

Medical Secrecy: Patients' Right of Access To Medical Records

The affirmative of the proposition that the patient has the right of free access to his records, and that he is not a full partner in the doctor-patient relationship until he exercises that right.

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The author asserts that the right of access to one's medical record derives from the implied partnership in the doctor-patient relationship. Errors and omissions are common in record keeping and free access is important to ensure that these will be corrected and the record completed. The risks must be taken that some patients will be harmed by full disclosure, or that the physician then will withhold important material from the record.

In Moscow, recently, a woman dying of a brain tumour, was thrown out of a Soviet hospital. Her offence? She looked, without authorization, at her medical record. Subsequently, the arrogance of the physician who took this action was much criticized in the Soviet press. At almost the same time, in Toronto, a young woman was forced to go to court to obtain access to her father's medical records. The family wished to determine the quality of the medical care he received before he died. Both of these cases raise interesting and important questions: why are physicians, in general, so reluctant to allow the individual's access to their own records? And, why are patients increasingly insistent upon their right of access?

THE DIGNITY OF THE PATIENT: Many people will have had an experience somewhat like the following. You are in the doctor's office. He has been taking notes as you describe your problems and symptoms. Then he is called from the room. The medical file is left, open, on the desk.

Who has not felt tempted, in such a situation, to take a surreptitious look at what the doctor has written in that file? Whether you succumb to this temptation or resist, you may feel belittled by the lack of open access to your record. As one patient put it, "It is not that everyone would want to know, but it is the assumption that you are not one of the team that is so undignified."

It is important to stress that the issue is not simply one of indulging idle curiosity. The issue, rather,

concerns the basic nature of the doctor-patient relationship. When patients' rights advocates insist upon the need for legislation to guarantee a patient's right of access to information in the medical record, they are rejecting, implicitly or explicitly, the physician's traditional paternalistic role as benevolent sovereign.

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CORRECTING MISTAKES AND PROTECTING CONFIDENTIALITY: Most patients are aware only vaguely that many people have access to their health records; and even fewer are aware that their record may contain serious errors and omissions.

Prompted by a patient's complaint, Siegler, an American physician, took the trouble to enumerate the number of persons who had legitimate access to the patient's hospital record (1). He was surprised to find that "at least 25 and possibly as many as 100 health professionals and administrative personnel at (his) university hospital had access to the patient's record and that all of them had a legitimate need...to open and use that chart." The patient who complained had a medical condition – mild chronic obstructive pulmonary disease – that was relatively straight forward and routine. Despite this, those with access to his file included six attending physicians – the primary physician, the surgeon, the pulmonary consultant, and others; 12 hour officers – medical, surgical, intensive-care unit, and "covering" house staff; 20 nurses (on three shifts); six respiratory therapists; three nutritionists; two clinical pharmacologists; 15 students – from medicine, nursing, respiratory therapy, and clinical pharmacy; four unit secretaries, four hospital financial officers; and four chart reviewers.

It seems obvious that the risk of serious errors and omissions is significant when the information in a patient's medical file is generated by such a large number of persons. Partly, this is because physicians and others vary in the level of skill and care they exercise in recording the information. The 1980 Krever Commission on confidentiality of health records cited many cases in which incorrect information was entered into patient files, with disastrous consequences. If patients have no right of access to the information in their files, they may be denied the opportunity to correct errors and omissions.

Moreover, in a variety of circumstances, people will be asked to waive the confidentiality of their health records. When you apply for life insurance, or welfare, or worker's compensation, or credit, or employment, you may be asked to release such information. How can patients make intelligent, informed decisions as to whether to give such permission for release of information unless they have access to their files and an opportunity to ensure that the information contained therein is accurate and non-prejudicial?

Given the large number of persons who have authorized access to the patient's personal medical record, and given the number of persons who may seek and gain illegitimate access to the computers in which such information is stored (not always very securely), it seems ironic that the one person who lacks access is often the patient. You may not agree entirely with Siegler when he declares that "medical confidentiality, as traditionally understood by patients and doctors, no longer exists" (1), but doubtless, there is some cause for concern.

THE DOCTORS' DILEMMA: The case in favor of patient access to personal medical records is so strong that one may wonder that so many physicians continue to resist. Some of this resistance may be attributed to the physician's desire to retain power over the patients. Monopoly of knowledge confers power. Those physicians who enjoy the status of "priest" and expect their patients to accept, without question, decisions made on their behalf, naturally will wish to retain exclusive control of access to medical records. This monopoly provides the ancillary "benefit" of making it difficult (if not impossible) for patients to use the legal system against incompetent or unethical physicians.

