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Benefits and Barriers for Adoption of Personal Health Records

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ABSTRACT

A Personal Health Record (PHR) is an electronic, universally available, lifelong resource of health information maintained by individuals. There are numerous potential benefits to PHRs, including improved patient-provider relationships, increased patient empowerment, and enhanced care safety, efficiency, coordination, and quality. However, privacy, security, cost, and adoption issues have been significant barriers to implementation. The purpose of this research was to determine how the use of PHRs affects patient outcomes, as well as to analyze benefits and barriers of adoption of PHRs. The methodology for the examination of the benefits and barriers to PHR implementation was conducted following the basic principles of a systematic review. From a total of 144 initial references 76 sources were deemed suitable for use in this research study. A series of issues have been repeatedly listed as key barriers to the use of PHRs by patients and physicians including, privacy and security concerns, costs, integrity, accountability, and health literacy. PHRs have given control to the consumer and have provided patients with autonomy and empowerment. Full intent of functionality and use of PHRs will occur when patients and providers believe the information is safe, accurate, reliable and applicable for improving health.

Key Words: Personal Health Record, Usage, Adoption Barriers, Empowerment

INTRODUCTION

While there is no universally accepted definition of a Personal Health Record (PHR), Caligtan and Dykes (2011) have defined (PHR) as an electronic, universally available, lifelong resource of health information maintained by individuals (RWJF, 2009). This definition infers the responsibility of content of PHRs rests with the patient. This, however, does not always hold true. The PHR is often used interchangeable with but separate from the Electronic Medical Record (EMR). The ownership of the PHR can be the patient, provider, or healthcare organization (Caligtan & Dykes, 2011).

According to AHIMA (2010) there are several key factors which comprise a PHR. The healthcare consumer should always have access to all health information and data must be complete, reliable, and accurate. The patient should be in command over how health information is accessed, used and disclosed. Additionally, the information contained in the PHR must be timely in nature. Finally, a PHR does not replace the patient's official medical record. It remains

a separate document from the medical record, but can integrate information from the official medical record.

The American Recovery and Reinvestment Act (ARRA) was enacted on February 17, 2009 and included actions to modernize the country's infrastructure, one of which is the Health Information Technology for Economic and Clinical Health (HITECH) Act (Dimick, 2009). The HITECH Act supported the concept of Meaningful Use of EHRs (CDC, 2012). Meaningful Use is the set of standards defined by the Centers for Medicare and Medicaid Services (CMS) Incentive Programs that govern the use of EHRs and allow eligible providers and hospitals to earn incentive payments by meeting specific criteria within three stages (CMS, 2013). Each stage of Meaningful Use (MU) has listed objectives of health goals to be met. The Patient Engagement Framework (PEF) as outlined by the National *e*Health Collaborative [N*e*HC] are aligned with MU Stages. During MU Stage 2 and the PEF "Engage Me" phase, interactive patient electronic forms for scheduling appointments and refilling prescriptions are promoted. The PEF phase "Empower Me" aligned with MU Stage 3 and pushed for increasing healthcare consumer involvement in decision making by expanding patient access to HER (CMS, 2012; HIMSS, 2014; N*e*HC, 2012). The PHR falls under the objective to engage patients and families with healthcare (Kannry, Beuria, Wang, & Nissim, 2012). Although not specifically stated, the PHR has appeared to be the tool to make this participation possible (Tang & Lansky, 2005).

There are three main PHR architectures: tethered PHRs, integrated PHRs, and standalone PHRs. Tethered PHRs are linked to a specific provider or healthcare institution and cannot be shared between systems (Nazi, Hogan, McInnes, Woods, & Graham, 2013). Functions of a tethered PHR generally include a medication list, problem list, test results, list of allergies, and links to personalized health information as well as communication tools where patients can e-mail the physician, schedule appointments, and request prescriptions (Bates & Wells, 2012). Additionally, tethered PHRs are read-only and patients do not have the option to edit the information contained within (Nazi, et al., 2013). Integrated PHRs are directly connected to the provider's Electronic Health Record (EHR) and are interoperable among other systems, allowing patients to view the medical record as documented by the provider and give patients the option to share this personal information (Detmer, Bloomrosen, Raymond, & Tang, 2008). Standalone PHRs are maintained by the patient or a third party, such as an insurance company (Maloney & Wright, 2010). Data provided by the third party can be added by the patient and, in some instances, can be modified by the patient. Standalone PHRs cannot be shared with healthcare institutions, even though they can be downloaded to a storage device (Tang & Lee, 2009). There have been numerous web-based portals, such as Microsoft HealthVault, that has been released by the Information Technology (IT) private sector (McCartney, 2008). Web-based portals allow consumers to build a health profile by creating a username and password and importing medical records from allowable partners. Additionally, it provides guidelines for vaccines as well as the option to connect to monitoring devices and health videos and articles (McCartney, 2008).

