

SOUNDING BOARD

GIVING THE PATIENT HIS MEDICAL RECORD: A PROPOSAL TO IMPROVE THE SYSTEM

DISSATISFACTION with the functioning of the medical-care system has become widespread. Four serious problems are maintaining high quality of care, establishing mutually satisfactory physician-patient relations, ensuring continuity and avoiding excessive bureaucracy. We believe these problems could be alleviated, in part, if patients were given copies of all their medical records. The record to a large extent embodies the informational product of medical consultation and treatment. In most exchanges in society a purchased product becomes the property of the purchaser, who is then free to evaluate the product on his own, have it evaluated by experts and choose freely among suppliers for any further services. Patients, physicians and planners and administrators would all benefit if the conditions of open information and freedom of choice that prevail in the market were to be introduced into the area of medical care.

At present, medical records are not routinely available to either physicians or patients. In theory, records are transferable within the profession; in practice, they are seldom transferred even in summary form, and even within one institution. By law, patients can obtain their medical records in 41 states only through litigation, in three states only through an attorney although not necessarily litigation, in one through showing good cause, and in one only after discharge from care. Only three "explicitly or implicitly allow direct access by the patient himself."^{1,2} It is indeed paradoxical that records are available primarily for setting the patient and physician against one another, and in most cases, only through the intervention of another professional!

THE PROPOSAL

We propose that legislation be passed to require that a complete and unexpurgated copy of all medical records, both inpatient and outpatient, be issued routinely and automatically to patients as soon as the services provided are recorded. The legislation should also require that physician and hospital qualifications (accreditations, memberships, etc.) and charges for services be recorded.

Hospital records should be available regularly to patients on the ward, and copies sent to them upon termination of the hospitalization. Outpatient records could be issued in two ways: copies could be sent directly from the physician's office; or records could be stored and mailed centrally. Although the latter approach would generate more red tape, centrally stored records could provide data for epidemiologic studies, be co-ordinated with activities of Professional Standards Review Organizations, and ensure against loss of his records by the patient. In addition, central record storage would facilitate a patient's option to refuse or accept the record anonymously.

EXPECTED POSITIVE RESULTS

The Proposal would benefit most participants in the medical-care system.

Patients

Information. At present, patients generally receive insufficient information on their own case,³ and their health knowledge is quite poor regardless of socioeconomic status, race, rural or urban background, age group or sex.⁴ Both physi-

cians and patients find this undesirable.⁵ In addition, inadequate transmittal of understandable information from physician to patient largely accounts for the widespread phenomenon of patient noncompliance with professional recommendations.^{6,7}

With record in hand, the patient would receive more complete information about his medical encounters, a source of satisfaction in itself. Patient compliance would probably improve, since the available record would supplant reliance on memory and would help the patient understand the rationale for treatment. Better records might even result as patients corrected mistakes in the history, and were encouraged by seeing their case described to keep relevant symptomatic notes for the next visit.

The record would serve as an educational tool. Patients would consult books or medical personnel about unfamiliar words, and thus learn professional terminology and concepts. Eventually, increased knowledge would lead to more appropriate utilization of physicians and a greater ability of patients to participate in their own care.

Continuity. The effects of replacing the "whole-person" physician by many specialist referrals have been exacerbated by population mobility, frequent use of emergency rooms, and physicians who cover one another's patients. Even when referred from another physician, patients must give the same history time and time again (a necessarily faulty one, since they are forgetful and do not know the details of their past professional care), and submit to the same laboratory and radiologic procedures repeatedly, because records are not at hand.

In contrast to this situation, implementing the Proposal would always provide a physician direct access to the history of the patient's previous care, complete with base-line data, drug schedules (a major problem⁸), hypersensitivities, etc. Patients would accordingly be subjected to fewer repeat tests, would be required to repeat but little information and would receive more complete, better informed care. The patients would at all times feel less "lost" in the system.

Choice. Patients have little opportunity to exercise informed free choice of physician in either primary or secondary care. The few criteria available for judging physician capability (e.g., specialty certification or hospital affiliations) are often unknown to patients or uninterpretable by them; they must use personalistic, nonprofessional criteria instead. Patients are inhibited from freely changing physicians, in part, by the expense of new work-ups, and by the difficulty of ever returning to the original physician if the new one should request the previous records.

