

Listening to Users: Older Adults Have Ideas on How to Improve Patient Portals

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Abstract

As people age and live longer, older adults are faced with growing demand to maintain personal health. One significant demand is to manage a range of personal health information to support physiological, cognitive, and psychosocial dimensions of healthy aging. Older adults may benefit from using consumer health IT to support their health information management activities. Patient portals are considered a promising tool for managing personal health information, increasing communication between patients and physicians, and improving patient engagement. Due to the Health Information Technology for Economic and Clinical Health (HITECH) Act (2009), near universal adoption of electronic health records is achieved in the U.S. and there is a growing availability of patient portals provided by health care providers across the country to offer patients online access to their health information. Patient portal adoption creates great opportunities and challenges for the growing and aging population. When compared with other age groups, older patients have shown lower levels of adoption rate¹⁻³ and older age are often identified as a barrier on portal adoption⁴. Getting older users' feedback on the technology and listening to their pains and suggestions are important to improve the design and adoption rate among this population. This qualitative study examined older adults' needs and preferences, particularly elderly adopters, for patient portals, and reported their design suggestions to improve the portal system. These suggestions may be helpful for patient portal designers and health care organizations deploying these systems.

Introduction

The intention of patient portals is to promote patient engagement and help managing personal health information and the HITECH Act resulted in a nationwide patient portal implementation among health care providers to offer their patients portal access. Although current evidence is not sufficient to prove the effects of patient portals on patient health outcomes^{5,6}, improvements has been observed in medication adherence, disease awareness, patient-doctor communication, and self-management of disease in the patient portal groups⁶. Consumer adoption of patient portals is becoming important for receiving quality health care including quick access to one's personal health information and making interactions with their health care providers outside of clinical visits. Older adults may benefit more from portal use than younger populations because of the increased occurrence of chronic conditions and higher medical complexity⁷.

Despite the benefits and the growing availability, widespread patient portal adoption remains low and currently only about one-third of the overall population actually access their online health data⁸. In particular, when compared with other age groups, older adults are lagging behind others on portal adoption¹⁻³ even though they have the highest health care spending and resource utilization, and older age is often identified as a barrier on portal adoption⁴. In addition, low adoption rates are most pronounced among older adults who age 75 and older, are racial ethnic minority, have less education, have less access and experience with technology, and who demonstrate low health literacy and numeracy skills⁹⁻¹¹.

Several interview studies¹²⁻¹⁴, mostly studied portal nonusers, investigated older adults' attitudes, needs, and use of patient portals. These studies found that barriers to portal adoption exist not only at an individual level, such as lack of interest and skills in technology, or fear of privacy and security issues, but also at an infrastructure level, including lack of resources in the residential facility to facilitate internet and technology access. Greysen et al.¹⁵ stressed functional limitations as a critical factor to impact older adults' internet use and highlighted the need to address functional impairment support in patient portals for promoting portal adoption across all groups of older adults. In addition, studies examined older adults' performance on patient portals found that older adults generally need more time and assistance with using the portal than younger generations¹⁶ and numeracy and internet experience are strong contributing factors on older adult's ability to perform health management tasks in portals¹⁷. A strong need for instructional support to assist older patients with portal navigation is discussed and recognized across the literature, particularly for those with little internet experience^{11,13,16} and limited health literacy^{18,19}.

Patient portals are designed for use by patients. However, current patient portals were developed by adding technology onto existing electronic health records (EHRs) systems, to meet the government's patient engagement

requirements, rather than to fully address the patients' needs. Patient portals have not been designed with older adults in mind^{12,20}, which presents challenges for them in using them. In addition, declines in perceptual, motor, and cognitive abilities often result in older adults having problems when interact with computer technologies²¹. Although a few studies¹²⁻¹⁴ have investigated older adults' perceptions about and use of patient portals, we still lack sufficient knowledge on how to make patient portals accessible to and usable by older adults, and how to design them while taking into account the needs, preferences, and abilities of older adults.

The goal of this study was to explore the range of older adults' needs and preferences relating to patient portals regardless of whether or not the older adults are currently using portals at all, and further use these insights to inform the portal design. Focus group interviews were employed as the main data collection method because ideas tend to emerge from groups and this method elicits a wealth of descriptive data that provides a range of viewpoints and insights. Primarily, this study was intended to delve deeper into older portal users' experiences and make design suggestions from an older portal user's perspective. It is believed that portal users might shed more light on the design part that could potentially make portal design more senior friendly and facilitate a wider portal adoption and successful use among older adults. This is distinct from prior studies^{12,13} in which portal users were often the minority among the participants. In addition, this study adds diversity to the corpus of publications on patient portal evaluations with older adults, in which study participants were often males, and young older adults (average age 60-70 years old)²⁰.

