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Patient Preferences and Perspectives on Accessing Their Medical Records

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ABSTRACT

Background: Personal health record platforms and patient portals have the potential to empower patients by providing access to health records, but not all patients may be interested in this. The purpose of this study was to explore inpatients' opinions on their hospital paper medical records after they had incidental access to them.

Methods: A survey and observational study were conducted in the computed tomography department at a large academic hospital. Patients in the computed tomography hallway were left with their paper records and either started reading them or not.

Results: Of 174 patients receiving the survey, 102 returned the questionnaire (59% response rate); two were excluded. Among the 100 included patients, 65 read their records, and 35 did not; 37.1% (13/35) nonreaders indicated interest to access their records but did not know they had the legal right. The physician's notes was the section that most patients read (n = 35, 53.8%) followed by the laboratory reports (n = 31, 47.7%) and nurse's notes (n = 29, 44.6%). Overall, 70.8% (46/65) of readers found their records easy to understand, and most found their records correct (64.4%) or complete (58.5%) and did not find anything unexpected (63.1%) or distressing (66.2%). However, a significant minority found errors in their records (7.7%) including missing test results, medications, and a wrong birthday. According to multivariate analysis, being female (odds ratio [OR] = 2.8; 95% confidence interval [CI], 1.0–8.0), younger than 60 years (OR = 3.0; 95% CI, 1.2–8.0), and having a higher level of education (OR = 3.9; 95% CI, 1.4–10.8) predicted readership.

Conclusion: A surprisingly high number of patients are still unaware of their legal right to access their health record. Predictors for access suggest a "social divide" in motivation and ability to access health records.

RESUMÈ

Contexte : Les plateformes de dossiers de santé personnels et de portail des patients ont le potentiel de responsabiliser les patients en leur donnant accès à leur dossier médical, mais ce ne sont pas tous les patients qui y sont intéressés.

Objectifs : Explorer l'opinion que les patients hospitalisés ont de leur dossier médical sur papier après que ces derniers y aient eu accès de façon accessoire.

Méthodologie : Une étude par sondage et observation a été menée au sein du service de tomodensitométrie (TDM) d'un grand hôpital universitaire. Dans l'antichambre de la salle de TDM, les patients ont été laissés avec leur dossier papier; certains ont commencé à le lire, d'autres non.

Résultats : Cent-deux des 174 patients qui ont reçu le questionnaire y ont répondu (taux de réponse de 59 %), dont deux ont été exclus. Parmi les 100 répondants retenus, 65 avaient lu leur dossier et 35 ne l'ont pas fait. Parmi ceux qui ne l'ont pas lu, 37,1 % (13 sur 35) ont dit être intéressés à le consulter mais ne pas savoir qu'ils en avaient légalement le droit. La section des remarques du médecin est celle que le plus grand nombre de patients ont lue (n=35, 53,8 %) suivie par la section sur les rapports de laboratoire (n=31, 47,7 %) et les remarques des infirmières (n=29, 44,6 %). Globalement, 70,8 % (46 sur 65) des lecteurs ont jugé leur dossier facile à comprendre, et la plupart l'ont trouvé correct (64,4 %), complet (58,5 %) et ont dit n'y avoir rien trouvé d'imprévu (63,1 %) ou d'inquiétant (66,2 %). Cependant, une minorité importante (7,7 %0 y a constaté des erreurs, notamment l'absence de résultats d'examens manquants ou de médicaments et une date de naissance erronée. L'analyse multivariable indique que le fait d'être une femme (OR 2,8, CI 1,0-8,0), d'avoir moins de 60 ans (OR 3,0, CI 1,2-8,0) et d'avoir fait des études supérieures (OR 3,9, CI 1,4-10,8) favorisent la lecture.

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Conclusion : Un nombre étonnamment élevé de patients ne sait toujours par que les patients ont le droit de prendre connaissance de leur dossier médical. Les prédicteurs d'accès laissent voir un « fossé social » dans la motivation et la capacité d'accéder au dossier médical.

