

Patient access to medical records and healthcare outcomes: a systematic review

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ABSTRACT

Objectives We conducted a systematic review to determine the effect of providing patients access to their medical records (electronic or paper-based) on healthcare quality, as defined by measures of safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity.

Methods Articles indexed in PubMed from January 1970 to January 2012 were reviewed. Twenty-seven English-language controlled studies were included. Outcomes were categorized as measures of effectiveness (n=19), patient-centeredness (n=16), and efficiency (n=2); no study addressed safety, timeliness, or equity.

Results Outcomes were equivocal with respect to several aspects of effectiveness and patient-centeredness. Efficiency outcomes in terms of frequency of in-person and telephone encounters were mixed. Access to health records appeared to enhance patients' perceptions of control and reduced or had no effect on patient anxiety.

Conclusion Although few positive findings generally favored patient access, the literature is unclear on whether providing patients access to their medical records improves quality.

BACKGROUND

Engaging patients as partners in their own care has garnered growing interest as a method for improving the quality of healthcare delivery.^{1–7} It is now widely acknowledged that a more patient-centered, collaborative approach is needed to foster patient engagement.⁸ To date, research has shown a trend towards improved patient satisfaction, health behaviors, and health status in response to patient-centered practices.^{9–10} One such practice is increasing patients' access to timely and accurate information. The Institute of Medicine (IOM)¹¹ advocates for unrestricted patient access to medical records. Furthermore, patients have a legal right to access their medical records,¹² and multiple studies have documented their general interest in doing so.^{13–19}

Providing patients access to their medical records may facilitate a more collaborative relationship between provider and patient.²⁰ Existing literature suggests that patient-accessible records can improve patient-provider communication,^{21–25} self-management,^{24–26} and patient satisfaction.^{20–27–28} A 2003 narrative review on the effects of patient access to medical records found that access improves communication between provider and patient, patient adherence, patients' knowledge about their own health, and is unlikely to cause patient harm.²¹ Despite these reassuring data, many providers are still wary of patient access to their records, fearing it may cause patient anxiety or increase provider workload.^{14–21–29–31}

The IOM has recommended six major aims for improving the quality of healthcare delivery: safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity.¹¹ Using the six IOM aims as a framework for assessing potential benefits and patient outcomes, we conducted a systematic review to determine the effects of interventions that provide patients access to their medical records. Our overall aim was to provide a timely synthesis of the growing body of literature on patient access to medical records in order to inform future policies and practices in this area.

MATERIALS AND METHODS

Data sources and searches

English-language articles indexed in PubMed with publication dates between January 1970 and January 2013 were included. Potentially relevant studies were identified using a combination of medical subject headings and free text phrases (see figure 1). Furthermore, we reviewed the bibliographies of each article to identify additional potentially relevant articles.

Study selection

Two investigators divided the task of screening the titles and abstracts of all articles retrieved through the medical subject headings and key phrase search. We included quantitative studies that assessed the effect of patient-accessible records (electronic or paper-based) on quality-related outcomes in adult populations. We defined medical records as any patient-specific information held by the physician and/or healthcare system (see figure 2). After the initial screening process, each investigator randomly selected and reviewed 10% of the other's articles in order to ensure consistency in the selection process. All discrepancies were resolved through consensus.

Data extraction and quality rating

One investigator extracted data from each article meeting the screening criteria and a second investigator extracted data for 10% of the articles in order to ensure reliability. Both reviewers scored each randomized controlled trial (RCT) using the quality of study rating form (QSRF).^{32–33} The reviewer κ for the QSRF was 0.534 (95% CI 0.411 to 0.674). In the case of disagreement, the reviewers analyzed the paper together to reach consensus.

