

Review Paper ■

The Effects of Promoting Patient Access to Medical Records: A Review

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Abstract The Health Insurance Privacy and Portability Act (HIPPA) stipulates that patients must be permitted to review and amend their medical records. As information technology makes medical records more accessible to patients, it may become more commonplace for patients to review their records routinely.

This article analyzes the potential benefits and drawbacks of facilitating patient access to the medical record by reviewing previously published research. Previous research includes analysis of clinical notes, surveys of patients and practitioners, and studies of patient-accessible medical records.

Overall, studies suggest the potential for modest benefits (for instance, in enhancing doctor-patient communication). Risks (for instance, increasing patient worry or confusion) appear to be minimal in medical patients. The studies, however, were of limited quality and low statistical power to detect the variety of outcomes that may result from implementation of a patient-accessible medical record. The data from these studies lay the foundation for future research.

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The objective of this review is to summarize the results from both interventional and noninterventional studies of the impact of providing adult patients access to the information in their medical records. Interventional studies included descriptive studies and controlled trials. Noninterventional studies analyzed the content of medical records and evaluated patient and physician attitudes toward the practice of sharing medical records.

Background

Legal and technologic trends are making medical records progressively more patient-accessible. There

was once only a single copy of the medical record, and a patient had to obtain a subpoena to look at it.^{1,2} The Federal Health Insurance Portability and Accountability Act of 1996 (HIPAA) stipulates that “patients must be able to see and get copies of their records, and request amendments.”³ Similar legal efforts are under way in Canada,⁴ the United Kingdom,⁵ Ireland,⁶ South Africa,⁷ and Australia.⁸ In the near future, information technology may make it even easier to provide patients a chance to review their records. Studies of technology that allows patients to access their records over the Internet have already been conducted (Middleton B, Brackett L. Initial consumer impressions using online health records. Presented at Towards An Electronic Paper Record (TEPR) 2000, 11 May 2000, San Francisco).^{9,10}

A patient-accessible medical record can potentially improve medical care in a variety of areas, particularly by enhancing doctor-patient communication.^{8,11–13} The Institute of Medicine report “Crossing the Quality Chasm” suggested that enhancing the flow of information among patients and medical providers would help reduce errors and improve quality.¹⁴ On the other hand, medical practitioners have had concerns about routinely giving patients access to written documents that are not intended for

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Table 1 ■

Outcomes from Studies of Patients Who Received Their Records: Summary of Evidence

Outcome	Controlled Trial: Statistically Significant Differences Between Groups	Controlled Trial: Nonsignificant Differences Between Groups	Descriptive Information: Quantitative	Descriptive Information: Anecdotal
Patient interest and acceptance			15 studies ^{9,28-30,32,44,46,50-54,57-59}	
Causing confusion and misunderstandings		1 study ⁵⁴	8 studies ^{30,33,46,47,50-52,61}	2 studies ^{28,53}
Educating patients	2 studies ^{43,44}	3 studies ^{51,54,58}	7 studies ^{34,46,52,57,61}	
Creating anxiety		3 studies ^{51,54,56}	5 studies ^{30,46,52,57,61}	2 studies ^{9,29}
Providing reassurance		1 study ⁵¹	3 studies ^{30,41,46}	1 study ⁵⁰
Empowering patients	2 studies ^{54,56}	1 study ⁵³	3 studies ^{41,52,57}	2 studies ^{28,60}
Promoting adherence	1 study ⁴³	5 studies ^{44,49,53,54,58}	1 study ⁴¹	
Concerns about sensitive items			1 study ³²	3 studies ^{29,33,52}
Concerns about confidentiality			3 studies ^{9,33,57}	1 study ⁶⁰
Improving doctor-patient communication	3 studies ^{53,54,56}		1 study ⁴⁶	3 studies ^{51,48,60}
Improving patient satisfaction		6 studies ^{49,51,53,54,56,58}	1 study ⁴⁶	4 studies ^{28,29,50,59}
Facilitating correction of errors			7 studies ^{32,42,46,48-50,57}	4 studies ^{9,27,51,60}
Effects on documentation	1 study ⁵⁹	1 study ⁵⁸	1 study ⁵⁷	1 study ⁴⁵
Demands on staff time		1 study ⁵⁴	1 study ⁵⁵	5 studies ^{31,46,50,51,60}

a lay audience and that may contain relevant information that is nonetheless inappropriate to divulge to the patient. Ethical arguments have been made both for patient access to the record (e.g., respect for autonomy, the right to informed consent) and against unfettered access (e.g., the right not to be informed of medical information that would undermine self-esteem, employability, or insurability).¹⁵

