
Research and Applications

Monitoring for change: the role of family and friends in helping older adults manage personal health information

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ABSTRACT

Objective: Although family and friends (FF) often play a significant support role in the health of older adults (OA), we know little about their role in personal health information management (PHIM). To address this gap and inform the design of PHIM tools, we describe the work, needs, and barriers of FF in the context of PHIM for OAs.

Methods: We conducted semi-structured telephone interviews with 52 FF identified by OA as being important in their health and PHIM. We analyzed interview transcripts for themes about FF information work, barriers, and support needs.

Results: FF play a supportive role in OA health maintenance, medical encounters, decision making, and daily activities. Monitoring, the ongoing process of seeking information related to the OA status, emerged as a key activity comprised of 3 phases: detection, interpretation, and action. Barriers to monitoring included OA choices and constraints, FF constraints, and difficulty with technological tools, resources, health information exchange between providers, social network dynamics, and physical distance.

Conclusions: FF frequently monitor for change in OA well-being, seeking up-to-date information to facilitate support of OA PHIM. Health information technology tools designed for FF can support all phases of monitoring by providing: (1) timely and granular levels of access to OA health information as the OA ages; (2) tailored health education for FF that is based on OA clinical data; and (3) networking platforms that integrate delegation, volunteering, and relevant resources, along with tools to facilitate support of OA appointment calendars and medication management. Such tools could reduce the burden of PHIM for OA and their loved ones.

Key words: aging, personal health information management, informal caregivers, health information technology, consumer health informatics, public health informatics

INTRODUCTION

The aging process brings increasing interactions with the health care system, which in turn increase the complexity of managing personal health information (PHI). Personal health information management

(PHIM) refers to activities supporting consumers' access, integration, organization, and use of their PHI.^{1,2} A growing number of studies investigating PHIM in the context of chronic conditions and aging demonstrate the burden of PHIM, and indicate that health information technology (HIT) has the potential to support PHIM

activities.³⁻⁹ Yet integration of HIT into the daily routines of older adults (OA), including family and friends (FF) who provide informal caregiving, is critical for successful use.⁸

PHIM is considered a type of “patient work”^{5,10,11} that occurs within the socio-technical context of tasks patients do, tools and technology they use, their physical environment, and organizational factors that facilitate safe and effective work.¹²⁻¹⁴ Prior studies have examined the socio-technical context of patient work related to heart failure,¹⁵ medication management,¹⁶ cancer,^{10,17} and chronic illness.^{5,18} Such studies have brought visibility to the patient work perspective, enriching design frameworks for consumer health technologies.¹¹ Although FF have long been recognized as critical actors in patient work,¹⁹ questions remain on how to formally integrate them in design frameworks for HIT that can better support PHIM.¹¹

Although some studies refer to the PHIM tasks of FF associated with informal caregiving, few explicitly characterize FF roles, needs, and barriers. For example, Holden et al.¹⁸ described barriers of patients and informal caregivers to heart failure self-care, including monitoring behaviors in the context of medication management.¹⁶ Without such descriptions, design recommendations are often limited to coarse features, such as proxy access, which do not fully address complex needs of FF and OA they support.²⁰ To address this gap and inform a broader range of HIT to specifically support the work of FF in a variety of OA contexts, we examined the information work, needs, and barriers of FF in supporting OA PHIM.

Understanding the perspective and needs of FF involved in PHIM is important for several reasons. Many FF feel responsible for the well-being of OA, sometimes assuming a caregiving role, assisting OA with PHIM, or serving as proxy health decision-makers.^{21,22} According to the 2011 National Health and Aging Trends Study, reliance on informal caregiving is increasing for OA, while availability of FF to offer informal caregiving may be decreasing.²³ Information needs of caregivers are complex²⁴ and often unmet,²⁵ while barriers to technological support are known to vary by age and disability.⁸ Supporting FF caregiving efforts through the development of tailored HIT could help minimize burden and stress.²⁶⁻²⁸

OBJECTIVE

The objective of this qualitative study is to describe the health information work of FF in the context of OA PHIM, identify barriers that stand in the way of that support, and offer design recommendations for supportive HIT.

METHODS

We conducted semi-structured telephone interviews with FF to understand their information work, barriers, and support needs in relation to OA health and PHIM. This study is part of the larger Studying Older Adults and Their Information Needs and Goals (SOARING) project²⁹ at the University of Washington (UW), a longitudinal study investigating PHIM needs and practices among 88 OA aged 60 and above in a variety of residential settings (i.e., independent living, retirement communities, assisted living), with the goal of informing HIT system design. In the primary SOARING study, we asked OA participants to refer us to persons in their life who were “involved in their health and health information management.” We did not specify a particular type of involvement, thereby encouraging consideration from the perspective of OA.

OAs provided names, contact information, and type of relationship (e.g., friend, family member) for FF whom we later recruited for interviews to analyze their role in helping with OA health and PHIM needs. The UW IRB approved all aspects of this study.

