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The Evolution, Use, and Effects of Integrated Personal Health Records: A Narrative Review

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Abstract

Objective: To present a summarized literature review of the evolution, use, and effects of Personal Health Records (PHRs). Methods: Medline and PubMed were searched for 'personal health records'. Seven hundred thirty-three references were initially screened resulting in 230 studies selected as relevant based on initial title and abstract review. After further review, a total of 52 articles provided relevant information and were included in this paper. These articles were reviewed by one author and grouped into the following categories: PHR evolution and adoption, patient user attitudes toward PHRs, patient reported barriers to use, and the role of PHRs in self-management. Results: Eleven papers described evolution and adoption, 17 papers described PHR user attitudes, 10 papers described barriers to use, and 11 papers described PHR use in self-management. Three papers were not grouped into a category but were used to inform the Discussion. PHRs have evolved from patient-maintained paper health records to provider-linked electronic health records. Patients report enthusiasm for the potential of modern PHRs, yet few patients actually use an electronic PHR. Low patient adoption of PHRs is associated with poor interface design and low health and computer literacy on the part of patient users. Conclusion: PHR systems that account for patient's needs and skills can facilitate their adoption. Common barriers are avoidable when patients receive adequate guidance on useful features as well as technical support. When implemented effectively, PHRs can increase patient participation in health management, and improve patient-physician communication and health related decision making.

Keywords: Personal Health Records; Electronic Health Records; Electronic Medical Records

1 Introduction

Involving patients in their health care using information technology (IT) such as interoperable personal health records (PHRs) may increase healthcare efficiency and improve quality while reducing medical errors [1]. The idea behind a PHR has existed for decades [2,3]. Initially, PHRs were in the form of paper medical records created and maintained by patients and used to augment healthcare provided in person [4]. These records, compiled and stored on paper by patients and families, allowed individuals to preserve their complete medi-

cal history [3]. As IT evolved, patients and families began to electronically store many health-related documents, including clinical notes from different health care providers, laboratory test results, and medication prescription records, essentially creating electronic versions of paper PHRs [3, 4].

Early patient-initiated PHRs have evolved into a wide variety of computer-based applications that allow patients to securely store health-related information such as laboratory test results; these can be maintained solely by patients or by both patients and clinicians [3, 5]. Currently, employers, healthcare providers, and third party organizations have deployed a variety of electronic PHRs differing in architecture and function [9, 10]. These PHRs range from original, stand-alone applications where patients enter the majority of their medical information to those integrated into the clinical health record [4]. In beginning to create standards for PHRs, the Markle Foundation's Connecting for Health Collaborative defined a PHR as "an electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment" [6]. Currently, an estimated 70 million insured patients have access to some form of electronic PHR and those who do not would like access [7, 8].

When integrated with provider-maintained electronic health records (EHRs), PHRs are electronically linked to clinical information in the EHRs, which are repositories of all electronically available patient medical information from multiple sources, and which are updated by health care providers [11,12]. With integrated PHRs, patients can view automatically populated medical information, such as laboratory test results [4, 9, 11]. They have advantages over stand-alone PHRs by allowing securely linked patient-provider communication outside traditional clinical encounters. Integrated PHRs provide a means to create a shared patient record through evolving features including patient-physician collaborative tools and interactive decision-making tools, personalized management tools for chronic conditions, integrated and linked health information resources, and patient-entered information [3, 4, 11, 13-16].

To inform healthcare decision-making, PHR development, and future research on clinical outcomes, this literature review summarizes the evolution, use, and effects of PHRs, with a focus on integrated PHRs. Four broad areas are address: (1) the characteristics of PHR use, including their evolution and adoption, (2) patient and provider attitudes toward PHRs, (3) barriers to PHR adoption and use, and (4) the effects of PHRs on patient management and outcomes.

2 Methods

Medline and PubMed were searched to identify English-language articles focused on PHRs and published between 1970 Ű 2011. Studies were included based on the content of titles and abstracts, removing those for which the abbreviation PHR did not stand for 'personal health record'. Of the 733 retrieved references initially identified in the search, 230 studies were selected as relevant based on initial title and abstract. Two independent reviewers (LRC and RH) screened these and a single reviewer (CRZ) verified the studies contained information regarding PHR evolution, consumer attitudes, barriers to use, and/or self-management through in-depth investigation of study content. Information from the final 52 papers, representing both qualitative and quantitative studies, was placed into four main categories: (1) the characteristics of PHR use, including their evolution and adoption, (2) patient and provider attitudes toward PHRs, (3) barriers to PHR adoption and use, and (4) the effects of PHRs on patient management and outcomes. Papers could contribute information to multiple categories (Tables 1-3).

