

Virtual Mentor

American Medical Association Journal of Ethics
September 2012, Volume 14, Number 9: 708-711.

JOURNAL DISCUSSION

The “Decrepit Concept” of Confidentiality, 30 Years Later

George L. Anesi, MD, MA

Siegler M. Confidentiality in medicine—a decrepit concept. *N Engl J Med.* 1982;307(24):1518-1521.

In his influential 1982 essay [1], Chicago physician-ethicist Mark Siegler attempts to open the eyes of physicians and patients to the fact that patient confidentiality, as it has been taught since the times of Hippocrates, is dead.

He relays the case of a patient who, having been admitted to the hospital for a simple cholecystectomy, had between 15 and 100 hospital staff and students peering regularly, and with professional justification, at his medical record. This was 30 years ago; anyone recently in an American academic teaching hospital would say these numbers are far higher today due to any number of factors, including the move towards sub-specialization in medicine, ever-expanding support services (e.g., diabetes education program, tobacco cessation service, etc.), and resident work-hour restrictions (requiring more handoffs between clinicians).

Despite the need for this access—for clinical care, hospital administration, and teaching—Siegler’s patient in the anecdote believes, in his gallbladderless gut, that his confidentiality has been breached. This breach is not in the traditional sense of a physician revealing information told in confidence to someone other than the patient outside of that pact, but a sense that, justified as it may be, a hospital chart read by 100 different people is by definition *not* confidential.

Siegler notes the conflict this creates between a patient’s desire for confidentiality and his or her desire for the best care, which is often provided in highly staffed teaching hospitals and in an economically complex manner that requires the participation of additional nonmedical hospital staff (e.g., compliance officers and chart auditors). This desired advancement in patients’ care, Siegler notes, comes at the expense of their eroding privacy—or at least requires a fundamental reworking of our understanding of it.

Siegler advocates a “need-to-know” approach in which only hospital staff who specifically need access would have it (despite previously noting that all 100 staff who viewed his patient’s chart were “justified” in doing so). He proposes divisions of the medical record—e.g., medical, financial—for which access would be specifically granted or denied based on the need to know, but rejects the idea of wholly *separate* records for treatments like psychiatric care; this, he believes, would

lead to clinically inferior care and is not logistically possible for many specialties. He favors more explicit explanation to patients of what “confidentiality” actually means in a teaching hospital. And finally, he proposes patient access and veto power, so that patients could designate certain portions of the record to be viewed only by their “principal physician” or a specific list of other clinicians.

Discussion

Siegler’s essay, now celebrating its thirtieth anniversary, contains both insights and inaccuracies, some due to its age and some independent of time.

It is entirely correct that the traditional *essence* or *notion* of patient confidentiality meant that personal information would only be shared with one’s own physician and a short list of necessary collaborators, but it does not follow that the present-day idea of confidentiality encompassing a larger circle of participants is invalid. While this larger circle may challenge the “letter” of respect for the patient’s sense of individuality and privacy, it is entirely consistent with the “spirit” of patient confidentiality. Certainly, clinicians not specifically involved in the care of a particular patient should not have access to his or her record. People either “need to know” because they have been brought into the patient’s care, or they do not need to know and should not have access.

Medical students pose a particular concern. Assuming for a moment that students are definitively *not* contributing to the health care team (and are merely learning from the experience), then surely they must never qualify as “need-to-know.” Similar arguments could be made about interns, then residents, and then perhaps even fellows, all of who have access to the record in part for training and do not have the experience of senior physicians. We generally allow them access, however, on utilitarian and perhaps justice-oriented grounds: all patients benefit from previous generations having allowed trainees to learn from them, and in turn today’s patients must repay that debt, doing what is best for society overall, as long as harm to them is minimized by proper supervision.

Partitioning the Record

Regarding Siegler’s proposal to divide, but not separate, the medical record, it is difficult to see a practical difference. A medical record can be divided into an unlimited number of discrete sections according to unlimited criteria; continually deciding which members of the hospital staff should have access to each section would not be reasonably possible. It would also be likely to work against the interests of the patient by preventing clinicians from fully understanding his or her condition. Siegler recognizes this problem in the context of separate psychiatric records (“it is often vitally important for internists or surgeons to know that a patient is being seen by a psychiatrist or taking a particular medication” [2]) but seems not to acknowledge that the same will occur if we call these “divisions” within a single record rather than “separate” records.

