Letters to the Editor

Am. J. Hum. Genet. 63:898–899, 1998

Familial Disclosure in Defiance of Nonconsent

To the Editor:

The ASHG statement on "Professional Disclosure of Familial Genetic Information" (American Society of Human Genetics Social Issues Subcommittee on Familial Disclosure 1998) asserts that patient confidentiality may be breached without the consent of the patient when giving genetic-risk information to family members may result in avoidance or treatment of a serious risk of harm having, at least in part, a genetic cause. The statement also asserts that the conditions for breaching of confidentiality should be discussed with the patient "both prior to genetic testing and again if the patient refuses to communicate results" (American Society of Human Genetics Social Issues Subcommittee on Familial Disclosure 1998, p. 475). Although this is consistent with the recommendations of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983) and of the Institute of Medicine Committee on Assessing Genetic Risks (1994), which came before it, we think that the prerogative to violate patient confidences that is proposed by this statement is unnecessary and misguided. In the spirit of debate anticipated by the ASHG Social Issues Subcommittee on Familial Disclosure, we offer the following critique.

The statement's recommendations rely on the exception to make the rule. It is probably accurate to presume that most patients will share important information with family members. In some small number of cases, patients will not want to share information about themselves with their family, and that is their right to decide. Control of information about oneself is a fundamental embodiment of privacy, and confidentiality—whether it arises out of the quasi-fiduciary nature of the provider-patient relationship or out of the implied or expressed contract of employment of a health-care provider by a patient—is the backbone of the provider-patient trust relationship. Furthermore, the physician or counselor cannot presume to have complete and accurate information about the patient's family history and interpersonal dynamics, about false paternity and adoptions, about the patient's relationships with his or her relatives, and about how information may be received by those others. Although problems of this nature may affect few families, they may be prevalent in cases giving rise to confidentiality disagreements. In these cases, providing genetic information to third parties could do more harm than good.

The statement fails to stress the necessary condition of consent to familial involvement, before any testing is performed. If the patient states, before testing, that she does not want to involve her family, regardless of results, then the provider must decide whether she is willing to perform the test under those conditions. If the provider truly believes that testing is in the best interest of her patient, she should perform the test and not be confronted with the ethical or legal "privilege" to violate her patient's trust. If she feels that these obligations to others outweigh her time-tested duties to respect and act in the best interest of her patient, she should decline to perform the test and should refer to another provider who may be willing to do so. It is essential that these considerations be fully engaged and resolved *before* any test is conducted.

The alternative solution offered by the statement will promote dishonesty and a lack of candor. The provider is at once instructed to build a trusting relationship with her patient (not with patient's family, it is important to note), to elicit information about first- and second-degree relatives, to counsel about the uncertain and sensitive nature of information that can be developed in genetic testing, and to discuss the possible familial-disclosure limitations on what the patient reasonably may expect to be an otherwise confidential relationship. According to the statement, the provider then is permitted to violate that trust, not merely "without consent" but in open defiance of nonconsent. To our minds, the risk posed by the exceptional, secretive patient is not so great as to justify the statement's policy.

Moreover, the statement's solution will not work. The secretive patient simply may not tell the inquisitive provider about his family, or he may lie. If the patient does not disclose all relatives' names, how will the provider know? Is the provider obligated to do any independent research? And, after testing, how will the provider know that all at-risk relatives have been informed by the patient?

The statement relies, inappropriately, on two recent U.S. state court opinions, Pate v. Threkel and Safer v. Estate of Pack. In the Pate case, the high court of Florida held that the physician's duty to warn family members at risk is fulfilled by telling the patient that relatives should be informed. In the Safer case, an intermediate appellate court in New Jersey held that the physician owes a duty of reasonable care to inform family members, which may include direct communication with identifiable family members even if that entails a breach of confidentiality. The Safer case is tied up in the courts on appeals regarding procedural issues. The New Jersey Supreme Court may not hear the case to resolve its substantive questions for several years, if ever. If anything, the Supreme Court of Florida's opinion in the Pate case should be accorded greater deference. It is, at best, much too soon and, at worst, erroneous to conclude, as does the ASHG subcommittee, that these cases "may indicate an increasing trend toward disclosure" (American Society of Human Genetics Social Issues Subcommittee on Familial Disclosure 1998, p. 480).

Health-care providers should not allow the fear of litigation and isolated judicial rulings such as that in the Safer case to dominate their ethical decision making. The courts as a general rule will not hold providers liable for harm arising from ethical practices, and the ASHG statement is an opportunity for the genetics community to embrace and advocate patient confidentiality, not to undermine it further. Unfortunately, the statement hedges about the bounds of the provider's obligations—and about their nature. The statement declares that it is permissible to disclose genetic information under certain circumstances, but it stops short of declaring an ethical duty to warn identifiable and contactable family members directly. Failure to articulate clearly the ethical bounds of physician discretion may invite the courts to do so, and, if the courts read the recommended privilege as arising from such a duty, then there may well be less discretion for the individual practitioner than is implied in the nuanced approach of the statement.

It is better public policy to respect patient trust, confidences, and decisions on family matters by limiting the provider's obligation to the following: (1) providing information about familial risk, testing, mitigation, and treatment; (2) urging patients to inform and involve at-risk relatives; and (3) securing express written consent to specific familial disclosures. Providers should have discussions that focus on the reasons for familial involvement, addressing issues such as the following: Has the patient considered the effects of sharing the test results, whether positive or negative—or even of revealing the mere fact that testing is called for—with her adult and minor relatives, including those with whom the patient has no active relationship? In contrast, what are the possible consequences of testing and withholding results? Does the patient imagine that she could withhold information from all relatives—or only from those who are estranged? Does the patient intend—or think it possible—to go to her grave while keeping the test results a secret?

Again, this dialogue and consent must occur and be settled before testing occurs. If no consent is secured, then the provider may refuse to conduct the testing, but, if she chooses to test, then there may be no disclosure of those results to third parties. This policy will achieve the aims of providing probabilistic risk information to family members nearly all the time; it avoids placing on the provider poorly defined and potentially unbounded duties that conflict with her quasi-fiduciary and contractual obligations to her patients; it avoids undermining the trust that patients place in their providers; and it is consistent and workable.

Acknowledgments

This work was supported in part by grants from the Greenwall Foundation, the Charles E. Culpeper Foundation, the National Institutes of Health (NIH), Department of Energy, and Veterans Administration Consortium on Informed Consent Research (all to P.S. and J.F.M.) and from the NIH National Human Genome Research Institute, Ethical, Legal, and Social Implications Branch (to M.K.C. and P.S.). The opinions expressed are solely those of the authors. The authors thank Arthur Caplan, Sheri Alpert, Barbara Weber, and an anonymous referee for comments on earlier versions of the manuscript.

Jon F. Merz, Mildred K. Cho, and Pamela Sankar
Center for Bioethics and Department of Molecular and Cellular Engineering
University of Pennsylvania
Philadelphia

References

American Society of Human Genetics Social Issues Subcommittee on Familial Disclosure, The (1998) Professional disclosure of familial genetic information. Am J Hum Genet 62:474–483

Institute of Medicine Committee on Assessing Genetic Risks (1994) Assessing genetic risks: implications for health and social policy. National Academy Press, Washington, DC

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983) Screening and counseling for genetic conditions. US Government Printing Office, Washington, DC

Address for correspondence and reprints: Dr. Jon F. Merz, Center for Bioethics, University of Pennsylvania, 3401 Market Street, Suite 320, Philadelphia, PA 19104-3308. E-mail: merz@mail.med.upenn.edu

0002-9297/98/6303-0032$02.00