

The Evolution of Personal Health Records and their Role for Self-Management: A Literature Review

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Abstract. A literature review has been conducted to gain an overview of the evolution of personal health records (PHR) and their role for self-management. This paper presents this evolution overview, based on review of abstracts from relevant publications in addition to full-text review of reviews. A search in the Medline database for 'PHR' and 'self-management' identified 62 unique publications. Of these, 90 % met the inclusion and exclusion criteria. The number of studies per year has increased heavily since the PHR and self-management context originated in the early 1990s. Nine studies described messaging functionality, eleven studies described shared access functionalities, and four described both. However, the general evidence remains sparse to document the value of PHR for self-management. Most PHRs are not based on patients' needs and do not support self-management. To be adopted by the users, and to be useful for self-management, PHRs need to be integrated with physicians' EHR systems and provide shared access both ways in addition to secure e-mail communication and educational modules.

Keywords. Personal health record, PHR, self-management, self-care, patient empowerment, review

Introduction

The aim of self-management is to increase patients' confidence and their ability to manage their symptoms and illness [1]. The core elements are education, learn problem solving and establish skills to overcome barriers, cooperation between patient and provider, and develop action plans and carry them out [1]. Self-management interventions have demonstrated positive effect on patients with chronic conditions [2]. It is well documented in a review of 67 reviews that self-management have both positive effect on patients' knowledge, patients' experience, patients' use of health services, in addition to effects on health behavior and health status [3].

Personal health records (PHRs) are supposed to offer and stimulate patient self-management [4]. In 2006, the American Medical Informatics Association and the Agency for Healthcare Research and Quality sat down in a roundtable to agree on the potential and the barriers of PHRs, and actions on how to move the PHRs closer to the health care mainstream [4]. A PHR system typically offers "a wide variety of features,

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including the ability to view personal health data, exchange secure messages with providers, schedule appointments, renew prescriptions, and enter personal health data; decision support (such as medication interaction alerts or reminders about needed preventive services); the ability to transfer data to or from an electronic health record; and the ability to track and manage health plan benefits and services”, p. 15 [5]. In this way, the PHR is a framework for education of both patients and healthcare providers [5, 6]. However, patients own their PHRs and control the access to PHRs [6].

In 2004, a survey involving 2242 USA citizens found that 42 % had used PHRs, but as many as 87 % were paper-based [7]. The PHR systems and models developed today are mainly electronic, standalone systems, tethered or integrated with the provider’s electronic health record [4].

Fuji 2012 evaluated 19 standalone PHRs to address how they met identified patient desires [8]. Only five PHRs met more than half of the patient desires. The findings revealed that standalone PHRs more or less functioned as repositories of health information, rather than as a tool to become more knowledgeable and to manage symptom and illness [8]. Detmer 2008 stated that only the integrated model with shared access for patients and providers to both the PHR and the electronic health records (EHRs) achieves the full potential for patients in managing their own health care [4].

The main purpose of this study is, based on review of abstracts and full-text review of reviews, to establish an overview of the evolution of PHRs and their role for self-management, as previously examined in scientific studies. This knowledge will be valuable for establishing state of the art understanding of the field, and for everybody planning to conduct research in the field or develop future PHR systems for self-management.

1. Methods

1.1. Search and assessment strategy

It was considered sufficient to search Medline only, to provide a first overview, as 75% of the articles included in a thorough systematic review within a comparable scope came from Medline [9]. We accessed MEDLINE through the Ovid interface, using no limitations. We based the search on medical subject headings (MeSH) and the Text Words (TW) field to search titles and abstract information. Review publications were used as a template to identify relevant MeSH terms and search words [10, 11]. The search strategies were pilot tested and modified to ensure that they identified relevant publications.

The search was built up around two search strings. The PHR and synonyms search string included: PHR, EPHR, personal health record, personal electronic health record, personally controlled health record, patient shared/held/carried record, patient accessible record, personal medical record, Health Records Personal/. The self-management search string included: self-management, self-care, Self Care/.

The authors reviewed and rated independently all abstracts as “relevant” or “not relevant”. The inclusion criteria were publications focusing on PHRs and PHR systems relevant for patient self-management. The exclusion criterion was lack of abstract. If “relevant”, the abstracts were rated according to the categories described in the Results section. The results were subsequently merged. In all cases where the reviewers

disagreed in the perceived eligibility of the publication or in categorising it, the two reviewers discussed the abstracts to reach consensus.

1.2. Content analyses of the reviews

All identified reviews were read in full text by the first author, and explored to investigate the evolution of PHRs and their role for self-management using content analysis [12]. Content analysis refers to exploring data through breaking it down into relevant explanations [12], or subheadings, to reply to specific questions [13].