Recruitment

Of the 88 OA SOARING participants, 49 OA identified 72 FF whom they considered important in helping them with their health or PHIM. We asked OA participants to contact FF they identified to let them know we would call for recruitment. We contacted FF and invited them to participate in a telephone interview, obtaining verbal consent before interviewing each of the 52 FF who chose to enroll.

Data Collection

We conducted and audio-recorded phone interviews between August 2015 and April 2016. All audio-recordings were transcribed. Participants received a \$25 gift card upon completion.

The interview guide consisted of structured and semi-structured questions (see [Supplementary Appendix S1](#)). The SOARING research team developed semi-structured questions based on OA interviews in the primary SOARING study, experience of the research team, and consultation with geriatric researchers and geriatricians. We designed questions to gain insight into FF role in supporting the health and PHIM of the OA. Two researchers trained in qualitative research (JT, JL) conducted the interviews. Structured questions collected demographics, technology usage, relationship with OA, and FF involvement in OA PHIM. Semi-structured questions focused on FF description of their access to OA PHI and involvement in OA health related activities.

Data Analysis

We summarized responses to structured questions using descriptive statistics, and analyzed responses to semi-structured questions using thematic analysis.³⁰ Three team members (AT, JT, KO) read through seven transcripts independently, and met weekly to reach consensus about the coding schema. One researcher (JT) then coded 10 additional transcripts applying the coding schema, using the qualitative software program Dedoose; a second researcher (KO) reviewed this coding for agreement.³¹ The 2 researchers met to reconcile differences and reached consensus before coding continued on remaining transcripts. From coding, we identified emergent themes describing the role and work of FF in supporting the health and PHIM of OA.³² We also delineated barriers to FF supportive activities.

RESULTS

Participant Description

Of the 72 FF contacted, 52 completed the interview. The average age of FF participants was 67; most were female, college educated, confident using a laptop or desktop computer, and owned cell phones ([Table 1](#)). FF were connected to 36 OAs, who had an average age of 78, were 58% female, 83% white, and 75% had a college degree. Fifty-six percent of these OAs had 2 or more chronic conditions (e.g., diabetes or arthritis) reflected by a mean Charlson comorbidity index of 1.7 (SD = 1.2).³³

[Table 2](#) summarizes FF relationships with OA. One third of FF lived in the same location as the OA. Of these, 71% (12/17) were spouses or partners.

Table 1. FF characteristics (n = 52)

Characteristic	n (%)
Female	40 (77)
Age (mean = 67 sd = 11, range = 42–92)	
40–49	3 (6)
50–59	12 (23)
60–69	11 (21)
70–79	20 (38)
80 +	6 (12)
Ethnicity	
Hispanic/Latino	1 (2)
Not Hispanic/Latino	51 (98)
Race	
Asian	3 (6)
White	48 (92)
Other	1 (2)
Education	
High school graduate	5 (10)
Some college	7 (13)
Associates degree	2 (4)
Bachelor's degree	14 (27)
Graduate/Professional degree	24 (46)
Relationship status	
Married/partnered	35 (67)
Divorced	7 (13)
Single, never married/partnered	4 (8)
Widowed	6 (12)
Employment status	
Employed for wages	13 (25)
Self Employed	8 (15)
Retired	27 (52)
Military	1 (2)
Unable to work	3 (6)
Computer Experience	
No experience	3 (6)
Some experience	8 (15)
Intermediate	20 (38)
Very Experienced	19 (37)
Expert	2 (4)
Confident in using:	
Laptop/Desktop	49 (94)
E-mail	48 (92)
Tablet	34 (65)
Video calling	26 (50)
Social media (e.g., Facebook)	26 (52)
Smart TV	16 (31)
Internet Use Frequency (last 12 months)	
Do not know	1 (2)
Never	2 (4)
Less than once per month	1 (2)
Weekly	8 (15)
Daily	40 (77)
Cell Phone ownership	50 (96)
Cell Phone Purpose in typical week (n = 50)	
Phone calls	42 (84)
Text messages	37 (74)
Browsing the web	22 (44)
Email	21 (42)
Calendar	21 (42)
Social Media	14 (28)

Although the vast majority of FF (88%) stated they were at least “slightly” involved in helping to gather, track, organize, or use information related to the OA’s health, 6 FF reported they were “not

Table 2. FF (n = 52) relationship with OA

Characteristic	n (%)
Relationship to OA	
Child	15 (29)
Spouse	12 (22)
Other family	7 (13)
Friend	18 (36)
Distance to OA	
Live at same location	17 (33)
<25 miles	27 (52)
25 + miles	8 (15)
“How close do you feel is your relationship with OA?”	
Somewhat close	5 (10)
Very close	32 (61)
Extremely close	15 (29)
“In general, how would you rate OA’s health?”	
Poor	6 (12)
Fair	8 (15)
Good	10 (19)
Very Good	21 (40)
Excellent	3 (6)
Don’t know	4 (8)
“How much do you feel you know about OA’s health?”	
A great deal	27 (53)
Quite a bit	16 (31)
Some	7 (14)
Very Little	1 (2)
“How involved are you in helping to gather, track, organize, and/or use information related to OA’s health?”	
Very involved	13 (26)
Involved	14 (28)
Somewhat involved	13 (26)
Slightly involved	4 (8)
Not at all involved	6 (12)

at all involved.” However, during interviews, these 6 FF described being involved in healthy activities and talking about health with the OA.

