

Theme: DOCUMENTS IN HEALTH CARE

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The Five-Volume Patient

“The core transaction in a healthcare system is still between the doctor and the patient”¹ and the content of every medical record, no matter what the medium, emanates from that core transaction.

Patient access to their own health information is now considered by many medical informatics researchers to be a key element of medical record systems of the future. Electronic medical records are expected to make that access easier; in fact, 44% of patients in the large study by Fowles et al.² expressed a *preference* for electronic access over paper. However, the goal of patient access to medical records cannot be fully realized given a reality of medical record documentation: the very content of the record is known to undergo a change during writing when a patient is expected to read that record in the future. The patient reader interferes with the patient’s story written by the doctor.

The participation, or nonparticipation, of the patient in the medical record process has been viewed through Foucault’s lens of power relations:

Health care professionals have usurped the power to represent patients in the system ... and the health record is the primary and most powerful means of accomplishing this .. Although the (subjective) voice of the patient is heard, regarding each problem articulated by the nurse, the patient is not a full-fledged member of the fellowship of discourse, is not a reader of the chart and has no responsibility for exchange of the written text.³

The late and eminent social historian of medicine Roy Porter considered that patients had so long been disempowered as to be rendered unavailable for study: for historians, "Rather, 'patients' are the constructs of medicine ... they can be studied only as they have been rendered visible by the "medical gaze." ⁴ Medical records constitute the artifact of that medical gaze. Barrett, a historian of 19th-century British colonial psychiatry, states that without the record, the patient "Paul" does not even exist:

[The patient] Paul, the intentional, unified subject ... could not be described without the format of the case record ... The documentary Paul was not a person doing things to other people but a summation of resultants—a passive conglomerate which lacked agency.

In fact, the record and the patient are synonymous:

Those patients with the most volumes [of case records] were approached with dismay by the staff, for the sheer weight of writing became an indication of immense chronicity or unresolvable problems. For staff, the very identity of such patients was primarily located in their case records...some patients were described in terms of the quantity and weight of their records, for example, as a "five volume case" or a "fork-lift job" (That is, it would take a fork-lift truck to transport the records.) ⁵

A real telling of the Patient's Story means taking the patient out of this passive role-- a non-person, represented by a collection of clinical documents--and empowering her as the author, even the editor, of the medical record which those documents comprise. In fact, the patient author is a key element of the U.S. federal government initiative, the National Health Information

Infrastructure, in which a "personal health record" created and maintained by the patient becomes part of that person's health information. This development brings new attention to the document model for medical records systems, the least dominant model in U.S. healthcare today.

Decades of research has focused on encounters between patient and medical record that take place in document space and document time. This paper reviews the two main streams of clinical research that have investigated these encounters: Patient Access to Records, and the Patient-Held Record. The dominant themes in these researches will be summarized. Finally, I will discuss the implications of these findings for future work with document-based medical record systems that involve patients in the process.

References

¹ Paul Takeri, MD, quoted in Morrissey J. (2001). Vendors say they're ready to deliver. *Modern Healthcare* 2001; 31(46): 28-30.

² Fowles JB, Kind AC, Craft C, Kind EA, Mandel JL, Adlis S. Patients' interest in reading their medical record: relation with clinical and sociodemographic characteristics and patients' approach to health care. *Arch Intern Med.* 2004 Apr 12;164(7):793-800.

³Hays JC. Voices in the record. *Image: The Journal of Nursing Scholarship* 1989; 21(4), 201-202.

⁴ Porter R. (Ed.) *Patients and practitioners: Lay perceptions of medicine in preindustrial society*. (1985) Cambridge, England: Cambridge University Press.

⁵ Barrett, RJ Clinical writing and the documentary construction of schizophrenia. *Culture, Medicine & Psychiatry* 1988; 12(3), 292-293.