Health Records and Privacy: What Would Hippocrates Say?

How to maintain the confidentiality of individual health records while ensuring their accessibility for insurance and research purposes has become a matter of sharply rising concern in recent years. The protection of individual privacy, in the face of the proliferation and sophistication of information systems, has been a hot topic for more than a decade. But the heightened post-Watergate sensitivity to public intrusions into private lives has cast an uncomfortable glare on the muddled patchwork of government and private policies—or lack of them—related to confidentiality.

The Privacy Act of 1974 was the federal government's first attempt at putting its own house in order by setting standards for access and use of federal files on individuals. Now Congress is getting ready to consider ways to extend this act to the private sector.

Health records in many ways exemplify the difficult decisions that have to be made. As Carole Parsons, former director of the Privacy Protection Study Commission, said, "Of all record-keeping relationships, medical records are the most intrusive"—that is, everyone has one, and they are more sensitive than, say, school records. Therefore, "other record-keeping relationships can piggyback on the essential qualities in medical relationships."

The prospect of National Health Insurance has lent considerable urgency to the need to adapt the Hippocratic oath to the computer age before the concept of "holy secrets" between doctor and patient is washed away in a swamp of data tapes. The absence of legal or ethical guidelines has already permitted many abuses of medical records to become institutionalized: for example, many employers, insurance companies, and moneylenders routinely make decisions about employees and clients on the basis of medical records to which they have freely been given access.

Psychiatrists have been among the first to raise the alarm. Members of this profession were rattled by the famed break-in of the office of Daniel Ellsberg's psychiatrist. They were even more shaken by subsequent testimony before the Senate by presidential aide John Ehrlichman, who said he did not understand why anyone bothered to break in when lawyers could easily have obtained the desired information.

The American Psychiatric Association has since spearheaded efforts to supplement the work of the Privacy Protection Study Commission through the establishment of a National Commission on Confidentiality of Health Records, chaired by psychiatrist Alfred M. Freedman of New York Medical College.

The NCCHR,* formed in June 1976, recently held a 2-day meeting in Washington in which it brought together representatives of health services, labor, criminal justice, public interest lobbies, and government to sort out what can be done to establish standards for the confidentiality of and access to health records.

Although the vast majority of breaches of confidence are not malicious in intent, the potential for damage was strikingly documented in a speech by Denver district attorney Dale Tooley. Tooley is in the process of handing down indictments to an as yet undetermined number of insurance companies who were customers of a scurrilous and now defunct outfit called Factual Services Bureau, Inc. Factual was in the business of stealing medical records—obtained by agents who represented themselves as doctors or lawyers to medical records-keepers—and selling them to companies who used the knowledge in negotiating claims.

Although Factual took advantage of the kind of loose record-holding that is easily remedied, the most serious issues are far more complex.

There is general agreement now that citizens should know what is in their files and who has them, and should have say in the use to which they are put. But there is considerable disagreement among various factions over the proper balance between an individual's right to privacy and society's need for information to keep insurance costs down, guard against fraud, pursue criminal justice, and conduct epidemiological research.

Pervading the discussions at the conference was the matter of employee health records. Union representatives claimed it is standard practice for employers to make adverse decisions on the basis of a worker's health record. They want employers to be kept in the dark about anything not directly relevant to a person's ability to perform his job; one union official even called for the elimination of corporation physicians. But this stance may conflict with an even greater concern, which is the need to collect data on hazardous substances in the workplace. For example, the hazards of vinyl chloride, which causes a rare liver cancer, were first noted by a Goodrich company doctor.

The need for medical records for epidemiological studies is burgeoning with new laws on toxic substances and occupational health. Since many long-term studies require identification of individuals for follow-up purposes, some scientists are worried that the newfound zeal for privacy will result in laws inhibiting investigations vital for environmental health. The Department of Health, Education, and Welfare is breathing a sigh of relief over the defeat of a proposed amendment to H.R. 3, a bill to control fraud in Medicaid and Medicare. Introduced by Philip M. Crane (R-Ill.), the amendment would have required any agent of the government wishing to obtain a personal medical file to obtain the explicit consent of the patient. Epidemiologists agree that such a restriction would result in samples so biased as to be worthless.

At a workshop on the research question, the participants agreed that there are research needs that override the need for individual consent. They added that such records should have legal protection from subpoena or other third-party attempts to get at them. (The National Institute for Occupational Safety and Health, for example, is trying to subpoena the records of all DuPont Chemical Corp. employees who have been exposed to vinyl chloride. DuPont has sued for an injunction, claiming it wants to protect its workers' "privacy.")

It was clear to participants at the conference that no single set of laws or policies will be adequate to cover the complexities of the privacy question; and the ramifications of individual decisions relating to health records are so convoluted that common sense would not always be adequate even if it were widely possessed. Model laws and proposed standards are now being bandied about. But privacy experts feel that the most important force for privacy protection will probably be general consciousness-raising.—C.H.

---

*Its offices are at 1211 Connecticut Avenue, NW, Washington, D.C. 20036.