Title: Older Adult Patient Concerns around the Security of Caregiver Proxy Portal Use

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Abstract

Background
Electronic patient portals have become common and offer many potential benefits for patients' self-management of healthcare. These benefits could be especially important for older adult patients dealing with significant chronic illness, many of whom have caregivers, such as a spouse, adult child, or other family member or friend, who help with healthcare management.

Patient portals commonly contain large amounts of personal information, including diagnoses, health histories, medications, specialist appointments, lab results, and billing and insurance information. Some healthcare systems provide proxy accounts for caregivers to use to access a portal on behalf of a patient. It is not well known how much and in what way caregivers are using patient portals on behalf of patients and whether patients see any information disclosure risks associated with such access.

Objective
The objective of this study is to examine how older adult patients perceive the benefits and risks of proxy patient portal access by their caregivers.

Methods
We conducted semi-structured interviews with 10 older adult patients with chronic illness. We asked them about their relationship with their caregivers, their use of their patient portal, their caregiver’s use of the portal and their perceptions about the benefits and risks of their caregiver’s use of the portals. We also asked them about their comfort level with caregivers having access to information about a hypothetical diagnosis of a stigmatized condition. Two investigators conducted thematic analysis of the qualitative data.

Results
All patients identified caregivers. Some had given caregivers access to their portals, in all cases by sharing login credentials, rather than by setting up an official proxy account. Patients generally saw benefits in their caregivers having access to the information and functions provided by the portal. Patients generally reported that they would be uncomfortable with caregivers learning of stigmatized conditions and also with caregivers (except spouses) accessing financial billing information.

Conclusions
Patients share their electronic patient portal credentials with caregivers in order to receive the benefits of those caregivers having access to important medical information, but are unaware of all the information those caregivers can access. Better portal design could alleviate these unwanted information disclosures.

Keywords
Caregivers, proxy, proxy portal access, patient portals, proxy portal accounts
Older Adult Patient Concerns around the Security of Caregiver Proxy Portal Use

INTRODUCTION

The introduction of electronic patient portals over the past decade has the potential to offer many benefits to patients, such as faster and more direct access to health information and test results and the ability to easily renew prescriptions, make appointments and communicate with health-care providers. However, these benefits may not accrue uniformly across patient populations, and research has shown that patient portal adoption is lower among older adults, who typically have more chronic health problems and increased needs for health services [1].

Many older adults have limited ability and motivation to use electronic patient portals [2]. However, their caregivers (such as adult children) may be able to leverage the benefits of such portals on their behalf. This usage of patient portal accounts by a caregiver is referred to as proxy portal use. Some portal systems allow patients to provide a caregiver with access to their portal by setting up a proxy account. While health-care systems that offer proxy access may encourage patients to setup proxy accounts for their caregivers, patients may simply share their portal credentials (username and password) with their caregivers.

Our research objective is to gain insight into how older adult patients with chronic illness think about caregiver access to information available on patient portals. We present a qualitative interview study with lower-income, older adult patients in an urban area in the US. We interviewed patients about their caregiver relationship, their own use of their patient portal, their caregiver’s use of their patient portal, and their comfort levels in sharing all of the information and functionality that a standard patient portal provides. We discuss our findings and provide a set of preliminary design guidelines for patient portal designers who wish to support this proxy portal use.

Barriers to Adoption of Patient Portals

Electronic patient portals can be viewed as an information and communication technology (ICT) that supports ‘aging in place’. Connelly et al. have found that evaluation of ICTs for aging in place requires multiple methods because of the wide variety of nuanced contexts in which older adults live [3].

Lyles et al. showed that lack of technical support and the fear of losing the doctor-patient relationship were barriers to adoption of patient portals for African-American and Latino patients [4,5]. Similarly, Ancker et al. found that the odds of being given an access code
for a patient portal were higher for patients who were young, English speakers, white, insured and female [6]. Patients with lower socio-economic status were less likely to make use of patient portals [7].

