Impact of Health Literacy on a Patient's Decision to Adopt a Personal Health Record

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Abstract

Health literacy is a concept that describes a patient's ability to understand materials provided by physicians or other providers. Several factors, including education level, income, and age, can influence health literacy. Research conducted at one medical practice in Florida indicated that in spite of the patients' relatively low education level, the majority indicated a broad acceptance of personal health record (PHR) technology. The key variable explaining patient willingness to adopt a PHR was the patient's health literacy as measured by the eHealth Literacy Scale (eHEALS). Adoption and use rates may also depend on the availability of office staff for hands-on training as well as assistance with interpretation of medical information. It is hoped that technology barriers will disappear over time, and usefulness of the information will promote increased utilization of PHRs. Patient understanding of the information remains a challenge that must be overcome to realize the full potential of PHRs.

Keywords: health literacy, personal health records, electronic health records

Introduction

As more physicians adopt electronic health records (EHRs) to obtain financial subsidies under Medicare and Medicaid, the opportunity to provide personal health records (PHR) to their patients will become more common.[1] A PHR is defined as "an electronic, lifelong resource of health information needed by individuals to make health decisions."[2] As implied by its name, the PHR is maintained by the patient and is not considered to be a part of the legal medical record.

One advantage of the PHR is its ability to provide improved communication between the patient and physician and allow the patient to become more engaged in the healthcare process.[3,4] Better physician-patient communication and increased patient involvement in decision making are vital components of a successful self-management program with improved patient outcomes and overall satisfaction with care.[5,6] Engaged patients want to understand the content of the PHR, including diseases and medications. This understanding is important in that it allows patients to recognize the benefits of access to their health information.[7]

Health literacy is defined as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions."[8] Low health literacy can lead to poor outcomes, such as longer and more frequent hospitalizations, higher usage of emergency rooms, and inability to manage chronic diseases such as asthma and diabetes.[9] Some indicators of low health literacy are having less than a high school education, speaking English as a second language, and being of advanced age with the accompanying decline in mental capacity, visual acuity, and/or auditory acuity.[10-12] These literacy statistics indicate that patients will need tools to aid them in interpreting and understanding the contents of the PHR to improve understanding of the diseases, medications, and terminology, which will lead to the competency to use the information to improve their health.[13-15]

PHR adoption and usage has been a challenge for numerous medical practices.[16-18] Patients may have difficulty interpreting the information provided to them.[19] To look at this issue more closely, the eHealth Literacy Scale (eHEALS) was used to determine how patients feel about their ability to find and appropriately use relevant health-related information on the Internet.[20] The eHEALS instrument was developed in 2006 as a self-reported tool based on a patient's perception of skills and knowledge in utilizing electronic healthcare (e-health) information.[21] It was designed to guide clinical decision making and health promotion based on the ability of a population to interpret e-health information. The similarities between health literacy

(obtain, process, and understand health information) and e-health literacy (find and use electronic health information) were determined by the authors to be appropriate for this research study. In addition, we attempt to define the characteristics of the patients who are or are not comfortable with their ability to use the Internet to find information about health and are or are not willing to adopt a PHR. The host physician practice wanted to know if the patient population would adopt a PHR if the practice provided the technology through the office EHR system. Actual adoption and usage were not measured in this study.

Background

According to Ajzen and Fishbein, the theory of reasoned action is based on behavioral intention as the main predictor of actual behavior.[22] An individual will develop a positive or negative attitude toward a behavior and will also respond to social pressures about the behavior. The social pressures are called "subjective norms" and refer to a person's belief that significant others view the behavior as favorable. These pressures are taken together with an individual's attitude to determine intention and ultimately change behavior.

Ajzen and Fishbein[23] include attitude as one of the predictors of a person's behavioral intention. In the context of health literacy, we want to determine a patient's attitude about his or her ability to find, evaluate, and use e-health information. The more favorable the attitude (confidence in finding and using health information), the more likely it is that the patient will intend to perform the behavior (adopt and use a PHR).

Subjective norms also affect the likelihood of a behavior. According to Ajzen and Fishbein, "the more a person perceives that others who are important to him think he should perform a behavior, the more he will intend to do so."[24] Therefore, if a physician is a strong advocate for the PHR and the patient also sees the value and importance of the PHR, the intention to change behavior will be positively affected. The physicians of the practice studied in the present research were supportive of the use of the PHR by all patients.

