REVIEWS

Patient accessible electronic health records for the chronically ill: a review of the literature

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Abstract

Background: Consumers with chronic conditions account for approximately 70% of all healthcare spending. The Chronic Care Model is a healthcare paradigm whose purpose is the achievement of improved patient outcomes by facilitating the delivery of patient-centered, evidence-based care. We conducted a review of the literature to examine the role patient accessible electronic health records (PAEHR) may play in implementing and supporting the Chronic Care Model.

Methods: A review of the literature was conducted using multiple databases (1950-2012). Publications included in the review were restricted to those using experimental or quasi-experimental methodology, English language and peer review.

Results: Published results indicated that PAEHR facilitated improvements in health literacy and patient-provider communication, and that personalization of content was viewed favorably. Research on the use of PAEHR by some disease groups suggests improvements in clinical outcomes.

Conclusions: The literature reviewed indicated that the patient experience for individuals with chronic illnesses could be enhanced through access to PAEHR. Improved satisfaction was noted for individuals with access to PAEHR with personalized content (e.g. lab results etc.). Use of PAEHR also improved patient-provider communication and increased personal knowledge and comprehension concerning individual condition and state of health. PAEHR for individuals living with chronic illnesses are an effective management technique that can help patients better manage the challenges of living with a chronic illness. These results indicate PAEHR have the potential to be a key component for actualizing the theoretical constructs of the Chronic Care Model by providing a platform for increased patient-provider collaboration.

Key words

Medical records systems, Computerized, Internet/online systems, Patient access, Patient access to records

1 Introduction

Chronic conditions have been defined as those disorders needing continuous or periodic management over a period of years or decades [1]. These include non-communicable conditions (e.g., cancer, diabetes, and cardiovascular disease), persistent communicable conditions (e.g., HIV/AIDS), long-term mental disorders (e.g., depression and schizophrenia) and ongoing physical impairments (e.g., arthritis and amputations) [1]. Due to their assiduous nature and need for ongoing monitoring and treatment, chronic conditions account for a dominant proportion of healthcare resource spending throughout the world and as such have been described as the healthcare challenge of the 21st century [1, 2] and is reported to reduce economic growth of a country by 0.5% with every 10% increase in the rate of chronic disease [3]. The management of chronic conditions is associated with increasing healthcare costs [4] and, in Canada, it is estimated that these costs accounts for 70% of all healthcare spending [5]. The increasing prevalence of chronic conditions, coupled with a struggling overburdened healthcare system [6] requires management solutions that can produce positive results both clinically and economically. The Chronic Care Model (CCM) is one strategy that evidence suggests may result in lowered costs and superior care [7-9].

Traditionally, chronic conditions were treated by practitioners, working in isolation according to acute episodic need, resulting in care that is splintered, unsystematic and unnecessarily replicated [10]. The CCM is a health services operational paradigm whose purpose is the achievement of improved patient outcomes by facilitating the delivery of patient-centered, evidence-based care [7, 9]. Fundamental to the CCM is the implementation of changes to decision support, delivery system design, clinical information systems and self-management support [7, 8]. Altering these elements in order to benefit physician-patient communication, increase information sharing and enhance patient understanding will improve overall patient education and allow for the optimization of patient self-management and a greater coordination of care [7]. One tool that may be useful in supporting a broader adoption of the paradigm shift for the delivery of care for chronic illness is the patient accessible electronic health record (PAEHR).

The PAEHR is an extension of the electronic medical record (EMR) or the electronic health record (EHR). The EMR and EHR provide an alternative to the standard paper-based medical documentation used by physicians in hospitals and independent practices, and commonly include an electronic record of patients' lab tests, diagnostic reports, medical images, and attending physician clinic notes. Traditionally these electronic documents were only accessible to the healthcare team. A review published in the Journal of Healthcare Engineering sites that implementation of an EMR in an institution has the potential to reduce economic burden, improve administrative processes and input requirements, and improve overall healthcare quality [11]. The existence of EMR/EHRs enable the institutional PAEHR, which is a digital rendering of a person's medical data and health information that is maintained by a hospital or other healthcare institution, however it can be accessed by both the individual and healthcare professional via a secure electronic portal [12].