In response to these issues, researchers have analyzed the content of medical and psychiatric case notes, and their analyses have questioned whether it is truly appropriate for patients to review their medical records routinely.¹⁶⁻¹⁹ The first part of this review summarizes these studies. Researchers have also evaluated the actual practice of patients reading their records, both through spontaneous patient requests and through clinical trials (Table 1). The questions addressed by these studies can be summarized in three categories:

1. **Effects on the patient.** How much interest do patients have in reading and contributing to the medical record? Does the patient-accessible medical record cause confusion? Is it educational, improving recall or understanding of the patient's medical conditions? Does it promote or relieve anxiety? Does it improve a patient's sense of empowerment (autonomy or self-efficacy)? Does it promote adherence? Are patients con-

cerned when sensitive items are included? Are patients concerned about confidentiality?

2. **Effects on the doctor-patient relationship.** Does the patient-accessible medical record improve doctor-patient communication? Does it improve patient satisfaction?
3. **Effects on medical practice.** Does the patient-accessible medical record improve quality by allowing patients to correct inaccuracies? Does it affect documentation? Does it create excessive demands on staff time?

Methods

Articles were identified using MEDLINE and HealthSTAR. The search was limited to English-language articles published from 1970 to June 2002. The major subject terms *medical records*, *patient participation*, and *patient advocacy* as well as the key word combination ("patient" and "access") were used. The bibliographies of the identified publications were also checked for potentially eligible studies. The search strategy was reviewed with an informatics librarian to maximize search sensitivity. Titles and abstracts were assessed for relevance. To focus on the impact of a patient reading his or her own records, studies that gave parents access to pediatric records were excluded from this review.

Relevant studies that were not clinical trials included analyses of clinical notes,¹⁶⁻¹⁹ questionnaires of physicians and patients,²⁰⁻²³ qualitative studies,²⁴⁻²⁶ and a case report.²⁷ There were three studies of patients who spontaneously requested to read their charts.²⁸⁻³⁰

Clinical trials were considered relevant if they allowed adult patients to review their own medical notes. Studies that provided only a truncated version of the medical record were also considered relevant if they included a doctor-generated list of medical problems at a minimum.³¹⁻³⁴ Studies that did not include full or abridged medical notes were not counted as clinical trials, although they provided background information about patients' reactions to the concept of a patient-accessible medical record.^{10,35-39} Studies that gave patients only computerized reminders for health care maintenance were not included and have been reviewed elsewhere.⁴⁰

Clinical trials of patient-accessible medical records were performed with medical outpatients,^{9,31-34,41-49} medical inpatients,^{50,51} obstetric outpatients,⁵²⁻⁵⁶ psychiatric inpatients,⁵⁷⁻⁵⁹ and psychiatric outpatients.^{60,61} These trials used heterogeneous methods of providing medical records and assessing outcomes. Clinical trials were grouped into two major categories based on study design: *controlled trials* if they contained a control group, and *descriptive studies* if they did not. Controlled trials assigned patients in either a randomized or a nonrandomized pattern. Details about the methods used in each clinical trial are available in the data supplement.

Many studies excluded certain patients or edited the records. In primary care clinics where giving patients access to their charts was the rule, less than 1% of patients were excluded from the program.^{41,45} In studies where patients were given access to truncated record systems, 5-8% of subjects were excluded based on psychosocial concerns.^{32,33} Other studies excluded potentially worrisome parts of the record. In a study of a truncated medical record, for instance, 18% of patients had diagnoses that were represented only as numeric codes or were excluded entirely.³² A study of an electronic patient-accessible medical record allowed doctors to deny patient access to selected records and automatically made psychiatric records "patient-deniable."⁹

Results

Analyses of Clinical Notes

Physicians, patients, and professional raters have analyzed medical¹⁶ and psychiatric¹⁷⁻¹⁹ case notes to see

whether they are appropriate for patients to read. These studies have raised concerns about the practice.

