College Students’ Exposure to and Perceptions of Online Personal Health Records

ABSTRACT

Personal Health Records (PHR) have the potential to place the patient at the center of healthcare information exchange and empower patients to become the stewards of their own health data. Yet, few investigators have examined patients' exposure to and perceptions of PHRs and none those of the college-age cohort.

For this randomized cross-sectional pilot study, we utilized a repeated-measures crossover design to compare college students' (N=33) exposure to and perceptions of two online PHR tools: Google Health and Microsoft HealthVault. Respondents evaluated these tools on six survey subscales: computer self-efficacy, value, ease of use, confidentiality, satisfaction, and intention of long-term use. None of the participants reported previous exposure to PHRs. The mean scores indicated that the students marginally favored Google Health over Microsoft HealthVault in five out of six subscales, but no statistically significant differences emerged between the two. Most participants had positive perceptions of both PHRs, although they were hesitant to commit to long-term use.

This study provided valuable information on participants' exposure to and perceptions of two major web-based PHR systems in preparation for launching the idea of keeping

PHRs in a college health setting. Future researchers might explore barriers to long-term use, as well as how to prepare college students for keeping their own health records.

Keywords: personal health records, electronic health records, Google Health, Microsoft HealthVault

INTRODUCTION

A Personal Health Record (PHR) is an electronic health record that an individual creates and maintains. Personal health records (PHRs) can enhance the flow of health care information by allowing instant access to vital health information in emergencies, and also when individuals are away from their primary care providers (PCPs). Patients who suffer from chronic diseases that necessitate ongoing monitoring, such as cancer, HIV/AIDS, rheumatoid arthritis, osteoarthritis, diabetes, hypertension, and heart disease, may benefit the most, as PHRs provide easy online accessibility to health information with patient portals and educational tools tailored to the needs of specific disease states.

PHRs have the potential to play a significant role in health care interoperability by enhancing multidisciplinary communication among providers. Since individuals own their PHRs, they have control over what content is posted and can grant permission to individuals for access to their health information. Typically, PHRs include core health information such as personal and demographic information, current health issues, insurance information, medical history, family history, medications, allergies, and laboratory and radiographic test results. Some also include advanced directive forms, spiritual affiliation, and lifestyle habits. The potential for PHRs to contribute to public health initiatives, such as monitoring disease outbreaks, has not been explored but one can imagine use in monitoring of health status of populations, assisting in management of disease outbreaks, empowering individuals to take control of their own health, and contributing to research. [1]

SIGNIFICANCE OF THE PROJECT

In spite of the aforementioned notable potential benefits, consumers have been slow to adopt PHRs[2]. In a July 2004 Harris Interactive online poll of 2,242 U.S. adults, 42% of the respondents reported keeping personal medical records.[3] .However, the vast majority of those did so on paper. Little has changed in terms of PHR adoption in the past several years. According to the IDC Health Insights' survey of 1200 consumers in February, 2011, only 7% of respondents reported ever having used a PHR, and fewer than half of these (47.6%) were still using one to manage their family's health.[4] Interestingly, 50.6% of the respondents to a study on consumer adoption of PHRs reported that the reason they had not used the online technology was lack of familiarity with the concept of a PHR.[2] Few investigators have examined exposure to PHRs and patients' perceptions of PHRs. No studies appear in the literature whose authors investigated these variables in the college age population.

College students often are away from their primary care providers for the first time, have fragmented health records, and may rely on their parents or others to manage their health information. Using a PHR could provide young adults a context within which to better understand their health and make more informed health care decisions. Since this population is by necessity learning to become more independent and develop health behaviors and habits that will have implications for their future well being, it is an opportune time for healthcare providers to discuss the importance of health records and the shift toward taking responsibility for stewardship of personal health information. Further, such discussions may motivate these individuals to take charge of their health and make better lifestyle choices and other preventative decisions.[4]

PURPOSES

The purpose of this study was to examine college students' exposure to online PHRs and to compare their perceptions of the two major online PHR systems Google Health (Google, Mountain View, CA) and Microsoft HealthVault (Microsoft, Redmond, WA). Each serves as a secure repository for patients to store, retrieve, and manipulate their own health records. Both include uploading and storage of health records, as well as search engine capabilities. These PHRs are available free via the Internet and are based on a business model of attracting more users to advertising-based web sites. It is important to note, however, that since completion of this study, Google Health was discontinued as of January 1, 2012. Users have been given until January 1, 2013 to download data stored in Google Health.[5]