3 Results

3.1 Evolution and Adoption of PHRs

Eleven papers described the evolution of PHRs and the settings in which they are used. Early examples of PHRs were paper-based and patient-maintained [3]. Use of paper-based PHRs has continued even after computerized information systems had become available. For example, parents have routinely collected their children's basic medical information and tracked their child's development and immunizations using baby books or have carried wallet cards containing basic personal medical data (i.e., emergency contacts, blood types and allergy information) [3,17]. Patients continue to keep some paper records despite the rise of electronic PHRs [18]. Currently almost half (42%) of Americans keep some form of a PHR, defined in this article as any single place where medical information is kept, and the majority (87%) are paper-based [19].

As IT developed, patients began creating digital rather than paper records. Electronic PHRs evolved as patients started entering their health information into computer-based applications [3, 4]. PHR functionality expanded to give patients the ability to view personal health information stored in their health care provider's records [4]. Web-based PHRs originated in the emergency room and included online emergency medical records [3, 5]. As practice and hospital-based EHRs

evolved, they merged with PHRs and have become a major source of the information contained within integrated PHRs. Patients now have access to integrated PHRs through their insurers or healthcare providers; however, patient adoption of PHRs has lagged behind this access. Preliminary estimates from the National Ambulatory Medical Care Survey (NAMCS) found that 51% of physicians reported providing patients with access to an integrated or partially integrated PHR (i.e. an electronic medical record (EMR) or EHR linked PHR) [20]. In a 2010 Consumer and Health Information Technology survey, however, only 7% of Americans reportňed having used either a stand-alone or an integrated PHR; a 2008 Markle Foundation survey reported fewer than 3% [13, 21-23].

3.2 Attitudes toward Adoption and Use of PHRs

Seventeen papers described patient or provider attitudes toward electronic and paper-based PHRs (Table 1). Patients are eager to use PHRs for their potential to improve health care delivery and outcomes but these positive attitudes do not translate into use [24-29]. Patients have mixed reasons for using or not using a PHR some of which are tied to their motivation to improve health outcomes and their relationship with their physician. Understanding patient motivation is important, particularly when designing and adopting PHRs [24]. Patients seek the ability to control access to their health information and believe they should have access [30, 31]. Patients view integrated PHRs favorably with one report finding that 60% of patients indicate they would use an integrated PHR to look up test results and record their medication, and another survey finding that 75% of patients would communicate with physicians electronically if given the option [8, 13]. Patients' motivation to participate in their health care fosters their interest in viewing their PHRs and viewing PHRs influences patients' care-related decision-making [24, 27, 32]. Diabetic patient users of an integrated PHR reported receiving care more quickly, and connecting with their doctor more easily [15]. An integrated PHR with features such as secure patient-physician messaging, medication history updating, and online requests for medication renewals was highly valued by elderly and disabled patients, patients with chronic conditions, and middle-aged female patients [33, 34, 35]. The ability to contact health care providers through secure messaging in an integrated PHR provided a feeling of security for patients in the Netherlands [26]. Patients want to view their records in order to have detailed information about their health, and those using an integrated PHR reported feeling more in control of their chronic conditions and a sense of illness-ownership, which motivated them to contribute information to their EHR [24, 27, 36]. Patients' satisfaction with their physicians influenced their use of an integrated PHR. Patients expressing satisfaction with their patient-provider relationship were less likely to use an integrated PHR than patients expressing dissatisfaction [25]. Those expressing dissatisfaction viewed access to their PHR as a means of gaining knowledge or control over their health.

Five studies reported on ease of use for patients accessing an integrated PHR [26, 28, 33-35]. More than 60% of patients with head or neck cancer in the Netherlands and the majority of middle-aged adult patients in the United Kingdom found an integrated PHR easy to navigate [26,28]. Female patients who used an integrated PHR rated various functions easier to use than males [33]. Several studies, however, reported that patients did not maintain health information in their PHRs despite ease of use. Elderly patients found value in using an integrated PHR for updating medications, health problems, and lab test information, yet failed to annotate certain health information such as immunizations and laboratory test results, which the authors attributed to difficulties with the user interface of the integrated PHR [34].