FF Work Supporting OA Health-related Activities

FF described a wide range of work supporting both OA PHIM and other aspects of life such as health maintenance, facilitating medical encounters, decision-making, and assisting in daily life. Our focus on PHIM also uncovered many supportive tasks related to health information. Table 3 summarizes types and prevalence of FF work with examples of PHIM tasks.

As FF described their work supporting OA, many expressed an ongoing need for gathering information to identify and respond to changes in the OA’s health and health information needs. We refer to this ongoing information activity as “monitoring,” which occurred in phases within the context of FF work and PHIM tasks to support the OA. We describe the monitoring work of FF, its 3 phases, and barriers to that work below. Figure 1 illustrates this framework.

Monitoring: An Overarching Information Activity

The goal of monitoring was for FF to better understand the OA status, and know when and how to lend support. We drew from fields of public health surveillance, patient work, and situational awareness to frame our analysis of monitoring activities.^{16,34–36} In this

Table 3. Types of FF Work, Including Prevalence of PHIM Tasks to Support OA

Work Category	Examples	PHIM tasks (n, %)
Helping to maintain health	Picking up medication from pharmacy Buying food for OA, cleaning out old food Providing exercise equipment Sharing in healthy activities (e.g., gardening, walking, exercise)	Managing medications (16/52, 31%) Tracking and taking care of health conditions (10/52, 19%) Reminding and encouraging OA to exercise (7/52, 13%) Providing information, reminding, or talking with OA about healthy diet (6/52, 12%) Helping set up medical technologies (3/52, 6%)
Facilitating medical encounters	Going to scheduled clinic visits Transporting OA to/from the emergency room	Being present during visit (23/52, 44%) Participating during visit (15/52, 29%) Helping to set up or look at the OA's patient portal (7/52, 13%) Preparing questions and information for visits (5/52, 10%)
Helping with decisions	Deciding on medical treatment, living situation, insurance	Listening and providing feedback as a "sounding board" (34/52, 65%) Researching and gathering information (28/52, 54%) Discussing emergency and end of life plans with OA (12/52, 23%)
Assisting in daily life	Managing household activities Assisting with personal care Facilitating outside activities Managing mail, do not call lists, junk mail	Troubleshooting and managing health insurance (e.g. coverage, rules, payments, paperwork) (16/52, 31%) Managing or helping with calendar or appointments (11/52, 21%) Managing finances (eg, paying bills, preparing taxes, watching OA financial choices, manage investments, manage trust documents) (10/52, 19%) Managing emergency documents (12/52, 23%) Taking on legal roles (eg, co-trustee, power of attorney) (5/52, 10%)