It would be a mistake, however, to view all opposition to patient access to medical records as a conspiracy of professionals against the public. As the American Medical Association has declared: "It is our position that the right of a patient to medical information from his physician is based upon the fiduciary relationship which imposes a duty to act in the best interest of the patient." It is frequently claimed that physicians have both a right and a duty to withhold information from patients when they judge this to be in the patients' best interests. Complete disclosure is opposed on the grounds that it is likely to alarm and upset patients needlessly. (Imagine the anxiety of the patient who reads his physician's tentative speculations, e.g., "query, possibility of cancer.") According to this view of the doctor-patient relationship, patients should be willing to trust the good will and sound judgement of their physicians.

In an editorial published by the *Journal of the Royal*

Society of Medicine (2), J.M.A. Northover, a British consultant surgeon, argues that patient trust in doctors would be undermined by giving patients access to their medical record: "Part of that trust is based on the understanding between the parties that the doctor regards helping the patient to come to terms with the disease and its implications as an important part of his or her job; many doctors feel that this responsibility requires the careful 'rationing' of information, the best interests of the patient determining just how that information is divulged." Northover concedes that patients frequently are underinformed but he insists that doctors should "resist the endeavours of those who advocate patient access to medical files", principally because "information management is an important aspect of proper medical care".

Northover buttresses his argument against giving patients the right of access to their medical files with the argument that these records usually are written in a language that for technical and other reasons would be of little practical use to patients. "Every doctor", he declares, "...would be horrified by the suggestion that the best way to inform a patient is simply to hand over a fairly incomprehensible, untidy and potentially frightening document." Patients are likely to be misled, and alarmed unnecessarily by the "dispassionately pessimistic" style preferred by many physicians in their note-taking, and by the sinister diagnostic possibilities included as part of a conscientious differential diagnosis. Northover confers the label "filophile" on those who favor giving patients a legal right of access to their files and accuses them of favoring "do-it-yourself" communication.

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Another potentially harmful consequence of giving patients the right to see their files would be that many physicians might change deleteriously their record-keeping practices; for example, they might attempt to remember potentially frightening diagnoses rather than entering them in the record. Or they might become reluctant to enter into the patient's record such unflattering comments as "working class background - ?? Poor self-image." The physician would omit such comments in order to avoid mutual embarrassment and to preserve the patient's confidence, but such omissions might lead to less efficient clinical management.

RESOLVING THE DILEMMA: Fortunately, there are ways of resolving or "dissolving" most of these objections. If medical records were written on the assumption that patients might see them, the physician would be obliged to replace technical jargon by good clear English, without prejudice to medical efficiency. It is conceded that, in the absence of supplementary explanation, the patient would find the information in the file often more confusing than edifying. However, the conclusion to be drawn from this is not that patients should be denied access to their files, but that the physician should be present when the patient receives the file, to provide necessary explanation and, where necessary, reassurance. Patients are entitled to know the truth about their medical status, and to have an opportunity to correct errors and omissions. It seems reasonable to assume that those who wish to protect themselves from such information generally will not request access. The process of explaining and interpreting medical records is likely to require some additional investment of the physician's time, but this would not be time wasted. Surely patients are entitled to receive both information and emotional reassurance.

The experience of having the physician explain the significance of the information in his history is likely to enhance the patient's trust and thereby contribute to good therapy. A trust based on shared knowledge is more valuable (because better founded) than one based on blind faith. As for the mental "distress" or "alarm" some physicians fear will result from free patient access we need to see some evidence of this. Such fears may be exaggerated or misplaced. A randomized clinical trial to assess the comparative therapeutic effects of access and secrecy might show that patients experience greater fear and anxiety when they are denied access to their files than when they gain access in propitious circumstances. Ignorance has a way of generating unwarranted anxieties and fears that can be more corrosive of patient morale and trust than would be produced by genuine knowledge (3).

As for the danger that the patient's morale may be undermined when he discovers in the record comments which are unflattering, we can respond that such comments have no place in the record in any event, because they have no medical justification. Thus, instead of writing "hypochondriac", the doctor would show a more professional attitude by recording that the patient seems unduly worried. This problem then could be discussed openly. If the physician cannot persuade his patient that this assessment is appropriate, the patient may choose to seek other advice. This outcome is consistent with a patient's right to autonomy, and should not necessarily be viewed as an unfortunate consequence.

Northover concedes that "it is a sad reflection on the medical profession that many members of the public are sufficiently dissatisfied by their doctor's inclination and ability to talk to them that they feel a need to seek access to their medical records to find out what is happening." But his opposition to legislation that would open medical files at the patient's request rests on his belief that "information management is an important aspect of proper medical care" and his belief that the Hippocratic principle of non-maleficence (not doing harm) requires that physicians carefully ration the information they give their patients.