The review of medical case notes found that over half of the case notes were "puzzling or unintelligible" to the patient (some because they were illegible), "alarming or worrying," "apparently insulting or objectionable," or "apparently deceptive."¹⁶ Because better charting practices (particularly recording legibly and avoiding disparaging characterizations of patients that are medically irrelevant) would have eliminated many of the concerns, it is hard to draw generalizations about the effects of a patient-accessible medical record from this study.

The psychiatric case notes appeared to be even more problematic—among records that were legible, roughly 80% contained entries that were potentially puzzling, offensive, alarming, or upsetting, as determined both by practitioners and patients.¹⁷⁻¹⁹ Psychiatric information and terminology may simply be intrinsically more sensitive than medical information. For instance, whereas patients and professional raters found the formulation "chronic schizophrenic" to be offensive, the same reviewers did not take offense at the formulation "chronic diabetic" or "known case of SLE."¹⁹

Patient Experience with Access to the Medical Record

Patient Interest and Acceptance

Although many patients are interested in reading their medical records when offered the chance, it is rare for patients to request to read their records spontaneously (see Table 1). In Denmark³⁰ and the United States,⁶² only 0.4% of medical inpatients and outpatients requested their records. Requests from psychiatric inpatients are also rare—less than 2% in one study.²⁸

Studies disagree about the motivations for spontaneous requests. In one survey, most physicians believed that patients requested to read their records for "further treatment, education, or additional information," but one-third of the physicians believed that the requests were prompted by "litigious motives" or "from the need to obtain secondary gain."²¹ A 1980 study of medical inpatients who asked to look at their charts while hospitalized concluded that the vast majority of unsolicited requests came from patients with personality disorders and contentious doctor-patient relationships.⁶² A study of psychiatric patients

from the same year concluded that many of the requests to read the record derived from grievances with the medical staff.²⁹ In contrast, a Danish study in 1988 found that patients most commonly sought records in “the wish for more information,” whereas “doubt . . . dissatisfaction . . . and/or perceived grounds for complaint were much less common.”³⁰

In clinical trials of patient-accessible medical records, roughly 75–95% of medical patients were interested in enrollment. Most who declined did so out of fears that access to the record would make them more anxious. Concerns were more prevalent in cancer patients: whereas 13% of these declined to participate because they thought the record would make them too anxious,³⁸ less than 5% of general medical patients or obstetrical patients expressed such concerns.^{32,52} Among psychiatric inpatients, Stein found that the vast majority (over 90%) of patients were in favor of a policy of open medical records.⁵⁷ Only a minority of psychiatric patients (25–39%), however, take advantage of the opportunity to review their records when it is provided.^{57–59}

Patients who in fact took receipt of their records were generally satisfied. Consistently, well over 80% of medical and obstetric outpatients appreciated the experience and would choose to view their records again.^{9,32,44,46,52–54,56} The majority of medical inpatients were also satisfied, although a significant minority (up to 30%) did not find the experience valuable.^{50,51} The majority of psychiatric patients (76–92%) also had favorable attitudes about being provided access to their records.^{57,61}

Two studies provide information about what parts of the medical record patients found particularly important. In one study, Australian general practice patients were surveyed about what a patient-held record should contain.²³ Patients particularly wanted it to include a history of immunizations, medical problems, allergies, and treatments. Another study observed patients as they viewed their truncated medical records on a computer screen. Most patients chose to look at their problem list, about half looked at their medication list, and one-third looked at their clinical examination.³³

Patients were less interested in elaborating on clinical notes themselves. About 50% of the general medical outpatients given a personal record of medical problems and prescriptions kept it up to date over a 2-year period.³⁴ In a descriptive study with medical outpatients, only about 20% of those who received

their records filled out an audit form that allowed them to correct and clarify their notes and problem lists.⁴² In a clinical trial with psychiatric inpatients on a forensic unit, none of the patients took advantage of the opportunity to write in the chart, although it was explicitly offered to them.⁵⁹