Clearly, adopting the Proposal would free patients to choose and change physicians more easily. Patients would also be able to make better judgments about their physicians, and to differentiate legitimate physicians from quacks. Comparing physicians on professional grounds would become possible to some extent. It would take little sophistication, for example, for the patient to correlate a surgical procedure with the presence or absence of surgical-board certification (as listed on the record). A sophisticated patient might want to research the diagnosis himself, and learn more about it while monitoring the physician. Such personal attempts might have the side effect of emphasizing to a patient the difficulty of medical practice, and enhancing the physician's legitimacy as an authority (on the basis of official status combined with recognized expertise).⁹

Published guides to medical care would soon flourish, and professional consultant services for records "translation," interpretation and evaluation would arise in response to consumer demand. Medical societies, universities, private

groups, or Professional Standards Review Organizations could operate such services, which would then function as noncompulsory, decentralized quality-enforcement mechanisms.

Physician-patient relations. The nature of physician-patient relations has conflicted with American cultural norms. Americans demand autonomy¹⁰; yet patients have been forced into profound dependency on physicians whom they must trust on faith alone, whom they can hardly understand, and to whom they have often had little real alternative. As a result, many patients have acquired paranoid feelings about the medical-care system — and acted on them. The Women's Health Movement takes matters into its own hands; the thriving business of quacks and cultists reflects a search for friendly attitudes in a hostile professional world, as well as the public's inability to discriminate on a scientific basis.¹¹

Availability of records would enable patients to be much more autonomous in making judgments and choices; less dependent, they would feel less paranoid. The increase in patient information would undermine much of the current suspicion of physicians' candor. Since provision of medical records to all patients would be obligatory, no physician would regard any single patient as impeaching his services. As patients became more familiar with medical concepts, physician-patient communication would improve. All these improvements would produce more harmonious physician-patient relations.

Physicians

Quality care. At present physicians have only limited means of evaluating one another's performance.¹² As a result, an incentive for practicing high-quality care is lost, and referring patients to other physicians of known competence is made more difficult.

An effect of implementing the Proposal would be decentralized peer review. After seeing several patients whom another practitioner had seen, in conjunction with their records, a physician could hardly help making an assessment of that physician's abilities and practice. In this way professional reputations would grow according to the concrete criteria of patient care. Anticipating this process, physicians would have a clear incentive to practice high-quality medicine, especially since the practices of the most reputable would probably increase. In many cases, favorable evaluation by a specialist of a primary practitioner's records, or vice-versa, would result in increased trust and more expeditious referral of the patient to the appropriate level.

In addition, the Proposal would provide physicians new opportunities to learn. Just as residents learn by caring for patients and observing how various specialists treat their patients after they themselves have done as much as they can, so physicians in whatever practice setting would have the same experience repeatedly. The freely available record would provide a more "longitudinal" view of a patient, and physicians would appreciate better (and treat better) the course of a disease. Since innovation proceeds mainly by the contagion effect, new knowledge would probably be put into practice more swiftly, and isolated practitioners reached more quickly.¹³

Satisfaction. Practitioners have become less satisfied with their role and status in society. One cause of discontent has been that professional prestige has centered around academic centers where scientific advances are made, and where articles published and rank achieved are convenient measuring rods. By contrast, practitioners have had happy patients and money to mark them as successful in the community at

large, but these advantages have counted little within the profession.

Another source of discontent has been intrinsic to the practitioner's role. Specialization and discontinuity have frustrated practitioners trying to provide for a patients' needs. Moreover, the strains in physician-patient relations have affected physicians probably even more than patients, since being a patient is only a part-time pursuit.

Decentralized peer review would provide recognition of excellence in the practice of medicine, and hence enhance the prestige of being a practicing physician. Patient records and the care that they reflected would become a source of pride open to the perusal of fellow professionals. The expected improvement in continuity would decrease frustrations, and improved physician-patient relations would add importantly to physician satisfaction.