There are numerous potential benefits to PHRs, including improved patient-provider relationships, increased patient empowerment, and enhanced care safety, efficiency, coordination and quality. However, privacy, security, cost, and adoption issues have been significant barriers to implementation (Fetter, 2009).

PHRs have a vast array of potential benefits to both patients and providers. The information incorporated into PHRs ranges from laboratory results or radiology images and reports to home measurements of blood pressure and blood glucose levels (USNLM, 2014). PHRs not only store data to the patient in a way which can be comprehended, but also offers a large body of healthcare information regarding interpretation of the results and actions that should be performed (Scherger, 2005). Through this process, PHRs may empower patients to take a more active role in the management and prevention of disease. Another benefit available through PHRs is alerts, including the need to refill a prescription or schedule a doctor's appointment (Gearon, 2007).

PHRs have had a major impact not only on patients, but also with healthcare providers. PHRs can help to reduce the amount of information missing in verbal communication between patients and providers (Versel, 2011). Through this, PHRs may not only reduce healthcare costs, but also improve the quality of care being provided and over all patient safety. While PHRs offer many benefits to both patients and physicians and other providers, there are still several concerns associated with its use (Bourgeois, Taylor, Emans, Nigrin, & Mandl, 2008).

The purpose of this research was to assess how the use of PHRs affects patient outcomes, as well as to analyze the benefits and barriers of adoption of PHRs.

METHODOLOGY

The methodology for the examination of the benefits and barriers to PHR implementation was conducted following the basic principles of a systematic review. The literature review followed the steps and research framework utilized by Yao, Chu, & Li (2010).

The use of this conceptual framework in the current study is appropriate because the focus of both studies is to show how new technologies (PHRs) can be applied to healthcare settings (hospitals and outpatient medical clinics) to enhance the care of patients, as well as this approach has been successfully replicated in previous studies, supporting its internal validity (Coustasse, Tomblin & Slack, 2013; Deslich & Coustasse 2014; Studeny & Coustasse, 2014). This framework was utilized to allow clear identification of the benefits of PHR and barriers to implementation of PHR in the healthcare delivery system. To research problems involving the current processes in the healthcare delivery system, it was first necessary to recognize the existing problems and issues that drive and impede adoption of electronic PHR by healthcare providers. Figure 1 illustrates the progression to the implementation of PHR and identifies the recognition of both benefits and barriers to its adoption.

INSERT FIGURE 1

The study was conducted in three stages: (1) identifying the literature and collecting the data, (2) analyzing and evaluating the literature found, and (3) categorizing the literature.

Step 1: Literature Identification and Collection

The key phrases 'Personal Health Record' or 'PHR' were combined with the terms 'use' or 'utilization' or 'adoption' or 'implementation' or 'benefits' or 'barriers' as inclusion criteria to search online scholarly databases for articles. Databases included EBSCOhost, PubMED, Academic Search Premier, ProQuest, Business Search Premier, LexisNexis, and Google Scholar. Information from the government websites of the Centers for Medicare & Medicaid Services, My PHR, and Modern Healthcare was used for updated statistics and data regarding PHRs.

Step 2: Literature Analysis

Literature was selected for review on the basis of governmental acts, Meaningful Use, and benefits and barriers to PHR implementation. Given that use of PHRs has been growing in recent years due to legislation and incentive programs, the search results were limited to those published between 2005 and 2013, attempting to stay current in research studies, and limited to English only. Only primary and secondary data from articles, reports, reviews, and research studies written in the United States (U.S.) were included in this research. References were reviewed and determined to have satisfied the inclusion criteria if the material provided accurate information about PHR with particular attention on benefits and barriers to its implementation. The literature search was conducted by BT and BV and validated by AC who acted as a second reader and also double checked if references met the research study inclusion criteria. From a total of 144 initial references, 76 sources were deemed suitable for use in this research study.