Confusion and Misunderstandings

Although only a handful of patients actually found their records to be “confusing,”^{28,46,57} patients commonly had difficulty understanding at least part of their records. In an early descriptive study, general medical outpatients were asked whether they could understand “all or most” of the information in various notes. The positive response was 60% for referral letters and only 20% for their general practitioner’s notes.⁴⁶ Legibility was a major problem—only 44% could even read their general practitioner’s handwriting. Several clinical trials also reported problems with legibility.^{51,53}

Legibility aside, 60% of medical inpatients given a patient-accessible medical record asked questions about vocabulary or meaning,⁵⁰ and almost half of the medical outpatients who were given a computer-generated problem list could not understand at least one of the entries.³³ Medical patients who spontaneously requested their records fared better. In the Danish study,³⁰ 83% of these patients understood “everything or nearly everything” in the record. The only study to report on comprehensibility of psychiatric notes found that all psychiatric outpatients gave favorable ratings when asked if they understood what had been written.⁶¹

Patient Education

Patient-accessible medical records improved recall and understanding of medical information by objective measurement in two randomized controlled trials. Among medical outpatients, smokers who received a copy of their most recent progress note were significantly more likely to identify smoking as a problem 2 weeks after their appointment, and this trend persisted at 6 months.⁴³ Older patients with chronic medical conditions also showed significant increases in their recall of medical problems and treatment plans that did not involve medications.⁴⁴

Other controlled trials failed to show an objective improvement in recall or understanding of medical information. These trials included a trial with medical inpatients,⁵¹ a trial with obstetric patients,⁵⁴ and a

trial with psychiatric inpatients.⁵⁸ The trial with psychiatric patients reported a trend toward “better insight” in the group of subjects who took advantage of the opportunity to read their records.

Patients reported subjective improvements in understanding their medical conditions in many studies. A randomized controlled trial with obstetric patients showed statistically significant improvements: whereas 12% of control patients reported that they “did not feel well informed during labor and delivery,” only 1% of patients who carried their records felt this way.⁵³ The majority of patients in several other studies reported that reading their records educated them about their medical condition.^{47,49,57} Similarly, although no controlled trial showed objective improvement in recall of medication regimens,^{44,51} the vast majority of the patients in a descriptive study felt that reviewing the medication list was useful.³³

Creating Anxiety

Patient-accessible medical records did not generate substantial anxiety or concern in most studies.^{28–30,50,51} In a descriptive study, however, 11% of medical outpatients reported “upsetting feelings” after reading their records. For obstetric patients, although a nonrandomized controlled trial reported that 23% found the records “difficult to understand or worrying,”⁵² two randomized controlled trials found that patients who carried their medical records were no more anxious than those who carried the standard cooperation cards (patient-carried cards with information to be passed from obstetrician to general practitioner).^{54,56}

There may be more risk for engendering worry among psychiatric patients. In one case series, for instance, a psychotic patient’s paranoia was further entrenched when a minor piece of information, which she regarded as vital to proving her sanity, was missing from the record.²⁹ In a descriptive study of psychiatric inpatients, a substantial minority (32%) felt more pessimistic after reading their records.⁵⁷ From 12% to 50% of psychiatric patients report becoming upset when they read their medical records.^{57,59,61}

Providing Reassurance

Excluding the patients who declined to read their records, there was great variability in the reassurance that patients derived from reading the record.

Significant benefit was demonstrated in medical patients who spontaneously requested and read their records: 68% felt more reassured.³⁰ Two descriptive studies of medical outpatients also found benefits in relieving anxiety: one reported that 30% found their records “reassuring,”⁴⁶ and another reported that 97% had less worry about their health after reading their record.⁴¹

More rigorous studies in other populations, however, failed to find any benefit. A nonrandomized controlled trial of medical inpatients showed no change in self-assessment of depression, anxiety, or contentment.⁵⁸

Empowerment: Improving Autonomy and Self-efficacy

Clinical trials in obstetric patients gave conflicting information about autonomy and self-efficacy. One randomized controlled trial of obstetric patients reported that patients were significantly more likely to report “I felt in control” and significantly less likely to report “I felt helpless.”⁵⁶ About half of the obstetric patients in a nonrandomized controlled trial also reported that carrying their records increased their sense of autonomy.⁵² Another randomized controlled trial, however, failed to find a significant improvement in patient self-confidence.⁵³