Planners and Administrators

At present, power in the health system is decentralized to the penultimate step — the physician. In the eyes of planners, administrators, fiscal intermediaries and the public that they represent, the physicians' autonomy is unchecked. Administrators and policy makers do not have the capacity easily to evaluate or control the appropriateness of medical care, nor have they been able to remedy such maladaptive forces as the drive for more and more physician specialization.¹⁴ Increasingly, they are turning to comprehensive organizational solutions that call for increased centralized decision making and an increase in provider aggregations, such as Health Maintenance Organizations, foundations for medical care, neighborhood health centers, hospital-based practices, Professional Standards Review Organizations, and comprehensive health planning. Most of these solutions would deliver more power to the proposers of reform.

The layers of bureaucracy implicit in all these proposals have familiar drawbacks. Quality control from record review and other centralized mechanisms faces many practical limitations.^{15,16} Increased centralization would probably decrease responsiveness to consumers because professionals would interact with one another more and patients less.¹⁷ Attempts to ensure a consumer orientation in policy making as in some neighborhood health centers have had only mild success.

Adopting the Proposal would reduce fears about physician accountability and quality. Self-regulating, decentralized peer review would provide better individual assessments than centralized review, since reviewers could correlate the patient himself with the record, instead of merely checking its internal consistency. Both inpatient and outpatient records would be used, and information would be generated precisely at the points of usage — patients and colleague physicians. On the other hand, some functions of centralized peer review, such as standards setting, would not be pre-empted.

The Proposal's improvement of continuity would supplement rather than supplant current administrative initiatives such as defragmentation of services. In addition, the specialty distribution of manpower would probably become more appropriate: the new prestige and satisfaction offered practitioners would make manifest the latent desires of many medical students to become family practitioners. These improvements would all take place without an increase in bureaucracy, as patients were enfranchised by decentralization instead of partially disenfranchised by centralization.

OBJECTIONS TO THE PROPOSAL

A number of objections to the Proposal may be anticipated. To begin with, various objections could arise from so strong a reliance on records. Records could be falsified, and diagnostic and treatment procedures made to look more complete and exhaustive than they were. A reliance on form rather than substance could develop, with no associated improvement in patient care.¹⁸ Or, conversely, practitioners could be led to do too much and be too complete for the sake of self-protection. With records so public, practitioners might be less free to practice in the most expeditious way possible, and the record might become a real burden. Moreover, judgment of medical-care quality on the basis of records could penalize a good practitioner who happened to keep poor records.

Certainly, records could be falsified, although verification procedures and patient recollection would serve as a check. Adherence to proper form would have little chance of passing for substantive validity in this decentralized system, as explained above.

Less-than-adequate work-ups are more common than more-than-adequate ones, so that a correction of this tendency would be salutary. With records traveling predominantly in the medical realm, despite the patient intermediary, medically warranted shortcuts should prove acceptable.

Finally, it must be stressed that medical records are not merely more red tape like insurance forms. The medical record constitutes an integral and vitally important part of the medical-care process, formalizing and focusing medical logic as well as facilitating memory. If a practitioner can somehow convince his patients that he is good despite records deficiencies (as might be true rarely), the Proposal would allow this relation to continue unhindered, whereas more centralized and routinized procedures would not.

A second objection might be that peer review of any sort can be questioned. Since professionals rely on peers as their primary reference group, peer support may take priority over quality review. It is safer for them to measure adequacy by academic degrees achieved than by competence demonstrated. There is, furthermore, an almost pathologic fear among practitioners that their practices will be found deficient¹⁹; probably much of this fear is motivated by the absence of any previous reviews, the lack of continuing education and the residual effect of medical-school intimidation. Some is no doubt motivated by beliefs about malpractice settlements.²⁰

Much of the unwarranted fear of review would be assuaged with experience. Moreover, decentralized review with voluntary sanctions might be easier to accept than centralized alternatives. Decentralized peer review should also be more effective since the medical profession is not really monolithic. After implementation of the Proposal any group could offer patients evaluation services and a majoritarian professional protective interest would accordingly be less effective, whereas the closed-door proceedings of centralized peer review would find dissenters excluded and overwhelmed.

A third possible objection would be fear that open disclosure of records would lead to more malpractice suits. What should be feared, however, is not more suits, but unjustified ones. The Secretary's Commission on Medical Malpractice has found that most suits are generated by poor patient care rather than greed and "... the unavailability of medical records without resort to litigation creates needless expense and increases the incidence of unnecessary malpractice litigation."²¹

A fourth objection would be that some might fear that physicians would be called upon to spend more time per patient, both in writing better records and in answering more questions.

