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Patient Empowerment by Electronic Health Records: First Results of a Systematic Review on the Benefit of Patient Portals

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Abstract. Patient portals provide patients with access to a provider-managed electronic health record (EHR). They may provide an interesting approach to increase patient empowerment. The objective of this paper is to provide a first overview of the state-of-the-art and the impact of patient portals. Based on a systematic literature search, we identified five evaluation studies on patient portals. These studies demonstrate only little effect of patient portals on patient empowerment.

Keywords. Patient portal, electronic health record, review, impact evaluation

Introduction

The emergence of the Internet and of the Electronic Health Record (EHR) has also brought new opportunities for a new and more active role of the patient (1-2) in his/her care. This is often denoted as patient empowerment, describing a situation where the patients' role is changing from a patronized patient to an informed patient and further to a responsible, autonomous and competent partner in his or her own care (3). One important approach here is the concept of "patient portals".

Patient portals can be defined as provider-tethered applications that allow patients to access health information that is documented and managed by a health care institution (4). As part of a patient portal, institutions may allow patients a typically web-based access to selected clinical data which is governed by the respective institutions as part of a person's EHR. The patients can then access clinical data, read and print it or integrate them into a PHR or any other (electronic or paper-based) type of patient-owned record. Besides providing sole access to EHR data, patient portals may also offer additional services such as medication refills, appointment scheduling, access to general

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medical information such as guidelines, or secure messaging between a patient and an institution (4).

At the moment, there seem to be little evidence whether patient portals can really increase patient empowerment.

1.1. Objectives

The objective of this paper is to review the impact of electronic patient portals on patient empowerment.

2. Methods

We systematically searched for evaluation studies on patient portals in scientific databases and journals such as PubMed, Cochrane Library, CINAHL, EMBASE, ACM Digital Library and the Evaluation Database (<http://evaldb.umit.at>). We included all kinds of study designs (RCT, non-RCT). We focused on studies that measured the impact of a patient portal on the outcome criteria such as patient satisfaction with the provided care, patient empowerment, costs and resource consumption, mortality or other relevant clinical parameters. We limited the search to papers after 1990.

We basically used Mesh terms to retrieve papers, using a combination of the terms "Medical Records Systems, Computerized", "Health Records, Personal", "Access to Information" or "Patient participation".

All papers that seemed eligible were read in full text by two researchers. Each study was systematically described addressing clinical setting, type of intervention, type of study as well as outcome.

3. Results

We identified 603 papers, 13 of them comprised an experimental or quasi-experimental study design. Of those 13 papers, 5 studies (5-9) were finally eligible and then analyzed in detail (see Table 1).

Table 1. Details of retrieved studies on patient portals.

Author/Year	Users	Selected functionalities of the patient portal
Tuil, 2007 (5)	Patients undergoing IVF treatment	Personal health record, offering access to own medical record with all available information concerning the patient's IVF or ICSI treatment, and tailored, context-sensitive clarification of clinical information.
Zhou, 2007 (6)	Patients that used KP Health Connect Online for longer than 13 months	KP HealthConnect, offering access of parts of their individual health record; health summary with problem list, medications, allergies; and health record with immunizations.
Grant, 2008	Patients with	"Diabetes-Mellitus-specific PHR" offering medication module to review

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(7)	Diabetes Mellitus Type 2	medications; view most recent results and current treatments; generate a DiabetesCarePlan based on patients' responses to the questions, to be used at the next clinical visit.
Earnest, 2004 (8)	Patients with congestive heart failure	SPPARO ("System Providing Patients Access to Records Online") offering online access to clinical notes, lab reports, test results
Ross, 2004 (9)	Patients with congestive heart failure	SPPARO ("System Providing Patients Access to Records Online") offering online access to clinical notes, lab reports, test results

Four of the found studies were randomized controlled trials (RCT), the remaining study combined a matched-control and a cohort study. The number of participants in each study ranged from 81 to 6.402 patients.

The found studies evaluated the impact on a variety of outcome criteria. One study (7) focused on changes in clinical outcome parameters, including HbA1c, blood pressure, LDL, and medication adjustments. One study (6) focused on changes of resource consumption, including office visit rates and telephone contacts. Two studies (5, 8) focused on changes of more subjective parameters such as patient satisfaction, patient knowledge, and patient anxiety; these were measured by validated questionnaires. The fifth study (9) combined several criteria and included changes of mortality, of treatment adherence, of resource consumption (message number) and of subjective parameters (subjective health status, patient empowerment, medication adherence).

Significant changes in the patient portal group, compared to a control group, could only be observed for the following parameters: decrease in office visit rates and telephone contacts (6); increase in number of messages sent (9); changes of the medication regimen (6); and better adherence to treatment (9). For the other parameters, studies did not find significant changes between intervention and control group.

4. Discussion

4.1. Answers to study questions

We systematically searched the literature and found five controlled studies focusing on the impact of patient portals. The studies were quite heterogeneous with regard to clinical setting, type of intervention and measured outcome. Basically, most of the measured parameters did not show a significant difference between intervention and control group. In particular, no significant changes could be observed for parameters related to patient empowerment.

Patient portals basically present clinical information to the patients. Can we expect that giving patient access to clinical information can have an impact? Ross et al (10) reviewed the outcome of 29 descriptive or controlled studies on adult's patient access to (paper-based) medical records, published between 1970 and 2002. The review found that several studies showed an improvement of doctor-patient communication by patient-accessible medical records. There were, however, only conflicting findings on improvements in adherence (such as adherence to treatment, smoking behavior), patient education (such as understanding or recall of medical information; feeling of being well informed), and patient empowerment (such as sense of autonomy); in these cases, some controlled studies showed an improvement, while others did not. No changes could be

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observed with regard to patient anxiety, patient confusion, patient depression, or patient satisfaction with care. Ross et al (10) summarized that studies suggest potential for modest benefits for example in enhancing doctor-patient communication, but that studies were of limited quality, and that more research is necessary.

Compared to paper-based access to records, online patient portals allow a patient independently and repeatedly accessing the information; the information is better legible; and the user can link the information to further sources of medical information available on the Internet (10). Also, patient portals can be adapted to the patient' wishes and knowledge level (5). They can also be completed by secure communication links with healthcare providers or other functions. Overall, we could expect a higher impact of online portals compare to paper-based access. However, as our results show, only little impact could be found.

4.2. Study limitation

We conducted a systematic literature search, and carefully chose the search terms; however, due to the variety of terms that may be used for patient portals, we cannot be sure to have retrieved all studies. We did not search for grey literature. The review was conducted by two researchers; any differences in judgment were solved by discussion.

5. Conclusion

Portals basically provide better information from the medical record to patients. However, better-informed patients are not necessarily healthier patients. Descriptive evidence from a large number of studies suggests that patients interested in access to their patient records, and that they find it helpful and useful. These findings, however, do not guarantee that there is in fact a measurable impact.

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