Health literacy may be another significant factor impacting adoption of patient portals, as it is correlated with higher perceived ease of use and usefulness of health information technologies [8]. Functional impairment may negatively impact the ability of older adults to use patient portals [9]. Given that functional impairment tends to be lower with younger populations [9] and that health literacy tends to be higher among younger populations [10], younger caregivers may be better equipped to use patient portals than some older patients.

Caregivers and Information Sharing
Caregivers (often family members) play an important role in assisting older adults living with chronic medical conditions, and some recent research suggests expanding the concept of ‘personal health informatics’ to ‘family health informatics’ [11]. Pang et al. have noted the need to design for patient privacy while sharing information with relatives [12]. The needs of informal caregivers, such as their need for social support, recognition as caregivers, and communication with other stakeholders, are complex [13, 14, 15, 16, 17]. Bosch et al. note the importance of making caregivers better-informed through access to systems such as patient portals [18].

Recent work looking into chronic illness patients with spousal caregivers demonstrates that it is important to support situations in which the values between patient and caregiver are in tune, as well as situations in which these values conflict [19]. While that work targeted spousal caregivers, similar patterns of conflicting values may emerge with other types of caregivers, such as adult children, siblings or close friends and neighbors. Designing to handle conflicting values around sharing and privacy between patient and caregiver becomes a critical component when looking at proxy access to patient portals.

Proxy Portal Accounts
Most electronic patient portal systems have some mechanism for provision of proxy accounts. This is common for parents of young children, where the parents get automatic proxy access to their children’s portals. However, only some patient portal systems allow proxy accounts to be established for adult patients. Healthcare systems that do not offer proxy accounts for adult patients may recommend that adults wishing to share their patient portal information share their login credentials with their caregiver. Sarkar and Bates argue that current health care systems do not adequately engage caregivers and note, “...although the Office of the National Coordinator acknowledges the importance of caregivers and family, broadly adopted standards for caregiver access to patient portals are not available” [20].
Caine et al. have investigated patient attitudes towards the sharing of their electronic health records (EHR) within medical systems [21]. They found that patients were unaware of how much information was in their EHRs and wanted much more fine-grained control over who could access this information. They wanted to know when their information was accessed and by whom. While their study did not specifically address issues of patient portals and caregiver access, the issues they discuss are relevant to the patient portal context.

In a survey of patients across all age groups, Wolff et al. found that patients share portal access with caregivers for information sharing purposes and emergency reasons, but also because they need technical help [22]. In a focus group study of adults over 75 years of age, participants raised concerns about autonomy and control, and the authors reported that it would be difficult to create a single model of access control for proxy accounts that would be suitable for all patient-caregiver dyads [23]. To our knowledge, these are the only two studies that investigate proxy portal usage.

**Health Information Security**

There are two inter-related issues with password sharing. Individuals frequently share their passwords with friends, co-workers, and relatives, allowing them to access a system account using the account holder’s credentials [24, 25]. In addition, individuals often engage in cross-system password sharing, in which they use the same password (or a similar password) across many systems [26, 27]. The sharing of passwords with others creates a significant information disclosure risk if the individual owning the credentials has also used the same password across multiple systems, such as a patient portal, online banking, and social networking.

One approach to improve privacy in the sharing of health information is the *break-glass* access control protocol [28, 29, 30]. This idea is based on the metaphor of the need to break the glass around a fire alarm. This can be applied to healthcare information because many people want to keep their health information private, but in the case of a life-threatening medical emergency, would want caregivers to have access to that health information. When this approach is applied to health information systems, any emergency that satisfies the ‘break the glass’ criteria allows specified people to access the information, but also creates an audit trail so that the patient and providers can see that the information has been shared, when it was shared, and with whom.

**METHODS**

This research fits within a larger longitudinal research project investigating older adult patients and caregiver usage of electronic patient portals [31]. In that project, a set of patients and caregivers have been interviewed periodically over a period of two years to understand patient portal adoption and usage. For this particular study into patient perceptions around caregiver access, we began by first doing a walkthrough of the patient
portal system at the academic medical center that is the home for our research team. We analyzed the functionality available in this patient portal and compared that to functionality in other portal systems to generate a set of common features. We then developed an interview study to more deeply understand how older adults perceive caregiver’s proxy portal access within the context of this standard feature set.