2. Results

2.1. Literature search results

The Medline search in December 2013 identified 85 references, including 23 duplicates. Of the 62 unique references, 56 met the inclusion and exclusion criteria. The two authors agreed 100 % with regard to inclusion and exclusion. Three references did not deal with PHRs, and we excluded three references due to lack of abstract. For categorization of the included references, consensus discussion was necessary for 15 references.

The oldest reference in the search was from 1983 and titled “Personal health records (PHR)” [14]. Unfortunately, the abstract was missing. The oldest included reference was from 1991. Figure 1 illustrates how the number of included papers increased heavily over the past two decades.

As many as 73 % of the 56 included papers were from the United States, while the remaining 15 papers were spread on nine countries. Three of the included papers described paper-based PHRs, the others described electronic PHRs.

The maturity level of the papers was categorized as follows: 14 concept descriptions, 6 system descriptions, 12 pilots, 3 study designs, 11 evaluations of use/implemented PHRs, 4 RCTs, and 6 reviews.

With regard to level of integration to support the patient in managing their health care [4], 9 studies described patient-provider communication through messaging and 11 of the studies focused on shared access to the PHR, while 4 studies included both functionalities. In three of the 11 studies, providers had access to the PHR. In four studies, the patient had access to the medical record (EHR) or parts of the medical record, like lab results. In three studies, both patient and provider had access to both record types.

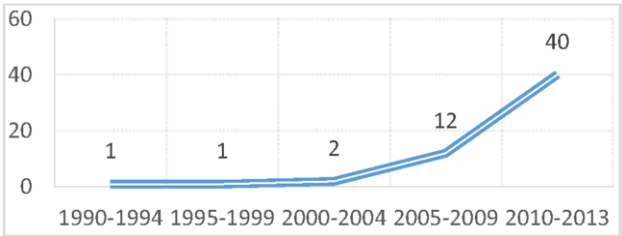


Figure 1. Number of included publications over the years

2.2. Evolution of Personal Health Records and their Role for Self-Management: Content Analyses of the Reviews

Two of the six reviews were excluded after reading the full text. Three of the four included reviews presented studies where the PHR system supported self-management [10, 11, 15]. Studies in Archer et al 2011 referred to positive effects due to patient access to lab-results, patient-provider communication, providers' update through PHR, patient understanding, and communication for prescribing medication [10]. Benhamou found eight studies with positive effects for type 2 diabetic patients, where patients felt safer, felt that non-acute problems were taken care of, and that it was easier to take care of themselves [15]. Tenford et al 2011 found three RCT studies of adults with type 2 diabetes mellitus that could document small improvements in some but not all diabetes care measures [11].

However, the general evidence remains sparse to document the value of PHR for self-management [10, 11, 15]. Most PHRs are not based on patients' needs and therefore do not support self-management [10, 16]. To be adopted by the users, PHRs need to be integrated with physicians' EHR systems and provide shared access both ways in addition to secure e-mail communication [10, 11, 15], and need to include educational modules [11, 15, 16]. In addition, RCTs and other trials of PHR effectiveness and sustainability for patient self-management are needed [10].

3. Discussion and conclusion

Self-management in the context of PHRs is a new and immature field. As many as 40 of 56 publications were published over the last four years (2010-2013), and 62.5 % of them were concept, system, pilot or study design descriptions, while only 37.5 % were evaluation of use, RCTs, or reviews. Nine studies described messaging functionality, eleven described shared access functionalities, and four described both. These functionalities are considered important for user adoption [4, 10, 11, 15], and together with the need for educational modules [11, 15, 16], these functionalities are required to realize self-management.

However, other functionalities also affect the adoption and use of PHR for self-management, and it might be challenging sometimes to explain adoption and non-adoption. The implementation and adoption of My Health Manager from Kaiser Permanente in US was quite successful, while the Health Space solution inspired by the Kaiser model was poorly taken up by the people in England [17]. In 2008, about 2.4 million had registered to use My Health Manager [18]. The solution was perceived useful and of good quality, both parameters being positive and significant predictors of actual usage [18]. The adjusted primary and specialist care office visit rates decreased 25.3 % and 21.5 % respectively, while the number of phone and e-mail contacts, consuming much less time, increased [19]. The adoption in England, however, was low, and the expected benefits were not realized [17]. The risk of being adopted or abandoned seemed to depend on that PHRs "align closely with people's attitudes, self management practices, identified information needs, and the wider care package (including organizational routines and incentive structures for clinicians)", p. 10 [17].

PHR has the potential to be a tool of great value to realize self-management and patient empowerment. However, as the results demonstrate, the field is still immature. General evidence remains sparse, and more studies on health effects and suitability are necessary.

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