Electronic health records complicate the debate, both by offering intriguing options for more easily subdividing the medical record (which may seem to help Siegler's argument) and by generating far more data and methods of sorting it, expanding the number of possible "sections" exponentially. Likewise, it makes peering into the chart far easier because the viewer does not have to be physically on the ward with the paper chart, but also makes tracking who does the viewing far easier. Whether electronic health records push us towards or away from confidentiality is yet to be determined.

Finally, the idea that patients should bear the burden of deciding which pieces of their medical information should be viewed by whom seems both cruel and impossible. The idea of picking a single "principal physician" to have sole access to the complete medical record is incompatible with the way medicine is practiced today, and may very well have been so in 1982. Is this principal physician the attending of record (who often rotates every week or two at teaching hospitals), the primary care doctor (who less and less frequently participates in inpatient hospital care), or the intern (who spends the most time with the patient but is less experienced and now is required to go off duty every 16 hours)?

Patient Access to the Record

It is presently entirely accepted that patients may have access to their medical records in some form [3]. The specifics of that right are more complicated [4]. While there is a fundamental right for patients to know their diagnoses and prognoses and what interventions they undergo, clinicians also have a right—and a clinical necessity—to think more freely about diagnoses than would be responsible to reveal routinely with patients. When, for example, a patient has, among other symptoms, fevers and malaise, malignancy must always be considered in addition to more common, less grave diagnoses. What purpose would it serve for clinicians to routinely tell patients they are considering malignancy when they are merely being thorough by ruling out an extremely unlikely possibility?

Furthermore, clinicians in general and physicians in particular have a language of their own that is difficult if not impossible for even highly educated nonphysicians to decipher; errors in interpretation, some dangerous, can occur without guidance [5]. It follows that providing patients a verbatim copy of their medical records would be a violation of both nonmaleficence and the right of clinicians to have a private place for their thoughts. A solution in many locations has been a distilled version of the medical record given to patients on demand that aims not to hide information but instead to present it in a useful and, from a practical standpoint, equally complete form for the patient [6].

Conclusion

Modern medicine has in some ways, as Siegler argues, abandoned the kind of confidentiality based on privacy. It has also greatly advanced the equally important principle of beneficence. Certainly we should aim to keep those who do not need to know out of the chart and place safeguards to avoid related abuses, but a further

sectioning of the medical record seems an unlikely if not impossible solution. More effective will be communicating with patients about their expectations for different forms of confidentiality and privacy in different health care settings to facilitate informed decisions. Surely, patients are well situated to decide between coming to an academic center and a private community hospital but not, especially, to decide which consultants should know that they carry a psychiatric diagnosis for which they are prescribed medication.

References

1. Siegler M. Confidentiality in medicine – a decrepit concept. *N Engl J Med.* 1982;307(24):1518-1521.
2. Siegler, 1520.
3. Huba N, Zhang Y. Designing patient-centered personal health records (PHRs): health care professionals' perspective on patient-generated data. *J Med Syst.* 2012 May 30 [epub ahead of print].
4. Wibe T, Helleso R, Slaughter L, Ekstedt M. Lay people's experiences with reading their medical record. *Soc Sci Med.* 2011;72(9):1570-1573.
5. Castro CM, et al. Babel babble: physicians' use of unclarified medical jargon with patients. *Am J Health Behav.* 2007;31 Suppl 1:S85-S95.
6. Liaw T, Lawrence M, Rendell J. The effect of a computer-generated patient-held medical record summary and/or a written personal health record on patients' attitudes, knowledge and behaviour concerning health promotion. *Fam Pract.* 1996;13(3):289-293.

George L. Anesi, MD, MA, is a resident in internal medicine at Massachusetts General Hospital (MGH) and a clinical fellow in medicine at Harvard Medical School in Boston. He is a member of the MGH Optimum Care Committee and Department of Medicine Quality and Safety Committee. He received his MD and MA in bioethics from Case Western Reserve University School of Medicine and his BS in biological chemistry and BA in chemistry from the University of Chicago, where he was editor in chief of the *Chicago Maroon*. His research interests lie at the intersection of medicine, policy, and ethics, and he intends to apply for fellowships in pulmonary and critical care medicine.

Related in VM

[Would Patient Ownership of Health Data Improve Confidentiality?](#) September 2012

[Electronic Health Records: Privacy, Confidentiality, and Security](#), September 2012

[Special Protections for Mental Health Treatment Notes](#), June 2012

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2012 American Medical Association. All rights reserved.