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Table 1. Summary of Participants, Portal Use, Caregiver Relations & Caregiver Portal Use

**Participants**

The recruitment objective was to engage patients who were racially diverse and representative of the population of older, low-income adults in the area surrounding the academic medical center. Participants in this study were selected from the participants who had participated in the larger longitudinal study. We conducted semi-structured interviews with 10 older adult patients (age range 60 to 71; 5 male, 5 female; 7 African-American, 3 White; see Table 1) receiving primary outpatient care from an urban academic medical center that serves predominantly Medicaid and non-insured patients. Participants were thus not asked to meet low-income criteria as individuals.
Interview Structure
Data collection was completed between June and August 2017 by two trained interviewers. Interviewers met participants in their homes. The interviews typically lasted between 30 and 60 minutes and were audio-recorded. The interviewers explained the study, and obtained signed consent. Participants received a $20 incentive for completing the interview. The interview study was approved by the academic medical center’s Institutional Review Board.

The semi-structured interview covered patient background, caregiver relationship, patient’s portal use, and caregiver’s use of the portal. We defined caregiver as ‘someone with whom you share your health information, and who helps you with your health care.’ We asked all patients about how secure they considered their health information on the portal, and whether they considered it more or less secure than social networking sites and online banking. The interview then specifically investigated the patient’s comfort level with caregiver access to the portal in the hypothetical situation of a stigmatized illness, as well as the comfort level with the caregiver accessing information such as past medical records and billing or insurance data. This part of the interview included laminated screenshots of the patient portal with notional data, which were used as visual prompts to remind participants of the various features being discussed and the kinds of information available on various screens of the portal. We specifically asked participants about whether they would be concerned with their caregivers seeing financial billing information on the portal. We asked this to see whether participants were aware of this information being on the portal and how they felt about sharing such information.

Data Analysis
Transcripts from the audio-recorded interviews were completed by a professional service and then edited for accuracy. Data analysis was conducted throughout the process, with the team performing ongoing reflection on interview transcripts as they became available. As the researchers reviewed the transcript narratives, they met periodically to discuss the themes, patterns and issues they found in the data [32]. The research team created an initial coding dictionary based on these discussions. Two of the interviews were coded and reviewed by four researchers who then refined the coding dictionary. All interview transcripts were then coded in a two-step process. Each transcript was coded by one research team member and then checked for coding accuracy by a second team member.

RESULTS
Seven of the patients had used the patient portal provided by the academic medical center, and four of them had allowed one or more of their caregivers to access their patient portal (see Table 1). Given the small sample size, these numbers are not meant to suggest typical levels of portal usage by patients or caregivers, but rather to suggest that there is some proportion of older adult patients that use the portal and some portion who do allow their caregivers to access their portals on their behalf.
**Caregiver Relations and Tasks**
All of our participants identified at least one caregiver. Most participants identified a close relative such as a spouse, sibling, or adult child as their primary caregiver. Caregivers helped with both health-related tasks and with household tasks, such as cleaning and cooking. The healthcare-related tasks that caregivers engaged in included getting patients to appointments, reminding them of medications, helping with diet and exercise, and communicating with doctors.

Eight participants had given their caregiver HIPAA (Health Insurance Portability and Accountability Act of 1996) authorization. Two participants were unfamiliar with HIPAA and were unsure whether or not they had granted anyone such authorization. Three participants identified multiple caregivers, and in these cases, there was a split of responsibilities with a local friend or paid assistant helping with day-to-day care, and a family member acting as a caregiver from a distance.

**Patient Portal Use**
Seven of the ten participants used their patient portal, though their perceptions of it and usage levels varied. P3 reported using her portal four times per week and mentioned using the portal for appointment tracking. P1 reported using the portal but explained that she did not like it at all, mainly because her health care providers had not responded to messages through the portal. Other participants had logged into the portal occasionally and two of the participants had forgotten their portal passwords and had not been able to log in recently. Participants reported using the portal to monitor appointment schedules, message with doctors, and look at test results. None of the participants reported using the portals to look at billing or make payments.