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Dr. Northover illustrates his position with the following example: "In a state of frightened desperation, a patient might ask: 'Have I got cancer?', whilst wanting to hear only one answer: 'No.' The good doctor will recognize the situation and will choose his or her words carefully and compassionately." The crucial question (ignored, however, by Northover) is this: "How can the doctor be sure that the patient does not want to know the truth?" Perhaps the doctor has misinterpreted the patient's real wishes; perhaps the doctor has projected his/her anxieties about cancer onto the patient. Failure to inform, however well motivated, will often produce more harm than good. Whether a patient suspects deception or is successfully kept in a state of complete ignorance, the lack of knowledge will often produce more harm than would have been produced by the 'painful' truth. I believe the risks associated with medical paternalism are too great to be brushed aside. This is not to deny that physicians ought to communicate painful information to patients with tact and sensitivity. The communication skills Northover calls for (pp. 93 and 95) will be no less important once patients have won the legal right to access their files.

This position does not deny that exceptional cases may require the withholding of certain specific information. But those of us who are not physicians will find it

difficult to accept that many patients who genuinely wish to remain in ignorance of their diagnosis or prognosis will insist upon seeing their record. In the rare cases where this does occur and a patient is harmed by the policy of openness, one may regret the harm and yet still insist that patients have a right to know what is in their records, and, in any event, that more harm is caused by the present policy of secrecy.

THE RECORDS OF PSYCHIATRIC PATIENTS: The case for complete openness and disclosure is least strong with respect to some kinds of psychiatric patient. In Sweden, where patients are entitled to ask for their medical records, doctors have the right to refuse access if they believe that such access might endanger a patient's life. This seems to be a reasonable compromise, although some patients' rights advocates fear that physicians, including psychiatrists and other mental health professionals often misuse their discretionary power over mental patients.

Sociologists have frequently noted that once a patient has been labelled as "mentally ill", mental health professionals tend to interpret all the patient's subsequent behaviour as evidence confirming the original diagnosis (4). Thus, innocent behaviour may be interpreted as pathological because of the context in which it occurs. Once a patient has been so labelled, and the label is recorded in the patient's file, it exerts a powerful influence upon all future decisions made with respect to that patient. If the patient has been mislabeled, much harm may result.

However, if mental patients (and/or their family or a court-appointed guardian) had a right of access to their records, psychiatrists might be encouraged to develop a more careful and scrupulous attitude towards record-keeping. Cohen has offered some evidence that, for many psychiatric patients, access to information about themselves can be therapeutically beneficial (5). Of course, there are some instances in which the risk of serious harm to the patient from access is so great that access ought to be denied. It seems to me that such cases are likely to be uncommon. Hence, a sensible policy would be to legislate a right to access but at the same time to incorporate in the law a set of criteria for non-disclosure. This would provide a safety buffer for such exceptional cases.

CANADIAN LAW: At present, only a few Canadian provinces have enacted legislation which confers upon patients the legal right of access to the information contained in their medical files. In Alberta, for example,

the medical record in the doctor's office belongs to the physician, and in the hospital it belongs to the hospital. The patient is entitled, upon request, to have access to the information contained in the record, but is not entitled to physical possession of the records.

In Quebec, medical records are regarded as property to be shared between physician and patients. Hospital records are shared between the institution, the physician and the patient. In neither case is the patient entitled to take the original record and amend it. Patients may be denied access to their records only when such access is deemed to be prejudicial to the patients' health.

Section 4.02 of the regulations under the Quebec Medical Act reads: "Except when it is prejudicial to the patient's health, the physician must respect the patient's right to information in the records which concern him and to obtain a copy of such records." With respect to hospital records, the Quebec legislation reads: "A recipient to whom an establishment refuses access to his record or refuses to give written or verbal communication of it may, on summary motion, apply to a judge of the Superior Court, Provincial Court, Court of the Sessions or Youth Court or to the Commission, to obtain access to or communication of it as the case may be. The judge shall order such establishment to give such recipient access to his record, or communication of it, as the case may be, unless he is of the opinion that it would be seriously prejudicial to the health of such recipient to examine his record."

CONCLUSION: Evidence from jurisdictions in which patients have gained the legal right of access to the information in their medical files suggests that only a minority will choose to exercise their rights. Does this mean that patients regard the right of access as of little importance?

The minority who seek such access seem to see the right as highly important. It is probable that the consumer's rights philosophy which has increased in strength during the last few decades will continue to spread and to influence "consumers" of health care, that is, patients. Whether or not the number of patients demanding access to their medical files continues to grow, it should be emphasized that the right of access is important even to those who do not wish to see their files. That is, it is important that patients know that they have the right to see what is in their files, even if they do not choose to exercise this right.

The attitudes and values of both physicians and patients have changed significantly over the past decade. Patients now expect to take more responsibility for their own health. Physicians are significantly less paternalistic than they used to be. This change in attitude has been

beneficial for both physicians and patients. It seems likely that when patients across Canada win the legal right to see their medical files, this change will enhance the values of patient autonomy and patient responsibility.

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