The patient must serve as the link between the provider and his or her health information.[25] This requires moving the healthcare focus from the doctor's office to the patient's daily routine at home. Adoption and ongoing usage of a PHR can facilitate this link. Patients believe if they are given access to their medical record, they will be able to manage their condition(s) at home.[26] The PHR can provide direct and timely communication with the physician and empower the patient to be involved and participate in the decision-making process about his or her health.[27]

Hypotheses

The following two hypotheses address two areas that pertain to this PHR research, namely demographic characteristics of a population and health literacy.

Hypothesis 1: Patients who are younger, are more educated, and have higher income are more willing to adopt the PHR than those who are older, less educated, and with lower income.

Hypothesis 2: Patients who have high levels of e-health literacy are more willing to adopt the PHR than those with low levels of e-health literacy.

Methods

The research is a cross-sectional study of patients' intention to use a PHR and its association with perceived health literacy, income, education, and age. The sample is a convenience sample because individuals must be patients in the selected medical practice to be included. The two locations of the practice utilized for the research are near large urban areas. The physician practice is composed of one family practice physician and four internal medicine physicians who were not part of a larger medical practice or health system. Institutional Review Board approval was obtained prior to commencement of the research, which took place in November and December 2009.

A pilot study was performed to determine issues with the survey itself as well as for face validity. Face validity was also attained through peer review by both clinicians (one MD and one RN) and nonclinicians. The pilot study data of 10 patients were analyzed; the Cronbach's alpha showed high reliability and other statistical measures were reasonable.

The eHEALS instrument measures a patient's knowledge, comfort, and perceived skill level to find, evaluate, and apply electronic health information to health problems.[28] To clarify, skills are not assessed directly; rather, the patient is asked to provide answers based on his or her perceived skills. Table 1 includes the questions on the survey instrument that were taken directly from eHEALS, along with possible answer selections and how they were coded for data analysis. Because the current research aims to make predictions based on an individual's intentions, intention to use the PHR as well as the individual attributes of age, education, and household income are considered. To improve the response rate, broad income ranges were provided for patients to choose from.

Table 1: Operational Definitions for Health Literacy

Questions	(Coded→Recoded) Answers
I know what health resources are available on the Internet.	(1) →(1) Strongly disagree
	(2) →(1) Disagree
	(3) →(1) Neither agree nor disagree
	(4) →(0) Agree
	(5) →(0) Strongly agree
	(6) →(1) Not applicable
I know where to find helpful health resources on the Internet.	(1) →(1) Strongly disagree
	(2) →(1) Disagree
	(3) →(l) Neither agree nor disagree
	(4) →(0) Agree
	(5) →(0) Strongly agree
	(6) →(1) Not applicable
I know how to find helpful health resources on the Internet.	(1) →(1) Strongly disagree
	(2) →(1) Disagree
	(3) →(1) Neither agree nor disagree
	(4) →(0) Agree
	(5) →(0) Strongly agree
	(6) →(1) Not applicable
I know how to use the Internet to answer my questions about health.	(1) →(1) Strongly disagree
	(2) →(1)Disagree
	(3) →(1) Neither agree nor disagree
	(4) →(0) Agree
	(5) →(0) Strongly agree
	(6) →(1)Not applicable
I know how to use the health information I find on the Internet to help me.	(1) →(l) Strongly disagree
	(2) →(1) Disagree
	(3) →(1) Neither agree nor disagree
	(4) →(0) Agree
	(5) →(0) Strongly agree
	(6) →(1) Not applicable
I have the skills I need to evaluate the health resources I find on the Internet.	(1) →(1) Strongly disagree
	(2) →(1) Disagree

Questions	(Coded→Recoded) Answers
	(3) →(1) Neither agree nor disagree
	(4) →(0) Agree
	(5) →(0) Strongly agree
	(6) →(1) Not applicable
I can tell high quality health resources from low quality health resources on the Internet.	(1) →(1) Strongly disagree
	(2) →(l) Disagree
	(3) →(1) Neither agree nor disagree
	(4) →(0) Agree
	(5) →(0) Strongly agree
	(6) →(1) Not applicable

All adult patients who were willing to participate during the six-week research time frame were provided with a letter introducing the survey as well as instructions on how to complete the questionnaire. Patient consent was assumed by a patient's willingness to participate in the research. The purpose of the research was briefly explained by the researcher (or office staff in her absence) to further encourage participation. The questionnaire was a hard-copy instrument that was completed by the patient in the office waiting room.