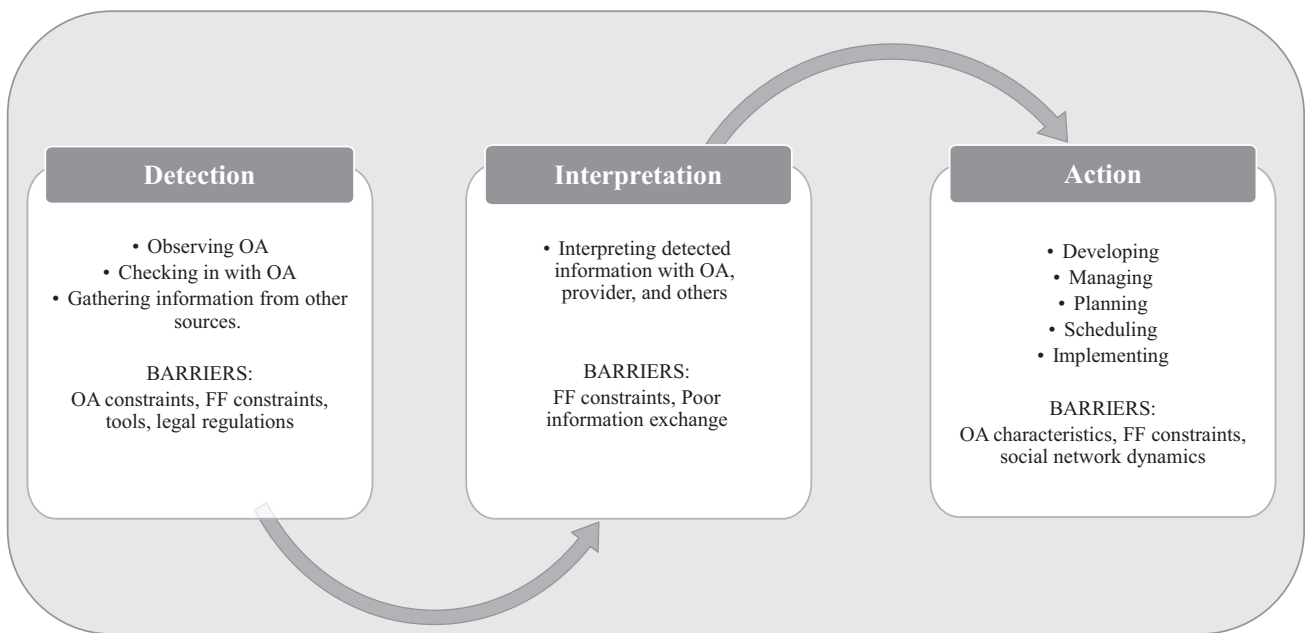


Figure 1. Monitoring activity occurring within FF supportive work.

framing, monitoring consists of 3 phases: (1) *detection* (or looking for) a change in the OA through observation or gathering information; (2) *interpretation* of that information to understand

the significance of the change; and (3) *action* in response to the detected change. Table 4 provides examples of monitoring activities for each phase with representative quotes.

Table 4. Examples of Monitoring by Phase

Phase	Example
Detection	Observing: “Right now I think my main role is just to kinda watch and communicate with him [OA] and keep my senses open for some kinda change”. (P22a, son)
	Checking in: “If I didn’t hear from her for a month or something, or let’s say two weeks, I probably would check in with her, and she would do the same for me.” (P26b, friend)
	From providers: “I feel that I am hearing firsthand from the physician what he’s telling him. So it’s like a second person hearing it also, besides himself.” (P15a, daughter-in-law)
	From other sources (e.g., internet, other FF): “I have taken the information she’s given me and consulted with research on the internet and consulted with some friends and family who are medically savvy.” (P8a, daughter-in-law)
Interpretation	With OA: “. . . we’re talking a lot. And I’m giving input. She makes her own decisions. But I’m giving input. Whether it’s wanted or not, but mostly, it’s wanted.” (P81d, friend)
	With family: “You gotta kinda keep your eye out and I’m like, is this real or is this suggestion? I don’t know. And that’s always – my brother and I talk about that a lot”. (P40a, daughter)
	With providers: “I think the most difficult is developing a clear picture of her entire health situation and then being able to relate that to a specialist. So it’s like a two-part problem. Do I have the complete picture and then have I taken the parts of the complete picture to bring to this specialist?” (P73a, son)
Action	Developing new systems: “. . . when he [OA] first became so sick is he stopped taking his thyroid medication. . . . He’s been taking that thyroid pill every day for 50 years, so it just didn’t occur to us to say, “Oh by the way, did you take your thyroid pill? It’s so simple. So. . . each time something happens, we’re like, “Oh, I guess we should ask about that too.” (P19a, daughter)
	Managing medications: “I would help fill her pillbox. Once a week. And then I would check sometimes – not consistently, but I would check sometimes, that they were being taken correctly. But she was pretty good at it.” (P31a, daughter)
	Managing finances: “I took over because he had unfortunately run into debt. He would order all of these things from catalogues and then didn’t realize – he said, ‘No, they’re paying.’ I said, ‘No, nobody’s paying you anything.’ He was such an organized person with money, but I don’t know how he got into debt.” (P15a, daughter-in-law)
	Planning and scheduling activities: “But we’ve both agreed that I will call him the day before he has any kinda appointment. . . . because he’s telling me he’s grateful to just be reminded, make sure he’s on track to fulfill the commitments and to go to the appointments he’s got.” (P22a, son)
	Planning and implementing transitions: “My sister and my wife were really involved in the making the decision and participating in it. We went and looked at a lot of different facilities.” (P19b, son)

Detection

Detection is the act of discovering or identifying a change in the health or well-being of the OA. Detection relied on (1) FF observing and “*checking in*” (P40a, daughter) with the OA and (2) FF gathering information from other sources, such as medical providers, the internet, OA patient portals, and other FF.

FF detected change through listening to OA share feelings, symptoms, or medical information. They also observed changes in OA actions and choices. Some took on watchful work frequently, checking in through phone calls or planned activities.

For other FF, detection was intermittent; motivated by the realization that time had gone by without checking or by events that indicated a possible decline in the OA health. For instance, one FF, whose family had agreed upon a “*full disclosure policy*” (P19b, son) with the OA, became more watchful after an incident in which his father did not ask for help when he was ill. While most FF looked for concerning changes on their own volition, one FF reported that his father asked him to monitor his financial transactions.