Keywords: Patient access; medical records; patient-accessible electronic medical records; EHRs

Introduction

The role of the patient has changed over recent years from that of a passive recipient of care to an active member of the decision-making team [1]. Today's patients are becoming more educated and often demand to be involved in the decision-making process regarding their health. This change has resulted from several factors that have taken place throughout our society in recent history.

First, patients have become health care consumers; consumerism has encouraged individuals to take control over their choices [2, 3]. Consumerism is also reflected in explicit legislation, which entitles patients to exercise control over the accessibility and content of their health information [4–7]. Second, with the aging population, chronic conditions account for more than two thirds of the global disease burden. Therefore, the onus of day-to-day monitoring and care of conditions such as diabetes or cardiovascular disease is moving from institutions to the patients [8, 9]. Health care policies in industrialized countries stress the importance of primary prevention to reduce risk factors such as obesity, hypertension, or lack of physical activity, which are common underlying risk factors for major chronic diseases [10, 11]. Third, information and communication technologies [7, 9,12–14] enable an unprecedented level of access to information, and patients no longer need to rely on their physicians as being the sole provider of health information [2, 9]. Access to relevant medical information and personal health information is a central prerequisite for the role of the patient as an active decision maker and participant in his or her health.

Major changes in legislations such as the European Union's Data Protection Directive, the Health Insurance Portability and Accountability Act in the United States, and the Personal Information Protection and Electronic Documentation Act in Canada entitle patients to exercise control over the accessibility and content of their health information [4, 5, 7]. The laws allow patients to not only view their medical records but also make changes to them and control which persons can or cannot access them. Along with the expansion of information technology and changes in legislation, various forms of medical records have been developed, some specifically for patient access and use.

Emerging approaches such as patient portals, patient-accessible electronic health records (PAEHRs) [15–22], personal health records [1, 9, 13, 23], and personally controlled health records [12,24–26] (terms that are almost used interchangeably) have the potential to incent empowerment and improve resource utilization, efficiency, and patient satisfaction [9, 18,20–22].

However, patients face many obstacles to inspecting their hospital medical records. At most institutions, hospital information systems (HISs) and other electronic records are used by clinicians for patient clinical documentation and communication. In the absence of patient-accessible electronic formats, patients are unable to view these records. In addition, despite the fact that records are still being printed, copied, and retained in binders, the paper charts create logistical challenges because they, too, are only for clinician use, and are not readily available to patients. Furthermore, differing policies between departments and institutions create confusion about which content patients can view and whether or not clinicians need to be present at the time of access [1].

It is unlikely that all consumers benefit equally or have equal interest in accessing medical records; this is dependent on other factors, such as patients' understanding of their medical condition and taking an active role in their care [5]. In a diverse patient population, it is important to understand whether ethnicity, education, socioeconomic status, or medical conditions influence patients' interest in accessing and using their medical records, and whether patient preferences should be taken into account from the start of development [8,15–21, 27]. Previously published studies have either surveyed patients on their perspectives regarding access to medical records without patients actually seeing what a "medical record" constitutes, [15–21, 27] or were conducted in a personal health record or patient portal setting, which confounds the question of access to records with variables associated with the digital divide (computer literacy, age, and education) and is further confounded by variables associated with individual implementations [15–21,27–29].

In this study, we eliminated some of these confounding factors associated with the digital divide by asking patients about their paper charts, which they spontaneously accessed. This was prompted by the observation that in the medical imaging department at a hospital, patients were often left with their charts while waiting to return to their hospital rooms. In many instances, patients took this opportunity to read through their records. This created a naturalistic experiment to capture inpatients' opinions on where they chose to review their records on their own.

The specific objectives of this study are as follows:

- To gain a better understanding of patients' opinions on their paper records after they read or skimmed them
- To discover whether a difference exists between readers' and nonreaders' perceptions on whether accessing their medical records was useful in aspects of care (such as identifying errors, improving their relationship, and trust