Statistical Analysis

Answers for all of the eHEALS questions and the question about intention to adopt a PHR were dichotomized such that "agree" contained all "agree" and "strongly agree" responses, while "disagree" included all "not applicable," "neither agree nor disagree," "disagree," and "strongly disagree" responses. It was felt that this would provide a clearer picture of the patient responses because patients who were assured of how they felt about e-health and the PHR would select one of the responses indicating agreement or disagreement. The PHR was explained to the patients prior to completing the survey, and the authors strongly believe that patients who were not sure or were undecided about e-health and the PHR would not adopt a PHR and were best categorized with the responses indicating disagreement. To consolidate the eHEALS data further, an eight-question index was calculated such that agreement with the statements resulted in a perception of a higher health literacy level. In this manner, patients who intend to adopt the PHR could be divided among high and low perceived health literacy levels.

Table 2 shows statistics for the demographic characteristics of the 562 patients in the sample. The Pearson chi-square test was conducted to determine the statistical significance of the relationship between demographic variables and PHR adoption. Further chi-square analysis was performed for each question on eHEALS to determine its relationship to PHR adoption.

Table 2: Demographic Characteristics of the Sample (*n* = 562)

Variable	Description	Percentage
Gender	Male	27
	Female	73
Age	25 years or younger	11
	26–40 years	28
	41–55 years	29
	56–70 years	25
	71 years or older	7
Education	Less than high school	14

Variable	Description	Percentage
	High school/GED	38
	Some college	29
	Associate's degree (AS and/or AA)	10
	Bachelor's degree	6
	Master's degree or above	3
Income	$20,000 or less	59
	$20,001 to $35,000	18
	$35,001 to $50,000	12
	$50,001 to $100,000	8
	$100,001 or more	3

Results

The total of 562 patients in our sample represented 14 percent of the total practice population. Overall, 74 percent of the participants indicated that they would adopt a PHR. The x^2 analysis reported in Table 3 indicates that none of the three demographic characteristics was significantly related to adoption of a PHR. The range 41–55 years was the most common age group (29 percent), and 77 percent of those patients were willing to adopt a PHR if it was offered. The majority of patients (52 percent) had a high school education or less, and 71 percent of those indicated a willingness to adopt a PHR. In addition, the majority of patients (59 percent) were in the lowest income category (less than $20,000 annually) for 2008, and 75 percent of those indicated a willingness to use a PHR.

Table 3: Demographic Characteristics versus Intention to Use a PHR

Variable	Description	Percentage Willing to Adopt PHR	x^2
Age	25 years or younger	70	.142
	26–40 years	80	
	41–55 years	77	
	56–70 years	73	
	71 years or older	67	
Education	Less than high school	63	.086
	High school/GED	78	
	Some college	80	
	Associate's degree (AS and/or AA)	76	
	Bachelor's degree	73	
	Master's degree or above	71	
Income	$20,000 or less	75	.493
	$20,001 to $35,000	80	
	$35,001 to $50,000	75	
	$50,001 to $100,000	79	
	$100,001 or more	62.5	
Note: No differences in responses by demographic category were significant at the $p < .01$ level.			

Cross tabulations between the eHEALS responses and intention to adopt a PHR are shown in Table 4. Comparisons of responses on all questions and PHR adoption were statistically significant at the .01 level. The notes to Table 4 indicate the overall average percentages for those patients who intend to adopt a PHR and agree with the eight statements on the eHEALS (indicating high health literacy) as well as for those patients who do not intend to adopt a PHR but agree with the eight statements.

