A Qualitative Study of How Patients with Type 2 Diabetes Use an Electronic Stand-Alone Personal Health Record

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Abstract

Background: Patient use of personal health records (PHRs) to manage their health information has been proposed to enhance patient knowledge and empower patients to make changes in their self-care behaviors. However, there remains a gap in understanding about patients' actual PHR use behaviors. The purpose of this qualitative study was to explore how patients with type 2 diabetes used a PHR to manage their diabetes-related health information for self-care. **Materials and Methods:** Fifty-nine patients with type 2 diabetes were interviewed 3–6 months after receiving initial training on a free-of-charge, Web-based PHR. Interviews were audio-recorded, transcribed, and analyzed using an iterative process of in vivo coding, categorization, and theme development. **Results:** Nine themes emerged, three of which expressed positive experiences: complete and accessible record; increased awareness; and behavioral changes. The remaining six themes expressed negative experiences: out of sight, out of mind; I would have used it if I were sicker; economic, infrastructure, and computer literacy barriers; lack of patient-provider engagement; double tracking; and privacy and security concerns. **Conclusions:** Despite some potential positive benefits resulting from PHR use, several barriers inhibited sustained and effective use over time. Provider and patient education about the benefits of PHR use and about the potential for filling in information gaps in the provider-based record is key to engage patients and stimulate PHR adoption and use.

Key words: e-health, medical records, mobile health, technology

Introduction

There are 18.8 million Americans currently diagnosed with diabetes, making the disease the seventh leading cause of death in the United States, as well as the leading cause of kidney failure, nontraumatic lower-limb amputations, and

new cases of blindness.¹ By 2021, approximately 40.3 million Americans (15.4% of the population) are projected to have diabetes, with annual healthcare spending for the disease increasing from \$206 billion to \$512 billion.¹ Despite the established efficacy of various approaches designed to manage diabetes, only 18.8% of patients reach treatment goals for blood glucose, blood pressure, and cholesterol established by the American Diabetes Association.²

The use of health information technology such as online patient portals and personal health records (PHRs) by patients has been recognized as a strategy to facilitate improvements in diabetes self-management and achieve treatment goals.³⁻⁵ The use of these technologies has been proposed to help patients better manage their medical conditions, enhance patient health knowledge, and empower patients to become partners in decision-making with their providers, ultimately leading to better health outcomes.⁶⁻⁸

PHRs are a prominent patient-centered health information technology. They have been defined as “an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR. Health information is generated by the individual owner of the PHR and may also be sourced from the various medical records of the individual's health care providers. The PHR is maintained in a secure and private environment with the individual determining rights of access. The PHR is separate from and does not replace the legal record of any provider.”⁹ PHRs can serve as a complete record of health information that is portable and accessible to the patient regardless of geographic location.^{7,10}

The promise of PHRs holds particular value for patients with chronic conditions such as diabetes, who have complex health needs, take multiple medications, and perform a variety of self-care behaviors to manage their condition(s).^{7,11} However, it is estimated that only 10% of consumers in the United States are using a PHR.¹² To date, five studies have examined the use of a PHR (either alone or in combination with other interventions) and its impact on diabetes clinical outcomes.¹³⁻¹⁷ The studies demonstrated mixed results, ranging from no impact of the PHR on glycosylated hemoglobin (HbA1c) levels to statistically significant changes in HbA1c levels; however, there was no way to determine if the PHR component of the intervention was what caused the change.

This early phase of PHR adoption presents an opportunity to better understand the perceived value and challenges of PHR use from actual users.¹¹ There are few prospective studies designed to identify factors leading to sustained PHR use or barriers that lead to ineffective use or nonuse.^{8,11,18,19} To address this current knowledge gap, the purpose of this study was to explore how patients with type 2

diabetes used a PHR to manage their diabetes-related health information for self-care.

Materials and Methods

This was a qualitative study guided by a conventional content analysis approach, a common framework used when knowledge gaps remain about a specific topic.²⁰ Seventy-two participants received hands-on training for using a PHR to manage their diabetes-related health information and were tracked for 3–6 months, corresponding to typical intervals between diabetes-care visits.²¹ This study was reviewed and approved by the university's Institutional Review Board (IRB protocol number 09-15470, approved August 2009).

