Saying Privacy, Meaning Confidentiality
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Schonfeld et al. touch on the ever-narrowing gap between clinical practice and research as they address issues of privacy (and confidentiality) in the prescreening and review process for research. Although they put forth a number of recommendations about the sharing of information within the medical and research community, their arguments for these recommendations are underdeveloped and conceptually confused. As a result, their recommendations lack adequate support, and in the case of other medical professionals, as we argue below, their recommendations are mistaken.

Schonfeld et al’s discussion of privacy is obfuscated by a failure to distinguish between descriptive privacy and the value of privacy. A descriptive account of privacy ought to provide the conditions for what constitutes privacy and what indicates a loss of privacy. For example, privacy could be lost as more people gain access to a piece of information or it could be lost when the individual is no longer able to control the information. An account of the value of privacy ought to explain why privacy rights or interests should be respected or protected. (Gavison, 1980)

The conflation of these two aspects of privacy can be seen in the following excerpt: “we grant privacy both to protect patients from the harms associated with others knowing their personal health information (beneficence) and because individuals have a right to determine the use of their person and personal data (respect for persons).” (2) Looking at the second half of this excerpt, Schonfeld et al. could mean: 1) that an individual’s ability to determine the use of personal data is what defines something as private, or 2) it could be that this control is why privacy is valuable. If 1), the loss of privacy occurs if an individual cannot determine the use of personal data, and this loss is problematic because it may lead the individual to harm. If 2), this loss is problematic both because it may lead the individual to harm and because the individual cannot control the use of personal data.

Three Concepts of Privacy
Schonfeld et al. do not articulate a consistent view of privacy. In the article privacy is often described as derived from other obligations. For example, the authors claim that patients should be able to control private information about themselves,1 invoking the principle of respect for persons (autonomy) from the Belmont Report. For example, “none of this constitutes a breach of privacy [because]

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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. (US Department of Health and Human Services 2003) Schonfeld et al. were led to this definition of privacy, and its limits (see Parent, 1983), by the regulations that they were criticizing.
their access to private patient information has been approved by the patient” (6); again, “there is no breach of privacy here, nor any perception of a breach: the patient has given her specific consent” (15). 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. (2) In still other instances, the authors claim “the information in a patient’s record belongs to that patient”, (3) 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 et al.’s recommendations and leads them to overstate their case regarding other medical professionals. Take for example, the research nurse. (12-13) Drawing on the worries about expanding the circle of individuals with access to information and the associated harms, Schonfeld et al. conclude that the research nurse would be violating the right to privacy of the patient if this nurse pre-screened 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 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 et al. conclude that allowing the research nurse to review the record would not be beneficent. (12-13) 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 et al. 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].” (7-8) We have {bracketed} the references to “privacy” to illustrate how little would change if they were left out. The heft of these arguments is not affected by “privacy.”

Many of the problems with Schonfeld et al.’s arguments can be traced to a misguided focus on the notion of privacy instead of confidentiality. In the healthcare context, discussions of privacy are made more complicated by the features of information sharing. 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 et al. 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 et al’s 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 by assuring the patient that information will only be disclosed in well-defined circumstances. 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 et al. 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 to not only minimize harms, but 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 ration would not preclude prescreening based on worries of beneficence. As Schonfeld et al. discuss it, concerns about beneficence aim to avoid negative consequences including employment or insurance discrimination, “risk of domestic violence, or simply shame or embarrassment.” (17) 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 et al. provide adequate support for the restrictions they recommend.

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References


http://www.hhs.gov/ocr/privacysummary.pdf