral letters. Now a system is available which could eliminate general-practitioner selection altogether and open the patient's record not only to the consultant but, if it is sent with the referral letter, to the records clerk, the outpatients sister and her staff, and if the patient is subsequently admitted, to ward staff as well. The print-out really will display sexual histories after referral for a bunion.

The efficiency from the point of view of hospital staff of greater access to information may prove desirable; demands for such access may increase. But what say are patients to have? How far do they know that what they say in privacy to their own doctor for one condition may be printed out in outpatients years later for another? Even when patients give written consent for disclosure they may not remember its significance. A growing number of patients are becoming surprised and angry to find that information given to doctors about, for example, depressive illnesses, may be used by other doctors to load or refuse life assurance years after the event.

General principles

The first general principle which needs to be clarified is

the legal basis of the ownership of the record and who has right of access. As Jones and Richards argue today, the legal position is unclear and they make a plea to the responsible professional bodies to take an ethical stand and take it quickly. Crombie (1973) has emphasized the crucial distinction between primary files, like the general practitioner's, which refer to individually identifiable people, and secondary files, which contain information in a form in which individual patients cannot be personally identified.

The new computer techniques provide ways of making primary files available in secondary centres and general practitioners will increasingly become involved with computerized records.

The second task must be to examine the tradition of the general practitioner selecting information for the appropriate specialist at referral. Is this simply an old-fashioned, out-of-date tradition or does it provide a precious safeguard against widespread dissemination of personal and intimate information?

Now is therefore the time to clarify the ethical rights of patients while the technology is still flexible enough to include safeguards—if patients and doctors still wish to do so. But time is running out.

As a general principle we believe that patients should be entitled to know and understand the degree of confidentiality of information given to any clinician.

References

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What kind of College?

A WIND of change is blowing through the corridors of the College. As if to celebrate its Silver Jubilee, the Council is conducting an unprecedented review of the role of the College and re-examining both its structure and function.

We publish today four discussion papers, all written by members of the Council. These documents were considered at a special meeting of the Council in December 1977, at which virtually all the members of the Council spoke in what was a thoughtful and reflective session. Analysis of these papers reveals some common themes.

Watershed

The first is the remarkable agreement from almost all sides that the College has reached a watershed in its development and that there is now a great need for

change. Twenty-five years has a symbolic significance, for the College has changed greatly since the far-off days of 1952.

The restlessness in some faculties, the discussion documents, and the complaints from some members of Council all add up to a call for reform.

Decentralization

The second general principle which runs through the documents and the debate is the call for more decentralization within the College. It has become generally recognized that the growing number of new members—especially younger members—and their interest in clinical medicine means new ways must be found to meet these needs. Local involvement becomes essential. Some members, like Marinker, call for decision-taking to move from the Officers to strength-