RESULTS

The PubMed search resulted in 1247 citations, and the bibliography review yielded 18 additional



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MeSH headings: "patient access to records," "access to information," "patient participation," "medical records," and "health records, personal"
Free text phrases "patient accessible," "patient access to medical record," and "patient portal"

Figure 1 Study search terms.

articles. The majority of citations were excluded based on abstract and title review (figure 3). Twenty studies were RCT and seven were uncontrolled observational studies (see supplementary appendix tables 1 and 2 for study details, available online only). Almost half of the studies focused on patient populations with chronic diseases including diabetes, cancer, heart failure, and hypertension.

Scoring

Twenty RCT were evaluated using the QSRF tool. The average score was 71 points (range 67–86).

Studies of effectiveness

Physical health outcomes

Seven studies included variables measuring biological outcomes such as laboratory values, body mass index, and blood pressure. Of these, four studies included diabetes-specific quality measures.^{34–37} Although glycated hemoglobin A_{1C} improved overall in three RCT, the difference between the intervention and control groups was significant only in one trial.^{34–36} An observational study suggested an association between personal health record (PHR) use and improved laboratory values (glycated hemoglobin A_{1C} and low-density lipoprotein cholesterol), blood pressure, and health maintenance screening in patients with diabetes;³⁷ however, blood pressure and low-density lipoprotein cholesterol were not significantly different between intervention and control conditions in one of the aforementioned RCT.³⁴ Two additional prospective studies examined the effect of PHR access on blood pressure control in patients with chronic disease and found no impact.^{38–39}

Psychosocial health outcomes

Five studies addressed psychosocial variables including depression, anxiety, contentment, and quality of life. All five studies included an anxiety variable.^{40–44} Three studies found no significant differences in anxiety between groups,^{40–41–43} while two studies found that anxiety decreased with access to medical information.^{42–44} Two studies evaluated self-reported depression and contentment in patients and found no significant differences between the

Inclusion: Study reported comparative data between an intervention and comparison condition, including uncontrolled observational studies and randomized controlled trials (RCTs).
Exclusion: <ol style="list-style-type: none"> 1. studies without a comparison group, 2. studies of parental access to pediatric patient records, 3. studies focused exclusively on access to psychiatric records (due to distinct legal and ethical issues, and 4. papers which did not meet the following criteria on the basis of the title and abstract: <ol style="list-style-type: none"> a. human study population; b. adults age 18 and over; and c. published in a peer-reviewed journal, book, or monograph.

Figure 2 Study eligibility.

intervention and control groups.^{40–43} Only one study measured quality of life and found that providing a paper copy of the medical record resulted in no significant improvement.⁴¹

Health behaviors and adherence outcomes

Four studies included measures of patient health behaviors, and outcomes were mixed.^{38–45–47} Two studies found no significant impact on adherence.^{45–47} A third study found that patients who received only a computer-generated health summary were more likely to attend their next routine appointment than those in the other groups receiving only a written PHR with health promotion advice, both the computer-generated health summary and the written PHR, or neither.³⁸ That study also measured other health behavior; recipients of the written PHR were significantly more likely to report drinking less alcohol, whereas those who received only the summary were significantly more likely to say that they did not feel the need to change their alcohol use. In a follow-up RCT, the use of medications, tobacco, and alcohol, and awareness of health maintenance did not appear to be influenced by access to a computer-generated health summary.⁴⁶

Recall of medical information

Two studies addressed patient recall of medical information as an outcome of patient access to medical records, and the results were mixed.^{43–48}

Usage of PHR

Three RCT compared usage of informational resources when given computer access to either personalized medical information or general health information, and found that access to personalized information increased the likelihood of usage.^{49–51}

Accuracy of the medical record

One uncontrolled observational study evaluated the influence of a secure web-based patient portal on the accuracy of medication lists in the electronic health record, and found no significant differences.⁵²

Perceived usefulness of access to medical records

One trial randomly assigned pregnant patients to use an internet-based pregnancy resource either with or without additional access to personal antenatal health records.⁵¹ Although both groups found the information easy to access and useful, there was no significant difference in perceived usefulness.