Methods

Focus group interviews were the data collection method for this qualitative study. Groups were further separated into elderly portal users and non-users to allow for more detailed discussion and to make comparisons between one group and another. In this study, 'portal users' were defined as individuals who were currently using a patient portal while 'nonusers' were individuals who were currently not using any portals.

Recruitment: The university's Institutional Review Board approved the study. Participants were recruited from Madison area through newsletters, flyers, and membership email lists in a senior center and flyers at nine Madison Public Library locations. All participants were required to be aged 65 or older, English speakers, have used the internet and a computer in the past three months, and have managed personal health information (either on paper or electronically) for more than one year. Interested individuals contacted the researcher either by phone or email. The researcher called the individual and administered a telephone prescreening regarding their eligibility based on the inclusion criteria and include questions on their current adoption of patient portals for focus group placement. Participants who were eligible were scheduled for a focus group interview by the end of the phone call. Four focus groups were conducted from February 19, 2016, to April 8, 2016, with three groups of elderly portal users (n = 15) and one group of elderly portal non-users (n = 5). All focus group interviews were conducted in a private, quiet room in the senior center.

Focus group procedures: For each focus group, after completing informed consent, participants were asked to complete questionnaires on their demographics, computer proficiency, and portal use (only for portal user focus groups). After reviewing the completeness of the questionnaires, the researcher provided a brief overview of the study procedures and goals, as well as rules for the discussion. A discussion guide was created to facilitate conversations and was pre-tested with two adults using think-aloud protocol to get feedback on the clarity and understandability of the guide. Examples of specific questions for portal users include: What are the things that you like/dislike about the portal? If you were going to design a portal system, what would you like in your portals? What will make this system easier for you to interact with?

The duration of a group session lasted an average of 90 minutes. Notes were taken by a note taker during the focus group to capture verbal content and nonverbal behaviors. At the end of each session, the researcher worked with the note taker to debrief. Focus group discussions were audio recorded for later transcription.

In order to strengthen the analysis and gather the most appropriate data, the researcher reviewed the recording and transcribed it verbatim in the next couple of days, wrote ideas onto sticky notes, and used affinity diagrams to quickly organize information and ideas before conducting the next focus group. Therefore, newly identified concepts could be examined in the subsequent sessions. Similar approaches of reviewing data to inform further data collection are used in methods such as grounded theory and it was felt that doing so would strengthen the data collection for the current study.

Data analysis: The researcher transcribed all focus group interviews verbatim. During this process, the researcher's initial thoughts and ideas were also noted down. Transcribed interviews, the researcher's initial thoughts, notes from affinity diagramming, and interview notes were imported into Nvivo 11, a qualitative data analysis program (<http://www.qsrinternational.com/>), to assist coding and note writing. Thematic analysis²² was chosen to identify themes within the participants' experience.

Results

Demographics: A total of 20 older adults participated in the focus groups. Male (20% of the sample) and female (80%) participants ranged in age from 65 to 87 years ($M = 74$, $SD = 6.6$). A large majority of the participants were Caucasian (90%) and the rest were African American (10%). Most participants (95%) rated their own health as good or higher. Among the 20 participants, 15 were portal users (within three groups) and five were portal nonusers (within one group). Portal users and nonusers were similar in their ages, gender, ethnicity, and health status; however, portal users tended to be more educated than nonusers that 80% of users obtained college degree or higher versus 60% of nonusers.

Portal usage: Fifteen participants were self-identified as portal users. The portal systems they were currently using were primarily versions of Epic MyChart (Epic Systems Corporation, Verona, WI). All accessed their portals through desktop or laptop computers and six of them also downloaded the mobile apps of the portal to their mobile devices (e.g., tablets, smartphones). None of them indicated receiving training on how to use the portal system. All users had adopted their portal system for more than two years and a majority (73%) of them used their portal once a month or more.

Likes: Portal users really enjoyed the ease of conducting health information management tasks online, such as making doctor's appointments, communicating with doctors, getting test results, and paying bills. They also appreciated the convenience of having one's health records available and accessible in one spot and pointed out the potential for a portal to be able to export their health records and pass them down as family health histories to future generations. Portal users pinpointed the fact that information provided through the portal is archived helped them mitigate the need to remember details and reduce the labor on paper tracking. In addition, the large majority of portal users expressed appreciation of automatic email notifications generated in the system reminding them of upcoming doctor appointments, or telling them about new messages or even test results that had appeared in their portal. As to them, email notifications worked as a trigger to access the portal.