Equipping healthcare consumers with ease of access to their personal health information may help in increasing their involvement in the self-management of their chronic condition [12]. In turn, this has the potential to positively influence the consumption of healthcare resources such that improved efficiencies and cost savings are realized [13]. Leonard et al. have identified consumers with chronic conditions (3C) as the most logical and necessary users of PAEHR [5]. This group of patients is estimated to encompass 40% of the population; they are inspired consumers of health information and the nature of their conditions support a consistent need to access health records over the long-term [5]. To determine both patient and provider tolerance for the adoption of PAEHR for the management of chronic illnesses a review of the literature was conducted to explore the impact of patient access to electronic health records on the patient experience for individuals living with chronic illness.

2 Methods

Articles for review were identified through a search of on-line databases, the personal collections of the authors and reference lists of relevant publications. Databases searched included Medline (1950-2012), EMBASE (1980-2012) and CINHAL (1981-2012). The search strategy, developed in consultation with a medical librarian, was first established in Medline using an appropriate combination of medical subject headings (MeSH) and keywords for the concepts of electronic health records and patient access. These headings and keywords were then modified appropriately for the remaining databases. In addition, non-indexed citations were searched via the Medline in Process database using free text converted from the pertinent subject headings mentioned above. Terms related to chronic conditions were not included in the search strategy in order to prevent a narrowing of the search and the subsequent loss of articles as a result of the criteria's inability to capture conditions, such as cancer, which are not traditionally thought of as chronic. This requirement was screened for manually during the independent review.

The initial search to retrieve all relevant articles was performed by a medical librarian. The titles and abstracts of the papers captured by the search were critiqued for potential inclusion by three reviewers independently (NKQ, KS, NA). Those citations labeled for possible inclusion underwent a detailed examination of the full text article to determine their suitability. Disagreements were resolved either by the achievement of consensus or, if required, by discussion with a fourth reviewer (SU).

All studies reporting on the usage and effects of patient access to electronic health records were assessed. All articles investigating patient access to paper records, opinion-gathering research on patient access without giving access to records, papers granting access to electronic reminders exclusively and those involving assisted access to patient portals were excluded. All non-English language papers, non-peer reviewed publications, review articles, news items and newspaper articles were also excluded. Included studies encompassed those employing a systematic approach to data collection in order to assess the impact of the use of PAEHR by patients diagnosed with one or more chronic conditions.

3 Results

From the 1872 studies returned and queried from the initial search, 22 were found to meet the inclusion criteria. Six studies were designed as randomized trials [14-19], 12 utilized quasi-experimental methods [20-31], two papers presented case studies [32, 33] and the remaining paper employed observational methodologies [34]. The majority of research was conducted in the United States [15, 17-19, 21- 23, 27, 30-35]; other papers were from the United Kingdom [14, 33], The Netherlands [20], Italy [26], Peru [24], Norway [25], South Korea [16] and Canada [28, 29]. Most of the sample populations were drawn from outpatient settings linked to a hospital or medical centre. Diabetes [16, 18-23, 25, 32-34] was the most prevalent chronic condition investigated; the remainder included cancer [14, 28, 29, 31], congestive and congenital heart disease [15, 17, 35], HIV/AIDS [24, 27], hypertension [36] and haemophilia [26]. Many of the studies involved PAEHR with features beyond simple access to information, such as patient entry of data [16, 18-29, 31-34] and patient-provider messaging systems [15, 17, 19, 21-24, 32, 33, 36]. The data from the included studies was coded and 5 themes emerged: 1) determinants of use by healthcare consumers, 2) barriers to adoption, 3) the patient experience, 4) clinical outcomes and 5) use of resources.

3.1 Determinants of use by healthcare consumers

Information regarding the determinants of use was categorized as being related to user characteristics, PAEHR content or time.