The study questions were: (1) To what extent have college students been exposed to PHRs? (2) What are college students' perceptions of Google Health and Microsoft HealthVault? (3) How do college students' perceptions of Google Health and Microsoft HealthVault differ? Six subscales were used to measure perceptions: computer self-efficacy, subjective satisfaction, perceived value of service, ease of use, confidentiality, and intention of long-term.[6, 7 ,8,, 9, 10]

LITERATURE REVIEW

According to data from research conducted by the California Health Care Foundation, over 60% of health care consumer respondents wished that their providers had more time to talk to with them about their health status and that of their families.[11] More than half of the consumers also reported difficulties in keeping track of their health information. Using PHRs helps individuals organize categories of health information.[11]

PHRs are beginning to emerge as an increasingly popular topic in health care settings including student health services and in the electronic health (e-health) movement. Empowering consumers to take charge of their health, and to be collaborative partners with their health care providers, requires that consumers have access to *their* health information. Today, many institutions allow patients to access their electronic health records (EHRs). Consumers are signing up for electronic access, not only to their EHRs, but also for communicating with their health care providers via email, online appointment scheduling, and prescription refills.

PHRs permit all health information to be stored securely and consolidated into an easily accessible account that can help consumers to become more informed and active in managing their own health care. However, there is no exact definition for PHRs, since they are continuously evolving. Current PHRs comprise one of four basic models: 1) provider hosted patient portal; 2) payer hosted patient portal; 3) employer sponsored; and 4) vendor hosted[4]. Each serves as a secure repository for patients to store, retrieve, and manipulate their own health records. All models include uploading and storage of health records, as well as search engine capabilities. These PHRs are available free via the Internet and are based on a business model of attracting more users to advertising-based web sites. P**HRs are standardized according to the American Society for Testing and Materials International (ASTM) I designation.**[12] T**he ASTM International Continuity of Care Record (CCR) denotes the main elements of electronic records by specifying a structured electronic format in XML coding to ensure interchangeability of CCRs across platforms. CCRs create a snapshot of patients' health data including personal and demographic information, emergency contacts, insurance information, problem lists, medications/allergies, immunizations, laboratory reports and tests, hospitalizations/surgeries, advanced**

directive forms, spiritual affiliation/considerations, and care plans.[12]

PHRs may also include insurers' claims data, clinician electronic health records (EHRs), pharmacy records, laboratory results, and patient entered data. Some PHRs also include clinical decision support systems and a variety of convenient applications such as appointment scheduling, referral requests, medication refills, and online billing payment. Patients can store health information obtained from a number of sources; upload information from health and fitness devices; provide information to multidisciplinary providers, schools, and trainers; and access a myriad of emerging social media. [13]

PHRs afford consumers the opportunity to become more active participants in their care since they can create, access, manage and maintain their own health care records. As heath care reforms evolve and more consumers become strategic partners in their health care, it is likely health care delivery models will change. One of the major catalysts catapulting the consumer movement is the World Wide Web. Health care information and knowledge are no longer just in the hands of health care providers. The Internet has democratized access to knowledge and created a new generation of net savvy consumers.[12, 13, 14, 15]

PHRs will create new opportunities to increase collaboration of care and foster partnerships between providers and patients. Providers will be able to link tailored health information based on a patient's medical condition(s), thus providing more patient-centric, individualized care. It is anticipated that this may lead to patients achieving a better understanding of their health problems, health care responsibilities and disease management strategies. According to the Markle Foundation, the majority of consumers would like to use a PHR to help them understand their providers' instructions more clearly.[16] Forker-Dunn discussed the next generation of health care delivery systems and the growth of a generation of net savvy patients. She posited that the eHealth train has not only left the station, but is rapidly moving down the track carrying tens of millions of e-patients and many possibilities for transforming patient self-empowerment, improving health outcomes and enhancing the patient–clinician relationship.[14]

Ferguson and Frydman described the first generation of e-patients and noted that e-patients have "better health information and services and have different, not necessarily better, relationships with their providers." (17 p..1148) Although PHRs hold the promise of empowering patients by making patients stewards of their health care data, it is not clear how consumers will become incentivized to do so. There are no financial incentives in the United States for patients, providers, or payers to encourage self-care management, with or without electronic support. However, financial incentives to providers and primary care teams for prevention and for meeting expected guidelines in patient-centered medical homes might encourage behavior change toward more active support of self-management and PHRs.