3.3 Barriers toward Adoption and Use of PHRs

Ten papers described patient or physician barriers to using electronic and paper-based PHRs (Table 2). A broad range of barriers to PHR adoption exists, many of which may be overcome by providing adequate technical support. Trends noted with paper-based PHRs, such as failure to document adult immunizations, laboratory test results, allergies and blood sugar, continued into electronic PHRs [17]. Difficult concepts, unfamiliar medical terms, and unknown abbreviations are commonly cited barriers [32]. Low computer literacy, low health literacy, and computer anxiety are additional patient-reported barriers in accessing electronic PHRs [37]. The time requirement for learning and, when information is not tightly linked between the PHR and EHR, entering personal health information into an electronic PHR system is problematic for patients as well as health care support staff [25, 37]. Nearly all breast cancer patients (98%) in one Canadian study required technical support when accessing their electronic PHR [38]. Barriers to using an integrated PHR included lost or unknown user names and passwords, and patients' lack of awareness of useful features [35].

Patients are better able to access and maintain a PHR when given tailored education, technical assistance, self-management support, consumer-friendly PHR interface

Authors/Year	Population	Design	Results	Implications According to Authors
Krist et al. (2012) 13	n=4,500, patient users of an interactive PHR (IPHR) from 8 primary care practices	EMR and survey data were analyzed to determine IPHR effectiveness	•Patients (25%) who used the IPHR were up-to-date on all services; double the rate for non-users	Practices need to inform patients about PHR's value and relevance to care
Witry et al. (2010) 16	n=28, physicians from 4 family medicine practices	4 focus groups to explore physician views of PHRs	•Physicians thought PHRs beneficial for certain patient populations (e.g., mobile populations) •Physicians expressed doubt about the likelihood of patients updating their PHRs	Providers are unfamiliar with electronic PHRs; physician use of electronic PHRs may increase with exposure
Tobacman et al. (1996) 17	n=100, patient users of a standalone PHR	Telephone questionnaire to determine acceptance, usefulness, and impact of PHR	•Adult patients were interested in PHRs	There is an unmet need among patients for PHR access
Winkelman et al. (2005) 24	n=12, inflammatory bowel disease patient users of an EMR linked PHR in Canada	Qualitative study using in-depth interviews and focus groups	•PHR access promoted a sense of illness ownership, healthy practices, and participation in illness management	Direct patient participation is crucial for developing and designing a PHR system
Zickmund et al. (2007) 25	n=39, diabetic patient users of an integrated PHR from 4 primary care practices	10 focus groups conducted to determine impact of an electronic PHR on patient-physician relationship	•Patients appreciated having access to lab results •Patients appreciated using the PHR to communicate directly with their PCP.	A good patient-provider relationship may diminish the perceived utility of a PHR
Brink et al. (2005) 26	n=36, cancer patient users of an electronic PHR and (n=36) general practitioners in the Netherlands	Questionnaires completed on PHR use after 6 week period	•PHR system was highly valued by patients •Patients (64%) reported increased knowledge of illness and treatment	Using electronic PHR in conjunction with clinical practice is recommended

Table 1: Attitudes toward Adoption and Use of PHR. (Continued on next page.)