Fifteen FF mentioned obtaining information while attending OA medical appointments. For instance, one FF stated that if she did not go to an appointment with her husband, by the time he got home “*he’s forgotten what they told him*” (P42a, wife). Several FF sought information outside of appointments by calling the provider’s office or the residential facility where the OA lived, or by scheduling an appointment with the OA provider.

Twenty-eight FF sought health information related to the OA via the internet using a variety of search engines and websites. Although only 15 OA used patient portals, 7 FF had accessed OA portals. Most FF accessed the portal with the OA for a one-time purpose, such as messaging the doctor or checking test results. FF also sought health information from other FF whom they saw as experts, either in having professional expertise or personal experience.

Interpretation

Interpretation is the process of discerning the importance and meaning of detected change to determine its significance. Interpretation occurred in a variety of contexts with different people (e.g., OA, other FF, healthcare providers).

Sometimes interpretation occurred with OA to help them process and understand PHI. Many FF reported their main role was to help the OA think through, interpret, and gather information to facilitate planning and decision-making. For example, one FF always read through the OA’s prescribed list of medications and possible side effects to make sure he understood what his parent was taking and to anticipate what might happen.

Other times FF interpreted information with family members, sharing pieces of information to create a fuller picture, and to decide if roles should change. This was especially true in families that viewed themselves as a team and who shifted roles and tasks depending on the needs and demands of different family members.

Interpretation also occurred with providers. FF who went to OA medical appointments filled information gaps for the provider, answered questions the OA was unable or unwilling to answer, and asked clarifying questions. One FF interpreted all medical information for her husband, saying, “*I’m the only one that grasps what’s going on here*” (P18a, wife).

Action

FF interpretation of a detected change often led to action. Action could be through developing systems for maintaining health at

home, managing different types of health information (e.g., medications, finances), and planning for future events, ranging from daily activities to transitions in care or living situation.

Developing new systems often occurred as an outcome of interpretation and understanding the OA's needs. For example, one FF and their family started closely watching the OA's medication management after he suddenly stopped taking a medication. Some action was temporary, based on a transition or temporary need. For instance, one daughter helped her mother set up a pillbox after she had a stroke and occasionally checked on its use, until "*after a few months... [the OA] was doing it herself again*" (P31a, daughter). Other action relied on ongoing detection. For instance, some FF reported taking on a greater role in managing OA finances.

Planning and scheduling was often the initial step in taking action. For example, FF helped OA coordinate and remember life events and activities, through calendaring, reminders, and other PHIM tasks. One FF managed a calendar on her phone, and told the OA the events for the next day. Another FF kept a large paper calendar and called the OA the day before appointments. Some FF laid the groundwork for an OA decision by planning the details for transitions in care.

Barriers to Monitoring

FF experienced a number of barriers to monitoring, organized by phase in Table 5.

Barriers to detection

FF described barriers to detection related to OA and FF constraints, available tools, and legal regulations.

OA lack of sharing PHI was a barrier to detection. FF stated that OA withheld information to maintain autonomy and privacy and not be a burden. The type of information withheld varied. In some cases, the OA's desire for privacy meant that FF did not go to medical appointments with the OA, missing an opportunity to become more aware of the OA's current health situation.

Change in OA cognition was another barrier to detection. Some OA were unable to organize their PHI in a way that they could access, remember, or communicate easily. FF found that OA declining memory, organizational skills, ability to take in information, and compromised judgment all affected their ability to manage PHI, which in turn affected FF access, understanding, and knowledge of OA PHI.

Similarly, FF had their own constraints that impeded detection. Some FF were uncomfortable seeking PHI from the OA's medical provider. Nine FF mentioned geographic distance as an added barrier, making it difficult to travel to appointments or visit the OA.

Patient portals provide potential access to clinical information, but there were barriers to accessing such tools. Many OA did not use patient portals. For those OA who did have a portal, some FF accessed OA PHI using the OA's username and password. Yet none mentioned having proxy access. Several FF commented on the inadequacy of portals, with one commenting that it was not "*easy to get a complete picture of all your coverage, all your medical records, in one place*" (P8a, daughter-in-law). Other FF said they would use the OA portal if they had access. Thirteen FF expressed a desire to access provider notes on the OA's health, test results, and prescribed medications. Many FF indicated that they were only interested in accessing clinical information if the OA specifically asked and there was a clear need.

Legal regulations, such as Health Insurance Portability and Accountability Act of 1996, also served as a barrier to obtaining OA clinical information. Only 5 FF reported having power of attorney. Many FF did not have legal access to OA clinical information, so were dependent upon the OA's communication and their own observations.

Barriers to interpretation

Barriers to interpretation reflect FF constraints and poor information exchange across healthcare systems.

A few FF relied on their professional health background to help them interpret the OA's health and concerns. However, most FF did not have this level of health literacy and many struggled to understand health information and the healthcare system. It was difficult for many FF to understand what OA activities were reasonable, when to call 911, and how to best care for the OA. Several FF had difficulty understanding medical coverage, and lacked knowledge about how to navigate insurance systems, obtain medication approvals, or obtain a second opinion. In some cases, FF were informed about OA clinical information, but could not remember the details.

