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Understanding Patient Perceptions of the Electronic Personal Health Record

Katherine Dontje, PhD, FNP-BC, William D. Corser, PhD, NEA-BC, and Greg Holzman, MD, MPH

ABSTRACT

Nurse practitioners are being asked to implement meaningful use initiatives including electronic personal health records (PHRs), yet little research has been done on the usability of the systems from a patient perspective. This qualitative study identified patient perceptions and barriers to the use of the PHR. Four themes were identified: access issues, perceived value of the PHR, potential usability, and security issues. Specific patient issues were those around the use of technology and health literacy issues. Nurse practitioners have an opportunity to work with patients and health information technology staff to address these issues and improve patient engagement through the use of PHRs.

Keywords: electronic health record, nurse practitioner, patient engagement, personal health record, primary Care

Nurse practitioners (NPs) are increasingly expected to integrate multiple national initiatives such as meaningful use of the electronic health record (EHR) into their practice settings. Meaningful use criteria were established through the Health Information Technology for Economic and Clinical Health Act of 2009 to in–centivize the implementation of EHRs in clinics and hospitals nationwide. The overall goal of this initia–tive was to improve health care quality and to assist the health care provider in meeting the triple aim of improving the patient experience, controlling cost, and improving quality.[1] One of the objectives of meaningful use is to improve patient engagement and encourage patients to participate in decision making related to their health care. One of the tools that has been envisioned to assist in meeting this objective is the personal health record (PHR). The PHR has the potential to provide a means to connect patients with their own health care records and information regarding health care treatments and plans.[2]

The PHR has been proposed as a means to facilitate a fundamental shift in the patient–provider relationship in which patients assume a more active role in health care decisions.[3,4] PHRs were initially developed outside the health care system as Internet-based tools and typically initiated by the patient as a means for them to organize their health care data. More recently, the PHR has been linked or "tethered" to the EHR through Web portals, which allow information to cross over between the PHR and patients' medical records.[5] The tethered PHR can provide patients with preventative health care reminders, educational materials, and self-management resources, which have the potential to encourage patient engagement and may yield improvements in overall health.[4] Furthermore, PHRs connected through Web portal systems have shown the potential ability to lower health costs by decreasing the number of unnecessary office visits and telephone calls when patient queries can be addressed through secure online communication.[6] Yet, PHR adoption by health care providers and patients continues to be limited, and data related to improving patient outcomes have not been well established.[7,8]

Despite the many benefits PHR systems can bring, there are still many current challenges regarding their accessibility and use within the clinical setting. At this time, there has been an overall lack of focus and funding related to the implementation and training of the PHR. This lack of focus has resulted in a situation in which few providers and patients have time to discuss and access the PHR.[9] In addition, primary care providers are faced with multiple quality

initiatives in the office setting including meaningful use, patient-centered medical homes, and the new *International Classification of Diseases, Tenth Revision* transition. Thus, providers have had to choose which of the initiatives to focus their efforts. Therefore, it is unlikely that most providers and organizations will emphasize PHRs unless there is an established link to a decrease in health care costs or a substantial improvement in the efficiency of care.[4]

In addition to systemic barriers to PHR implementation, there are also obstacles regarding individual patient adoption and the use of PHRs. Current literature suggests that patients who view themselves as reasonably healthy are less likely to access their PHRs.[4,10] Underserved, low-income, and elderly populations may also have trouble gaining Internet access or be unfamiliar or uncomfortable using such computerized systems.[11] Concerns surrounding security of health information have been suggested in the literature and may be an impeding factor among many PHR users.[8] In addition, patients are often frustrated by the differences in PHRs linked to different EHR systems. There is not yet a single uniform PHR system designed to interface across health care systems.[8,12] This frequently places the burden of understanding how to navigate different PHR systems on the patient. Despite these numerous patient-related barriers, minimal information has been published regarding the PHR preferences and expectations of typical patients.