Authors/Year	Population	Design	Results	Implications According to Authors
Jones et al. (1999) 27	n=783, general medicine and dental practitioners, and patient users of an electronic, stand-alone medical-dental PHR in the United Kingdom	3 part study: survey, randomized trial, and assessment of PHR records	•Patients felt positively about the PHR and recognized their role in maintaining information within •Dentists and doctors expressed positive attitudes towards the PHR	Patient's positive attitudes towards PHRs may increase after extended utilization
Pyper et al. (2004) 28	n=606, patient users of an integrated PHR in the United Kingdom	Postal distribution of questionnaire	•Patients concerned with the security and privacy of the PHR •Majority of patients wanted access to their records	The ideal PHR should be developed by a patient-physician partnership
Zayas-Caban et al. (2007) 29	n=7, patient users of a hypothetical PHR system	2-part interviews conducted to determine how well patients understand PHRs	•Adult patients expressed positive attitude concerning access to electronic PHR •Patients understood how they would use PHR to manage their health	Patients' needs should be addressed in the design of and education about PHRs
Cox et al. (2008) 30	n=1202, stakeholders, healthcare consumers, and patient users of an integrated PHR	Telephone, paper and web surveys plus focus groups assessed consumer's views	•Stakeholders trusted a PHR developed by a not-for-profit over one developed by government or private-sector organizations •Consumers expressed privacy concerns	A community outreach and communications program may inform the development of a PHR
Keselman et al. (2007) 32	n=103, chronic disease patient users of both paper-based and electronic PHRs	Survey to determine patient needs and experiences with their health records for optimizing PHR design	•Patients felt a secure, online PHR provided easy access to EHR •Patients felt medical records should be reviewed and discussed with health professionals to enhance patient comprehension	PHRs should offer the ability to view radiology reports, physicians' notes, and diagnostic images
Hassol et al. (2004) 33	n=1,421, patient users of an integrated PHR and (n=10) primary care physicians	Online survey and focus groups with patients; one-on-one interviews with physicians	•Positive patient reports on ease of use and satisfaction with PHR	PHRs improve efficiency and effectiveness of health care

Table 1: Attitudes toward Adoption and Use of PHR. *(Continued on next page.)*

Authors/Year	Population	Design	Results	Implications According to Authors
Kim et al. (2007) 34	n= 46, Elderly and disabled patient users of an electronic PHR	PHR database log analyzed to determine patient usage patterns	•Amount of activity by participants suggests that users found the electronic PHR valuable	Information for behavior of users/nonusers should be studied to optimize electronic PHRs for underserved populations
Hess et al. (2007) 35	n=39, patient users of an integrated PHR	Focus groups, patient's reactions to an electronic PHR in diabetes self-management	•Trusted, centralized health information was useful to patients •Participants most appreciated electronic communication feature and health-related management tools •Frequent users reported a sense of empowerment	Patients highly valued the secure, electronic messaging feature of the electronic PHR
Cimino et al. (2002) 36	n=13, patient and physician users of an integrated PHR	PHR log file, online questionnaire, and telephone interview data analyzed	•Patients felt increased ownership of their health •Patients were impressed with the PHR •Physicians reported improved communication with patients	PHR systems may improve health outcomes for select groups of patients
Wiljer et al. (2010) 38	n=250, cancer patient users of an integrated PHR in Canada	Log files analyzed to assess the impact of electronic PHR access	•Patients preferred receiving PHR support by phone as opposed to email	Optimizing PHR functionality may decrease human error
Pyper et al. (2004) 52	n=100, patient users of an integrated PHR in the United Kingdom	Interviews conducted to evaluate first-time patient-users' experience with an electronic PHR	•Patients found the PHR useful and easy to use	PHR access may improve patient care; requires additional resources to support future demand

Table 1: Attitudes toward Adoption and Use of PHR

design, and access to trained staff [4, 29, 32, 37, 38]. Implementing these support mechanisms may require additional resources. Patients battling cancer found learning how to use an integrated PHR system was not difficult after receiving personal instruction [26]. Integrated PHRs could alleviate comprehension barriers by providing online terminology support such as using a text translator to clarify medical terms [32, 39]. In addition, offering patients emotional, informational and/or tangible support when accessing EHR/EMR data may increase the perceived and actual utility of an integrated PHR [24].

3.4 Role of PHRs in Self-Management

Eleven papers examined patient use of electronic and paper-based PHRs in self-management (Table 3). PHR functions helping patients to better manage their health care allow them to enter, record, and track their own health information. Interactive features within EHR-linked PHRs have the potential to increase patient participation in illness management, improve patient-physician communication, and increase a patient's sense of illness-ownership [14, 32, 36]. As it stands, there is currently a lack of concrete evidence that PHRs fulfilled the expectations set for them. While several studies have reported on improved clinical markers for patients with chronic conditions using integrated PHRs, few have demonstrated effects on clinical outcomes [15, 23]. This may be due to the inherent complexity of conducting health IT research, the variability in characteristics and features of electronic PHRs from practice to practice, or the absence of agreement about the standard definition of a PHR [34, 41].