Several FF did not understand the use of medical technology, such as pacemakers and blood glucose monitoring devices, sometimes necessitating a search for further information. In other cases, the technology was helpful, as in the FF who said she "*didn't have to keep as close tabs on [the OA]*" because he now had a glucose monitor. (P14a, wife)

Additionally, several FF made statements about the lack of information exchange across healthcare systems, particularly related to medication changes, immunizations, and test results. For example, one FF spoke of her frustration that a nursing facility would have given the OA the wrong medication during a transition in care if she had not advocated for the correct medication based on her knowledge.

Barriers to action

FF experienced barriers to action, based on OA characteristics, their own constraints, and dynamics of social networks.

Although some FF were ready to help and understood what to do, OA personal values and emotions sometimes became barriers to FF action. One FF tried to help her mother manage medication using pillboxes and a phone reminder system, but stated "*the systems are only as good as the user.*" (P35a, daughter) Several FF noted that OA experienced fear and anger related to possible change, especially related to transitions, such as going to rehabilitation or receiving nursing care. These changes made taking action stressful.

Some FF experienced barriers to action because of the OA's cognitive and physical decline, making it difficult to plan, problem-solve, and act. One family reached a point where they could not take their aunt out of her home because they could not get her in and out of the car.

FF also dealt with their own constraints and struggles, including limited caregiving experience and access to supportive resources. One FF commented on the constraint of her personal schedule; she was only available for medical appointments on her day off from work. Another was frustrated that her father made inaccurate assumptions about her availability. Some FF were unable to help because of geographic distance.

For the most part, FF social and familial networks were facilitators of action. FF spoke of communicating with each other, assigning roles for different tasks, and switching roles when necessary. One FF spoke of a family member as a barrier to action, saying he was frustrated with his sister's inability to make a decision, and took charge.

Table 5. Barriers to Monitoring

Barriers to detection	
OA constraints	<p>Discomfort with sharing PHI: “Generally I’m always checking on his well-being, but strategies, that’s a tough one. You have to be – he’s not – he won’t not answer my questions, but he won’t volunteer.” (P14b, daughter-in-law)</p> <p>Changes in cognition: “So things like that would’ve fallen through the cracks if I hadn’t seen that letter. He is remembering, but not remembering very well at his age. (P15a, daughter-in-law)</p> <p>Organization challenges: “God knows where they keep it. They have trouble finding things, so I’ve tried to say, “Here’s the file, and it’s right here by the phone,” but last time we went to look for it to change it, I couldn’t find it.” (P14b, daughter-in-law)</p>
FF constraints	<p>Discomfort seeking information from provider: “I kind wanted to call her doc and see what was going on, but I’m not real comfortable with that because they don’t really know me, and they would be uncomfortable telling me what was going on. So I feel like I’m in a hard spot and a rock.” (P66a, friend)</p> <p>Physical distance: “It’d be nice to know what kinds of things I should know about in case of an emergency like what sorta prescriptions he’s taking or precautionary medical kinds of things. Because I live at a distance, it’d be nice if there were other perspectives.” (P22a, son)</p>
Tools	<p>Lack of access to HIT: “I hear kind of secondhand from mom when she gives me a report, but it might be helpful to me to have the medical perspective as well.” (P78a, daughter)</p> <p>Lack of trust of technology: “Because I hate computers.” (P8d, friend)</p> <p>Inadequacy of portals: “If they had doctors’ notes on there, or if they had information other than test results, I probably would. But if there are no doctors’ notes, what’s the point?” (P81d, friend)</p>
Legal regulations	<p>“Yes, if I could have any sort of private channel with the doctor. And that, of course, comes up against very important rules and ethics about doctor patient relationship.” (P18b, daughter)</p>
Barriers to interpretation	
FF constraints	<p>Health literacy: “. . .how do I assess how bad it is? What do I do to know whether I really do need to call?” (P14b, daughter-in-law)</p> <p>Memory: “Yeah, now that you – yeah, I do know that. But I can’t remember the name of the. Oh my God, that’s terrible.” (P36a, husband)</p> <p>Problems using medical technology: “The pacemaker was really scary for me because I’ve not had experience with that as far as my caregiving.” (P23b, daughter)</p>
Poor information exchange among healthcare systems	<p>“When I go to [medical provider], they’ll send me out with, “Here’s a list of her medications. Bring back this form from the doctor’s office, which says ‘Here’s the procedures he performed. He’s what he’s found. Here’s what his discharge instructions are.’” Those type of things. So, even in that situation, I’m still shuttling information.” (P73a, son)</p>
Barriers to action	
OA characteristics	<p>OA personal values and emotions: “You know, an old dog and new tricks. At that age, people generally feel they are going to do what they’re going to do. . . .” (P14b, daughter-in-law)</p> <p>OA cognitive decline: “The dementia makes our relationship very difficult as well as any problem solving around health.” (P18b, daughter)</p> <p>OA physical decline: “This is probably the first year that we won’t be able to do that because my sister’s house is all steps. And she’s been able to do it up to this year but now it’s just too hard for her to get up and down the steps anymore. You know, it’s too dangerous.” (P23b, daughter)</p>
FF constraints	<p>Level of relevant knowledge and experience: “I’m just going with my instincts. I don’t know what else to do. I’m trying the best of my ability to help him and make him comfortable, and not let him fall through the cracks where this medicine is concerned and if he’s taking it or not.” (P15a, daughter-in-law)</p> <p>Access to supportive resources: “I would like to find out more about what kinds of agencies are available that can give some of these volunteer work or anything like that, like what I’m trying to arrange on my own – of people coming. Is there a facility like that who provides? But then there’s a trust issue, also, of letting anybody that come in there – that’s the other part of it.” (P15a, daughter-in-law)</p> <p>Time and availability: “I wish I had more time, but because I work full time, I don’t make him as much of a priority as I would like. . . .” (P39b, daughter)</p> <p>Distance: “I have visited Seattle 7-8 times in the last 10 years, and we have gone on vacation together more than that. But I can’t see how her health is from a distance. Face time helps.” (P83a, friend)</p>
Social network dynamics	<p>“I didn’t ask her because I wasn’t interested in her answer anymore.” (P73a, son)</p>