Step 3: Literature Categorization

Abstracts of the articles were reviewed first to determine the relevancy of the data to the study. If academic articles and studies were found to be relevant from the abstract reviews, the data were analyzed and categories were generated based on the findings. The findings are presented in subsequent sections of the results, which are 'Benefits of Using Personal Health Records' and 'Adoption Barriers of Personal Health Records'.

RESULTS

User Profiles of Personal Health Records

In a research conducted by Forsyth, Iedema, Lassere, and Maddock (2009), patients who were currently active in decision making about their own health already recorded some health information. The patients were comfortable carrying health information and took some responsibility for their health. Patients who were passive about making choices regarding their health did not see a need to carry their information. This type of patients' communication with their physician was adequate (Forsyth, et al., 2009).

According to Hickner, Jain, Nowacki, and Tenforde (2012), PHR users were younger, had greater incomes and higher education, and were identified as non-Hispanic whites. Patients who had lower income and education with chronic illnesses were more likely to report benefiting from using a PHR. Zieger (2010) found that 55% of patients without a college degree stated that

after using a PHR, patients asked providers questions which would not have been asked otherwise. Among users with incomes of less than $50,000, 58% reported experiencing an improved relationship with physicians as a result of using a PHR. Furthermore, 40% of PHR users with multiple chronic conditions reported taking steps in improving their health (Zieger, 2010).

A survey conducted by Barron, Dhopeshwarkar, Edwards, Kaushal, and Sparenborg (2012) found the majority of respondents regarded the following factors of electronically sharing medical records as either essential or highly important: viewing protection (98%), ability to see who viewed their data (93%), capability of selecting which elements of their medical record can be shared (81%), and the option to avoid sharing information electronically (86%). Sixty-nine percent of respondents thought approval must be required before another individual viewed their personal health data. The survey reported consumers who were more likely to use PHRs demonstrated certain characteristics. These consumers shared personal data over the Internet, previously performed healthcare-related activities online, and believed PHRs would increase protection of private health information, Engaged consumers believed PHRs would improve safety and/or quality of their care considered easy to use websites as important for online health services, or had a college education (Barron et al, 2012).

Terms like repression, denial, narcissism, avoidance, and response development are acknowledged as possible hidden reasons why many individuals do not devote much time focusing on their health information (Roop, 2007). The fact is most people do not like pondering illness, infirmity, and mortality, even when it may benefit them. Tracking an investment portfolio will always be more enjoyable than using a PHR to track blood pressure (Roop, 2007).

According to Duriseti, Greenwald, Kooshesh, Ma, & Menon (2012), many physicians are agreeing to use PHRs, but physicians differ by practice, location, and gender. Furthermore, female, suburban physicians, those with higher patient volume practices, and those serving Medicaid and average or increased numbers of minorities had decreased probabilities of willingness to use PHRs. Meanwhile, surgeons, obstetricians, psychiatrists, international graduates, minority physicians (particularly, self-reported Asians), those with any knowledge of using an EHR, and physicians in group practices all had an increased odds of willingness to use PHRs (Duriseti, et al., 2012). Rural physicians and those employed by hospitals had significantly higher odds of usage (Lemieux, Torres, & Wynia, 2011). Physicians working in the Emergency Room/Department were highly likely to utilize a PHR if it was available, though the physicians did not want to spend more than several minutes interacting with the system. Additionally, the physicians were more willing to use the technology for patients with multiple medical problems and those with a higher illness severity (Duriseti, et al., 2012).

Benefits of Personal Health Records

The Markle Foundation (2008) conducted a survey which found four in five adults thought PHRs would provide a benefit for managing their health. Kahn et al. (2010) performed a study on PHRs use which identified that 80% of PHR users believed it helped them better manage their health problems. Rosenberg, Shnaiden, Wegh, and Juster (2008) piloted a study that showed by sending clinical alerts to patients patient compliance was increased by 12.5%.

The researchers reported clinical alerts concerning monitoring, screening, and diagnostic tests to patients, compliance in these areas increased by 26.4% (Table 1).