3.1.1 User characteristics

Four U.S. based trials reported higher frequency of PAEHR usage among Caucasian [15, 18, 27, 34], non-Hispanic [15, 27] and younger [18, 27, 34] participants. Zickmund et al. reported on a connection between patient dissatisfaction with the patient-provider relationship and increased interest in the use of PAEHR [23]. Two studies reported that users who logged in more frequently were of superior health status [18, 27], while a third reported contrary findings as the users in their study experienced more symptoms and had more visits with providers [15]. Burke et al. found participants were significantly more likely to login to their PAEHR while in hospital as opposed to post-discharge [35].

3.1.2 Content

Patients were more likely to access PAEHR if the information provided was personal as opposed to general [14] and were less likely to access chronic disease consumer education pages in contrast to personal data [17]. Four studies with automatic log file tracking reported that laboratory results were one of the most commonly viewed pieces of information [15, 17, 19, 27] while features involving patient input such as psychological profiles, feedback questionnaires or comment fields were generally the least accessed tools [20, 27, 33]. Data from patient questionnaires revealed that 98% of the HIV/AIDS patients from one study reported accessing the lab results with 88% finding the feature to be useful [27]. Wiljer et al. reported that, while 98.4% of participating breast cancer survivors perceived a benefit from online access to laboratory results, only 64.8% of the participants reported viewing their lab data online [29]. Images as opposed to textual data were most commonly accessed by participants in a study by Burke et al. involving surgical patients with congenital heart disease [35].

3.1.3 Time

Usage appeared greatest within the initial months following activation of patients' accounts or introduction to the PAEHR. Ross et al. noted that, among people suffering from congestive heart failure, site visits were highest in the first 3 months [17]. Khan et al. reported a median duration of continued intermittent access of 6 months among HIV/AIDS patients [27]. In regards to continued access, Earnest et al. documented interest in maintaining a connection with the PAEHR among 85% of study participants at the trial's end [15]. While Jones et al. noted at follow-up that 80% of the cancer patients in their study (intervention and controls) preferred meeting directly with a healthcare provider rather than through access to computer or booklet information; participants from the intervention arm were more likely to choose the electronic record [14]. Participants in one study said that using the PAEHR was, simply, time consuming [36].

3.2 Barriers to adoption

Comprehension of medical information, privacy issues, computer literacy and reliability of technology were cited as potential challenges related to the use of PAEHR by healthcare consumers. Greenhalgh et al. cited difficulty with adoption and experienced a high rate of abandonment, which authors believe is due to the poor design and implementation of the system, as well as poor timing (i.e. UK health consumers were not ready for PAEHR) [33].

3.2.1 Comprehension of medical information

Patient comprehension of medical terminology and health-related information has been identified as a challenge to PAEHR use. Papers by De Clercq et al. and Earnest et al. documented patient difficulties with understanding medical terminology [15, 20, 36, 31]. Several groups advocated for an edited version of the electronic medical record that provides explanatory information [15, 23, 29] or a glossary of medical terms [31] and is easier to understand for use by patients [15, 24].

3.2.2 Privacy and confidentiality

Two citations indicated that issues regarding confidentiality and privacy were not major concerns among the patient populations studied [15, 23]. Zickmund et al. noted that the diabetic patients in their study failed to observe the improved security provided by the portal in the form of encrypted e-mail [23]. 31% of the participants in the paper by Kahn et al. disagreed with the statement that the electronic information provided was confidential [27].