DISCUSSION

Principal Findings

We identified monitoring as foundational PHIM work that supported common caregiving tasks of maintaining health, facilitating medical encounters, helping to decide, and assisting in everyday life. These categories are consistent with past findings.^{37,38} The monitoring process, which includes detecting, interpreting, and acting, helped FF gain an up-to-date understanding of and address the OA's current situation.

Studies on patient work have investigated similar constructs to FF monitoring. Prior work describes the workflow of OA and their caregivers in the context of heart failure, medication management, and chronic illness, which informed our framing.^{15,16,18} For instance, Mickelson et al.¹⁶ describe monitoring similarly as macro-cognitive work in the context of medication management. Our description of FF monitoring extends this prior work by specifically detailing FF work connected to OA PHIM given a variety of chronic health and living contexts (i.e., independent, residential and assisted living settings). A key difference from prior studies for many FF in our study was the need to detect change in the face of uncertainty related to the OA's potentially changing health status and undefined FF roles.^{39–42} Gwizdka's temporal description of 4 types of personal information applies well in this situation. Although a FF can be well informed "today," everything could change tomorrow, which might entail a change in role and a greater draw on limited resources of time, energy, abilities, and money.^{1,43} In this context the concept of information as a tool "to make sense of a reality assumed to be both chaotic and orderly" is apropos.⁴⁴ [p. 39]

Barriers to self-care have been studied in-depth in the context of socio-technical systems and specific health conditions,¹⁵ but have not focused on the barriers that FF face in helping OA with PHIM in various OA residential living situations and chronic health conditions. For instance, many FF reported barriers accessing adequate PHI for detection, which limited understanding the full picture and acting in response. A major barrier was lack of disclosure by the OA, often due to desire for autonomy or changes in cognition. A number of studies demonstrate that patients prefer to maintain control of their PHI, and tailor how they share information based on preferences for independence, privacy, time, energy, relationships, information quality, and concern about burdening others.^{20,45–47} Other research describes the uncertainty that informal caregivers of OA with chronic conditions often live with, and their need for general and tailored health information that is detailed, proactive, timely, and communicated at different times of illness.²⁵ We saw similar dynamics in our interviews that extend our understanding of barriers FF face.

Design Implications for Supportive Technology

HIT could facilitate solutions to these barriers, by supporting both the information work and needs of FF as they strive to help OA manage their health and PHI. HIT could also address the concerns of OA as they attempt to maintain control while allowing others to help. To serve both needs, design of HIT should consider the physical, cognitive, organizational, and environmental limitations and capabilities of both OA and FF, while also being convenient, easy to use, and offering meaningful help such as personal clinical information and provider recommendations.^{8,48,49} Although some advocate for "patient driven" HIT,⁵⁰ there are few recommendations for how to design systems that support roles of FF in the health and PHIM of

OA, while also being attentive to privacy concerns. We offer design recommendations for HIT according to the phases of monitoring.

HIT and detection

FF look for observable clues to a change in OA health and needs. Many technologies address this need for PHI, ranging from wearable devices to in-home sensors.^{51,52} Because these technologies are not always welcomed by OA who value privacy and autonomy, some researchers have designed options for OA to control the information flow.^{51,53} HIT could be further improved to allow FF to track, organize, and share observed changes or concerns over time, with the specific goal of indicating when meaningful change occurs or when action is needed.