PROJECT DESIGN

This study was designed to examine the challenges and barriers of access to the PHR through a patient's perceptive. Institutional review board approval was obtained at the university level. Data collection was through a series of 6 semistructured participant focus groups. Five open-ended questions were asked at each of the focus groups to stimulate conversation and discussion. The focus groups were tape recorded and transcribed verbatim. Individuals were identified as participants through a multistep process. First, the health information technology group identified all individuals over the age of 18 who were seen in the last 3 months at 2 primary care clinics. These individuals were sent a confidential letter that explained the study and directed them to contact the principal

investigator of the study if they were interested in participating. Once the individuals self-identified, the principal investigator called them and scheduled them into a 60-minute focus group. Focus group transcripts were analyzed using a common qualitative content analysis method. The authors individually reviewed the transcriptions and examined them for major themes across the data.

The sample for this study was comprised of 21 adults reporting an average age of about 64 years (standard deviation = 11.60 years). The majority (95%) were white. Over 80% of participants reported having completed undergraduate or graduate college programs, and approximately 62% were currently married. Judging from individual participant responses, the authors later concluded that about 10 participants (48% of the total sample) had actively accessed/tried to access their PHR before their respective focus group.

During the data analysis, the main themes identified in the focus groups were the following: (1) challenges with PHR access issues, (2) a lack of current perceived value of the PHR, (3) opportunities for improved usability or improvements needed to increase the use of the PHR, and (4) concerns about security. Within these themes, there were a number of subthemes. PHR access issues included a lack of awareness of the PHR, difficulty getting onto the system, and perceived value in contrast to time required to learn a new system. The perceived value of the PHR included the possibility of being able to review and update clinical data, e-mailing providers, organizing their health record to share with other providers, and usability of the information obtained. The potential improvements included the ability to review laboratory values and radiology, correcting their own information, coordinating across providers, and making or changing appointments.

DISCUSSION/SUMMARY

Patient engagement is being increasingly emphasized as an essential component of high-quality health care. NPs have long supported the concepts of partnering with the patient and personalized interactions.[13] One of the challenges to realizing the full potential of the PHR is determining how to best educate and engage diverse patients in the use of the PHR.[4] Even though

about half of the sample participants had accessed their PHR before the study, most participants had clearly not been regularly using the PHR. Judging from these participant comments, several had gotten in 1 time and concluded it was not helpful so they had not continued to use the PHR. Others had tried to access the PHR through the Web portal but concluded it was too cumbersome and that communicating with their health care providers through the phone system was still easier and faster. These finding represents the challenge for NPs now working with the health information technology services to support changes in the PHR that will make systems more patient centered.

The ease and usability of the PHR may not always be an issue of the capability of the systems but rather reluctance of the office or health system to fully activate all PHR functionalities. Providers and administrators in other settings have cited various reasons for this including cost and worries that patients will overuse the system.[4] As information systems are stretched to meet a variety of mandated initiatives, the engagement of the patient and patient problems in accessing the PHR may not be the first initiative to receive adequate support and implementation.

One of the other issues for patients in this sample was their difficulty interpreting much of the information in the health record. Many patients who accessed the PHR system expressed concern that much of what is available is in medical terminology, which can be difficult for them to interpret. This may be a common theme when providing patients access to their health records because most of what is in the PHR is simply a transfer of complex health information from the patient's health record. Therefore, it is especially important that NPs consider health literacy issues when encouraging patient engagement.

Many participants indicated that they thought the use of the PHR could increase communication with outside providers but had found that each provider or health system had their own PHR. In effect, these individuals were being asked to navigate 2 to 3 different PHRs. This shows the need for improved interoperability between PHR systems in order to exchange information that is necessary to improve the quality of patient care.[8] Only when patients can see the benefit of improved communication between providers and themselves will the PHR truly meet its potential.

