Information Sharing Preferences of Older Patients and Their Families

Bradley H. Crotty, MD, MPH; Jan Walker, RN, MBA; Meghan Dierks, MD; Lewis Lipsitz, MD; Jacqueline O’Brien, BS; Shira Fischer, MD, PhD; Warner V. Slack, MD; Charles Safran, MD, MS

**IMPORTANCE** Elderly patients often share control of their personal health information and decision making with family and friends when needed. Patient portals can help with information sharing, but concerns about privacy and autonomy of elderly patients remain. Health systems that implement patient portals would benefit from guidance about how best to implement access to portals for caregivers of elderly patients.

**OBJECTIVE** To identify how patients older than 75 years (hereinafter, elders) and family caregivers of such patients approach sharing of health information, with the hope of applying the results to collaborative patient portals.

**DESIGN, SETTING, AND PARTICIPANTS** A qualitative study was conducted from October 20, 2013, to February 16, 2014, inviting participants older than 75 years (n = 30) and participants who assist a family member older than 75 years (n = 23) to 1 of 10 discussion groups. Participants were drawn from the Information Sharing Across Generations (InfoSAGE) Living Laboratory, an ongoing study of information needs of elders and families based within an academically affiliated network of senior housing in metropolitan Boston, Massachusetts. Groups were separated into elders and caregivers to allow for more detailed discussion. A professional moderator led groups using a discussion guide. Group discussions were audiotaped, transcribed, and analyzed inductively using immersion/crystallization methods for central themes.

**MAIN OUTCOMES AND MEASURES** Central themes regarding sharing of health information between elderly patients and family caregivers.

**RESULTS** Seven lessons emerged from 2 main themes. First, sharing information has consequences: (1) elders and caregivers have different perspectives on what is seen as the “burden” of information, (2) access to medical information by families can have unintended consequences, and (3) elders do not want to feel “spied on” by family. Second, control of information sharing is dynamic: (4) elders wish to retain control of decision making as long as possible, (5) transfer of control occurs gradually depending on elders’ health and functional status, (6) control of information sharing and decision making should be fluid to maximize elders’ autonomy, and (7) no “one-size-fits-all” approach can satisfy individuals’ different preferences.

**CONCLUSIONS AND RELEVANCE** Information sharing and control are complex issues even under the most well-meaning circumstances. While elders may delegate control and share information with family, they want to retain granular control of their information. When using patient portals, simple proxy access may not adequately address the needs and concerns of aging patients.

Published online July 6, 2015.
Families face many challenges with the care of aging parents. Medical care can be complex, care coordination is difficult, and elderly patients may face diminishing health and cognitive function as time passes. Elderly patients often share control of their personal health information and decision making with 1 or more family members or friends to help navigate this complex situation. When the need arises for family caregivers to take a more active role in care, it can be challenging for these proxies to manage an elderly patient’s health information and decision making while at the same time respecting the patient’s preferences, privacy, and priorities.

Patient portals, defined as secure websites that provide individuals with access to their health data and communication with their clinical team, can be a hub for families, although to date few portals explicitly support caregiver roles. When they do, it is often through proxy access that may not account for nuances in privacy preferences, and little to no guidance is available when patients may wish to bring their family into the fold in the role of caregivers. Furthermore, it is not clear how patient portals can best facilitate dynamic control in a straightforward way and address important dimensions of information sharing (what information, to whom, when, how much, and under what circumstances) together with control of information flow and decision making. Prior studies have shown that patients desire granular privacy control of their data in electronic medical records, but how this desire for control relates to aging, family dynamics, and patient portals is not known.

As part of a broader inquiry into the information needs and preferences of elderly patients and their caregivers (the Information Sharing Across Generations [InfoSAGE] Living Laboratory, an ongoing study of information needs of elders and families), we sought to identify how patients older than 75 years (hereinafter, elders) wished to share their health information with their caregivers and to understand how elders and families approached the spectrum of information sharing and control. Here, we address how attitudes and needs for sharing personal health information change as time passes.