PARTICIPANT RECRUITMENT

Patients were recruited from two internal medicine clinics and an endocrinology clinic in a Midwest metropolitan city. All of the clinics were part of the same academic medical practice. Medical record review was used to identify patients meeting the inclusion criteria: a diagnosis of type 2 diabetes with an HbA1c value of $\geq 6.0\%$, no concurrent diagnosis of impaired cognitive function (e.g., dementia), English speaking, and self-reported access to a computer and comfort with using a computer. Eligible patients were contacted via telephone a week before their next scheduled appointment and had the study explained to them. Patients who indicated interest in participating were asked to come a half-hour early to their appointment in order to obtain informed consent. At the visit, the study was again explained to patients, and those indicating continued interest were consented. Although all prescribers at each of the clinics were notified of the study, only the researchers and research assistants obtained informed consent.

PHR SELECTION

Microsoft (Redmond, WA) HealthVault[®] was used as the study PHR. It is an online stand-alone PHR that is available free of charge and was determined to have the greatest number of features patients desired in a PHR based upon previous published studies about PHR use. These features included the ability to do the following: share health information with others; receive feedback based on the entered health information; have information presented in layman's terms; have health information be private and secure; have e-mail or secure messaging with healthcare providers built-in to the PHR; have interoperability with providers' health records; print out the information in the PHR; create new sections in the PHR for health-related information such as indicating an individual is an organ donor; customize the visual appearance of the PHR; restrict access to specified parts of the PHR; and have personalized support based on individual needs.²²

PHR TRAINING

An instruction manual was created to guide PHR training and was provided to participants post-training. It included PHR screenshots with accompanying written instructions guiding users through the process of signing up for the PHR and using it to maintain diabetes-related health information. During training, the participant con-

trolled a laptop computer while a researcher/research assistant provided instruction on using the PHR. Although the PHR supported data entry for several laboratory values and the creation of additional data fields as needed, participants were only required to demonstrate the ability to enter the following diabetes-related information: birth date, height, weight, medical condition(s), medication(s), blood glucose level, blood pressure, HbA1c, low-density lipoprotein cholesterol, and dates of last eye and foot exams. Each of the required pieces of information contained dedicated subfields allowing participants to indicate a date and time (e.g., when a medication was started, when a medical exam was conducted, when a laboratory value was recorded). Additional information such as a high blood glucose value that may have been due to the patient forgetting to take his or her diabetes medications could be recorded via a free-text subfield. During training, field notes were recorded about difficulties participants experienced or comments that provided insight into their attitude and behaviors toward diabetes self-care. Participants were not required to use the PHR in any specific way but were given instructions to use it as needed for self-management. Participants were provided with the study director's office phone number and e-mail address and were directed to contact him if they had any questions or needed any assistance with the PHR.

DATA COLLECTION

All participants were interviewed at their follow-up visit 3–6 months after PHR training using an interview protocol designed to explore participants' use of the PHR. This purposeful sampling procedure ensured that the researchers would achieve data saturation.^{23,24} The central question guiding the interview was "How have you used the PHR to manage your diabetes-related health information?" Questions were specifically designed to gain a deeper understanding of the following topics: what the PHR was used for; how it fit into the participant's life; the most useful aspects of the PHR; barriers to PHR use and strategies used to overcome these barriers; how PHR use changed diabetes self-care; how PHR use changed the relationship with their diabetes care provider; and how PHR use changed their tracking and management of health information. Interviews were conducted in-person after the participants' follow-up visit or via telephone if the participant was unavailable immediately after his or her visit. Each interview took approximately 15–20 min. Field notes were taken during each interview to provide clarity of context for participants' comments. Interviews were audio-recorded, transcribed, and reviewed for accuracy by the interviewer. All data were de-identified prior to analysis.

DATA ANALYSIS

An iterative approach was used to analyze the data, beginning with multiple readings through each transcript to immerse the researcher in the data and gain an overarching perspective of participants' responses.²⁰ Data immersion allowed the researchers to engage in a reflexive process: reflecting on their own backgrounds and beliefs that could potentially bias interpretation of participant interviews and to gain awareness of these biases during the data analysis

and interpretation.²⁵ This was followed by individual coding of each transcript to identify key concepts. Memoing and *in vivo* coding procedures were used to maintain the integrity of the participants' own words and experiences.²⁶ During this coding process each researcher referred to field notes from both the PHR training and the participant's interview to gain additional context beyond the information available solely in the transcripts. Researchers' thoughts and insights were captured in notes made in the transcript margins next to each code and used for further refinement. Once coding was complete, codes capturing similar ideas were grouped together to develop categories centered on participants' use of the PHR to manage their diabetes-related health information. The researchers met to compare categories and resolve differences in interpretation of coding leading to category formation. The researchers examined and discussed the relationships between the different categories using the central research question as a guiding framework for discussion. This discussion resulted in the emergence of themes, identification of meaningful quotes representative of each theme, and the confirmation that data saturation was achieved.

