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Effects of Adult Patient Portals on Patient Empowerment and Health-Related Outcomes: A Systematic Review

Elske Ammenwerth[a], Alexander Hoerbst[b], Stefanie Lannig[c], Gerhard Mueller[c], Uwe Siebert[d], Petra Schnell-Inderst[d]

[a] *Institute of Medical Informatics, UMIT – University for Health Sciences, Medical Informatics and Technology, Hall in Tirol, Austria*

[b] *Research Group eHealth and Innovation, UMIT, Hall in Tirol, Austria*

[c] *Institute of Nursing Science, UMIT, Hall in Tirol, Austria*

[d] *Institute of Public Health, Medical Decision Making and Health Technology Assessment, UMIT, Hall in Tirol, Austria*

Abstract

Patient portals are offered by health care organizations to facilitate health information sharing and patient empowerment and support patient-centered care. The aim of this systematic review is to assess the effect of patient portals on patient empowerment and health-related outcomes. After a systematic literature search, ten randomized controlled trials (RCTs) were included in this review. Of these, seven RCTs were conducted in the United States., two in Canada, and one in Japan. Study characteristics, risk of bias, and outcomes were extracted. varied in terms of intervention, included patients, and outcome.. Most studies found no or only a small, clinically non-relevant effect of patient portals. The review showed that future research should develop a taxonomy to describe patient portal functionalities to facilitate the aggregation of evidence.

Keywords:

Electronic Health Records, Review, Patient Participation

Introduction

Patient-centered care has gained importance in both medical research and clinical practice. The concept of patient-centeredness is based on patient empowerment, patient participation, and shared decision-making [1–3]. Health information sharing and patient engagement in health care decisions are seen as preconditions for patient-centered care [1].

To facilitate health information sharing and patient involvement in the care process, healthcare organizations are increasingly offering their patients' access to their health data in the institution-based electronic health record (EHR). Patients can access these data and integrate it into any (electronic or paper-based) type of personal health record [4].

The interface that provides EHR access is called patient portal [5]. These portals are typically web-based, allowing patients independent access to their data from anywhere as a primary feature. A patient portal may also offer additional features such as medication refill requests, appointment scheduling, secure messaging, personal health-related reminders, individual therapeutic recommendations, personal diaries, and social networking with other patients.

In addition to being offered by healthcare organizations, EHR access may also be offered to patients on a national level. Some countries, including Austria, Denmark, and Sweden, have already started eHealth projects to make selected health-related data from various healthcare organizations available to their citizens [6].

A uniform theory or clear evidence of how EHR access via patient portals might contribute to patient-centered care and related concepts such as patient empowerment or patient participation or even improved health outcomes, does not exist. Nevertheless, qualitative reviews have shown that patient portals may improve patient empowerment, patient adherence, and clinical outcomes [7,8]. However, systematic reviews on patient portals have found inconclusive results to date [8–12]. As all of these reviews were published before 2015, it is possible that more evidence is now available. In this systematic Cochrane review, we assess the effects of providing access to EHR for adult patients on patient empowerment and health-related outcomes. We summarize characteristics of the identified Randomized Controlled Trials (RCTs) and present preliminary results on the effect of providing access to EHRs for adult patients on patient empowerment and health-related outcomes.

Methods

We used a Cochrane protocol for conducting this review [13]. We systematically reviewed RCTs investigating the effects of providing EHR access to adult patients. First, we developed a patient portal taxonomy describing seven functionalities:

- *Access*: Access to health-related data (e.g., visit notes, test results, medical history).
- *Remind*: Personalized health care reminders (e.g., for mammography or immunization).
- *Request*: Transactional services (e.g., scheduling appointments, prescription request).
- *Communicate*: Bilateral communication (e.g., secure messaging).
- *Share*: Patient self-documentation and sharing (e.g., patient uploads of blood pressure measurements).

- *Manage*: Disease management (e.g., individualized recommendations from guidelines).
- *Educate*: General health-related education (e.g., disease information leaflets).

Primary outcomes for this Cochrane review are the effect of EHR access on patient knowledge and understanding, patient empowerment, patient adherence, patient satisfaction, and adverse events.

Secondary outcomes for this review are health-related outcomes including quality of life, psychosocial health outcomes, health resource consumption, and patient-provider communication.

In our review, all studies offering EHR access to adult patients were included, independent of the medical condition of the patients. Only studies where EHR access was provided via a web-based application were included, thus excluding office-based systems. Only RCTs were included.