INSERT TABLE 1

PHRs have provided greatest benefits for individuals with multiple or chronic conditions and in emergency situations where first responders can be provided critical medical information (HRSA, 2013a) (Table 1). According to a survey conducted by Wuerderman et al. (2005), 78% of patients surveyed reported PHR usage provided them opportunity to offer physicians valuable health information. Sequist, Zaslavsky, Colditz, and Ayanian (2011) found patients who received reminders from physicians through their PHRs about colorectal screenings had higher screening rates by 8.3% at one month than those who did not. Among patients who viewed the electronic message, 30% were more like to be screened compared to those who did not use a PHR (Table 1). According to Kahn et al. (2010), PHRs have the ability to provide patients with a plethora of valuable information. These authors conducted a study which found access to laboratory results, information about specific health conditions, and healthcare resources in the community were useful to 80% to 90% of the patients. PHRs have proven to be a vital resource for patients seeking additional health information to help to make crucial health decisions and guide clinical outcomes (Pagliari, Detmer, & Singleton, 2007). According to Hufnagel (2009), PHRs enhanced patient safety, quick care delivery and improvement in quality of care. In financial terms, in 2008, PHRs were estimated to save in between $13 to $21 billion in annual potential benefit savings to the U.S. healthcare system (Kaelber & Pan, 2008) (Table 1). One of the most profound benefits perceived with the increased use of PHRs was the encouragement of patients to take a more active role in their care, which promotes a healthier lifestyle, improves efficiency of care, and helps to reduce healthcare costs (CCIT, 2009).

Physician Benefits Associated with PHR Use

Heise, Asche, and Oderda (2011) conducted a study on the use of PHRs and found 74% of physicians thought PHRs could improve patient safety. This same study reported that 40% of physicians suggested PHRs could improve efficiency and help reduce healthcare costs. The same authors found 81% of physicians thought PHRs would increase patient involvement in their care. Additionally, Wynia, Torres, and Lemieux (2011) performed a study focused on physicians' views of PHRs which identified 53% of physicians utilizing PHRs relayed it increased the quality of care. Finally, in 2010, Witry, Doucette, Daly, Levy, and Chrischilles surveyed 28 family practice physicians and found a majority of physicians believed certain features of PHRs such as up-to-date medication and allergy lists were useful in improving patient safety.

Barriers to Personal Health Records

A series of problems have been repeatedly listed as the key barriers to the use of PHRs by patients and physicians including, privacy and security concerns, costs, integrity, accountability, health literacy and legal and liability risk (Aleman, Senor, & Toval, 2010; HRSA 2013b). Kahn et al. (2010) found that 31% of patients did not believe that the information in their PHR was confidential (Table 2). Electronic PHRs have presented a problem to individuals who are

illiterate, do not know how to use a computer, or do not have access to a computer (CCIT, 2009). Kim et al. (2007) conducted a study on the use of a PHR in 46 elderly individuals and found 50% used the PHR only once and did not complete all areas of it. Additionally, Kim et al. (2009) performed a study on an elderly population which revealed of 13% of the participants who used the web-based PHR, 80% of these individuals required assistance. In 2011, Yamin et al. conducted a study which divided PHR users into categories based on their Socio Economic Status (SES). These authors identified individuals classified as high SES used the PHR 86% more than those in the low SES category.

The most recognized barrier to using PHRs is the risk of security or confidentiality breaches, since not all parties have legal or ethical obligations to respect the privacy of patients. When physicians are distressed about the reliability of the information held in PHRs, the integrity of these products have been questioned. Tang et al, (2006) reported the PHR may threaten control, autonomy, and authority of some providers (Table 2). Moreover, PHR vendors have dealt with a difficult balancing act around integrity and what it means to the consumer and provider. Many consumers want total control over what information shows up in the PHR and who gets to view it; yet if physicians believe a PHR is inaccurate or incomplete and if physicians are denied the option to share it with colleagues consulting on the case, then physicians will be less likely to utilize the information. The intent of technology will not accomplish the benefits it should (Dunn & Wynia, 2010). Similarly, patients and physicians are unable to share PHR information across organizations because of interoperability issues (Emani, et al., 2012). While coding standardization has developed, logistics of implementing transparent interoperability across disparate systems has remained an enormous, daunting task (Table 2).