Dislikes: The biggest complaint is the lack of data exchange between different portals. Over a half of the portal users chose to see doctors in different systems that were using separate EHRs. Some of them managed two or more portal accounts that were tethered to different EHRs while some chose to stick with their main one and kept paper records sent from doctors who were out of the system. No matter which option they chose, it all ultimately increased patients' health information management load and led to a discouraging portal experience. Age-related declines in vision and how those eye conditions, diseases, and vision impairments impact older adults' computer work were discussed in groups of both users and nonusers. When elders were having eye problems or healing from eye surgeries, this would limit their computer use and a phone call was preferred as opposed to online communication. In addition to vision problems, limited accessibility support in patient portals adds another layer of obstacles to portal use for elders.

As to suggestions on how to improve the portal design, several themes began to emerge from the interviews. These themes centered on specific portal features.

Complete records: One of the most desired features mentioned by portal users was the ability to access their complete medical records. They wanted to have one system, which is patient-controlled, that includes a patient's life-long health information (including past health history), and is able to communicate and share information with different health information systems. This idea is similar to the theoretical framework of an integrated personal health records system²³ that is consumer-centered.

Good patient education materials: Providing good patient education materials is another most desired portal feature. Portal users had mixed feelings on the patient education materials that the system linked to, such as Healthwise® Patient Education Materials. They appreciated that the portal provided this feature since the materials and explanations sometimes indeed helped them better understand the medical terms or lab tests; however, they were unsatisfied because of the dead links and materials that were not easy to understand. Portal users found it irritating to

get error pages when they clicked on linked source. One portal user concluded: “Good information on the diagnoses. We should not have to go to another source and Google it and get the answers.”

Better designed automated notifications: Portal users didn’t want to just check occasionally to see if they might have new information entered in the portal. They wanted to be notified electronically when something in the portal changed or was updated. Regarding the content of notified messages, users preferred to know more. The message should not only tell the user there is new information in the portal, but also specify the category of the alerts, such as lab results, billing statements, messages, appointments, or care/health reminders. Having more information on the alerts allows users to judge the level of importance of the information and decide when and how to deal with the information. In addition to that, portal users wanted the system to provide transparent notification settings so that they could have more control over notifications, and make choices based on their preferences regarding what to be notified about and how they want to be notified in terms of timing and methods.

Advanced billing features: As medical expenses compose a large portion of annual spending for many older adults, the majority of participants kept accurate paper records on their medical bills at home including premiums, dental and vision care, prescriptions, and appliances, which was indeed a lot of paper work. They had them ready for undertaking tax returns to determine whether they could get tax deductions for medical expenses each year. Older participants, particularly users who had already used the portal to pay their medical bills, wished to have some advanced billing features in the portal to help them keep track of all their medical bills for tax purposes. They wanted the system to provide simple data entry for other medical expenses so users could input expenses that weren’t paid through the portal, and calculations could be made on the interface such as a running total for a certain period.

Technical/Instructional support: Portal users expected to see an online help system in the patient portal, which is a common feature in software design; unfortunately, many patient portal systems either didn’t provide it or put the Help information at the bottom of the screen to make it almost invisible to users: “Where is the HELP button? (portal users)” In addition to desiring a Help button, both users and nonusers felt that some level of training was necessary to help them use a portal and raise awareness of other features that they may use in the future. They also enumerated several titles for training purpose, such as “MyChart for dummies,” “MyChart 101, 102, 103,” “What’s available in MyChart?” and wanted the training content to cover not only the basics such as how to navigate the system, compose messages, and get test results, but also advanced topics such as how to manage MyChart on multiple devices. When asked about the training format, participants had varying preferences, from a hard copy like a folded brochure, to one-on-one or small group training in the clinics, to online tutorials. Regarding the training place, almost all participants agreed that the clinics should provide the training, because different health care organizations may provide different portal features. A few of them also considered senior centers as another potential space since these facilities have already provided technology training to older adults.

