Editorial

Sacred Secrets: Confidentiality, Informed Consent, and Diagnostic Testing in the AIDS Era

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Whatsoever things I see or hear concerning the life of men, in my attendance on the sick or even apart therefrom, which ought not to be noised abroad, I will keep silence thereon, counting such things to be as sacred secrets.

—Oath of Hippocrates

The AIDS epidemic has illuminated the status of medical confidentiality and, in doing so, has cast a long shadow. Concerns about confidentiality have pervaded public policy debates about control of the epidemic, and they have forced hospitals to reassess the ethical and legal ramifications of long-accepted practices.

In a simpler time, not very long ago, a physician could assure patients a degree of confidentiality that today seems virtually ironclad. Now, times are anything but simple, and absolute confidentiality rarely exists. A physician is expected to document all relevant clinical information in a medical record, whether that record is kept in a hospital or private office. Secrets, even sacred secrets, can no longer be tucked away in a physician's memory, safe from intrusion, to be remembered as needed, to be used to gain understanding or to provide comfort. Instead, scores of individuals have access to that recorded information.[1] Not only do those who provide care, such as consultants, house staff, nurses, aides, and technicians, have access but so do many others-others who have no personal relationship to the patient and, perhaps, no direct responsibility even to the hospital. The concept of confidentiality has thus evolved from being a covenant between physician and patient to a utilitarian compromise: secrets are shared with those who have a need to know. Ancient or modern, however, confidentiality is intended to serve the patient and to prevent disclosure to those who have no such need to know.

Although worries about medical confidentiality have surfaced from time to time,[1] the evolution of the confidentiality concept has been generally accepted as beneficent and useful. Patients are usually helped, not harmed, by the sharing of clinical data among health professionals. Moreover, we cannot imagine how care could be provided effectively without widespread sharing of such information. Before AIDS, we could be reasonably comfortable; the tradition of medical confidentiality, even in its modern extended form, seemed rarely to cause problems.

The realities of AIDS have destroyed our sense of comfort.[2] We cannot ignore the dramatic and egregious examples where confidentiality has been breached and patients harmed. The public's fear and morbid fascination with AIDS have intruded upon the lives and deaths of the more celebrated AIDS victims and have led to the kinds of sensational and lurid speculation and loss of privacy rarely seen with other diseases. Nor can we ignore the more common but less dramatic examples of patients who have lost jobs, been rejected by families and friends, or simply found that they had no place to go after it became known that they were infected with the human immunodeficiency virus (HIV).

Tragedies that have resulted from the loss of confidentiality provide powerful support for the need to develop special safeguards to prevent unwarranted disclosure of information about individuals infected with HIV. It is hardly surprising, therefore, that HIV testing has received considerable attention. By mid-1987, 17 states had enacted AIDS-specific legislation to enhance confidentiality,[3] and similar bills were pending in other states,[4] even though laws already exist in every state that generally protect medical record confidentiality." Also by mid-1987, at least four states had enacted laws requiring written informed consent before HIV tests can be obtained.[3] Guidelines from the Centers for Disease Con-

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trol[5] and others[2,6] emphasize the need for both confidentiality and informed consent.

Mechanisms to assume confidentiality are reasonable and ethically sound. A strict requirement for informed consent before obtaining an HIV test also appears to be useful, at least at first blush. After all, if we cannot offer an absolute pledge of secrecy for all of the reasons cited above, it seems only reasonable to make certain through informed consent that a person understands the potential effects of test result disclosure and is nonetheless willing to be tested. Moreover, strict informed consent requirements seem ethically appropriate. Patients should have autonomy, and autonomy cannot be easily abrogated. However, a person cannot have meaningful control over his own medical care unless he understands the implications of his decisions. 'Thus, both information and consent are essential if a patient is to exercise autonomy. Notwithstanding this logical construction, informed consent has been controversial.'-") Residual paternalism probably explains some of the opposition to informed consent, but more credible opposition holds that, on occasion, informed consent may not serve a patient's best interests. Such is the case with HIV testing.

Requirements for informed consent for HIV testing cause serious practical and ethical problems in several ways. First, such requirements are harmful if they help to absolve the testing institution of its responsibilities to take every reasonable effort to prevent improper disclosure of test results. Some written consent forms, in particular, are effectively written to protect the testing institution. They describe in detail the various adverse consequences that can result from disclosure of test results and require the test candidate to accept those consequences. This approach effectively shifts the burden of dealing with confidentiality from the testing institution, where it properly belongs, to the patient. One must ask whether this is a proper use of informed consent since it does little to benefit the patient.

Second, strict informed consent requirements may actually cause harm by paradoxically requiring confidentiality to be breached. This occurs, for example, when a patient is unable to provide meaningful consent and permission for testing must be obtained from a next of kin, guardian, or court. Such situations are likely to arise with increasing frequency in the future as HIV testing is used more often to evaluate neuropsychiatric disorders. In every such instance, the very act of seeking permission to test imperils confidentiality. In such settings, it seems ethically preferable to allow a physician to determine whether testing is necessary and, if so, to obtain the test without advance permission.

Third, physicians lose the ability to invoke "therapeutic privilege"[10] when informed consent is mandatory. This privilege is based upon the recognition that, on occasion, a physician may need to withhold selected information because of a concern about a patient's emotional well-being. This problem commonly arises in association with needlestick exposures of personnel to patients who are infirm, very ill, and who have few identifiable risk factors for HIV infection. Rather than burden the patient with yet another fear by obtaining informed consent for HIV and hepatitis B testing, many physicians will elect to forego testing altogether. The practical effect of that refusal is that the exposed staff member suffers prolonged anxiety and uncertainty.

These restrictions imposed by mandatory informed consent requirements do not pertain to the majority of candidates for diagnostic HIV testing who are able to understand and are willing to agree to testing. Nonetheless, to the extent that such requirements imperil confidentiality or interfere with appropriate diagnostic testing, they are harmful.

The practical and ethical problems raised by HIV diagnostic testing will not be quickly or easily resolved. It seems clear, however, that hospitals should take steps to make such testing safer and more effective for patients. Hospital-wide efforts should be undertaken to reemphasize to all staff members-employees as well as voluntary staff-that they have a fundamental obligation to maintain all medical information as confidential. Disciplinary action should be taken against anyone who inappropriately discloses privileged information. Hospitals should also vigorously and systematically evaluate their actual practices to assure confidentiality. Useful guidelines for managing medical records have been published.[11] If these steps are taken, the major risk that results from HIV testing will be reduced.

In states where no laws or regulations govern hospital testing procedures, hospitals should consider establishing a policy about the need for informed consent. Although it is tempting to make consent mandatory to provide added protection to the hospital and its patients, it must be recognized that an absolute, unyielding consent requirement may introduce additional practical and ethical problems. If a hospital elects to implement a requirement for written informed consent, special care should be taken to assure that it emphasizes the hospital's responsibility to prevent disclosure and that it does not actively discourage testing.

None of these steps will guarantee that HIV test results will remain confidential. And none will provide immunity from suit. But they will bring us closer to the ideals of serving our patients' interests while remaining silent about their sacred secrets.

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