Results

Fifty-nine of 72 participants completed interviews. Six participants did not return for a follow-up visit with their diabetes care provider during the study period and could not be reached. Seven participants asked to be excluded from the study. The remaining 59 participants were on average 59 years old (range, 28–80 years), had their initial diagnosis of diabetes 13 years ago (range, 1–38 years), were 61% female ($n=36$), and were 71% white/Caucasian ($n=42$), and all were at least high school graduates (37% had a bachelor's degree or higher levels of education). Twenty-three of the 59 participants (39%) were still using the PHR at follow-up. Overall, participants reported mixed experiences with the PHR. Although participants acknowledged that the PHR can be a useful tool, many practical aspects of use outweighed potential benefits. Nine themes emerged from the data analysis, organized according to participants' positive and negative experiences with the PHR.

POSITIVE EXPERIENCES

Complete and accessible record. Participants valued the PHR as a self-maintained, self-controlled complete record of their health information. Participants described using the PHR as a "personal data vault" and a "general overall record of my health." This was helpful for participants who were not previously tracking their health information or for those only using their memory to remember their health information. Even for individuals already using other tracking tools, the PHR facilitated tracking additional types of health information, for example, maintaining use of their glucometer for daily blood glucose readings and using the PHR for yearly laboratory tests (e.g., lipids).

Participants also valued having their health information in one location accessible anywhere with Internet connectivity, both for emergency situations and being able to share it with their healthcare

providers. As one participant stated, "if something happens and I needed medical records, now they can get it," and another noted that "if I come in and they want to see what my history is then it's easy to get into a computer and bring it up."

Increased awareness. PHR use increased participants' awareness of changes in their blood glucose readings. The ability to graph blood glucose readings within the PHR allowed participants to see long-term cause and effect better than on paper or a glucometer, illustrated by one participant sharing, "I like that I can track my glucose level and I can see what I've been doing and if food is what was causing me to have highs or lows."

Behavioral changes. PHR use highlighted areas for self-care improvement, which led some participants to make behavioral changes. One participant shared that "it allowed me to adjust my insulin because if it [blood glucose levels] was too low then I wouldn't take as much." Using the PHR led several participants to exercise more and lose weight, led one participant to begin monitoring her blood pressure, and another to "check my sugars more like I'm supposed to."

NEGATIVE EXPERIENCES

Out of sight, out of mind. Participants shared a wide range of issues that limited opportunities to engage with the PHR, including personal illness, family and work responsibilities, temporary residential displacement, and traveling. These issues were major barriers to PHR use, resulting in participants forgetting their usernames or passwords and leading to nonuse. For most participants the PHR was not viewed as a crucial tool in their daily self-management of diabetes; as one participant expressed, "I never got into the habit of doing it. It was out of sight, out of mind."

I would have used it if I were sicker. Some participants who were adequately managing their diabetes care believed the PHR was not needed because of their positive health status. As one person shared, "my A1c has been steady. So I didn't feel like I really needed to use it as often...that wasn't particularly useful for me." Another participant believed he would have used the PHR if he was uncontrolled and/or needed to check his blood sugars more frequently: "I could see if I was trying to see trend lines, like if I did glucose daily or multiple times during the day."

Economic, infrastructure, and computer literacy barriers. Economic barriers inhibited PHR use, including cost of Internet access and computer hardware problems. One participant shared that he "got rid of my computer service [Internet access] because I couldn't afford it." Other participants had their computer break down and did not have the financial resources to fix or replace it. Participants also lacked alternate means of computer access if their primary access was unavailable (e.g., if their home computer broke, they could not use a work computer for personal use). Even for participants with consistent access to a working computer, unstable Internet connectivity or

slow speeds were barriers to PHR use. One participant faced unreliable Internet connections at the public library, whereas another participant lived in a rural area with only a dial-up connection. Finally, despite asking participants to self-identify being comfortable using a computer, issues related to computer literacy were expressed, exemplified by the comment, "I'm not a computer person so for me to get on to it, it took a while."