One of the areas that have been identified as a barrier to PHR is that of concern about security of information.[4,8] In this study, however, we had a mix of comments from participants about concern for the safety and security of their health information. Some indicated they did have concern about having their personal health information "hacked into." Yet, other participants expressed that in the electronic age anything from bank records to health records need to be accessed electronically, and they felt that systems were being put in place to monitor security. This result may in part be related to the relatively high levels of completed education of our participants, possibly leading to their comfort with technology security measures. The provision of more secure PHR systems has the potential to increase the use of the PHR and support the adoption of these systems by both patients and providers.[8,12]

LIMITATIONS

This qualitative study examined a small convenience sample of patients' perceptions of the one common type of PHR. This self-selected sample had a relatively high education level, and the majority reported being white, limiting the generalizability of these results to other populations. One key issue in applying these results to other settings is the variety of PHR and EHR systems now used by our nation's health care systems.[8] Although the results of this study only reflect the PHR of one vendor, they were generally consistent with the experiences and preferences documented in other studies that were using other PHRs across the country.[7,12,14]

IMPLICATIONS

The data from this study have identified some key areas that patients see as challenges and barriers to the use of the PHR through the Web portal. Concerns identified by participants in this study related to the difficulty accessing the PHR, lack of support for using the system, limited perceived value of accessing the PHR, and difficulty understanding the information contained in the PHR because of the use of medical terminology. NPs should work to implement strategies to improve the utilization of this tool. While

designing implementation strategies, consideration should be given to developing more patient-centered delivery systems. In order to more fully engage patients, it will be important to include patients in the development and refinement of PHR products. By engaging the patient in this process of PHR system changes, future PHR systems can be developed to address many of their major preferences and concerns.[7,9]

Health literacy issues should also be considered as we work to refine PHRs. Earlier research has suggested that the information in PHRs should be formatted using "easy-to-understand" language to facilitate patient understanding.[4] Similar to other studies,[10,15] many of the participants in our study have identified that information in the PHR was often difficult for them to understand. Many of the participants in this study were interested in having the PHR Web portal configured so that links would be provided to reputable sources of information to assist in interpretation of their medication names, diagnoses, and other laboratory results. NPs have the ability to be the patient advocate in the area of health literacy and work with the health information technology individuals to provide information in a way that the average patients can understand. If the PHR is developed in such a way that allows for easier understanding of terminology, it has the potential to become a much more effective engagement tool.[9]

FUTURE WORK

The patient issues and concerns outlined in this article highlight the need to identify specific solutions to the challenges patients face in the use of health information technologies such as the PHR connected to the EHR through Web portals. To date, most research related to the PHR has focused on provider perspectives. Far fewer studies have been conducted to evaluate patients' perspectives about how they would like to see information arranged in the PHR Web portals and what parts of their health care information they would like to have most readily available. Notably, studies that have examined the potential for patient engagement through PHR use have shown that even after the initial successful use

of the PHR, usage patterns decrease significantly over time.[8,15] Future focused research should identify specific ways to facilitate improved patient engagement and their sustained use of the PHR.

To more fully evaluate patients' perspectives of the PHR, studies should include larger diverse samples in settings with a variety of PHR systems. At this point, there is little information that actually shows a change in patient behaviors or outcomes related to the use of the PHR. Future studies are needed to evaluate what are the best ways to use PHR Web portal systems and if there are specific types of interventions related to either preventative care or chronic care capable of leading to improved patient outcomes. Without such studies, NPs and other clinicians will be left with trying to select from and implement PHR Web portal systems that are neither evidence based nor likely to impact patients' health care outcomes. JNP

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All authors are affiliated with Michigan State University. Katherine Dontje, PhD, FNP-BC, is the Director, Graduate Clinical Programs and can be reached at dontje@msu.edu. William D. Corser, PhD, RN, NEA-BC, is an associate professor. Greg Holzman, MD, MPH, is an associate professor and associate chair for preventive medicine. In compliance with national ethical guidelines, the authors report no relationships with business or industry that would pose a conflict of interest.