A descriptive study in medical outpatients also suggested improvement. Patients who engaged in record sharing visited the office less frequently, prompting the authors to speculate that they may be more effective in addressing medical problems on their own.⁴²

Psychiatric outpatients in a descriptive study were also observed to “participate more in their long term care.”⁶⁰ Similarly, in a descriptive study of psychiatric inpatients, 85% felt that open access to records helped them “take a more active role in treatment” and 71% felt more confident as a result.⁵⁷ In contrast, psychiatric patients who spontaneously requested access to their records generally “felt little or no different about themselves” after reading them.²⁸

Promoting Adherence

A randomized controlled trial showed statistically significant improvements in smoking behavior. Smokers who received progress notes after periodic health examinations were significantly more likely to reach the composite end-point of reducing smoking or quitting at 6 months (65% vs. 29%). There was no difference, however, in the standard end-point of

quitting. In a descriptive study of medical outpatients, roughly 80% of the patients indicated that they were more careful to follow medication recommendations and that access to their records inspired them to make lifestyle changes.⁴¹

Other controlled trials showed no improvements in adherence. Randomized controlled trials of older patients with chronic illnesses⁴⁴ and patients with first stroke⁴⁹ found no significant differences in patient-reported adherence to pharmaceutical and nonpharmaceutical treatments. Obstetric patients also failed to show a significant difference in health-related behavior (such as avoiding smoking, drinking alcohol, or breastfeeding) in two randomized controlled trials.^{53,54} A nonrandomized controlled trial of psychiatric inpatients also showed no effect on adherence with the treatment program.⁵⁸

Concerns About Sensitive Items

Patients who find sensitive items in the medical record generally find inclusion appropriate.³³ Only a handful (less than 5%) of patients request that sensitive items be excluded or identified by a code.^{32,52}

Concerns About Confidentiality

Few studies reported information about concerns about confidentiality. In a descriptive study of medical outpatients, 3% had such concerns,³³ and in a descriptive study of psychiatric inpatients, 12% reported concerns.⁵⁷ Not surprisingly, these concerns were greatest among psychiatric patients with paranoid delusions.⁶⁰

A patient-accessible electronic medical record, PCASO, was designed with substantial safeguards to maintain privacy and confidentiality.⁹ Satisfaction with these safeguards was excellent among patients. Although the safeguards were cumbersome in comparison with other Internet sites, the authors concluded that "some 'challenge' is acceptable and may even have value, in that it contributes to the perception of safety."

Clinical Trials: Effects on the Doctor-Patient Relationship

Improving Doctor-Patient Communication

A randomized controlled trial of a patient-held prenatal record reported statistically significant benefits in doctor-patient communication. Obstetric patients who were given access to their records were nearly one and

a half times more likely to say that they found it easier to talk to their doctors and midwives.⁵⁴ Another randomized controlled trial found significant improvements in communication in mothers who had previous deliveries but not in first-time mothers.⁵⁶

Interestingly, a randomized controlled study of patient-held obstetric records suggested that an improvement in doctor-patient communication led to an adverse clinical outcome—a statistically significant increase in assisted deliveries.⁵³ Patients who held their records were informally noted to express "greater concern about having pain relief." They were also more likely to receive epidural anesthesia, which is associated with a higher rate of assisted deliveries. The authors speculated that patients who held their records became more vocal about their concerns and thus altered clinical practice in ways that were ultimately detrimental.