The potential for PHRs to contribute to public health initiatives such as monitoring disease outbreaks, has not been explored but one can imagine use in monitoring of health status of populations, assisting in management of disease outbreaks, empowering individuals to take control of their own health, and contributing to research[18]. A first step, however, is encouraging individuals to keep their own PHRs. In order to make this possible, providers need to address some important barriers to full adoption.

BARRIERS TO IMPLEMENTATON OF PHR

The notion of patient ownership, control, and storage of data continues to be hampered by major unresolved issues in PHR adoption. Traditionally, providers have been legally responsible for recording and safely storing accurate and timely patient care health records. Some of the unanswered questions that continue to inhibit more widespread use of PHRs include the following: 1) How much provider-generated information do patients have a right to view? 2) What if a patient's providers do not agree to share information? and 3) How will patient entered data be incorporated into providers' electronic records? For example, will blood pressure or glucose readings from home and from a variety of caregivers and care settings be populated in the same portion of the database? [8]

Currently, there are no stipulations to guide how access to and interoperability of PHRs will be provided. These are critical issues to solve, as most consumers' medical records are scattered in many different locations with a variety of providers. PHRs vary in their content, scope, source of information, owner, location of the record, technical approach and access to the record. Unfortunately, to date most PHRs are not standardsbased and few support an easy way to transport records between PHR products. Security concerns are also a potential barrier to widespread PHR adoption. The Markel Foundation reported that the majority of people in their research studies believe that technology provides adequate security protection and they would not be reluctant to use PHR features.[16] In a Harris poll, almost two thirds of respondents were most concerned about privacy and security.[3] . Other concerns were potential error, access to their information in an emergency, and inability to keep their information up to date. Further, respondents did not want their PHRs managed by their insurance companies or the government. However, they reported trust in their physicians to host, manage and access their PHR.[18] Lack of computer literacy also represents a significant barrier to widespread PHR adoption, but less so in a college population as most college students are computer literate, as they are required to be by the education institutions.[8]

Thus, there will need to be a significant socio-cultural paradigmatic shift to address the challenge of instituting the ubiquitous use of PHRs (u PHRs). Issues of software incompatibilities with PHRs and thus lack of interoperability with an institution's EMRs must be addressed. Nurses, as the largest number of knowledge workers in US health, will need to receive sufficient continuing education in order to become part of the PHR movement and become involved in educating the public. Finally, ethical issues, especially those of security and privacy protections must continue to be addressed by proponents of PHR for both consumers and providers.

METHODOLOGY

Study Design

For this randomized cross-sectional study, the research team utilized a repeated measures crossover design and created a 45-item survey instrument to assess participants' perceptions of the PHR tools, their prior exposure to PHRs, and demographic information.

Sample and Setting

The target study population included undergraduate and graduate students enrolled at a small university in New England. The target accrual for this pilot study was 30 to 40 participants.

Informed Consent

The university's Institutional Review Board (IRB) granted approval for the study. Participants completed the surveys in the privacy of their homes, responses were completely anonymous, and the researchers had no access to the participants' personal health information. The waiver of consent was thus supported, so informed consent was implied for students who completed and returned the survey to the researchers.

Study Instrument

A crossover design was utilized to reduce any potential effects of viewing one PHR before the other. The self-administered survey instrument was adapted from previously validated tools in the literature and included the following factors to elicit perceptions: computer self-efficacy, perceived value of service, ease of use, confidentiality, subjective satisfaction, and intention of long term use.[6-10; 13]

The survey included 38 items to assess perceptions, two questions to determine exposure to PHRs, and five demographic items. A 7-point Likert scale (1= strongly disagree, 7= strongly agree) was used for all perception questions, so participants could indicate the degree to which they agreed or disagreed with each statement. Internal consistency reliability testing was completed on each of the 6 subscales using Cronbach's alpha. See Table 1 for the items for the constructs/subscales in the survey instrument.

Data Collection

With the permission from university professors, the principal investigators presented the study to potential study participants in the classroom setting. They described the study to students using standardized handouts and a brief PowerPoint presentation. Standardized presentations enhanced the consistency of communication between the researchers and study participants. Presentations included information such as study objectives, eligibility criteria, the risks and benefits of participation, confidentiality, and a participant's right to withdraw from the study at any time without the risk of penalty or repercussion. Participants were also informed that their classroom grades would in no way be affected by their willingness or refusal to participate in the study. Following each presentation, students were allowed time to ask further questions about participation. Surveys and study information were then distributed in a randomized fashion (Group A or Group B) to potential participants.