Methods

Study Design
We conducted a series of 10 professionally moderated focus groups from October 20, 2013, to February 16, 2014, with 5 groups of persons older than 75 years and 5 groups of spouses and adult children who were caring for a relative older than 75 years. The study took place in partnership with Hebrew SeniorLife (HSL), an academic senior health care organization affiliated with Harvard Medical School that provides a network of care for approximately 5000 elders annually. Hebrew SeniorLife includes 5 senior living communities and serves as the main study site for the InfoSAGE Living Laboratory. Although HSL has traditionally served the Jewish community in metropolitan Boston, it is a nonsectarian organization that offers services to all. The residential communities comprise different types of living arrangements, from government-subsidized housing to more affluent condominium living, as well as different levels of care, from independent living to skilled nursing. Residents and family caregivers in these communities constituted the study population for the project. All group sessions were held at the facilities where the elders lived.

Each group session lasted approximately 90 minutes and was audiotaped and transcribed verbatim. Participants received $50 as compensation for their time. The Beth Israel Deaconess Medical Center and HSL Institutional Review Boards approved this study. Participants provided written informed consent for the study.

Recruitment
We partnered with housing directors, social workers, and resident coordinators in HSL residential communities to recruit participants who were invited via flyers and direct outreach through local social workers. Caregivers could be adult children, spouses, or other relatives and did not have to be linked to participating elders. Community directors assisted with purposeful sampling to recruit participants across living settings, such as assisted living and skilled nursing. We tried to include participants from diverse ethnic backgrounds although we were limited by the ethnic backgrounds of the residential population. We did not recruit participants with cognitive impairment. We collected demographic information from all participants, including the frequency of Internet use.

Discussion Guide
A discussion guide created by the research team and moderator was used to facilitate conversations. The first 5 groups of caregivers and the first 2 groups of elders focused on sources of information and communication and encouraged discussion of privacy concerns as they arose (eAppendix 1 in the Supplement). Not all modules were discussed in every group, and we adjusted the guides in an iterative fashion in tandem with our analysis, refining questions as needed. At a mid-project checkpoint, we felt we had not reached saturation with respect to privacy preferences and the governance of personal health information, so we placed more emphasis on those issues in the last 3 groups of elders (eAppendix 2 in the Supplement).

Analysis
After each group session, the observing investigators and moderator summarized their impressions of the group and its major themes. Three of us (B.H.C., J.W., and J.O.) initially reviewed each of the focus group transcripts independently and inductively developed coding categories to describe important topics. We then reviewed each transcript together, discussing our different codes and identifying new coding categories until we reached consensus. We used the immersion/crystallization technique to analyze the transcripts for themes, using an iterative process. One of us (B.H.C.) then reviewed the transcripts again to apply the codes related to information sharing; these codes were reviewed again by the group until consensus was reached. We organized the quotations and corresponding codes into theme segments using ATLAS.ti.
Table. Characteristics of Focus Group Participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Valuea</th>
<th>Caregivers (n = 23)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4 (13)</td>
<td>7 (30)</td>
</tr>
<tr>
<td>Female</td>
<td>26 (87)</td>
<td>16 (70)</td>
</tr>
<tr>
<td>Age category, y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>41–60</td>
<td>0</td>
<td>9 (39)</td>
</tr>
<tr>
<td>61–65</td>
<td>0</td>
<td>8 (35)</td>
</tr>
<tr>
<td>66–70</td>
<td>0</td>
<td>2 (9)</td>
</tr>
<tr>
<td>71–75</td>
<td>1 (3)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>76–80</td>
<td>3 (10)</td>
<td>0</td>
</tr>
<tr>
<td>81–85</td>
<td>11 (37)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>&gt;86</td>
<td>15 (50)</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Asian</td>
<td>1 (3)</td>
<td>0</td>
</tr>
<tr>
<td>White</td>
<td>29 (97)</td>
<td>23 (100)</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Mixed/other</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Educational level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤Eighth grade, but did not graduate</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Some high school, did not graduate</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>High school graduate or GED</td>
<td>5 (17)</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Some college or 2-y degree</td>
<td>5 (17)</td>
<td>3 (13)</td>
</tr>
<tr>
<td>4-y College graduate</td>
<td>6 (20)</td>
<td>6 (26)</td>
</tr>
<tr>
<td>Some graduate school</td>
<td>2 (7)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Masters or doctoral degree</td>
<td>12 (40)</td>
<td>11 (48)</td>
</tr>
<tr>
<td>Internet use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>5 (17)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>About every 2 weeks or less</td>
<td>5 (17)</td>
<td>0</td>
</tr>
<tr>
<td>About once per week</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>≥2 Times per week but not every day</td>
<td>2 (7)</td>
<td>0</td>
</tr>
<tr>
<td>Daily or almost every day</td>
<td>18 (60)</td>
<td>22 (96)</td>
</tr>
</tbody>
</table>

Abbreviation: GED, general educational development certificate.