Patients with chronic conditions may have the most to gain from using integrated PHRs. Improvements in diabetes-related clinical markers have been reported in studies using PHRs that incorporated systematic, active interactions between patients and providers, including improved glycemic control and blood pressure [15, 42, 43]. Adult patients with type 2 diabetes using an integrated PHR were more optimistic about their chronic disease management and their relationship with their primary care physician [43]. Although patients appreciate viewing their medical records, some have a greater need to record daily personal health information in a PHR [44]. Providing patients with type 2 diabetes with the option to upload measurements such as blood glucose levels can enable physicians to make between-visit medication adjustments [15]. Physicians and patients from primary care practices in mainly urban settings regarded the integrated PHR as an essential component of care and a means to establish active patient involvement [45].

4 Discussion

Patients embrace the idea of PHRs, but adoption has been slow as patients lack the knowledge and training required to fully engage with integrated PHRs, and remain unaware of useful features [16, 35, 46]. Patients' understanding of integrative PHRs' value and relevance to care may increase patient adoption; therefore, practices may need to offer a wide range of materials and processes to inform patients [13]. Overall, patients prefer integrated PHRs due to privacy concerns and their desire to be connected to their doctors [7, 18, 47]. Patients report an interest in communicating with their providers and are less interested in adding health-related data [18, 47]. Specific features of integrated PHRs, such as the ability to look up test results and email physicians, appeal to patients, yet patients are deterred when confronted with unfamiliar medical terms and the need to memorize user names and passwords, or are lacking in health and computer literacy. PHRs will likely be more successful and effective when practices provide guidance to health care professionals in health record management and when patients receive both educational and technical support when accessing PHRs [29,46]. When used effectively, PHRs can engage patients in their health care, resulting in increased illness ownership and positive health outcomes. However, conclusive evidence of the clinical value of using PHRs is needed as studies have yet to demonstrate the effects of PHR adoption on clinical outcomes [18].

The ideal PHR actively engages patients in sharing and exchanging health information with their clinicians by offering a full spectrum of high functioning health IT capabilities to improve patient care and outcomes beyond the traditional clinical encounter. However, a consensus on what information to include in an integrated PHR has yet to be reached [18]. Some integrated PHR systems offer such functionality, but do not provide patients with all possible capabilities [48]. Future integrated PHRs will likely offer secure patient-physician messaging, incorporate decision-support systems, evaluate patents' needs using evidence-based guidelines, and contain applications that offer behavioral feedback and the capabilities for individualized recommendations [18, 35, 43, 48, 49]. Furthermore, the adoption of national standards for integrated PHRs will be necessary to ensure the integrity and long-term sustainability of PHRs [50]. The Certification Commission for Health IT has recommended certification for specific PHR features, including privacy, security, interoperability, and

Authors/Year	Population	Design	Results	Implications According to Authors
Tobacman et al. (1996) 17	n=100, patient users of a stand-alone PHR	Telephone questionnaire to determine PHR acceptance, usefulness, and impact	•Patients failed to record medical information	Patient use of a PHR may increased over time
Zickmund et al. (2007) 25	n=39, diabetic patient users of an integrated PHR from 4 primary care practices	10 focus groups conducted to determine impact of a PHR on patient-physician relationship	•Patients expressed privacy concerns with email feature •Patients who expressed satisfaction with their physician were less likely to want PHR access	Educating patients about e-mail security and offering direct provider e-mail may encourage patient use
Brink et al. (2005) 26	n=36, cancer patient users of an electronic PHR and (n=36) general practitioners in the Netherlands	Questionnaires completed on PHR use after 6 week period	•Patients (25%) encountered technical difficulties while using the PHR •General practitioners questioned PHR utility; the majority did not use the PHR	Integrated PHRs may increase patient and provider use
Keselman et al. (2007) 32	n=103, chronic disease patient users of both paper-based and electronic PHRs	Survey to determine patient information needs and experiences with their health records	•Lack of patient comprehension of medical terms/abbreviations, medical record information, and lab test results	Patients need carefully designed PHRs and comprehensive patient data
Hassol et al. (2004) 33	n=1,421, patient users of an integrated PHR and (n=10) primary care physician	Online survey and focus groups with patients; one-on-one interviews with physicians	•Patients reported problems with information accuracy and completeness in their medical records	Patient and provider needs are best met when EHR data is accurate and complete
Kim et al. (2007) 34	n= 46, Elderly and disabled patient users of an electronic PHR	PHR database log analyzed to determine patient usage patterns	•Patients did not fill certain fields in their PHRs with 'Immunizations' being the least updated information category	Analyzing system usage logs led to improvements of the studied PHR

