Saying Privacy, Meaning Confidentiality

Abraham P. Schwab, Lily Frank & Nada Gligorov

Indiana University–Purdue University Fort Wayne

CUNY Graduate Center and Mount Sinai School of Medicine

Mount Sinai School of Medicine

Version of record first published: 02 Nov 2011.

To cite this article: Abraham P. Schwab, Lily Frank & Nada Gligorov (2011): Saying Privacy, Meaning Confidentiality, The American Journal of Bioethics, 11:11, 44-45

To link to this article: http://dx.doi.org/10.1080/15265161.2011.608243

Full terms and conditions of use: http://www.tandfonline.com/page/terms-and-conditions

This article may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, redistribution, reselling, loan, sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden.

The publisher does not give any warranty express or implied or make any representation that the contents will be complete or accurate or up to date. The accuracy of any instructions, formulae, and drug doses should be independently verified with primary sources. The publisher shall not be liable for any loss, actions, claims, proceedings, demand, or costs or damages whatsoever or howsoever caused arising directly or indirectly in connection with or arising out of the use of this material.
Saying Privacy, Meaning Confidentiality

Abraham P. Schwab, Indiana University–Purdue University Fort Wayne
Lily Frank, CUNY Graduate Center and Mount Sinai School of Medicine
Nada Gligorov, Mount Sinai School of Medicine

ThreE CoNcepts of privacy

Schonfeld and colleagues do not articulate a consistent view of privacy. In the article, privacy is often described as derived from other obligations. The authors claim that patients should be able to control private information about themselves, invoking the principle of respect for persons (autonomy) from the Belmont Report. For example, “none of this constitutes a breach of privacy [because] their access to private patient information has been approved by the patient” (31); again, “there is no breach of privacy here, nor any perception of a breach: The patient has given her specific consent” (31). The authors also derive the value of privacy from the principle of beneficence from the Belmont Report. Specifically, they associate the expansion of the circle of individuals who have access to a piece of information with an increasing possibility of harm to patients. In still other instances, the authors claim “the information in a patient’s record belongs to that patient” (31), reminiscent of Judith Jarvis Thomson’s view (1975) that the right to privacy is derivative of the rights associated with property and with the rights over your person.

These varied sources of the concept of privacy produce a confusing account. This diminishes the support for Schonfeld and colleagues’ recommendations and leads them to overstate their case regarding other medical professionals. Take, for example, the research nurse. Drawing on the worries about expanding the circle of individuals with access to information and the associated harms, Schonfeld and colleagues conclude that the research nurse would be violating the right to privacy of the patient if this nurse prescreened medical records for research. The support for this conclusion changes depending on the source for the right to privacy. When privacy is based on respect for the person/autonomy, it would be legitimate to access the patient’s medical record only if the patient has

1. It should be noted that their discussion of privacy responds directly to and challenges the HIPAA Privacy Rule. This rule explicitly defines the protection of privacy in terms of control. That is, to keep the Privacy Rule regarding an individual’s information one must get the consent of the individual for the use of information (U.S. Department of Health and Human Services 2003). Schonfeld and colleagues were led to this definition of privacy, and its limits (see Parent 1983), by the regulations that they were criticizing.

Our work was funded in part by 1R01HG004856-01 as a component of the Human Microbiome Project, a National Institutes of Health (NIH) Common Fund initiative.

Address correspondence to Abraham P. Schwab, Indiana University–Purdue University Fort Wayne, Philosophy Department, 2101 E Coliseum Blvd, Fort Wayne, IN 46805, USA. E-mail: abeschwab@gmail.com
consented. Granting access to the research nurse without patient consent would be a clear violation.

When privacy is based on beneficence, the conclusion is quite different. Schonfeld and colleagues conclude that allowing the research nurse to review the record would not be beneficent. Their view is based on the claim that any expansion of the number of individuals with access to a patient’s medical record carries an unacceptable increase in risk. This view, however, treats all risk as equivalent. It seems to confuse increasing the number of health care professionals with access with increasing the number of friends or strangers with access. Because friends and strangers have limited if any obligations to keep information to themselves, each additional person increases the risk that more and more individuals will gain access to the information. In turn, this increases the risk that an individual who will use the information for purposes of harm will gain access. When an additional health care professional gains access, the increase in risk is not commensurate. Health care professionals have strict responsibilities (see Kipnis 2006) to keep information to themselves (and related health care professionals). As a result, when one additional health care professional gains access to patient information, the increase in risk is negligible. Therefore, when privacy is grounded in beneficence, concerns for privacy will not lead to the prohibition of a research nurse reviewing a patient’s medical record.

CONFIDENTIALITY, NOT PRIVACY

Even if the conception of privacy could be clarified, the value of including “privacy” in discussions of appropriate uses of patient information remains unclear. Take, for example, this argument Schonfeld and colleagues use to support their recommendations: “to the extent that a clinician-investigator already knows (private) information about a potential research participant (there is no expansion of the patient’s privacy and therefore) no harm is conferred [by the review of the patient’s information]” (30). We have (bracketed) the references to “privacy” to illustrate how little would change if they were omitted. The heft of these arguments does not depend on the notion of privacy.

Many of the problems with Schonfeld and colleagues’ arguments can be traced to a misguided focus on the notion of privacy instead of confidentiality. In the health care context, discussions of privacy are made more complicated by the need to share information. Patients reveal information to health care professionals in such a way that makes it possible to diagnose and treat illness. In these instances the shared information is no longer private, but it remains confidential. The concerns Schonfeld and colleagues raise are questions of confidentiality, questions of how information should be disseminated after it has already been shared with a health care professional.

The obligation to maintain confidentiality addresses Schonfeld and colleagues’ concerns about beneficence in two ways: First, it prevents information about the patient from being disclosed in ways that could be harmful to the patient; second, it provides health care professionals with valuable information for diagnosing and treating patients. Confidentiality also addresses respect for persons/autonomy because it restricts the sharing of information to a certain group of people and for a specific use, patient care.

What is at issue in Schonfeld and colleagues (2011) is how confidentiality protections, thoroughly discussed in terms of clinical care, should be extended to the screening process for medical research. In clinical care, clinicians aim not only to minimize harms, but also to directly produce benefits for patients. Research as an activity, however, is not designed to produce individual patient benefit. Consequently, researchers are more likely to be disqualified from access to confidential information when the risk–benefit ratio is used to determine the legitimate uses of patient information. Yet in cases like that of the research nurse, the risk–benefit ratio would not preclude prescreening based on worries of beneficence. As Schonfeld and colleagues discuss it, concerns about beneficence aim to avoid negative consequences, including employment or insurance discrimination, “risk of domestic violence, or simply shame or embarrassment” (30). Those harms can and should be prevented by confidentiality protections, both for clinicians and for researchers. Only if they illustrated, as they do not, that these harms are more likely because of a modest increase in the number of health care professionals with access to a patient record could Schonfeld and colleagues provide adequate support for the restrictions they recommend.

REFERENCES