Table 4: eHEALS Responses versus Intention to Adopt a PHR

Question	Response	Intend to adopt *N*(%)	Do not intend to adopt *N*(%)
1. I know what health resources are available on the Internet.	Agree	233 (56)[a]	54 (38)[b]
2. I know where to find health resources on the Internet.	Disagree	185 (44)[a]	90 (62)[b]
	Disagree	152 (36)[a]	88 (61)[b]
3. I know how to find health resources on the Internet.	Agree	289 (69)[a]	63 (44)[b]
	Disagree	129 (31)	81 (56)
4. I know how to use the Internet to answer my questions about health.	Agree	318 (76)[a]	69 (48)[b]
	Disagree	100 (24)	75 (52)
5. I know how to use the health information I find on the Internet to help me.	Agree	302 (72)[a]	59(41)[b]
	Disagree	116 (28)	85 (59)
6. I have the skills I need to evaluate the health resources I find on the Internet.	Agree	286 (68)[a]	59(41)[b]
	Disagree	132 (32)	85 (59)
7. I can tell high quality health resources from low quality health resources on the Internet.	Agree	207 (50)[a]	35 (24)[b]
	Disagree	211 (50)	109 (76)
8. I feel confident in using information from the Internet to make health decisions.	Agree	264 (63)[a]	40 (28)[b]
	Disagree	154(37)	104 (72)

Note: All responses were significant at the $p < .01$ level based on Pearson chi-square test.
[a]Patients who intend to adopt a PHR and agree with the eHEALS statement. The mean overall percentage for those patients who intend to adopt a PHR and agree with the above statements (indicating high health literacy) is 65 percent.
[b]Patients who do not intend to adopt a PHR but agree with the eHEALS statement. The mean overall percentage for those who do not intend to adopt a PHR but agree with the above statements (indicating high health literacy) is 38 percent.

The eHEALS eight-question mean percentage showed that of those who intended to adopt the PHR, 65 percent indicated a high perceived health literacy level. Therefore, 35 percent of patients who do want to view and use a PHR do not feel comfortable with their ability to use the information they are provided for health decisions (low perceived health literacy level). For those patients not intending to adopt a PHR, 38 percent perceived a high level of health literacy. Therefore, those patients who perceive a high level of health literacy are more likely to adopt a PHR than those patients who have a lower level of health literacy.

Table 4 indicates that certain statements are more closely correlated with intention to adopt the PHR. Two such eHEALS statements were number 4, “I know how to use the Internet to answer my questions about health” (76 percent), and number 5, “I know how to use the health information I find on the Internet to help me” (72 percent). These statements closely relate to the definition of health literacy, which includes the ability to obtain and understand health information. Among patients not willing to use the PHR, the percentages of agreement for these same statements are 48 percent and 41 percent, respectively.

The seventh statement, "I can tell high quality health resources from low quality health resources on the Internet," resulted in a much lower level of intention to adopt, with 50 percent of patients who intend to adopt the PHR agreeing with this statement, and 24 percent of those not willing to adopt agreeing with the statement.

The hypothesis testing results are as follows:

Hypothesis 1: Patients who are younger, are more educated, and have higher income are more willing to adopt the PHR than those who are older, less educated, and with lower income. This hypothesis was not supported because none of the factors (age, education, and income) were found to be statistically significant with chi-square testing when compared to the willingness to adopt a PHR.

Hypothesis 2: Patients who have high levels of e-health literacy are more willing to adopt the PHR than those with low levels of e-health literacy. This hypothesis was supported because the e-health literacy questions were significant at the $p < .01$ level based on Pearson chi-square testing.

Discussion

The first question on the survey was "I intend to use a personal health record in the future." Because the physicians planned to provide a PHR, they wanted to know if their patients would use it. As noted above, 74 percent of the participants indicated that they would adopt the PHR. To get an idea of the patients' ability to use an online PHR and even to understand the content of the PHR, the eHEALS questionnaire was used to assess the patient's level of comfort and skill in using technology for e-health purposes. The eight-question index indicates that 65 percent of patients who intend to adopt the PHR have a high perceived health literacy level. This favorable attitude toward finding and using health information improves the likelihood that patients will adopt and use a PHR, according to the theory of reasoned action.[29]

Patients at risk for low health literacy included the 52 percent who have a high school education or less, the 7 percent in the category of those 71 years or older, and the 59 percent in the lowest income category of $20,000 or less. In each of these categories, the majority of patients were willing to adopt a PHR. Therefore, patients in this practice at risk for low health literacy, with low education, advanced age, and/or low income, are willing to adopt the PHR, and many perceive their health literacy level to be high.