Table 2: Barriers toward Adoption and Use of PHRs. (Continued on next page)

Authors/Year	Population	Design	Results	Implications According to Authors
Hess et al. (2007) 35	n=39, patient users of an integrated PHR	Focus groups, patient's reactions to an electronic PHR system in diabetes self-management	•Patients reported not knowing their username, password, and features included in access to PHR •Patients reported inaccurate information and missing lab results	Patients may abandon PHRs if their expectations are not met
Lober et al. (2006) 37	n=38, elderly, disabled patient users of an integrated PHR	Surveys distributed to measure patient barriers with an electronic PHR system	•Patients experienced computer literacy issues and computer anxiety •Cognitive impairments among participants affected their ability to maintain information in their PHRs	Patients could create and maintain PHRs with assistance from registered nurses
Wiljer et al. (2010) 38	n=250, cancer patient users of an integrated PHR in Canada	Log files analyzed to assess the impact of access to an electronic PHR	•Patients experienced technical difficulties and required technical support while using their PHRs	PHR access requires technical and healthcare staff support
Pyper et al. (2004) 52	n=100, patient users of an integrated PHR in the United Kingdom	Interviews conducted to evaluate first-time patient-users' experience with an electronic PHR	•Patients requested explanation of medical terms and tests/results •Patients (70%) found errors in their medical records	Patients need time and assess to support staff when using their PHRs

Table 2: Barriers toward Adoption and Use of PHRs

Authors/Year	Population	Design	Results	Implications According to Authors
Krist et al. (2012) 13	n=4,500, patient users of an interactive PHR (IPHR) from 8 primary care practices	EMR and survey data were analyzed to determine IPHR effectiveness	•Patients who used the IPHR increased uptake of preventative services	PHRs with high functionality may improve patient outcomes
Ralston et al. (2009) 15	n=83, type 2 diabetes patients using an integrated PHR	Case study to evaluate the success of an initiative targeting patient access to care	•Patients received care faster and easier •Connecting with physicians made easier •Patient glycated hemoglobin levels decreased	Diabetes patients benefit from care management features in PHRs
Tenforde et al. (2011) 23	n=21, published research articles on PHR adoption and attitudes, clinical outcomes, and existing PHRs.	Literature review of MEDLINE articles on PHRs (published between 2000-2010)	•Affects PHR access on patient outcomes difficult to determine •Study limitations included lack of patient blinding and generalizability •Studies show inconsistent improvement in diabetes care with PHR access	Although evidence supporting PHRs, clinical value is limited; PHRs may empower patients in self-management
Winkelman et al. (2005) 24	n=12, inflammatory bowel disease patient users of an EMR linked PHR in Canada	Qualitative study using in-depth interviews and focus groups	•Having the patient's voice guide EMR structure promotes a sense of illness ownership •A PHR that supports self-care is most useful for patients	A useful PHR is customizable, provides informational, emotional, and tangible support
Brink et al. (2005) 26	n=36, cancer patient users of an electronic PHR and (n=36) general practitioners in the Netherlands	Questionnaires completed on PHR use after 6 week period	•PHR detected patient problems undiscovered during regular visits •General practitioners (61%) expected health IT to play an important role in oncology care	An elderly, relatively computer illiterate patient group could use and appreciate the value of a PHR
Keselman et al. (2007) 32	n=103, chronic disease patient users of both paper-based and electronic PHRs	Survey to determine patient needs and experiences with their health records for optimizing PHR design	•Desire for health self-management prompted patient interest in PHRs •Viewing PHRs resulted in patient engagement in care-related decisions and actions	Optimization of PHR functionality will enable patient participation in health care
Kim et al. (2007) 34	n= 46, elderly and disabled patient users of an electronic PHR	PHR database log analyzed to determine patient usage patterns	•Patients (96%-100%) updated their medications and recorded past and present health problems •Free-text field was used to record questions, note, and reminders	Interactive features in integrated PHRs are important and useful for patients

Table 3: Role of PHRs in Self-Management. (Continued on next page.)