*a Data are presented as number (percentage) of patients unless otherwise indicated.

Results

Thirty elders (within 5 groups) and 23 family caregivers (within 5 groups) participated in the study (Table and eAppendix 3 in the Supplement). Most elders (26 [87%]) were older than 81 years; one-third (10 [33%]) used the Internet either rarely or never, and 18 (60%) used it daily or almost every day. While many of the elderly participants initially reacted favorably to sharing health information with caregivers, our discussions revealed several nuances, in particular about maintaining control of access to information and decision making. Our analysis identified 7 lessons related to how elders wished to share information with caregivers. We grouped these lessons into 2 main themes: consequences of sharing information and dynamic control of information sharing.

Consequences of Sharing Information

Different Perspectives on the Concept of “Burden”

Elders and caregivers had different perspectives and vantage points, most notable when discussing the concept of “burden.” Caregivers felt that having information would decrease their stress, but elders wished to maintain control of information so as to not burden their children with their illnesses and problems. For example, one elder discussed how she preferred to keep information from her daughter despite hardships: “I have a daughter living in [a nearby town] and I don’t even think she’s aware of how my day goes. I have poor health and occasionally I’ll discuss that with her. But I still want to protect her and her family from any of the problems that I face.”

Caregivers said that they had to be assertive to find information that would help their parent, and that systems such as patient portals would help assuage some of the stress of caregiving: “I feel like unless I call it doesn’t get done….I still feel like I control everything….Maybe the computer is something that could help....”

Unintended Consequences From Family Access to Medical Information

Many family participants wished to have access to their elderly parents’ medical records to be able to better coordinate care, appointments, and communication with the family. However, elders and caregivers alike noted that it can be difficult to navigate such a transparent system. Caregivers may learn information previously withheld from them (eg, past biopsies, abortions, pain medicines) or may disclose information to physicians that their elder may wish to withhold: “It’s hard in these situations where you want to be an advocate and bring things to light but you don’t want to hurt your parent.”

Conversely, the elder participants voiced concerns that access to medical records might promote anxiety in children: “I think there is another problem though with children having access. Sometimes they have more anxieties than the parents have.”

Proper Use of Information

Elderly participants were comfortable with their children having information about their daily functioning, although only if it would be helpful: “We do not want it to spy on us; we want it to rescue us.” While caregivers of elders living independently in retirement communities wished to be able to know how their parent was doing, the elders sometimes preferred to keep them at arm’s length: “I just would not want my children having to even be concerned really with my everyday activities. I am here, I am in a protected environment. If something happens to me, I would be able to communicate with them that there was an emergency and I do not think they should be concerned or involved in my every [day].”

When thinking about modern devices to support independent living at home, elders were wary of the possibility of false alarms: “You know, do I get up to have breakfast, maybe someday I will sleep till 10 and have breakfast late, and should they...
get alarmed with that? I mean that’s nuts. It would make me very uncomfortable.”

**Dynamic Control of Information Sharing**

**Elders Retaining Control of Decision Making as Long as Possible**

The more independent elder participants had a difficult time picturing themselves losing control of their decision making capabilities and having to rely on their children. Throughout discussions, elders acknowledged the importance of keeping a sense of control of their health care and decision making: “I think it’s a control issue with me…. I manage my medical care and everything else in my life and I keep [my children] in the loop after it’s done.”

Although elders were for the most part willing to share at least some of their health care decisions with their families, they were clear about wanting to keep full control of the flow of information and any initial decisions: “I always keep my family in the loop after the fact…. my health is an open book, just not beforehand. I don’t want anyone second-guessing me.”

