Use of Patient Portals for Personal Health Information Management: The Older Adult Perspective

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Abstract

The personal health information management (PHIM) practices and needs of older adults are poorly understood. We describe initial results from the UW SOARING project (Studying Older Adults & Researching Information Needs and Goals), a participatory design investigation of PHIM in older adults (60 years and older). We conducted in-depth interviews with older adults (n=74) living in a variety of residential settings about their management of personal health information. A surprising 20% of participants report using patient portals and another 16% reported prior use or anticipated use of portals in the future. Participants cite ease of access to health information and direct communication with providers as valuable portal features. Barriers to the use of patient portals include a general lack of computer proficiency, high internet costs and security concerns. Design features based on consideration of needs and practices of older adults will facilitate appeal and maximize usability; both are elements critical to adoption of tools such as patient portals that can support older adults and PHIM.

Keywords:
Patient portals; older adults; health information management

Introduction and Background

A patient portal is a type of personal health record (PHR) that is connected to an electronic health record (EHR) system. Patient portals provide a secure website through which patients can access their clinical data. They are a key component of most EHR architectures and an important focus of meaningful use because of their potential to streamline the delivery of patient-centered health care. Features of patient portals may include secure messaging, after-visit summaries, medication lists, allergy lists, laboratory results, and appointment scheduling. When used effectively, patient portals can empower consumers by enabling active management of their own care. However, we know little about how patient portal use fits into the broader personal health information management (PHIM) practices of various groups, such as older adults.

Within the general U.S. population, there is considerable interest in patient portals. Nearly 80\% of consumers participating in a 2008 Deloitte Survey of Health Consumers expressed interest in accessing an integrated medical record that provides information on personal test results, doctor visits, and hospital stays. Of those participants, 75\% expressed a desire for online portals that facilitate appointment schedules, email communication with physicians, access to test results and medical records\textsuperscript{1}. Other research also shows similar findings with regard to interest in using online personal health records\textsuperscript{2,3}. However research about the usage patterns of various users, as well as the association between use of patient portals and quality of care and health outcomes, is sparse.
In particular, research evidence about PHRs and older adults is limited. Witry et al. examined views of family practice physicians and staff about the benefits, barriers, and use of PHRs by older adults, in relation to medication use. They concluded that the family practice physicians did not have a complete understanding of the benefits that PHRs can offer patients. Several studies highlight the challenges that older adults face when using PHRs, such as physical or cognitive limitations and low computer literacy. Providers have also raised concern that use of PHRs could introduce privacy risks to patients. Other providers worry that older adults may be especially vulnerable to “getting scammed” while using electronic or online PHRs.

These findings demonstrate providers’ hesitancy to promote the use of PHR among older patients, whom they see as susceptible to privacy violations. Security has been examined by Weitzman and colleagues in the context of personally controlled PHRs. By studying a PHR called Indivo, the researchers identified important concerns of older adults about a possible breach in security. Older participants felt they had “less to lose” than younger participants, if a security breach occurred. However, the same participants expressed worry that information disclosure through a PHR could impose an emotional burden on their family members. Other researchers have focused on older adults’ use of PHRs for a range of functions, such as home medication management and information sharing with providers. For example, Kim et al. explored the use and utility of PHRs in a low-income population of older adults. The 33-month study involved 44 older adult residents of a federally funded housing facility. Researchers assessed use of and user satisfaction with a web-based PHR, the Personal Health Information Management System (PHIMS). Use among the residents was low, with only 13% of eligible residents using the system and, of those, about half used the system on only one occasion. This study concluded that the majority of the low-income elderly would not benefit from PHRs, due to poor technical skills, low health literacy and limited physical/cognitive abilities. Thus, older adults face considerable barriers in their adoption and use of PHRs and other information technology that could support PHIM. In addition, patient portal technologies have not been designed with consideration to older adults’ needs and preferences, which may explain why older adults have been slower to adopt these new technologies for managing personal health information.

Our SOARING project, a 5-year Agency for Healthcare Research and Quality (AHRQ) funded investigation, is designed to address this gap by establishing an understanding of the PHIM practices and needs of older adults. Based on Grounded Theory and the ecological framework of the Balance Theory, we sought to identify current health information practices and needs among older adults living in a variety of residential settings. Using focus groups, in-depth interviews with longitudinal follow-up, and participatory design with older adults and their key stakeholders, our goals are to develop older adult-centered guidelines to assist developers in the design of useful and usable health information management tools that better serve older adults.

We report here on our initial findings from semi-structured interviews concerning older adults’ use of patient portals for accessing and organizing health information.

Methods

Recruitment

As part of our larger SOARING study (http://www.nwphp.org/research/projects/current/health-information-management-older-adults), we conducted semi-structured interviews with older adults (≥ 60 years) to better understand how older adults manage their health information. We recruited participants from residential communities, assisted living facilities, and independent residences in King County, Washington. Recruitment efforts included presentations, flyers and key contacts at senior centers, community organizations, and older adult communities. We employed purposive sampling to ensure a diverse representation of age, gender, socio-economic status (SES), racial and ethnic backgrounds, across a range of living situations. With regard to diversity of living situation, for instance, we recruited several participants who were self-described as either currently homeless or recently homeless (n=3).
Inclusion criteria included age 60 years and older, the ability to read and speak English, and lack of cognitive impairment, measured by a score of 4 or higher on the 6-item screener to identify cognitive impairment\textsuperscript{15}. The University of Washington IRB approved all study procedures (IRB #45853).