We systematically searched electronic libraries including Central, Medline, Embase, PsycInfo, Scopus, and CINAHL; in proceedings of Medinfo, AMIA, and MIE; and in major health informatics journals. We also searched for studies cited in earlier systematic reviews on patient portals and in identified RCTs. Two authors independently screened all titles and abstracts to determine whether they meet the inclusion criteria.

The following information were extracted by two authors using the software Covidence (Version v1062 115d548c):

- Study identification (e.g., country, clinical setting).
- Study methods (e.g., aim of study, intervention and control group, number of arms, study design, funding source).
- Population (e.g., target group, inclusion and exclusion criteria, age, gender).
- Intervention (e.g., name, functionality, usage patterns).
- Risk of bias (e.g., random sequence, allocation, blinding, selective outcome reporting) [14].
- Outcomes (e.g., methods and timing of assessing outcomes, instruments used, methods for follow-up, effect size, mean change in intervention and control group, adverse events, measure of uncertainty).

Primary and secondary outcome results were extracted in systematic evidence tables. More details of data extraction are published in a Cochrane protocol [13].

Results

We identified ten studies that represent distinct RCTs on EHR access for adult patients (seven RCTs and three cluster RCTs). Figure 1 shows the flow chart of this systematic review. The studies included between 78 and 4,500 patients.

Identified studies were very heterogeneous in terms of included patients' diseases (hypertension, diabetes, asthma, glaucoma, congestive heart failure or unspecific) and outcome measures (e.g., frequently patient adherence and health-related outcomes, less often patient satisfaction and patient empowerment), making meta-analysis challenging.

Seven RCTs were conducted in the United States, two in Canada, and one in Japan (Table 1). The majority of studies were published in 2012 or earlier, indicating a scarcity of newer studies.

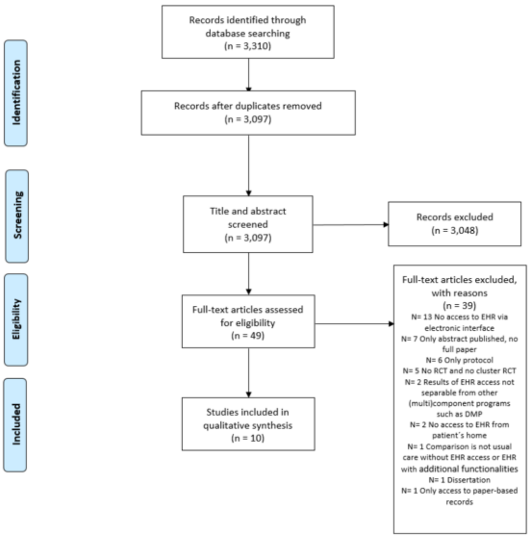

Figure 1 – Flow chart of the systematic review on patient portals.

Table 1 –Identified randomized studies.
H-r = health-related outcomes.

Study	Country	Included patients	Outcome
Ahmed (2016) [15]	Canada	Asthma	H-r Outcome
Grant (2008) [16]	United States	Diabetes mellitus	H-r Outcome
Holbrook (2009) [17]	Canada	Diabetes mellitus	Adherence H-r Outcome
Kashiwagi (2014) [18]	Japan	Glaucoma	H-r Outcome
Krist (2012) [19]	United States	Unspecific	Adherence
McCarrier (2009) [20]	United States	Diabetes mellitus	Empowerment H-r Outcome
Ralston (2009) [20]	United States	Diabetes mellitus	H-r Outcome Health Resources
Ross (2004) [21]	United States	Congestive heart failure	Empowerment Adherence Satisfaction

Tang (2013) [22]	United States	Diabetes mellitus	Adverse Events Health Resources Knowledge Adherence Satisfaction Adverse Events H-r Outcome
Wagner (2012) [23]	United States	Hyper-tension	Health Recources Empowerment Patient Satisfaction H-r Outcome

Table 2 – Functionality supported by the patient portals

	Access	Communicate	Share	Manage	Educate	Remind	Request
Ahmed 2016	🟩	🟩	🟩	🟩	🟩		
Grant 2008	🟩		🟩	🟩			
Holbrook 2009	🟩		🟩	🟩	🟩		
Kashiwagi 2014	🟩						
Krist 2012	🟩		🟩		🟩	🟩	
McCarrier 2009	🟩	🟩	🟩	🟩	🟩		
Ralston 2009	🟩	🟩	🟩	🟩	🟩		
Ross 2004	🟩	🟩			🟩		
Tang 2013	🟩	🟩	🟩	🟩			
Wagner 2012	🟩	🟩	🟩	🟩	🟩		

Table 2 shows functionality supported by patient portals, based on our taxonomy. All included studies offer “access to data”, as this was an inclusion criteria. No portal offered the functionality “request”.