Studies of patient-centeredness

Patient satisfaction

Eleven studies included primary outcomes related to satisfaction with various aspects of the patient experience, including care provided,^{36–40–42–47–53–54} provider–patient communication,¹⁸ information provided,^{49–51} consultation,⁵⁵ and perceived quality of care.³⁹ In eight studies, no significant differences were found when patients were given access to their medical information via the internet, on a USB stick, or in paper form as compared to no access or access to general information only.^{18–39–42–51–53–54} Only three found a moderate improvement in patient satisfaction when given access to physician notes,^{47–55} a copy of the letter sent from their specialist to their general practitioner, or a computerized medical record summary.⁴⁹

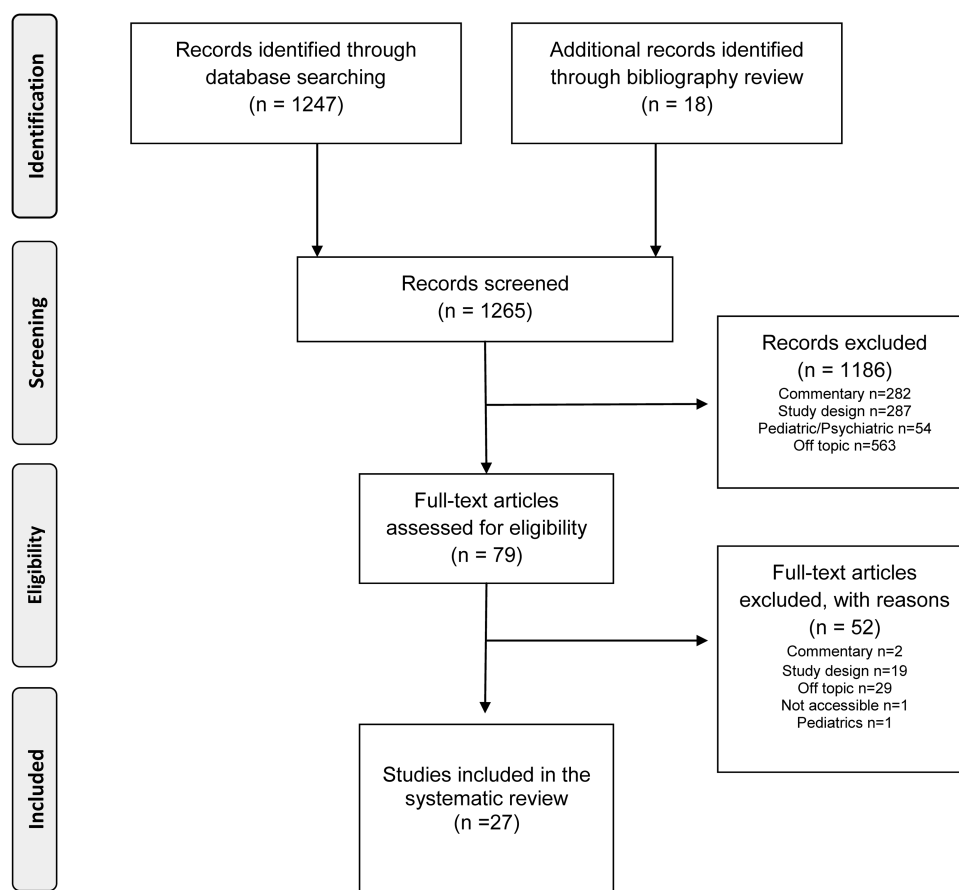


Figure 3 Flow diagrams of study report selection.