**Semi-structured interviews**

We conducted semi-structured, 60-90 minute interviews with each participant. In most instances, interviews took place at a participant’s place of residence. After obtaining consent, we audio recorded the interview, photographed artifacts associated with PHIM, and made field notes. The interview session consisted of a demographic survey followed by a series of semi-structured questions concerning health and the use and organization of personal health information. Topics covered in the interview guide included: health conditions, management of health conditions, interactions with healthcare providers and corresponding materials received, health-related record keeping, health information seeking, and use of patient portals. Examples of specific questions include: Do you keep any records related to your health? What information (if any) do you keep track of to keep yourself healthy? What tools do you use to track your health information?

Initially, we asked participants to describe their general experience with technology and we did not focus on any specific technology or tools. However, over time, due to the frequency with which participants mentioned patient portals, we added structured and semi-structured questions regarding patient portals. In introducing this section of the interview, we described patient portals to participants as, “Websites used to access your health records or to communicate with your provider team.” Local examples of Epic MyChart and Cerner PHR were shared with participants. We probed with questions to explore barriers and facilitators to patient portal use among participants.

**Analyses**

Interview audio recordings were transcribed by a professional transcription service. Two research team members reviewed the transcripts and notes for discussions related to portal use. Demographic survey data were summarized with descriptive statistics using Microsoft Excel.

**Results**

**Participants**

*Demographics:* We interviewed 74 participants. Of those interviewed, 20% (15/74) reported using a patient portal, such as Epic MyChart\textsuperscript{TM} (Epic Systems Corp, Verona, WI), to help manage their health information. Table 1 compares demographics of the 15 portal users with demographics of the remaining 59 participants who report not using a patient portal (“portal nonusers”). Portal users ranged in age from 61 to 93 years, and most lived independently in a private residence (60%) and had college education or higher (67%). Although portal nonusers were similar in age, fewer were college educated (53%) and more lived in retirement or assisted living facilities (74%). Whereas 28% of portal nonusers reported having an informal or unpaid caregiver, only 7% of portal users reported this. Eighty percent of the portal users identified themselves as white.
Table 1. Participant demographics and living situation

<table>
<thead>
<tr>
<th></th>
<th>Portal Users (n=15)</th>
<th>Portal Nonusers (n=59)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (SD)</td>
<td>76 (7.4)</td>
<td>78 (10.2)</td>
</tr>
<tr>
<td>Female</td>
<td>87%</td>
<td>59%</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some high school or less</td>
<td>0%</td>
<td>5.1%</td>
</tr>
<tr>
<td>High school graduate</td>
<td>6.7%</td>
<td>13.6%</td>
</tr>
<tr>
<td>Some college</td>
<td>26.7%</td>
<td>28.8%</td>
</tr>
<tr>
<td>College graduate</td>
<td>20.0%</td>
<td>33.9%</td>
</tr>
<tr>
<td>Post graduate</td>
<td>46.7%</td>
<td>18.6%</td>
</tr>
<tr>
<td>Living situation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retirement community</td>
<td>20%</td>
<td>49%</td>
</tr>
<tr>
<td>Assisted living facility</td>
<td>13%</td>
<td>25%</td>
</tr>
<tr>
<td>Private residence</td>
<td>60%</td>
<td>17%</td>
</tr>
<tr>
<td>Other (e.g., homeless)</td>
<td>7%</td>
<td>9%</td>
</tr>
</tbody>
</table>

Note: Later in this section, we discuss a group of “potential portal users.” In this table, portal nonusers (n=59) include these twelve participants we later mention as potential portal users.

Technology use and experience: Our preliminary analysis found that most portal users (93%) reported using a computer 6-7 days per week and 47% rated themselves as “very experienced” computer users. All reported having learned to use a computer 10 or more years ago and having Internet access where they live. In contrast, the majority of portal nonusers reported having used computers less than 6 days per week (30%) or not all (36%), 25% lacked Internet access where they lived, and 19% reported they had not learned to use a computer. Among the 52 participants (portal users and nonusers) who use computers, the most common use of computers was emailing and browsing the Internet.

From the interviews, two themes emerged with regard to patient portals: ‘facilitators,’ characteristics, uses or other attributes that encouraged or eased utilization of a patient portal, and ‘barriers,’ individual or systems level obstacles to patient portal use.

Facilitators of portal use

The majority of patient portal users made positive comments about the specific portal they used. Easy access to health information, more direct communication with providers, and the ability to make appointments online were cited as valued features.

Many (9 of 15) portal users mentioned ease of access to health information, as illustrated in the quotes below:

- ...they have the whole record there. That’s what I love about it.

- The doctor has email, and you can get the lab results from there. So anything I need to know, like, if I think my potassium is too low or something, I can check it and see.