These seemingly conflicting results do present a challenge in light of the known risk factors for low health literacy. Physicians who plan to provide a PHR for their patients should look beyond the demographic characteristics, which may not represent the patient population in terms of their perceived health literacy. For example, age is not a significant predictor for PHR adoption. Also, patients who are less educated may try to compensate by seeking health information through the PHR format. Low income level was also not found to be a predictor of PHR adoption, which could indicate that these patients are still interested in technology, likely are familiar with it, and have access to the Internet. In this research, a better predictor of eventual PHR usage is how patients perceive their health literacy. With this in mind, careful consideration is warranted to provide tools for interpretation as well as additional staff to assist patients with PHR usage.

Overall, supplying patients with education and other tools, such as access to their medical records, has the potential to decrease healthcare encounters and costs. One tool that was developed to facilitate communication was an "infobutton" used by women to access Pap smear results online.[30] This was part of the Patient Clinical Information System (PatCIS) provided by New York Presbyterian Hospital. Definitions for frequently encountered diagnostic terms were made available to aid patients in reading and understanding their reports. Providing patients with such a tool is an important step in allowing patients to take ownership of their healthcare outcomes. Using glossaries and "plain language" at a level the patient can understand enhances understanding and communication.[31,32] Providers are encouraged to take the time to tell patients the action steps that are needed and use multiple forms of communication to improve understanding.[33]

Limitations

Possible limitations included the consistency of the office staff in explaining the purpose and importance of adopting the PHR to the patient, including their attitude (positive or negative). This may have been mitigated in part through the use of written information in addition to the oral instructions. The researcher was present during the majority of the research. Some patients mentioned that they were so pleased with the care they receive that they would do anything the physician requested of them.

Therefore, these patients may want to please the physician by providing what they perceive as "good" answers rather than truthful answers.

The use of dichotomized answers for the question regarding intention to adopt and the eHEALS questions might skew the results slightly. However, the majority of the patients did agree with PHR usage and felt they could understand and use the information. The use of the eight-question index to provide an overall ranking of patient perception of e-health literacy allows for a useful summary of the data. However, Norman and Skinner[34] did not utilize the data in this manner in their original formulation of the eHEALS questionnaire.

The generalizability of one internal medicine/general practitioner practice is a possible limitation. However, the similarity of general medical office procedures and workflow patterns in comparable practices within the state of Florida may improve this. In the sample used for this research, homogeneity (majority white, majority women, majority with high school education, etc.) detracts from the generalizability of results to minorities and better-educated patients. It should be noted that every effort was made to include all patients who presented for appointments at the practice in an effort to improve generalizability. However, the questionnaire was only available in English, so those patients who could not read English were excluded from participating.

Future Research

Due to the fact that PHRs are a relatively new technology, further research on potential methods to improve use of the PHR is important. This research used a questionnaire to determine if patients intend to adopt a PHR. If the practice moves forward with offering the technology, future research may include longitudinal data looking for positive correlation between the maintenance of a PHR (with clinical review and follow-up) and the ability of patients to read and understand written health-related materials, including prescription bottles. Lower education levels are well known to be correlated with lower levels of health literacy.[35,36] However, diabetics with low literacy levels are willing to take action to improve the management of their disease.[37] Therefore, a closer look at the patients' understanding and ability to use information supplied by providers is a worthwhile endeavor. This research could include a closer look at what contributes to the willingness of patients who are at risk for low health literacy to adopt a PHR as well as the inclusion of patients who do not speak and/or read English (by providing the questionnaire in other languages).

This study aimed to determine the relationship between a patient's perceived ability to find and understand e-health information and that patient's willingness to adopt and use a personal health record. Factors known to play a role in health literacy were also investigated to determine if additional relationships existed within this patient population. The theory of reasoned action provided a framework for a patient's willingness to use a PHR based on his or her attitude toward using electronic health information.

Results indicated that 74 percent of the practice's patients do intend to adopt a PHR if it is made available to them. These findings are encouraging in this population of candidates who are socioeconomically unlikely to adopt a PHR (low income, high school education). However, follow-up longitudinal research will be required to determine if the patients (and providers) indeed access the data and use it to improve health status and outcomes.

As the population ages and technology provides enhancements for healthcare, PHRs will become a more common option offered by providers who are implementing electronic health records. Neither patient nor provider can exist in a vacuum, and the ability to communicate in this manner may bridge the gap of missing information needed for improved care management. With improved continuity of care and increased cost savings as the incentives, all third-party payers should see the benefit in improved reimbursements for providers who offer a PHR. The key to ultimate success will be the patients' willingness to adopt and use the PHR as they participate in improving their own healthcare and well-being.

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