'Informed' patient

Three studies measured pregnant women's perceptions of being informed when provided with access to their medical records,^{40 54 56} of which two found a significant effect.^{54 56}

Patient involvement in care

Seven studies measured various aspects of patients' involvement in their care. In two, there was no significant difference in self-efficacy between the intervention and control groups^{18 44} whereas in a third study, patients with type 1 diabetes reported greater diabetes-related self-efficacy when provided access to the entire health record compared to a web-based diabetes case management program only.³⁵ Studies of pregnant women found that patients who carried their full antenatal records endorsed greater perceptions of control of their pregnancies^{40 56} and greater ease in talking to doctors and midwives than control group participants.⁴⁰ An RCT to study the effect of PHR access on patients undergoing in-vitro fertilization found no effect on measures of patient empowerment.⁵⁷ Another RCT evaluating the effect of PHR access found a statistically significant, although clinically negligible, difference in empowerment scores among patients with hypertension in the intervention group.³⁹

Studies of efficiency

Two observational studies included measures of efficiency, telephone and office visit rates, among PHR users and non-users. One measured the frequency of primary care office visits and documented telephone contacts after PHR adoption.⁵⁸ While both groups experienced a decrease in annual primary care office visit rates, the effect was significantly greater in the PHR

user group. Telephone call rates significantly increased in both groups, but more so among non-users. The second study found that PHR users increased office visits and telephone contacts in the year following activation compared to the year before activation, while non-users showed decreased office and telephone encounters during a similar 2-year period.⁵⁹ PHR users as a group had significantly more after-hours clinic visits, emergency department visits, and hospital visits.

DISCUSSION

Our systematic review found that studies of interventions that provided patients access to their medical records have addressed three of six IOM quality domains: effectiveness, patient-centeredness, and efficiency. The effects of patients' access to medical records on measures of safety, timeliness, and equity remain understudied.

Despite concerns that might have been raised about patient access to medical records such as the potential for patient anxiety and confusion, our review found no current evidence to substantiate any negative patient outcomes resulting from access to health information. Notably, access to medical information did not increase patient anxiety,^{42 44} a common fear endorsed by physicians.^{44 60 61} Conversely, the effects of PHR access on workload and system efficiency merit further evaluation. For instance, a better understanding of how PHR and related technologies increase or decrease system burden can help with resource allocation decisions related to managing patients who use these tools.

Future research in this area should focus on interventions that target and measure actual health record usage and engagement

in care. For example, some of the studies measured outcomes among patients who were already PHR users, primarily white, and with higher incomes and private insurance compared to PHR non-users.³⁷ PHR use may thus be a marker for characteristics related to better health outcomes, and providing access alone is unlikely to be sufficient to improve outcomes for all types of patients. For PHRs to be widely used for routine patient communication, or as 'backup systems' to mitigate care delays,⁶² issues of equity in PHR adoption and use need to be addressed.⁶³ Conversely, certain design features of the PHR may be able to influence patient engagement. For instance, we found that patients given access to personalized information accessed electronic resources more frequently than those given only general educational information.^{49–51} Whether carefully targeted PHR design can enhance equity and engagement among groups at higher risk of negative health outcomes remains to be seen.

Our review covered a relatively small group of studies in an emerging area of enquiry, and as such we erred in the direction of including smaller and less methodologically rigorous studies. The heterogeneity of study populations, intervention content, and measurement strategies varied, making it difficult to synthesize the evidence. The possibility of selective reporting and publication bias cannot be excluded. Fairly restrictive search criteria were used to address primary study aims, and thus we may have excluded papers not classified under our search terms. We attempted to minimize this problem by reviewing bibliographies to locate additional articles not identified through database search.

In conclusion, our systematic review examined the effects of patients' medical record access and revealed few overarching trends. There was minimal evidence of psychological harm to patients. Limited evidence suggests that patients with access to medical records have improved levels of satisfaction, but evidence was less clear for other aspects of quality, and was absent for effects on patient safety, timeliness, and equity. Although few positive findings generally favored patient access, in light of mounting pressures to make medical records transparent to patients,⁶⁴ more rigorous research is needed to evaluate this practice.

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