**Security Concerns**
All participants remarked that they expected the information to be seen by healthcare staff only and that information on the portal was kept more private than information on Facebook. In comparing the portal to online banking, a number of participants felt they could not comment because they did not do online banking, while others felt the portal was equally secure or more secure than online banking. Most participants thought it was very unlikely that someone could hack into their portal and steal their health information. Participant responses demonstrated that they do not consider their medical information to be of high value or interest and are therefore not very concerned about information security issues when using the portal.

**Caregiver Portal Use**
Four of the ten participants had given their passwords to one or more caregivers so that the caregiver could access the portal. P1 talked about how she had set her portal password to something easy to remember, and shared it with her daughter, who mostly checks it for appointments. In asking about who has access to her portal, P3 noted that multiple
children and her home healthcare assistant all have access, but only use it on an as-needed basis. P5 has two caregivers: a daily home healthcare assistant and a brother with whom he shares his health-care issues. His brother, who has HIPAA authorization and power of attorney, can login to his patient portal, but has not done so to his knowledge. P5 has not given his home healthcare assistant access to his patient portal, despite noting that they are ‘good friends.’ P7 also has two caregivers, a local neighbor and a sister who lives in another state. His sister has access to the portal and used it to follow appointments as P7 went through cancer treatment. However, P7 has not given his neighbor caregiver access. The neighbor takes him to the hospital in medical emergencies and helps him when he is not well, and P7 says if it became important or useful, he would consider giving her access to the portal.

**Thematic Analysis**

A number of themes emerged around comfort level with caregiver portal access. Most of the participants, even those who were not on the portal or who had not granted caregivers access to the portal, saw benefit in their caregiver being able to access the portal. Although two of the ten patients interviewed (P6 and P8) used their portal themselves, they had caregivers who were not Internet users and would be unable to use the patient portal.

**Health Literacy Assistance**

One of the main reasons participants felt caregiver access was beneficial was in the caregiver’s ability to help them understand the information on the portal, such as doctor’s messages and test results. For example, P3 described how her caregivers help her understand the information that is there:

“I don’t understand all this, all these abbreviations. So she [health assistant] opened it up, she and my daughter-in-law, and they were reading and letting me know that my red blood cell count was very low and my white blood cells were my hemoglobin was out of whack, my TSH levels were out of whack.”

Similarly, P8 mentioned a close friend who works in the medical field and could act in the role of caregiver (though does not currently). She noted how helpful it could be to have this friend access her portal, saying “she may understand some of the stuff better than I do.”

**Caregivers as Communication Gatekeepers**

In multiple instances, caregivers helped to keep the rest of the family informed or helped to explain difficult medical situations to family members. For example, P3 who gives her daughter-in-law portal access, noted

“My son is one of those people that he can’t take what’s happening, so I explain it to her [daughter-in-law]. She’s in the medical field as well, and she’s a CNA [Certified Nursing
Assistant] at [clinic] and she and her best friend [name] is a registered nurse, they get together and explain to him what’s going on with me.”

This quote demonstrates both the benefit of caregivers with medical knowledge having portal access and those caregivers using that information to communicate the situation to other family members. P7 described the benefits of his sister having portal access: “she, sort of keeps the other family members informed, so it serves a purpose there, too.”

**Stigmatized Health Issues**
The portal in use at the academic medical center is full featured and includes full medical records and past diagnoses. When asked about the security of information on the portal, P1, who is a regular portal user and was familiar with the amount of information available, noted:

“Now, probably if I were HIV+ and was trying to get a job, I might be a little more sensitive about things like that. But I don’t know. I’m not real worried about it.”

This comment demonstrated that the concerns about privacy of information on the patient portal may be moderated by the presence or absence of stigmatized health issues (both from the perspective of the portal being hacked and the perspective of the portal being accessed by caregivers). P2 had an HIV+ diagnosis, and he expressed reticence about sharing his patient portal with his caregiver friend. This participant noted that he had not shared his HIV+ status with his caregiver, although he admitted that he would be okay with her finding out about his status through the portal if there was an emergency and she needed access in order to help him.