No other studies reported statistically significant benefits in communication, but there was suggestive evidence of benefit. Medical outpatients who were given access to a truncated medical record in a descriptive study commented that it helped answer questions that their busy physicians could not answer at the time of the visit or that the patient forgot until afterward.³³ Although no quantifiable benefits in patient-provider communication were shown in a nonrandomized controlled trial of medical inpatients, there were "numerous individual instances" in which access to the medical record prompted doctor and patient to have "useful discussions."⁵¹ Psychiatric outpatients and their providers believed that a patient-held shared record improved communication in a descriptive study.⁶⁰

Improving Patient Satisfaction

Controlled trials of patient-accessible medical records did not show any benefit in overall patient satisfaction in medical outpatients,⁵¹ medical inpatients,⁴⁹ or obstetric outpatients.^{53,54,56} In a descriptive study of medical outpatients, however, 80% reported that access to records gave them more confidence in doctors and made them feel better understood.⁴⁶ Psychiatric inpatients reported no overall change in attitude toward doctors and nurses both after spontaneous requests to read their records²⁸ and in a nonrandomized controlled trial.⁵⁸

Patient-accessible medical records are particularly helpful for patients who are concerned about what might be hidden in the chart. Demystification of the

record improved satisfaction for such patients in a study of those who spontaneously requested their records²⁹ and in a descriptive study of medical inpatients.⁵⁰ In nonrandomized controlled trials of psychiatric patients, demystification even benefited some who did not read their records but "said that the very fact that they could see the charts obviated the need to do so and increased their trust in the staff,"⁵⁹ sometimes leading to better acceptance of therapy.⁵⁸

Clinical Trials: Effects on Medical Practice

Correcting Errors

Patients found inaccuracies in the medical record in many of the studies. A descriptive study of medical inpatients found that half of patients "made some addition or correction on a point of fact."⁵⁰ Although only one stroke patient found an error in the record in a controlled trial,⁴⁹ in two descriptive studies of medical outpatients 12–25% of patients found incorrect or missing information in their notes.^{33,46} In a descriptive study, 68% of psychiatric inpatients reported that the patient-accessible medical record gave them an opportunity to correct inaccurate information.⁵⁷

Two clearly serious errors were identified. In one incident, a pregnant patient corrected her record to indicate that she was Rh-negative, prompting a change in management.⁵¹ In a study of psychiatric outpatients, a patient-held shared record helped identify a potentially serious drug interaction between a monoamine oxidase inhibitor and a phenothiazine that were prescribed by different physicians.⁶⁰

Otherwise, it is not clear to what degree the inaccuracies were meaningful. In a study in which outpatients audited their own records, 41% of patients made corrections, but the correction led to a change in problem lists or treatment plans in only 8%.⁴² In another study of medical outpatients, four respondents (2%) reported incorrect diagnoses, but the patients' doctors disputed this claim and still considered the diagnoses correct in all but one of the cases.³²

Although patient-accessible medical records offer patients the opportunity to correct errors in the record, patients may also *introduce* errors if they make unauthorized additions to or deletions from the medical record. A case series described two incidences in which obstetric patients made unauthorized changes to a patient-held medical record.²⁷ In one case this

alteration led to an unexpectedly preterm elective caesarian section with serious consequences.

Effects on Documentation

Effects on documentation were primarily evaluated in the psychiatric literature. Although both patients and staff had the impression that patient access to the records changed documentation patterns, little change was identified on objective analysis. In a descriptive study, 66% of psychiatric inpatients felt that open access to medical records made the staff more accurate in what they wrote, and over half of the psychiatric staff reported omitting intimate details of a patient's personal life that the patient might be upset to find in print. When records were studied objectively, however, the only findings were an increase in notations of disruptive behavior and more entries labeled "error" rather than being crossed out or erased.⁵⁷ A controlled trial of psychiatric inpatients failed to find any objective changes in charting practices at all.⁵⁸ In another controlled trial, staff members on a forensic psychiatric unit were concerned that patients would seek reprisal for comments made in the medical record. Nonetheless, after patients were granted access to the record, there was no statistically significant change in the number or length of negative and positive comments in the record.⁵⁹

The only study of medical patients to refer to changes in documentation by medical staff was a descriptive study from a general practice that routinely gave patients access to records. The common impression of the practitioners was that clinic notes were "not materially affected" by the knowledge that patients may subsequently read them.⁴⁵

Demands on Staff Time

When medical staff members are interviewed about the impact of providing medical records to patients, a frequent concern is the time that they will spend explaining it to patients. As one editorialist observed, "I imagine that if I were to have to explain to every patient the meaning of his having a slightly raised serum potassium value nine years ago, then it might take up a lot of time that I could spend more usefully."⁶³