There was substantial heterogeneity across studies regarding instruments used and study outcomes. For example, the three studies measuring patient empowerment used four different questionnaires. For two of these instruments, there was no statistically significant difference in patient empowerment. For the other two instruments, the effect was statistically significant, but the effect size was too small to be clinically relevant.

Eight studies measured changes in health-related outcomes. These include a outcomes such as asthma control and mortality, but mostly risk factors such as hemoglobin A1c (HbA1c), blood pressure, low-density lipoprotein and body mass index. Of the six studies measuring the effect on HbA1c, two found a statistically significant, yet small improvement. Of the four studies measuring the effect on blood pressure, only one found a statistically significant, small improvement.

When looking at usage patterns, the functionality offered by the patient portal was often not used consistently. For example, in one study, the number of logins declined over time [21]. In another study, less than 25% of patients used the portal consistently [20]. In one RCT, 16% of patients never logged in over the three-month study period [15]. Users of the patient portal were more often male, white, commercially insured, and college-educated [16,19].

Sub-group analysis of the intervention group revealed that, in this group, portal users show better outcome than portal non-users in three studies [19,20,22].

Discussion

We identified ten randomized controlled studies that evaluated the effect of patient portals on a range of outcomes. In summary, most studies found no evidence for an effect or only a small, clinically non-relevant effect.

Two studies reported no differences on mortality [22,24], and none of the included RCTs reported other adverse effects of patient portals. In general, EHR access may increase feelings of confusion and anxiety when patients read clinical information that is unclear to them [8], but this effect was not reported in the included studies.

EHR access, like many other digital health solutions, is sometimes said to be created for “people like me”, meaning that these digital solutions may only address the needs of “[…] well-educated and well-to-do users rather than the needs of the most disadvantaged in society (the disempowered, disengaged, and disconnected” [25]. Two studies [16,19] found indeed that active portal users were more often white, male, and college-educated.

Among other factors, health literacy may help to reliably interpret content provided in the EHR. The level of health literacy may influence the frequency of use and the potential benefits from accessing EHR. data Besides disease-specific knowledge in one study [22], health literacy was, however, not analyzed in any study.

Three studies found that active users showed better outcomes compared to non-users in the intervention group. The concept of “implementation fidelity” [26] refers to the degree in which an implementation is delivered and used as intended. Low frequency and duration of portal usage may show low fidelity and may explain lack of visible effect. Another likely explanation for the better effects in users may be patient characteristics (e.g., education status) that may be associated with both higher portal use and better health outcome; therefore, the identified difference may be an overestimation of the true effect.

Nine of the ten reviewed RCTs included patients with various chronic diseases (Table 1). While earlier research assumed that chronic patients may benefit from patient portals [27], we did not find clinically relevant effects for this group. We thus do not expect to see effects from portals in other user groups.

Due to the small number of studies, further sub-group analysis such as patient group, portal functionality, or fidelity of implementation are not possible.

We were not certain that we have identified all RCTs on patient portals, due to various terms describing the intervention or the observed effects. So, we also searched in major health informatics proceedings, references of other portal reviews, and references of the identified RCTs.

Conclusions

Preliminary results of this systematic review of RCTs of patient portals did not reveal clear evidence of substantial and consistent positive effects of patient portals on patient empowerment and health-related outcomes.

The number of identified studies, however, is small, quite diverse, and many were published in 2012 or before . Also, in several studies, a part of the intervention group did not use the patient portal consistently.

Future research should develop a taxonomy to describe patient portal functionalities to facilitate the aggregation of evidence in future systematic reviews.

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This abstract is based on a draft pre-peer review version of a Cochrane Review. Upon completion and approval, the final version is expected to be published in the Cochrane Database of Systematic Reviews (www.cochranelibrary.com).

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Address for correspondence

Elske Ammenwerth, UMIT, Institute of Medical Informatics, Eduard Wallnöfer Zentrum 1, 6060 Hall in Tirol, Austria, elske.ammenwerth@umit.at.