P5, when asked about caregivers accessing information about a hypothetical HIV diagnosis, responded this way:

“You don’t want everybody to know, but then the ones that are close to you that are actually gonna have to be the ones there for you, you would have to let them know.”

This quote highlights that there is a tension between needing care help and feeling embarrassed about such a stigmatized condition.

P7 raised a number of concerns about caregiver portal access. One concern was that his neighbor caregiver, who does not drink alcohol, would see that he drinks alcohol if she had access to the portal. This demonstrates that having caregivers who are slightly more distant in relationship can cause tensions in considering sharing access to a patient portal, because lifestyle information is often captured and recorded as part of routine health checkups. P7 also did not like the idea of his caregivers learning about a hypothetical mental health diagnoses. He also expressed a concern about a hypothetical diagnosis of HIV, noting:
“I don’t think I’d want them to know. No, I don’t think so. I think that would be considered sort of private, ... I mean I hope that never happens, but I wouldn’t feel real comfortable.”

Emergency Access
Several patients discussed the benefits of caregivers being able to access the portal in case of an emergency. While patients who had granted portal access to their caregivers saw benefits of this access in cases of emergency, this was also true for participants who had not granted portal access to their caregivers. This was clear in the case of P2, the participant who had an HIV+ status, but had not shared that status with his caregiver. He admitted that he would be okay with his friend caregiver accessing his portal in case of emergency, but his comment expresses a high level of reticence, even about emergency access: ”..if it had to be, so be it. If it came down to it.” The finality of this comment suggests that giving her access would definitely be a last resort, only if he really needed help from her. P7 has a sister living out of town who serves as a distant caregiver and a neighbor who serves as a close-by caregiver. This was the participant mentioned previously who felt that he would not want his neighbor to have access to the portal because she might be able to see that he drinks alcohol. But, he expressed that in an emergency, he could see the benefits of her being able to access the portal and communicate with his out-of-town family.

Billing Privacy
Most participants, even those who were regular users of the portal, were unaware that billing information was available on the portal. Some participants who had close family members as caregivers were not concerned with those caregivers seeing billing information. P4 explained her openness in this area: “That would be fine too because, if something happens to us, we’re older, they’re gonna be responsible for that.” P9 noted that she would not want her niece caregiver to see the balance in her bank account, but she would be okay with her niece seeing the medical bills on the patient portal.

Some participants had definite concerns about their caregivers accessing their portal and seeing billing information, and this tended to vary with the relationship between the patient and the caregiver. For example, P5 responded that he would be comfortable with his brother seeing billing information, but not his home healthcare assistant. P8, who has a husband caregiver that does not use the portal at all, spoke about possibly giving her best friend portal access and described how she would trust her friend with health information, making appointments, renewing prescriptions, but, “Well, I’d rather keep the billing stuff private... I’ve just always been, my finances are my business.”

P7 was not comfortable with anyone having access to his billing information. He did not realize that there was billing information on the portal, and in thinking about his sister and neighbor caregivers, noted “I would rather they not see that.. an invasion of my
private life, I guess.” These comments show that feelings about caregivers seeing medical billing information are quite varied, with some participants feeling quite uncomfortable about such information being disclosed to caregivers through the portal.

DISCUSSION
The participants typically shared their current health information with their caregivers, whether through the portal or other means of communication. The only exception to this rule was when there was a stigmatized condition, such as in the example of the participant who is HIV+ and had not shared that status with his caregiver, but would be okay if she found out the status if she needed to, in case of emergency. This situation is a perfect example of where the ‘break-glass’ paradigm of access control [29] could be applied to good effect.

We found that older adult patients see benefits in having their caregivers access the patient portals, and four of ten participants gave caregivers access by sharing their login credentials. The fact that none of these participants setup official proxy accounts for their caregivers suggests that they either did not know those accounts were available or they considered the process to get those accounts too burdensome. Regardless of the reason for password sharing, the practice is concerning, especially given research that shows people use the same or similar passwords across multiple systems [26, 27]. Older patients who share their portal password with a family member may also be inadvertently giving that family member access to their bank account or email. However, this practice is an easy way for older patients to share their information with their caregivers, and is likely to continue regardless of how easy proxy account setup becomes.