Telephone access: A few portal nonusers stressed the importance of getting access to health information for every older adult regardless of their computer and internet adoption status and claimed that they should be able to have a similar service through other means as portal users get from a web patient portal. They proposed having an automated phone system similar to a telephone banking system to make features/information in a web patient portal also accessible through phone calls:

They need some sort of access for people, so they don't have to feel like they have to have a computer at home to access it...if they have some way of calling up, putting in the number, having it go into MyChart and having it tell you what you might wanna know, or do you have messages started and this is something that you need to know for the next two weeks or something like that or your test results have come back: press one for test results, press two if you need to be connected to the front desk or something of that order...We are an aging population and I have always had a really good vision, but I can't see to do this stuff up on a computer now (portal nonuser).

Discussion

This study conducted four focus group interviews (three user focus groups, one non-user focus group) to explore older adults’ needs and preferences concerning patient portals; in particular, the study intended to highlight the insights from elderly portal users. The design suggestions from this study may make the adoption and use of the portal systems easier for all groups as Fist et al²¹, the human factors experts, generally stress that design interventions that benefit older adults also benefit most user groups.

Older participants desire more development attention on providing good patient education materials in patient portals. Information seeking is an activity that places demands on many cognitive abilities, such as attention, working memory, source memory, and visual speed²⁴. For many older adults who possess little knowledge about the internet and search engine processes, and who may also exhibit difficulties in tuning out irrelevant information and experience, declines in cognitive abilities, searching health information online, and finding good health information can be an intimidating and frustrating experience. This makes providing good patient education materials a very important portal feature for older adults. The education materials provided in the portal should be patient-friendly and successfully meet patients' information needs, so that older patients don't need to go to other sources for information.

An important insight this study adds to the prior work is that older adults value system-automated notifications and reminders because it could help with age-related declines in performing prospective memory tasks. Prospective memory is referred to as the ability to remember delayed intention²⁵. It is an essential ability to meet everyday life challenges across the life span and is especially important in old age with increasing self-management tasks and health-related prospective memory demands (e.g. taking medications at prescribed times or going to a doctor's appointment at 3pm). Although procedure tasks (e.g. brushing teeth) and crystallized intelligence (e.g. vocabulary) appear to stay stable with age, the ability to do irregular prospective memory tasks tend to decline with age²⁵. This suggests that reminders are a real benefit to older adults, particularly for irregular tasks. Moreover, older participants desired a better designed automated notification system to meet their needs. This calls for future research on this portal feature and notifications and reminders should also be carefully designed with respect for users to alleviate information overload.

Another age-related deficit is retrospective memory that refers to remembering information from the past²⁵. Filling out medical history forms or answering doctor's questions regarding one's past health events all requires patients to have a good retrospective memory in order to provide accurate information, which can be a real challenge for older adults because of declines in retrospective memory. This suggests that including one's health history in a patient portal and ultimately keeping a lifelong health record is beneficial for older adults, which can ease their anxiety with and reduce cognitive load in remembering all their medical details, and moreover written records can provide more accurate and reliable information than recalling from one's memory.

Although patient portals make many of the PHIM tasks more convenient, the tie to a single provider-based EHR and the lack of interoperability across multiple providers are still a huge impediment, and elderly portal users in this sample highlighted this impediment as their main frustration. Current patient portals are insufficient in terms of tracing ongoing processes of coordinated care and capturing data at other health encounters, because they tether to a single EHR system. More work needs to be done to take patient portals out of silos. As government requirements on patient engagement continue to evolve, and as consumer expectations for user-friendly consumer health information technology increase, the next few years will be critical for the development of patient portals.

Future research is needed to study specific features more in depth and identify how to design these features to better support the management of personal health information by older adults. In addition, a better understanding of other key stakeholders on patient portal adoption, such as caregivers, health care providers, and health care organizations, will also inform design and promote patient portal adoption by this important population.

Limitations

This study has some limitations to note. First, patient portals that were examined in this study were all versions of Epic MyChart provided by one vendor (Epic Corporation Inc) from one geographic location. Design considerations for Epic MyChart may not all be relevant to patient portals provided by other vendors such as Cerner. However, it is important to note that current patient portals typically provide a similar set of core features, and Epic MyChart was one of the mainstream portals on the market that has also been widely researched in the literature^{12,17}, making the study results on one vendor-provided patient portal still valuable and being able to give insights to portal design in general. The second limitation was that the majority of the participants in this study were white females. Individuals from other ethnicities or male older adults may have different needs and preferences that may have been unaddressed in this study. However, white female participants can still add diversity to current literature on portal evaluations with older adults²⁰. Finally, this study disproportionately recruited more elderly portal users and focused on portal users' needs and preferences, which complements groups of older adults in prior studies in which elderly portal users were the minority¹²⁻¹⁴.

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