Authors/Year	Population	Design	Results	Implications According to Authors
Cimino et al. (2002) 36	n=13, patient and physician users of an integrated PHR	PHR log file, online questionnaire, and telephone interview data analyzed	•Improved interactions with health care providers •Patients reported taking a more active role in their healthcare	Access to PHRs enhanced patients' understanding of their conditions and improved communication with their physicians
Grant et al. (2005) 42	n=244, diabetes patient users of an integrated, diabetes-specific PHR	Randomized control trial among 11 primary care practices	•Patients who used the PHR were most likely to modify their medication regimens	Integrated PHRs may facilitate medication initiation and dosage adjustment, leading to improved clinical outcomes
Holbrook et al. (2009) 43	n=511, type 2 diabetes patients using an integrated PHR in Canada	Questionnaires to evaluate PHR use	•Patient optimism increased in the intervention group compared to control •Patients in the intervention group were satisfied or more satisfied about their diabetes care after using the PHR	PHRs may contribute to improvements in blood pressure and glycated hemoglobin levels
Ventres et al. (2006) 45	Unknown, patients and physicians using an electronic PHR	An ethnographic study including participant observation, interviews, and taped encounters, to identify factors influencing physician and patient use	•PHR use enhanced patient-physician communication •Patient concerns were influenced by their level of comfort with computers •Physicians expressed frustration about the time needed to learn how to use the PHR	The effects of introducing PHRs into clinical practice may not be universally positive; consideration of factors influencing how PHRs are viewed and used in medical practice is advised

Table 3: Role of PHRs in Self-Management

functionality [51].

Multiple studies have examined patient attitudes towards PHRs and usage among special populations. Specific patient populations, such as those with chronic or multiple illnesses, may benefit directly from integrated PHRs, which could motivate continued use [18]. However, current evidence demonstrating the benefits of PHRs in chronic disease management is lacking. The existing evidence showing that PHRs have value is restricted to diabetes management [15,35,42,43]. Patients in developed countries with diabetes tend to utilize PHRs more than healthy patients [15,35,42,43,47].

Studies examining the effects of age, race, ethnicity, and sex on patient attitudes and usage have been inconclusive, demonstrating effects of these variables in some comparisons but not others [7, 18, 34, 37, 47]. Factors such diagnosis, age, gender, and country of origin may account for the reported variation. Patient motivations for using a PHR are tied to and highly influenced by the patient-physician relationship, physician attitudes toward PHRs [16, 25,18,47], and the desire for illness ownership [16] and control over the dissemination of medical information [25, 28, 30, 31]. Patients are likely to adopt, use, and value an integrated PHR that is user-friendly [34, 26, 28], provides a high level of privacy and security [25, 30], and offers advanced features such as messaging, editing, and medication renewal capabilities [33, 34, 35]. Patient adoption and use will increase as health IT developers integrate patient feedback in the development process.

This review includes several limitations. First, the majority of studies included in this review were authored in the United States. However, 13 of the 52 papers selected were authored outside the United States, including five from Canada [18,24,38,41,43], four from the United Kingdom [14,27,28,52], and the remaining from Spain [11], Serbia [12], Germany [10], and the Netherlands [26]. Second, biases in the literature include small sample size [15, 42], non-random, self-selected samples [25, 30, 32], and limited ethnic, racial, and socioeconomic diversity [13, 15, 28,33,42,52]. Only one paper included nonŰEnglish speaking participants [45]. Finally, although we have discussed many of the important findings and themes in the literature, it was not possible to detail every factor affecting PHR evolution and adoption, patient user attitudes toward PHRs, patient reported barriers to use, and the role of PHRs in self-management.

5 Conclusion

Integrated PHRs have the potential to improve the patient-provider relationship, enable shared decision-making, and allow the healthcare system to move toward a more personalized healthcare delivery system. Integrated PHRs will have a broader impact on public health as they evolve higher levels of functionality and as physicians increase PHR adoption [13]. Since 2012, the federal government has given over $5 billion to providers and hospitals for the adoption and meaningful use of qualifying PHRs [47]. Beginning in 2014, providers and hospital are required to make PHRs available to 50% of patients and achieve an adoption rate of 10% [47]. Incentivizing providers and hospitals to adopt and become meaningful users of EHRs will provide more patients with the opportunity to use PHRs. However, the available evidence demonstrating that PHRs can support their intended use is insufficient as the existing literature on PHRs is limited and inconclusive [7, 18]. Further patient- and physician-focused research on factors affecting PHR adoption and frequency of use is needed to improve PHR functionality, inform health IT development, and determine what motivates patients to not only adopt but to continue using PHRs.

Conflicts of Interest

No potential conflict of interest to report.

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