Many FF wanted access to clinical information, but only a few were able to access the OA's portal. In a study of healthy OA, <10% of portal users allowed access to an adult child.⁵⁴ Many adult patients want granular control (i.e., the ability to permit or restrict access to different users) over the information in their electronic medical records, and some researchers recommend developing technologies with granular permission settings.^{55–58} For example, one HIT solution could allow FF to request needed information based on their helping roles, and facilitate communication among providers, other FF, and OA, in ways that honor the OA's desire for privacy and autonomy and strengthen caring relationships.^{59,60}

HIT systems should "take into account who will be using the tool, who has access to what information, and how these factors may change over time."⁴⁹ [p. 411] Systems should also take into account the changing nature of aging, in which OA could lose capacity to access PHI or to effectively make choices about who should have access. Many FF expressed that they generally would not need information unless there was a significant change in the OA's health status. However, unless permission is given prior to such an event, it is difficult to obtain access. A useful innovation might help the OA plan for prospective FF information access, based on the OA's projected physical/cognitive decline and provide flexibility and tailoring to individual user needs. Yet, HIT should also protect the OA's autonomy and choice in the midst of decline,^{49,61} which creates design tensions to overcome.

A plan for increased FF information access over time, dependent on defined roles and events, could include access to OA providers to ask questions or voice concerns. Optimally, FF would have their own PHR login for proxy access, and would be able to view clinical information based on OA permission given at a granular level, or from predetermined legal roles. This could help FF to reach an adequate level of situational awareness to better monitor the OA's health.

HIT and interpretation

Studies investigating patient access to their electronic health records indicate the potential for increased patient understanding and patient-provider communication.^{62–64} Providing granular access to the OA's portal could improve FF understanding of the OA's PHI, and their ability to communicate concerns with clinicians.

FF who care for OA need tailored information to help them understand the OA's situation, what support to provide, and when.^{25,65} Tailored educational programs that are linked to OA diagnoses or conditions could assist FF in their supportive role. For example, such links could include tutorials on key signs and symptoms, detecting and responding to emergencies and managing health insurance. Systems that address aspects of this directive in-

clude the patient clinical information system,⁶² OpenInfoButton,^{66,67} and the Comprehensive Health Enhancement Support System.^{68,69}

HIT to support action

HIT also has great potential to support FF action as they assist OA through PHIM and informal caregiving tasks.

Social networking sites such as CaringBridge can be used to solicit help from others.⁷⁰ However, more work is needed to develop dedicated tools for FF to sign up to help OA, while also protecting OA privacy and autonomy.⁶⁰ Individually tailored social networking platforms are needed that integrate volunteering, delegation, and communication between social network members, including FF and OA.

These platforms could connect FF to OA tasks, facilitating reminders, tracking, and health maintenance, and offering relevant resources for action, such as insurance decisions, paying bills, and end of life decisions. There are a variety of local and national information resources,^{71,72} but emerging apps could better index these resources by city and ZIP code.

Limitations

Our sample of OA-identified FF was largely female, white, and college-educated, which could limit the generalizability of these findings to broader groups. Our sample was dependent on identification by OA participants in the primary SOARING study, which reflects the limited size of participant population in the original qualitative study. OAs identified our FF participants as those who helped them with their health or PHIM. We did not ask the OA to define what that help was, and found that some FF did not initially perceive themselves as helping with PHIM. Although the primary SOARING study was longitudinal and utilized in-home interviews with OA, the use of telephone interviews with FF reported here may have limited our ability to obtain contextual information. Yet, our sample size of 52 is relatively large for a study of this nature and use of telephone interviews enabled us to reach some FFs who lived at a distance. We do not know if those FF who declined participation were different from our study population. We did not collect economic data or health-related information from FF. Relationships between these FF factors and monitoring, as well as implications for HIT, should be explored in future work. Further investigation of relationships among potential mediating factors (e.g., demographics, income, health, time constraints, quality of life) in a larger sample of OA and FF could yield a broader understanding of the intertwined needs and roles of FF and OA in PHIM.

CONCLUSION

Many FF actively provide help to OA in their life. A critical component of this support is monitoring the changing health and needs of OA as they age. Monitoring requires information to detect, interpret, and act in the interest of the OA. Although FF are often ready to help, confusion about roles, insufficient information, and barriers to information access make monitoring OA health and wellbeing difficult. HIT systems, designed with an understanding of changing FF roles and tasks, have the potential to address this dynamic interchange and help FF more effectively and efficiently support OA as they age.

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COMPETING INTERESTS

None.

CONTRIBUTORS

AT was responsible for the study design. AT, KO, AH, and GD created the interview guide. JT and KO collected and coded the data. JT, KO, AH, and AT analyzed and interpreted the data. JT, AH, KO, GD, and AT contributed to drafting, writing, and reviewing the manuscript. All authors gave input to the final version and provided final approval of the version to be published.

SUPPLEMENTARY MATERIAL

Supplementary material is available at *Journal of the American Medical Informatics Association* online.

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