Although this might be true for any single visit, productivity would probably not be impaired. Increased time spent on writing a record would be productive time, not wasted time, because the quality of clinical decision making both at the moment and in the future would improve (since other physicians would have a better longitudinal view of the patient). Additional time spent on patient education would likewise represent an increase in quality; moreover, the time presently spent (19 per cent of internists' time in one study²¹) would be used more efficiently. Proper patient education, improved continuity of care, and many of the other improvements anticipated to emanate from the Proposal's implementation would be expected to decrease the time per follow-up visit as well as reduce the number of visits per person per year. Even if spreading medical care as widely as possible were to take precedence over improving its quality, it is not clear that slighting medical-record keeping and health education would be desirable.

A fifth objection would be that implementing the Proposal might offer ammunition to patients who are already too directive with physicians. One motivation of such patients, however, is distrust of the professional's concern, and revealing the full record might curtail some of that distrust.

Sixthly, patients might misuse the records to treat (or mistreat) themselves — much self-dosing and pill borrowing already occurs. Making records available might well have the opposite effect, however, since the obvious discrepancies between various illnesses would be manifest. At any rate, the proper approach to the self-dosing problem is through tighter prescriptive habits and better patient education, both of which would be facilitated by the Proposal's implementation.

Seventhly, adopting the Proposal clearly would interfere with current practices of dealing with the patient with a terminal illness. At present, great discretion is allowed the physician in communicating the prognosis, and quite often he decides not to disclose it directly — in one recent study in Great Britain only 6 per cent of terminally ill patients were told of the prognosis.²² Far too often, by all accounts, medical personnel handle the problem of the dying patient by avoidance and denial, whereas it would frequently be better for patients if the situation were confronted openly.²³ Still, flexibility would be possible. Circumlocution on the record would allow the patient to deny if he wished. The physician and patient could agree before the results were known to tell or not to tell. A patient himself could decide not to look. The only excluded possibility would be the physician's withholding information the patient desired.

Eighthly, psychosomatic disorders would present a similar problem. Direct communication of the physician's knowledge would be a distinct improvement in many cases. Still, the possibility that a disorder was of psychosomatic origin would usually be placed in a constellation of organic possibilities, and the emotional problem could be approached gently as the other possibilities were ruled out.

Ninthly, some might object, theoretically, on the grounds that the medical-care system should be organized to provide for care without patient initiatives. For example, the system, not the patient, should inform a dentist before he operates to give penicillin prophylactically to a patient with congenital heart disease.

Implementing the Proposal would supplement rather than contradict this precept. The patient should act as a

backup; that safeguard will be necessary even after comprehensive systems have fully matured. In addition, patient contributions make any structured system more responsive and less bureaucratic.

Finally, the objection can be made that middle-class patients already have better access to physicians and more sophistication in dealing with them than poorer patients do, and the Proposal will only reinforce that advantage.

Although it is true that the middle class will be able to interact with physicians more effectively, and will be more mobile in switching physicians, it is also true that the poor receive care of much lower quality at present.²¹ The lower class will be able to use some of the tools provided by the Proposal, and the overall effect on quality should benefit the lower class substantially. Given their present relative positions, which class would benefit more is not clear.

IMPLICATIONS FOR GENERAL REFORM

The Proposal represents an incremental rather than a comprehensive change; its implementation should improve medical care at once and exert a salutary influence on the system's continuing evolution. Despite the fact that the Proposal promotes free communication and patient autonomy, it would not interfere with centralizing reforms, such as Health Maintenance Organizations and Professional Standards Review Organizations. On the contrary, as the evolution of socialist economic systems indicates, autonomous influences are sometimes essential even within administered systems.

More specifically, countries with tightly organized medical-care systems tend to have different expectations in physician-patient relations — Sweden is a good example.²² If the United States system is to evolve toward more formal organization, care will have to be taken to structure that system so that our own preference in physician-patient relations will be preserved (or resurrected). In addition, the United States has a traditional respect for family practitioners often lacking in other countries; we would be well advised to nurture this functional attitude. The Proposal would contribute to preservation of both these positive qualities as our medical-care system evolves.

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