In practice, this problem did not appear to be substantial. A controlled trial of medical inpatients found that physicians needed to spend extra time to address the discussions raised by patients' seeing their own

Table 2 ■

Issues Regarding Patient-accessible Medical Records Not Addressed in Cited Studies

- Helping patients improve coordination of care
- Revealing serious diagnoses (for instance, via pathology reports demonstrating malignancy) before the doctor-patient encounter
- Leakage of private patient information to others, such as family members who may look at the records
- Lost confidentiality of “third party” information about the patient from family members, social workers, and other interested parties with sensitive information
- Effects on patient litigiousness

records.⁵¹ In most studies, however, merely giving the patient access to his or her record did not appreciably increase workload.^{31,46,50,54} In fact, although 36% of obstetric patients forgot to bring their records to at least one appointment,⁵⁵ patient-held records actually improved efficiency because they were still more likely to be available at the time of the appointment than hospital-held records.^{53,54} Use of a shared record for psychiatric outpatients also helped staff coordinate their efforts more efficiently.⁶⁰

Discussion

The overall impression from the studies that we reviewed is that patient-accessible medical records are unlikely to cause harm in medical patients and have the potential for modest benefits. Because of the studies' limitations, it is not possible to reach definitive conclusions about most of the outcomes that we discussed. Limitations of the studies in our review include small sample sizes (limiting statistical power to confirm or to exclude many of the outcomes), use of unstandardized instruments for assessment (making comparisons across studies difficult), and limited exposure to the intervention (suggesting that the “dose” may have been insufficient to generate a “response”). Bias was also introduced in studies that did not use randomized controls. These studies were also unable to address other issues that have been raised about patient-accessible medical records (Table 2).

The most consistent finding across studies is that patient-accessible medical records enhance doctor-patient communication. This finding was supported by three high-quality trials of patient-held records in obstetric patients and confirmed by several descriptive studies. Improvements in adherence, patient education, and patient empowerment were also

found in randomized controlled trials, although in each case other controlled trials failed to find a benefit. There were reports of patients identifying factual errors in their records, but it is difficult to assess the rate of finding clinically important errors. These benefits appear to be conferred with minimal risk, at least for the nonpsychiatric patient population. Although medical patients find parts of the record difficult to comprehend, few find the records worrisome or upsetting, and patient satisfaction with the process is high. Promoting patient access to records does not appear to create excessive demands on staff time, negatively impact documentation, or adversely affect the doctor-patient relationship. Overall, adult medical patients are likely to look upon patient-accessible medical records favorably and to employ them reasonably.

The impact of promoting access to records appears to vary among different patient populations. Some of the strongest evidence of benefit came from studies of obstetric patients. This population may have been particularly suited to using patient-held records because they had regular visits over a fixed period of time in anticipation of a dramatic and usually positive outcome. Psychiatric patients, in contrast, are more likely to find the experience worrisome or upsetting. It may be reasonable, therefore, to limit patient access to psychiatric records or for a mental health professional to be available when patients review psychiatric notes.⁵⁷ Because even general medical records may contain potentially worrisome psychological content, these findings support the practice of allowing doctors to exclude certain content from routine patient review.

The future of patient access to medical records is likely to involve electronic medical records. In contrast to the use of paper records, electronic medical records should be perfectly legible. Internet-accessible records can be viewed repeatedly and in the context of rich sources of medical information available on the World Wide Web, potentially increasing the potency of the intervention. Future research will demonstrate whether this technology will allow patient-accessible medical records to realize their potential to improve patient satisfaction, patient understanding, and quality improvement without creating new hazards.

Conclusion

Overall, studies of patient-accessible medical records suggest modest improvements in doctor-patient

communication, adherence, patient empowerment, and patient education. Although patients find parts of the medical record difficult to understand, patients who are offered a chance to review their medical record are generally satisfied with the experience. Few medical patients found the experience confusing or upsetting, but a significant portion of psychiatric patients became more worried and pessimistic after reading their records. Because the studies were small, often lacked strong controls for bias, did not use validated assessment tools, and had a limited exposure period, these data cannot be definitive; however, they do establish a foundation for future research.

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