Study Plan

Participants enrolled in this study were randomly assigned to one of two groups to avoid systemic bias. Participants in Group A went online, created a PHR using Google Health, and completed the survey assessing their demographics, previous exposure to PHRs, and perception of the online system. Next, these participants created a PHR using Microsoft HealthVault and completed a survey assessing their exposure to and perception of this second online system.

Participants in Group B went online, created a PHR using Microsoft HealthVault, and completed the survey assessing their demographics, exposure to, and perception of the online system. Next, participants created a PHR using Google Health and completed a second survey assessing their exposure to and perception of this second online system. Figure 1 summarizes the study design. Figure 2 shows the instruction sheet for Group B.

Participants were sent follow-up email reminders after two weeks to complete the online PHR and surveys. Research staff then collected the surveys during subsequent classes. Data collection took place over a period of two months from March to April 2010. In total, researchers collected 34 surveys and analyzed 33, since one was incomplete.

Data Analysis

Data analysis was performed using SPSS Version 17.[20] Six survey subscales were computed based on previous research.[9-12] The study team created subscale scores by calculating the mean of all items on each scale. Team members then calculated descriptive statistics for all subscales and employed Cronbach's alpha to evaluate the internal consistency reliability of the subscales. Wilcoxon matched pairs signed ranks tests were conducted to compare differences in subscale scores between the two PHRs. The Wilcoxon test was used due to skewness in the subscale data.

Survey items CONF7 and USE6 were worded in a negative direction (that is, higher agreement levels were indicative of negative perceptions). These items were omitted from their respective subscales due to increased reliability of the survey upon their removal (as well as potential respondent confusion on these items). CONF7, addressing the withholding of sensitive information, was analyzed separately due to its importance in this research. USE6 was not analyzed separately.

SUMMARY OF FINDINGS

Demographics

The majority of study participants, 97%, were female; 84% were graduate students, while 16% were undergraduates. Three percent of the study sample identified themselves as Hispanic/Latino and the remaining 97% as Caucasian. In a separate item, 18% of respondents reported being multi-racial. The mean age of participants was

27.97 years. None of the participants had ever used the Google, Microsoft, or any other PHR tool prior to the study.

Reliability Testing (Internal Consistency)

Cronbach's alpha was used to test the reliability of each subscale. Table 2 displays alpha coefficients for Google Health versus Microsoft HealthVault by subscale. Reliability coefficients ranged from .882 to .995, indicating that all subscales had strong internal consistency.

Wilcoxon Matched Pairs Tests

Table 3 shows the means and standard deviations of each subscale for Google Health and Microsoft HealthVault. Higher means are indicative of more agreement. The Wilcoxon matched pairs signed ranks test was used to compare the two PHR tools on each of the subscale scores as well as on CONF7. None of the tests was statistically significant (see Table 3).

DISCUSSION OF FINDINGS

The mean scores for all subscales, with the exception of Computer Self-Efficacy, all were higher (indicating more agreement) for the Google Health PHR than for Microsoft HealthVault. However, there were no statistically significant differences in participants' perceptions of the two PHRs. Perceived Value of Service was the only subscale that showed a marginally significant difference between Google Health and Microsoft HealthVault (p=.088). This implies that there may not be a major impact from the June 2011 decision of Google deciding to shut down[5] its PHR platform in the eyes of the college-going user. Overall, participants had a moderately positive perception of both PHRs with means ranging from 5.00 to 6.39 on a 7-point scale. However, participants were ambivalent about long-term use of the systems (with means of 3.78 and 3.28, respectively, for the Google and Microsoft tools). The subscale with the highest overall ratings for both PHRs was Computer Self-Efficacy.

LIMITATIONS AND FUTURE WORK

Limitations of the Study Of the two hundred subjects recruited for this study, 34 chose to participate, with one participant completing only half of the survey. Interestingly, the majority of subjects recruited for this study were undergraduate students, and this population had the lowest rate of participation. The overall low response rate is a major limitation of this study. Timing might also be a factor with a sample of students—competing demands for time might interfere with willingness to engage in optional activities with no bearing on grade or progression in a program.