Elders expressed a level of certainty in their decision making abilities and did not want their family to hinder their sense of control. Caregivers stressed that “it always has to start with the patient” and that the control should ideally rest with their parent as long as possible: “[My mother-in-law is] very good at letting me do certain things… but there is a part of it that she wants to retain and do herself, so I will respect that when we go [to an appointment together].”

**Gradual Transfer of Control Depending on Health and Functional Status**

Control exerted regarding health information depended on the context of an elder’s age and health status. Elders acknowledged that sharing all parts of their health information would be important during an emergency but would not be necessary or ideal on a day-to-day basis. Elderly participants recognized that health information and decision making are more likely to be shared as they age or as health issues arise: “I think [it] is not the kind of thing you think about when you’re younger; it comes with aging, then it is probably a gradual thing.”

Some caregivers thought their parents liked delegating health care decisions to others: “I think she allowed us to step in, and in her case she likes it. She doesn’t mind that we’re taking some of that stress away.”

**Fluid Control of Information and Decision Making**

Family caregivers frequently voiced how important it was for them to coordinate care for their parents while respecting their preferences and preserving their sense of autonomy. They also recognized that there were boundaries in their involvement in decision making for the elder: “I always say to her, ‘do you want me to come in [to the doctor’s office], do you not want me to come in?’ and it can be fluid. It’s all about respect for the parent or in-law. They have to be in control.”

While caregivers recognized that they were transitioning into a more involved role in their parent’s health care, they were challenged to find a way to be actively involved while enabling their parent to retain at least some control of the information and decisions being shared: “So I’m trying to balance the independence so she can walk over, but then I don’t always hear what happens to her in the appointment.”

Elder participants were worried about the instances when they and their caregivers expressed different preferences about access to their health information and medical decisions. For example, an elder may not always agree with treatment recommendations from caregivers: “There are many times…children always want much more aggressive treatment than their parents.” They were also leery of children taking too much control of their lives: “Some families are very much in control of everything. I have a daughter who can run the world, [or at least] she thinks she can. When my husband would ask her sometime to help with something, he’s always sorry he asked her because she then takes over.”

**No “One-Size-Fits-All” Approach to Information Sharing**

While we did not hear from elders that they were opposed to sharing information with family, it was clear from our discussions that there is no one-size-fits-all approach to the sharing, use, and control of personal health information. The extent of sharing varied by individual, by specific situations, and by preexisting relationships with caregivers or other proxies. One elder stated, “I think it just goes to the dynamics of your family. If you are open with your family, you continue to be open. If you haven’t been, then that transfers into your medical [information sharing].”

While some elders and caregivers have a relationship that is more open and elders are willing to share health information, other elders preferred to have more granular control regarding sharing their health information with caregivers: “There are people who are much more open to telling people things and asking for things. Some people can’t do that. I don’t like to ask for anything. And I also don’t like my children to have to get involved.”

**Discussion**

In this study, we report the opinions of elders and family caregivers about the sharing of health-related information. We found broad support for sharing personal health information with caregivers if such sharing would benefit the elder, but concerns arose about autonomy and control, respect for preferences, micromanagement and snooping, and unintended information disclosure. The more independent elders were most concerned about ceding control of their health information and decision making to their children. Elders identified areas where they would be uncomfortable with caregivers learning certain pieces of clinical information directly through a patient portal. However, the desire to control all aspects of their health information waned as their health and functional status declined. In general, caregivers were sympathetic to these concerns and wanted to preserve elders’ privacy as much as possible.

Our findings may be applied through the lens of Communication Privacy Management theory, which incorporates concepts of private information, boundaries, co-ownership, and...
ruct and has been used previously in the health and sociol-ogy literature.25 In this context, elders choose to share informa-
tion with caregivers, who become co-owners of that informa-
tion. Sharing, with both intended and unintended conse-
quences, leads to some degree of new vulnerability for the elder.26 Conversations can shape the boundaries that control the private information, but boundary “turbulence” may occur if the elder and caregiver are not in agreement.