Direct communication with providers and the ability to easily make an appointment were cited as other positive features of patient portals:

- You can email back and forth with your doctor if you don’t necessarily need an appointment.

- I like the fact that I could, rather than calling and running the risk of a note being taken wrong or misunderstanding what I said, it’s there. It’s in my own typing. It’s there. And I can send my doctor notes about my blood pressure, or ask her a quick question. I love computer medical technology.

- ...it’s a faster and better way to communicate with my doctor about things. You see, before, the only way I could communicate with my doctor was call over to adult medicine and leave a message if I had to.

Additionally, we heard many positive comments regarding the ease of use, such as:
...it’s been really good, and helpful, and easy to utilize. They made the system user friendly.

I like that it is easy to access and easy to navigate.

MyChart is really cool. ... I can make an appointment online with my doctor. All my doctors there are listed. I just click on the one I want.

Regarding management of health information, several participants mentioned a dramatic reduction in their health information record keeping with portal use.

I used to file things away in file folders, but now I pretty much just go check, and if I want to find out what my blood pressure’s been for the last five years, all I have to do is go online and they have these nice little lists.... So they made me kind of lazy really, as far as keeping other records. Because it’s right there.

**Barriers to portal use**

*Potential portal users:* Of the 59 nonusers, 20% (16% of the total participants interviewed) mentioned some relationship to patient portals. Four participants stated they had previously used a portal, three participants had use of a portal through a family member, and two participants indicated they would like to use a patient portal in the future.

Within this potential portal user group, problems with logging in were provided as reasons for no longer using patient portals:

- Because I don’t use it all the time, I forget what the password is and what the user I.D. is.

- I gotta make sure I still have my password and everything so I can get back on it.

Some of the potential portal users expressed positive attitudes towards patient portals, but cited the cost of maintaining internet access as a barrier to their use:

- The experience was great. If I had internet at home, if I could afford internet, I would definitely use MyChart on a regular basis.

- But for many people, we cannot afford the internet. I can’t afford $29 a month.

*Portal Nonusers:* Many of the remaining participants classified as portal non users had never heard of a patient portal and/or expressed negative attitudes towards the use of portals. Participants who did not use patient portals primarily cited personal reasons, such as general aversion to or difficulty using computers, and security concerns:

- My brain will only stand so much confuzzling.

- I’m not interested [in patient portals]. I don’t like any of my things on the web or whatever you call it. I’m against all that.

- Well, I’m paranoid of computers. People get their identity, they find out their weaknesses, and they swoop in, and I really don’t feel like broadcasting all my stuff on the internet.

Of note, factors intrinsic to specific patient portals, such as difficulty navigating a site or interface design, were not mentioned by any participants.
Discussion

Over the last twenty years, there has been growing emphasis on the involvement of health consumers in their own healthcare. Important to the success of the consumer health movement is accurate, accessible, and understandable health information to assist with treatment and health decisions. Older adults are the largest consumers of health care and expend the greatest proportion of US health care dollars. Thus, their participation is key to the success of this consumer movement towards greater health autonomy.

Despite reported barriers to the use of PHR technologies by others, 20% of the older adults we interviewed use patient portals to manage their personal health information. These participants express enthusiasm about the access to health information, direct communication with providers, and ease of scheduling that patient portals offer. These factors appear to serve as important facilitators for adoption of patient portals by older adults.

We found that those older adults who use patient portals do so because the use of the portal facilitates efficient and easy access to health information, medical reports, and clinical appointments. This is consistent with prior studies investigating older adult adoption of new technologies, such as automated teller cards and cell phones. These studies indicate that older adults generally lag behind younger adults in adopting new technologies, but will adopt new technologies when they feel these technologies enhance convenience, are useful to their daily lives, and are easy to use. An important insight our study adds to prior work is that patient portals appear to play a small but substantial role in facilitating PHIM in older adults.

As in prior research, we identified several barriers to the use of patient portals by older adults. Our results indicate that these barriers are not only limited to the individual end user level, such as computer knowledge or prior training, but also exist at a systemic level, including infrastructure that hinders Internet access and lack of resources within residential facilities to equip residents with tools that facilitate access.

Our findings provide initial insights into the PHIM needs and practices of older adults regarding patient portals. Further research is needed to better understand what factors related to form (mobile phones, tablets, desktop computers) and function are most important to include in patient portals when designing user interfaces that facilitate management of personal health information by older adults. A better understanding of the role of caregivers in portal use will be the focus of future studies involving interviews we will conduct with key stakeholders. By establishing an understanding of the PHIM practices and needs of older adults, we can substantially inform the design of supportive technologies and promote the adoption of patient portals by this important population.

Conclusion

Despite broader issues of accessibility, such as computer use and Internet access, study findings highlight the small but substantial role of patient portals as a platform to facilitate management of personal health information among older adults. The use of patient portals demonstrates their growing potential and role in helping older adults maintain the health, wellness, and independence they desire. Design features based on consideration of needs and practices of older adults will facilitate appeal and maximize usability, which are critical to adoption.
References


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