Limitations that are inherent in self-administered surveys must be considered when interpreting the results of this study. These may include lack of environmental control in which the surveys were completed, variation among participants in their ability to understand the questions, and the overall clarity, organization and format of the survey instrument. In the survey, there are two items (CONF7 and USE6) written with reverse wording (that is, high levels of agreement were indicative of negative perceptions) and these questions were omitted from the subscales. However, CONF7 was directly pertinent to the study and was, therefore, analyzed separately.

FUTURE WORK

Future researchers need to explore how computer self-efficacy, subjective satisfaction, ease of use, and confidentiality affect perceived value of PHRs and intention for long-term use. A larger and more diverse sample would permit the use of regression models to predict these outcomes and allow for the inclusion of demographic factors as well. To increase response rates, researchers might need to provide an incentive for the participants such as entry into a drawing. The use of the Technology Acceptance Model (TAM) theory as postulated by Davis[6] and Davis, Bagozzi, and Warshaw[19] may provide a useful theoretical perspective to advance the understanding of this work. Moreover, since use of electronic PHRs is in its infancy, there are opportunities both to introduce them through college health services and follow participants longitudinally after graduation. Attending college is for many students the first time they have had to assume responsibility for their own personal health care and record keeping, thus an ideal opportunity to introduce PHRs.

CONCLUSIONS

Personal Health Records have the potential to place the patient at the center of health care information exchange and empower individuals to become the stewards of their own health care information. PHRs can have a significant effect on an individual's health and continuity of care by facilitating health data information exchange among the patient and multiple providers, settings, and disciplines. As clinicians learn to manage health care in an ever-evolving environment of advanced web-based communication, it is essential that they understand the value of e-communication tools such as PHRs to provide coordinated, comprehensive, quality care. Having essential health information accessible to providers at each patient encounter will result in patients receiving more efficient care and achieving more effective health care outcomes. There is a need for clinicians to be educated on the usefulness and power of PHRs, and to participate in the PHR movement and education of the public. This study provided valuable information on participants' exposure to and perception of two major web-based PHR systems.

In June 2011, Google announced that Google Health will only continue service through January 1, 2012 and that data will be available for download through January 1, 2012[20]. Since the respondents' assessment of differences between the two systems – GoogleHealth and Microsoft HealthVault-- examined in this study were not statistically significant, it remains to be seen whether there will be a major impact on use of PHRs from Google shutting down its PHR platform.[5]

Moving forward, a significant socio-cultural paradigm shift will be necessary to address the challenges of assuring the ubiquitous adoption of PHRs. For PHRs to be useful, consumers will need to be able to add information themselves and have the ability to import information from health care organizations and health plans[12,13,15,16]. Future researchers should employ strategies to increase the number of participants and diversity of the study population, refine the survey tool, and further explore barriers to intention to engage use of PHRs for the long term.

The potential for PHRs to contribute to public health initiatives such as monitoring disease outbreaks, has not been explored but one can imagine use in monitoring of health status of populations, assisting in management of disease outbreaks, empowering individuals to take control of their own health, and contributing to research[2]. Introducing the use of PHRs to college students will facilitate use in several arenas including collection and pooling of data on sports' injuries, onset of chronic diseases, monitoring of health status during young adult years, and documenting health promoting behaviors.[1]

Table 1. Cronbach's Alpha Coefficients for Google and Microsoft PHR Tools

Survey Subscale	**Google Health**	**Microsoft HealthVault**
Computer Self-Efficacy	.893	.904
Perceived Value of Service	.951	.952
Ease of Use	.995	.979
Confidentiality	.915	.908
Subjective Satisfaction	.931	.932
Intention of Long-Term Use	.922	.882

Table 2. Subscale Means, Standard Deviations and Wilcoxon Matched Pairs Tests

Survey Subscale	Google Health	Microsoft HealthVault	Wilcoxon Matched Pairs Tests
	Mean (SD)	Mean (SD)	P-values
Computer Self-Efficacy	6.30 (1.02)	6.39 (1.08)	.345
Perceived Value of Service	5.15 (1.57)	5.00 (1.27)	.088
Ease of Use	5.93 (1.35)	5.76 (1.26)	.180
Confidentiality	5.34 (1.28)	5.20 (1.14)	.303
Subjective Satisfaction	5.38 (1.33)	5.32 (1.14)	.399
Intention of Long-Term Use	3.78 (1.58)	3.28 (1.32)	.199
CONF7 Withholding Sensitive Data	5.24 (1.32)	5.09 (1.57)	.911

Figure 1. Pilot Study Plan