We saw that some patients have concerns about sharing information about stigmatized medical issues, though it tends to be hard for patients to consider these hypotheticals. The hypotheticals that caused the most privacy concerns were related to mental illness and sexually-transmitted infections.

We saw significant concern from some of our participants regarding the billing information that is available in the portal being accessible to caregivers. While people tend to be quite private about their personal finances, this issue did not pose a concern when the caregiver was a spouse.

Design Considerations
While patient portal systems allow for the setup of proxy accounts, those accounts provide proxy users with access to everything that the patient can access. The following considerations are based on the idea that existing proxy accounts could be modified to allow the benefits of caregiver access, while addressing the common privacy concerns noted by our interview participants. These considerations should be taken as starting points for further research and discussion, given that our findings are based on a small
sample of ten patient interviews.

- Promote the use of proxy accounts by allowing easy setup of proxies online, using simple, clear language.
- Provide a simple checklist of access controls, with screenshots, to help patients decide what information/functionality to grant the caregiver.
- Provide a default proxy account configuration that includes access to most information and functions, but requires an opt-in for the complete medical record, billing and insurance information.

These guidelines will only be useful if patients actually set up official proxy accounts for their caregivers. Some patients will likely continue to share their portal credentials with caregivers and some healthcare systems do not offer proxy accounts for caregivers, which means password sharing is the only way for caregivers to access a patient’s portal. For these reasons, we offer the following design guidelines for systems to help mitigate issues when passwords are shared with caregivers:

- Remind users when creating or changing passwords on the portal that they should choose unique passwords that are different from passwords on other important systems such as email and online banking.
- Provide a ‘break-glass’ mechanism that allows patients to specify who can be given access to the portal in case of emergency. Then, ensure that the system logs that access and provides clear alerts and login history on the portal so that the patient is made aware when someone has used the emergency ‘break-glass’ mechanism.
- Ask users to identify themselves when logging in to a portal. For example, after logging in to a portal, the system could prompt the user to define themselves as either the ‘patient’ or a ‘caregiver’. If the user chooses caregiver, the system could ask their name and relationship. This could then be added to all of the logs and communications inside the portal so that the patient and caregiver would be separately identified. This could help the patient be able to see when their caregiver logged in, and monitor for abuse of the system. This would also help healthcare providers know who they are communicating with through the portal.

One issue with the last guideline of having an identification step after login is that it could actually be seen as condoning or encouraging the sharing of portal credentials. One way to ensure that patients and caregivers do not view this as condoning the sharing of passwords is to respond when a caregiver self-identifies by asking them to talk to their patient about setting up proxy access and by sending a message to the patient that
encourages them to set up a proxy account for that caregiver. In this way, the practice is allowed, but the system also nudges users towards a more secure mode of interaction with the system. This only makes sense if the patient portal system provides adult proxy accounts, and it is currently unclear how many portal systems in the United States actually provide this functionality.

Conclusions
We have presented the results of a qualitative study with ten older, low-income adults who receive outpatient primary care through a university medical center in a small city in the US. We have investigated how these older patients share health information with their caregivers, and how these patients feel about sharing electronic patient portal access with caregivers. While two previous studies have investigated patient attitudes about proxy portal use, ours is the first study to frame these attitudes around the full set of standard portal features and to consider both the security and privacy concerns that may come into play. Our results suggest that patients typically share their login credentials with caregivers rather than setting up official proxy accounts. Regardless of the access mechanism, this proxy portal access provides no granularity of control over the information shared through the portal, and patients express some discomfort with the sharing of data around stigmatized illnesses and financial obligations. We suggest some guidelines to improve both official proxy portal accounts and standard portal accounts, to allow all stakeholders to reap the benefits of caregiver proxy portal use, without incurring inadvertent information disclosure risks or other security breaches.

ACKNOWLEDGEMENTS
This research was supported by grant “Blinded for Review” from the Agency for Healthcare Research and Quality.

CONFLICTS OF INTEREST
None of the authors report a conflict of interest related to this research.

REFERENCES


31. Blinded for review