3.2.3 Computer literacy and reliability of technology

Zickmund et al. identified computer literacy and the need to learn new applications as barriers to the widespread use of PAEHR [23] and Wagner et al. noted that older generations may have lower computer literacy which can impact PAEHR adoption [36]. Common to many of the studies was that participants reported either owning their own computer or having easy access to a computer [15, 16, 19, 20, 23]. In addition they were frequent users of the internet [24, 29] with a high degree of computer literacy among study participants [26]. Qualitative data suggests that most participants found the applications easy to use [20, 26, 27, 29, 31], however, technical issues related to accessing and navigating the applications did exist [28, 29, 33, 36] and were a significant source of frustration in some cases [21]. Technical problems resulted in many patients asking for process improvements, access to an online support service [29] and streamline login procedures [24]. Data from Wiljer et al. revealed that the support needs of breast cancer survivors accessing PAEHR were not clinical but in fact revolved around technical issues such as logging-in and resetting passwords [28]. Similarly, studies by Hess et al. and Kahn et al. identified forgotten user names and passwords as impediments [22, 27, 29] to accessing PAEHR. Goldberg et al. found that technical issues prevented some diabetic patients from utilizing the electronic record to a significant degree [32]. Greenhalgh et al.

report that the abandonment of their PAEHR system is likely due to flawed design and implementation, making the system frustrating and difficult to use for patient participants [33].

3.3 The Patient experience

Access to the PAEHR was identified as having an impact on the patient experience. The experience was impacted by: 1) PAEHR functionality and its relationship to patient satisfaction, 2) the patient-provider relationship, 3) patient empowerment and self-efficacy and 4) self-management of chronic conditions.

3.3.1 Functionality related satisfaction

In general, satisfaction ratings related to patients' experiences with PAEHR were relatively high [26, 27]. A randomized trial involving cancer patients found that those participants with access to personal as opposed to general electronic health information had greater levels of satisfaction and were more likely to find the information relevant [14]. Khan et al. and Wiljer et al. demonstrated that in post-intervention responses study participants reported that having access to their laboratory results online would be helpful [27, 29]. In addition, several papers reported that participants found the ability to access laboratory results via the electronic record to be both more efficient [15, 21, 23, 32] and anxiety reducing [15, 21, 32] in comparison with traditional methods. Jones et al. found that the percentage of cancer patients exhibiting anxiety after 3 months of electronic health record access decreased in the personal information group and was unchanged in the general information cohort [14]. Data from a pre and post-intervention self-report anxiety measure showed an insignificant decrease in the mean anxiety scores of breast cancer survivors accessing their electronic health record online [29].

Another feature users appeared to value was the ability of the PAEHR to act as a memory aid [15, 22, 32]. The electronic record was useful as a vehicle to support the recollection of provider conveyed information during office visits [15] as well as a system for reminding patients about upcoming appointments [22] and the need for regular and follow-up care [32].

3.3.2 The patient-provider relationship

Zickmund et al. reported on concerns of participants that use of the electronic health record would jeopardize both their current mode of communication and the relationships they had developed with their providers; and were therefore apprehensive to use the technology [23]. Three studies recorded patient frustrations when abnormal results were not followed-up by providers [21] or results were either absent [29] or their posting was delayed [27]. One study reported patient expectations from the physician, particularly in what is reported and made available for viewing [36]. However, those participants actually accessing the PAEHR felt that communication with their health care professionals improved [15, 17, 22, 31], their concerns were better understood [17] and health issues were more highly valued [21]. Specifically, participants acknowledged that the ability to correspond electronically with their healthcare providers improved communication by opening up access [21, 23] and reducing response times to messages [23]. Also, the PAEHR was found to give participants the sense they were better prepared for medical appointments [27, 29, 31] and had a stronger patient-provider bond by enhancing the patients' feelings of security [21, 32]. Participants perceived the provider as a support who is continually monitoring their condition, ready to take action if required [21, 32]. Goldberg et al. and Ralston et al. both concluded that PAEHR create an environment that allows for a collaborative relationship where providers and patients can work together to co-manage the patients' chronic conditions [21, 32].

3.3.3 Patient empowerment and self-efficacy

A number of studies have commented on participants' perceptions that PAEHR provide a greater sense of control over one's condition and therefore act as a mechanism for empowerment [15, 22, 23, 27]. Several papers have also documented subjects' claims that access to the electronic health record helped them to understand and learn more about their chronic disease and health in general [14, 15, 20, 22, 29, 31, 32]. Some participants observed that the computer provided information was limited [14] while others noted that increasing the information provided by the PAEHR would help them to control their diabetes better, leading the authors to consider information sharing between patients as a means to promote patient empowerment [25]. Objective analysis has failed to demonstrate significant changes in participant self-efficacy scores from pre to post-intervention [17, 29].