Quality of data is paramount to making PHRs useful for both providers and healthcare consumers (Robeznieks, 2007). There has been questioning regarding the degree to which individuals should be able to control access and the form this control may take. Some PHR systems have allowed users read-only access, while others have given total power to the user (Fernández-Alemán, Señor, & Toval, 2012).

With regard to cost, patients have been able to access and manage a PHR free of cost the majority of the time Kaelber, et al., (2008a) found the net value of provider tethered and third party PHR architectures to the U.S. healthcare system could range from a loss of $29 billion to a cost savings of $11 billion annually while the cost to install existing PHR architectures for 80% of the U.S. population for provider tethered PHRs could exceed $130 billion (Table 2). Additionally, annual costs have been estimated around $43 billion dollars with a break-even point of approximately 59,000 active users (equivalent to a practice size of roughly 30 full-time providers) for provider tethered PHRs (Kaelber, et al, 2008a). The time required to examine the PHR, add information to it, and use it in medical decision making is also not free. Additional costs can be associated with PHR data which may be incomplete, inaccurate, or difficult to verify, resulting in liability concerns for physicians (Dunn & Wynia, 2010). The cost of the PHR may be counterbalanced by improved health activities and decreased administrative fees which may transform into reduced healthcare costs (Aulakh, et al., 2009).

Physician Risks Associated with PHR Use

Yau, Williams, and Brown (2011) conducted a qualitative study on ten family practice physicians and found one of the most frequently addressed concerns with the use of PHRs was the accuracy of the information provided. According to Wynia et al. (2011), about 79% of physicians had apprehensions regarding the accuracy of information patients placed in their PHRs (Table 2). Witry et al. (2010) conducted a survey on 28 family care physicians which found validity of the information in PHRs was voiced as one of the top concerns. In 2011, Heise et al. revealed that 94% of surveyed physicians stated accuracy of information as one of their main concerns (Table 2).

Another of the most frequently addressed issues in regards to the use of PHRs has been the possibility of an increase in the physician's workload (Kaelber Jha, Johnston, Middleton, & Bates, 2008b). In the Heise et al. (2011) study evaluating physician's feelings towards PHRs, the authors found 100% of the physicians involved were concerned about the increased workload associated with the use of PHRs (Table 2). Additionally, Yau et al. (2011) performed a survey on ten physicians and found increased workload to be one of the most frequently addressed issues.

Fears of lack of reimbursement have led to hesitation in adoption of PHRs by some physicians (Etzoini, 2010). In the Wynia et al. (2011) study concerning physician use of PHRs, it was found that 63% of physicians were concerned about not be reimbursed for the time spent updating PHRs (Table 2). Finally, Yau et al. (2011) identified lack of reimbursement for PHRs use as one of the main concerns of the physicians surveyed.

Another barrier to the adoption of PHRs by physicians has been uncertainties of the extent to be held accountable for the contents of the PHR and treatments performed based on the information (Wynia & Dunn, 2010). Wynia et al. (2011) conducted a study regarding physician views of PHRs and found 79% of physicians were concerned PHRs may contain incorrect information, and an additional 76% feared they would be liable for that information.

INSERT TABLE 2

DISCUSSION

The purpose of this research was to examine the effect of the use of PHR, as well as to analyze the benefits and barriers of adoption or use of PHR. The results of the literature review have suggested although there were several benefits identified with patient use of PHRs, the results of this research study suggest multiple concerns have also emerged regarding patient utilization of PHRs.

Multiple factors, including education level, income, age and gender, can influence health literacy. Even with the potential benefits of PHRs, access may not be dispersed equitably. Low health literacy is particularly frequent among elderly individuals, those with a chronic illness or disability, those who are poverty stricken, non-English speaking individuals, and persons with a mental illness, all who may be less able to capture the benefits of PHRs (Burke & Torpy 2011). To value the total potential of PHRs, patients must be able to understand the information. Low

health literacy is constantly linked with more hospitalizations; increased emergency care usage; fewer mammography screenings and influenza vaccines; poorer ability to exhibit proper medication intake; poorer ability to understand labels and health messages; and, among elderly individuals, poorer overall health status and increased death rates .(Berkman, Crotty, Donahue, Halpern, Sheridan, 2011). These characteristics have resulted in the indication patients need tools to aid them in understanding and interpreting the contents of the PHR to improve understanding of the medications, terminology, and diseases, which can lead to the capability to improve their health by using the information (Fottler, Noblin, & Wan, 2012).