Lack of patient-provider engagement with the PHR. Most participants did not share the PHR with their physician. Participants perceived that the "doctor already has all my information." Additionally, although all clinic providers were informed of their patients' participation in the study, no participant discussed his or her provider asking to see the PHR or wanting to view it when asked by the participant.

Double tracking. Participants still used other mechanisms for tracking health information, including their memory, printouts, handwritten records, a Microsoft Excel™ spreadsheet, and their glucometer. Participants were comfortable with their existing mechanisms, so what was typical for the patient did not change with the introduction of the PHR. For example, one patient used the PHR but maintained use of his Excel file because "being able to average and get my blood sugars in Excel is what I am used to." Participants noted that using the PHR takes an "additional step" (i.e., logging in) and contrasted it negatively with other record-keeping mechanisms, illustrated by a participant who stated, "just give me a piece of paper and I can write it down."

Privacy and security concerns. Few participants voiced concerns about the privacy and security of information maintained in the PHR. For those who did, concerns ranged from personal fears to technical questions. One participant shared, "I'm a private person and dislike my entire life being recorded on some electronic device." Another participant wondered if the PHR "is adequately secure enough, because it's in the cloud and I'm always a little worried. Are the insurance companies watching or how secure is it? Those are part of my concerns."

Discussion

Three primary benefits of PHR use emerged in this study: developing a complete and accessible record of health information, enhancing awareness of patients' diabetes management, and stimulating behavioral changes, thus achieving some of the promise inherent in PHR use. The PHR also helped patients at different levels of self-care engagement, from those who previously had not tracked their health information to patients who did so regularly. The PHR did not replace existing record-keeping tools, as some participants either double-tracked their information or used the PHR as a supplementary record (e.g., to track yearly laboratory values while using other mechanisms to track daily blood glucose levels).

However, many barriers continue to inhibit sustained and effective PHR use. Several barriers cannot be easily addressed (e.g., personal

illness or temporary residential displacement), nor can infrastructure issues such as slow public Internet speeds or lack of high-speed Internet access in rural areas. Instead, focus should be placed on addressing barriers that can be overcome. There is a clear need for the PHR to be integrated into patients' typical self-care routines in order to sustain use over time. A strong patient-provider relationship has been associated with PHR adoption, and provider support may also help patients integrate PHR use into their self-care behaviors.²⁷ Yet the PHR has not engaged providers to a great degree. Prior research has revealed that 25% of physicians did not know about PHRs, and 60% did not know if their patients used a PHR.²⁸ Patients in this study indicated that their providers did not show interest in viewing the PHR. This is consistent with prior research indicating only 42% of physicians were willing to use a PHR in their practice.²⁹

For the PHR to add value to care delivery, providers must become more educated about the PHR and promote its use as a tool in patients' diabetes self-care. Providers should consider integrating the set-up of a PHR into diabetes education programs. Having a complete and accessible record and increasing awareness of the impact of self-care on clinical outcomes are valuable not only for patients who are uncontrolled and not achieving their diabetes goals, but also for patients who are adequately controlled or perceive not needing an additional care tool. Providers should also help patients understand that use of the PHR can yield a more complete picture of a patient and allow for more fully informed medical decision-making.^{30,31} Given the fact that not all electronic health record systems are interoperable, providers still possess an incomplete picture of the patient; these are information gaps that the PHR can help fill.³²

Increased provider engagement can also address economic barriers for patients. Using strategies such as providing access to computers in physician offices for patients to use can help lower these economic barriers to PHR use and allow patients who may otherwise be affected by the digital divide to engage with this tool.

Security and privacy concerns were rarely discussed by participants despite being identified in the literature as a potentially large barrier to PHR use.^{11,33,34} Although the following is unlikely because of participants' high educational levels, participants in this study may not have expressed concern owing to a lack of knowledge about the potential for security and privacy issues with a stand-alone PHR. Alternatively, participants may simply be willing to accept security and privacy risks for the potential positive gains resulting from PHR use. Further exploration is needed to better understand what prompts security and privacy concerns by patients and how these concerns can be addressed.

Understanding the potential PHRs have for facilitating patient knowledge gains and engagement in self-care, addressing accessibility issues inherent in technology use, and educating providers about the benefits of PHR use are crucial for enhancing adoption and effective use of PHRs.

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