Indeed, despite recognized benefits of sharing informa-
tion, participants discussed how disclosure may have unin-
tended consequences, particularly with respect to parent-
child relationships. Elders wished to be in control of infor-
mation, wanting to actively decide when sharing would be appropriate, and wanting to avoid situations in which family members could undermine their decisions. They described being uncomfortable with their children having access to some types of information, particularly about past diagnoses and treatments. Other analyses using the Communication Privacy Management theory note that family members may also overstep bounds and share information with phy-
sicians against the elder’s wishes25—a concern of which our caregivers were also wary. However, elder participants noted that as time passed and they anticipated increasing frailty, they would be more comfortable with sharing information and de-
cision making. Changes in health are also likely to precipitate shifts in needs, preferences, and boundaries regarding shar-
ing information and decision making.19,20

Implications for Patients and Families

Ultimately, sharing information and control is a negotiation be-
tween the elder and the caregiver. Patient portals may not ac-
count for all of the permutations and preferences related to in-
dividual families’ dynamics. However, policies and procedures for shared access should be developed proactively in the event an elder becomes sick or disabled and needs family involve-
ment at that time. As a part of broader efforts at having conver-
sations about end-of-life preferences, control of personal health information may be important to include.19

Implications for Patient Portals and Institutions

These findings have important implications for the design of patient portals, and they can extend to online social net-
works for caregiving and connected sensors and devices. Proxy or other role-based access into the elder’s personal health rec-
ord may be beneficial for reducing the caregiver’s stress and lead to better coordination of care.20 Prior studies have iden-
tified that, for a caregiver who is engaged in day-to-day care for an elder, access to health care-related information can be an important mediator of stress and can measurably influ-
ence the effectiveness of the caregiver.21 For the most part, how-
ever, these studies do not differentiate between the needs of a fully independent elder and one who has chosen to share governance of personal health information with caregivers.22 Patients who are able to maintain functional independence may be less comfortable with broad information sharing until a clear need arises. Many patient portals and eHealth ecosystems are not capable of addressing these state changes in functional sta-
tus and related privacy preferences.23

In studies of the governance of patient portals, we found a broad range of approaches beyond simple proxy access.24-25 On a spectrum, access can be a fully shared account (same username and password) or a separate account with complete proxy access, role-based access that would differentiate types of caregivers, or customized access whereby permissions could be individually assigned to caregivers.26,27 Each of these types of access becomes progressively more complex to implement, use, and maintain.11 Configurations with less than complete proxy access may not be helpful in the context of a rapidly chang-
ing situation, such as an acute illness, during which the patient is unable to adjust settings.28,29

Future iterations of patient portals should account for varying information sharing preferences of patients. Although many patients and families may be well served with complete proxy access and appreciate simple interfaces, some patients may wish to set controls on the information available to their prox-
ies. In the latter case, solutions are needed to address chang-
ing needs. These solutions may be facilitated by a person, such as an administrator granting greater access when a clinical judgment is made to invoke a health care proxy for decision making. Solutions could also be technologically mediated, such as a feature that allows family caregivers to override boundaries on their own if the need arises, initiating a new set of predefined privileges.

Our results should be interpreted in the context of our study design and limitations. The participants were drawn from a single organization and were predominantly female, white, and well educated; these findings may not be broadly gener-
alizable to the larger population. A much higher proportion of participants had earned graduate degrees than one would find in the general population. These differences may overrepre-
sent functionally younger participants who may be more attuned to nuances and perhaps more inclined to be restrictive about sharing information. Last, elderly patients who are more dependent on family or who live in assisted living facilities or with family may have different perspectives.

Nevertheless, participants raised realistic clinical situations and pointed to specific concerns about sharing information and wanting a degree of control not provided by current portals. Focus groups often raise ideas for further study. It will be important to test these findings in more diverse groups and to get elders’ and caregivers’ feedback on features designed to address their needs.

Conclusions

We found that elderly and caregiving participants supported information sharing, even in light of the possibility of unintended consequences. For many families, it is unlikely that ac-
cess to information elements will be controlled statically, but they instead will be determined by a negotiation between el-
ders and their caregivers as needs evolve over time. To help with this negotiation, patient portals should anticipate the need for different levels of information sharing during times of relative wellness and illness.
Information Sharing Preferences of Older Patients and Their Families

Original Investigation Research