Emani, Williams, and Yamin (2011) found that non-Hispanic blacks and Hispanics, who normally receive poor-quality health care in the U.S., also have less frequently adopted the PHR. Possible explanations may include computer literacy, awareness and alleged benefits of the PHR, and Internet access. Also, statistics on Internet access nationwide have shown a gap, with minority racial/ethnic groups less likely to have Internet access compared with non-Hispanic whites.

With the rapidly evolving field of healthcare technology, PHRs have emerged as a novel way for patients to manage their own healthcare and improve their personal health. Multiple surveys studies found that the majority of patients thought that PHRs would be beneficial in assisting them to better manage their healthcare information. PHRs allow the patient to become more involved in their care. PHRs have had a major impact on not only patients, but physicians as well. Research identified that PHRs act to empower patients to take an active role in their care, which improves the efficiency and overall quality of care. One of the greatest benefits perceived by the physicians surveyed was the increase in patient safety associated with the use of PHRs. Many providers have yet to even attempt the implementation of electronic record-keeping. While studies revealed that physicians perceived PHRs as a useful resource, it was also found that some reservations existed in regards to the impact it may have. As the research has shown, the use of PHRs was regarded as having the potential to increase physician workload, while providing no additional reimbursement. Furthermore, multiple studies found that physicians had reservations to be liable for the information contained in the PHRs, including inaccurate information that may have been added by the patients. Healthcare has not been as rapid as other industries to adopt this type of IT. Numerous reasons, from privacy constraints to cost, are given for the holdup (Yoffee, 2008).

Along with privacy concerns, providers also have concerns with the integrity of the PHR. Despite how secure patient-entered PHR data is, it is still not data from the official medical record. Some physicians have been concerned with the reliability of data in a PHR since the technology was first introduced to consumers. However, these same physicians, just like most physicians, would rely on the same data given by a patient verbally. That contradiction aside, questions linger as to how physicians can guarantee the medication list and other information in a PHR is correct (Goedert, 2009).

This literature review is not without limitations. The heterogeneous quality of literature, research bias, and publication bias may have affected the availability and quality of the research. Also it was out of the scope of this review to perform a systematic review with very stringent

criteria and to measure the effect or to weigh sources for comprehensive accurateness, and reliability given the very different quality of data.

An important policy implication of PHRs is the protection of online health information and the development of tools for secure data exchange. Consumers who adopt PHRs will require that the information be private and protected, ownership lie solely with the consumer, that storage and use of the data be approved by the consumer, and that the data be easily portable and in a format that is clear. These functions will allow consumers to obtain advice and receive information to determine their best health options. The policy changes that will likely lead to improved consumer adoption of PHRs include expanding PHRs' functionality, establishing PHR information standardization, facilitating the secure exchange of health information, improving consumers' access to PHRs, and help consumers understand the information contained in a PHR (Aulakh, Bosworth, Kahn, 2009). Many providers, payers, and policymakers have supported the use of PHRs, but further research is required to evaluate the barriers to implementation and to support patients in adoption and use.

CONCLUSION

The success of PHRs will hinge on whether PHRs benefits outweigh the barriers which rests on the success of the healthcare organizations, providers and information technology being able to engage patients. Low engagement population groups need to be targeted to establish a confidence level guaranteeing confidentiality, information control and collaborative information sharing.

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Promote Adoption

| Benefits |

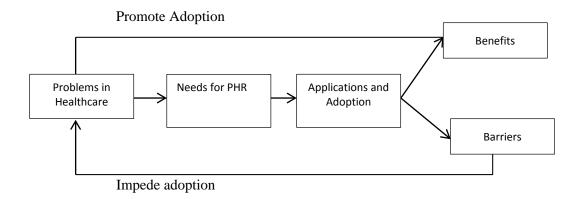| Problems in Healthcare | → | Needs for PHR | → | Applications and Adoption |

| Barriers |

Impede adoption

Figure 1:   Research Framework: Use of PHRs