3.3.4 Self-management

There have been many studies indicating that accessing the PAEHR resulted in patients feeling more deeply invested in their healthcare and therefore better able to manage their chronic illness [15, 20, 21, 27, 29, 32]. Specifically, participants noted that use of the electronic health record helped them to track the progression of their disease [15, 21, 36] and strengthened their efforts at self-coordinating care [15, 22, 36]. A randomized trial performed by Ross et al. found a statistically significant increase in patient compliance with medical advice and a non-statistically significant improvement with adherence to medication when compared with controls [17].

3.4 Clinical outcomes

The majority of research examining the effects of PAEHR on clinical outcomes originated from studies involving participants with diabetes mellitus [16, 18, 19, 32, 34]. Grant et al. reported increases in the number of patients receiving medication adjustments in the PAEHR-intervention group as compared with control [18, 32]. Three randomized trials reported improvements in glycosylated hemoglobin (GHb) when participants were given access to their PAEHR [16, 18, 19]. Ross et al. reported no significant change in health status and no adverse effects attributable to the use of electronic records by patients with congestive heart failure [17]. Results from one study [34] suggest that portal use may be used as an indicator of HbA1C, though the authors cautioned that the clinical significance of their finding needs to be further examined [34].

3.5 Use of resources

The literature suggests that the effects on resource utilization resulting from PAEHR access corresponded to 5 main areas: i) in-person services, ii) patient generated messages, iii) workload, iv) training and v) financial cost.

3.5.1 In-person services

No significant differences were found in the number of office visits [19, 22], or the rate of hospitalizations [17] or total inpatient days [19]. Ross et al. reported an increase in the number of emergency room visits by intervention arm participants but noted that they did not appear to be chronologically related to use of the PAEHR [17]. The intervention participants in Kwon et al.'s study accessed the PAEHR in lieu of 2 to 3 outpatient visits to the diabetes center [16].

3.5.2 Patient generated messages

While the number of electronic messages sent and total correspondence involving participants accessing their PAEHR was higher, there was no significant change in the number of telephone messages received by clinicians' offices [15, 17, 22]. Issues dealing with medication and appointment scheduling accounted for 49% of the correspondence from diabetic patients in Ross et al.'s paper [17] and Wiljer et al. found that technical concerns involving site access, logging in and resetting passwords for example, were responsible for 98% of the contact with breast cancer survivors in their study [28].

3.5.3 Workload

In order to off-set the expected increased workload Ralston et al. and Goldberg et al. utilized a case management model employing a nurse practitioner [19, 21, 32] who self-reported spending, on average, an extra 4 hours per week responding to patient messages and updating the care plans of the 42 intervention arm participants [19]. Others reported lower figures. In Ross et al.'s study [17] it was 5.6 minutes per participant per year that nurses spent answering computer messages and 10.5 minute average per query was required to deal with activation key issues in the paper by Wiljer et al. [28]. Pattacini et al. commented that the PAEHR compensated for the increased workload by providing patient related information generated by participants in an electronic format, thereby circumventing the need for data transcription [26]. Hess et al. noted improved efficiencies resulting from the use of asynchronous communication between the provider's office and the patient with respect to scheduling, medication renewals and the dissemination of lab results [22]. The providers and support staff from three studies reported that, while the total number of messages received from participants accessing their electronic health record was greater, there was seemingly no increase in workload [15, 17, 22].

3.5.4 Training

Several studies made reference to the need for training for participants and/or staff [15-17, 19, 24, 26-29, 32, 35]. The degree of training varied from a 6 hour course [26] to a brief introduction [29], with participant training most commonly provided by case managers or clinicians [19, 26, 29, 32, 35]. Three papers also mentioned the provision of a user's guide [15, 17, 26].

3.5.5 Financial cost

Ralston et al. reported that the technology behind their web based system had a relatively low financial cost and was already being used by many participants for other daily applications [19]. Jones et al. calculated that, when linked to an automatically populating electronic medical record, the personalized health record would cost the equivalent of the general health information system which in turn would be 40% less than the cost of printed booklets [14].

4 Discussion

The literature reviewed indicated that the patient experience for individuals with chronic illnesses could be enhanced through access to PAEHR. Improved satisfaction was noted for individuals with access to PAEHR with personalized content (e.g lab results etc). Use of PAEHR also improved patient-provider communication and increased personal knowledge and comprehension concerning the user's condition and state of health. PAEHR used in this manner are an effective management technique that can help patients better manage the challenges of living with a chronic illness [7, 30, 31]. Patients and physicians who have agreed to participate in a year long PAEHR trial, referred to as the OpenNotes project, were surveyed before the start of the intervention to understand their views and expectations in using PAEHR [30]. Patient responses to this pre-intervention survey suggest that participating patients anticipate PAEHR access will let them better understand their health condition, feel more in control of their care, more prepared, better able to remember their care plan, and better able to self-manage their condition [30].

There are a number of characteristics that PAEHR should possess in order to reduce barriers to adoption and maximize patient engagement. Foremost among these is the requirement that the electronic record must be easy to use. Access initialization and content navigation should be intuitive and straight forward, with a support mechanism in place to help with technical questions [28]. Technical support should be reachable via telephone and/or the internet so that technical issues encountered by users could be easily remedied. In addition, information in the PAEHR should be personalized and, where appropriate, include laboratory results. Furthermore, comprehension of information in the PAEHR may be facilitated by use of simple language [24], multi-lingual interfaces, pictures or images and the provision of a glossary of terms, legend or data key [15]. Use of a patient-provider messaging system and patient reminder application would make use of the electronic record more attractive to patients.

There is inconclusive evidence as to the effectiveness of the use of PAEHR on clinical outcomes. A review of papers examining clinical outcomes strongly supports the use of PAEHR as part of the management strategy for diabetes mellitus, however this review failed to provide conclusive evidence on clinical outcomes associated with other non-diabetes mellitus chronic conditions.

The effect of PAEHR usage on overall resource utilization is a difficult parameter to quantify. While electronic record programs will no doubt require additional resources including staff and patient training, infrastructure and technical staffing; the cost and supply benefits of the PAEHR, realized through process improvements and enhanced patient health status, are somewhat enigmatic. Physicians participating in the OpenNotes Project anticipate that they will spend time responding to patient questions outside of regularly scheduled visits and spend more time finalizing their visit notes, however they feel that patients will be more satisfied with their care and better able to self-manage their conditions [30]. Therefore, PAEHR implementation is perhaps best approached with a view to providing superior patient-centered care rather than as a means to reduce financial costs or workload.

A number of limitations should be taken into account when considering the results of this paper. The heterogeneity of PAEHR components and capabilities, such as messaging systems and patient data entry, reduces the generalizability of the outcomes of our study. As a literature review, publication bias is an ever-present concern. Our review of non-indexed material may have provided some protection from this issue. Lastly, our sample size may be misrepresented by the fact that several of the 22 papers included corresponded to findings from a single body of work such that, in essence, only 17 different PAEHR were reported on.

5 Conclusion

The PAEHR is an important tool in the promotion of patient self-management for health care consumers living with chronic illnesses. The use of PAEHR by this population has the potential to enhance the patient experience while improving clinical outcomes and minimally impacting resource utilization. There is inconclusive evidence concerning the effects on healthcare providers' attitudes and practices; non-diabetes mellitus related clinical outcome measures; and objective indicators of changes in patients' behavior. In order to maximize the positive impact on the patient experience and increase support for the chronic care model through the endorsement of chronic disease self-management, the electronic record should be simple to use, contain personalized information that is easy to understand and allow for the efficient communication of both provider and patient-generated health data.

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