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Understanding views on everyday use of personal health information: Insights from community dwelling older adults

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Abstract

Background—Older adults apply various strategies to pursue healthy aging, but we know little about their views and use of personal health information to accomplish those ends. Methods: As a first step in formulating the role of personal health information management (PHIM) in healthy aging, we explored the perspectives of older adults on health and health information used in their everyday lives through four focus groups with 25 community-dwelling adults aged 60 and over.

Results—We found that the concept of wellness—the holistic and multidimensional nature of health and wellbeing—plays prominently in how older adults think about health and health information. Participants expressed wellness from a position of personal strength, rather than health-related deficits, by focusing on wellness activities for staying healthy through: (1) personal health practices, (2) social network support, and (3) residential community engagement.

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Declaration of interest

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Conclusion—Although these themes involve personal health information, existing PHIM systems that focus on disease management are generally not designed to support wellness activities. Substantial opportunity exists to fill this wellness support gap with innovative health information technology designed for older adults. Findings carry implications for the design of PHIM tools that support healthy aging and methods for engaging older adults as co-producers of this critical support.

Keywords

Healthy aging; older adults; personal health information management; stakeholder engagement; wellness

Introduction

As rates of chronic disease and injury increase with age, older adults and their caregivers are faced with increased demands to maintain personal health. One significant demand is keeping track of a growing range of personal health information to support physiological, cognitive, and psychosocial dimensions of healthy aging (1, 2). Examples of personal health information include health status and history, tracked symptoms, medication lists, appointment schedules, and other information individuals keep about their health. Personal health information management (PHIM) is the process by which individuals create, seek, organize, and share personal health information to actively participate in their lives and their own health care (3–6). Insofar as health maintenance is dependent on personal health information, PHIM is critical to healthy aging across physical, cognitive, and social dimensions of life (7). Yet to inform supportive health information technologies (HIT), we need to learn more about how older adults view and use personal health information to accomplish those ends.

Older adults are the heaviest users of healthcare services in the United States, but in general have been reluctant to adopt HIT, such as searching the Internet for health information, filling prescriptions or scheduling medical appointments online, or exchanging e-mail with healthcare providers (8). HIT designed specifically for older adults range from personal health records (9–10) and medication management systems (11–13) to smart homes (14–18), assistive technologies (19–20), connected devices (21–25), and “gerontechnologies” that leverage ubiquitous and ambient computing (26–28). Although many computer-based interventions do not require older adults to be technologically savvy to be effective (29), adoption and use of HIT depend largely on solutions optimized to meet the specific needs and capabilities of older adults (21). Lack of perceived benefit is a common barrier (30, 31), which could reflect that HIT is not designed to fully support the unique information management challenges and needs of older adults (21), including limited health and computer literacy, (30, 32) physical and cognitive usability challenges (8, 29, 32–34), lack of trust in technology (30, 35), and difficult tradeoffs among autonomy, assistance, privacy, and security (14–16, 31, 36). Addressing these needs is especially important as older adults continue to live longer, turn to senior housing options, and confront a growing range of HIT opportunities.

In addition to meeting the needs of older adults to promote adoption of HIT (19, 26, 31), supporting healthy aging may require a focus broader than simply the physiological function of an individual. However, relatively little HIT incorporates management of information related to other dimensions of health and well-being (22). The information management needs and practices of older adults are poorly understood. For example, many older adults need help navigating online sources of health information (37), but we do not know what additional support is needed for keeping and sharing this information with providers or caregivers. As people experience multiple chronic conditions, the burden of unmet information management needs only intensifies (38). Characterizing the PHIM practices and perceptions of older adults around health and health information could provide valuable insights to guide the design of HIT that will better meet their needs for healthy aging (39).

Accumulating research on PHIM from the perspective of patients demonstrates the “work” it takes to manage personal health information outside the clinic in everyday life (3, 5, 38, 40–43). PHIM needs are well documented for some groups, such as people experiencing cancer (44–46) or chronic illness (38, 47), but less specifically for older adults (9). Prior research has examined older adults’ needs for home medication management (11, 12, 39) and sharing medical information with providers (38), but we know little about the broader PHIM needs and practices of older adults for healthy aging. We are investigating the PHIM needs and practices of older adults through the “SOARING” project (i.e., Studying Older Adults and Researching Information Needs and Goals) (48, 49).

As an initial step to inform the design of supportive HIT from a foundational understanding of older adults’ PHIM practices and needs, we engaged older adults in an exploratory focus group study to better understand their perspectives. Specifically, we sought to answer research questions about how older adults view personal health and how they use personal health information in their day-to-day lives. Laying a foundation for future work on PHIM, we report findings regarding the role of personal health information in the pursuit of healthy aging from the perspective of older adults. This effort addresses a significant gap in the literature where older adults’ PHIM practices and needs are under studied.

Methods

We conducted four focus groups with community-dwelling older adults aged 60 and older. Each focus group was comprised of between five and nine participants and lasted roughly 90 minutes. During focus groups, we guided participants through discussion to gather their perspectives on health and health information in their everyday lives. We synthesized insights gathered across groups on participants’ views and use of health information to better understand the role of PHIM in pursuing healthy aging.

Participants

We engaged community-dwelling older adults who were residents of retirement communities and 60 years of age or older. Although many definitions of older adult include individuals 65 years of age and older (50), we included individuals 60 years of age and older to get a broader perspective among people approaching and meeting this definition. We chose community dwelling older adults because they are a group that aims to maximize and

maintain independence and are generally still responsible for managing their own health information, compared to older adults living in nursing homes who depend on others to manage their health information.

The University of Washington Institutional Review Board approved all recruitment and study procedures. Prior to the start of each focus group, we obtained written consent to study procedures from all participants. The consent process informed participants about the study aims, that their participation was voluntary and they could stop at any time, and that all collected data, including the audio recording of the session, would be used only for research purposes. As is customary for this type of research study at our institution, participants received a \$25 gift card as a token of appreciation for taking part in a focus group.

Recruitment process

We recruited a convenience sample of participants from four diverse residential communities with broad socioeconomic representation from the Seattle metropolitan area. Recruiting from residential communities offered a convenient way to participate, while offering insights into the role community living plays in health and health information. We used purposive sampling (51) to stratify recruitment across residential community sites. Staff at each of the four residential community sites helped to recruit participants by posting recruitment flyers in common areas and approached residents to share flyers about taking part in a focus group session. Table 1 summarizes characteristics of the four residential community sites. Compared with sites 1 and 2, sites 3 and 4 were considered to cater to residents of lower income because they offered housing subsidies. All participants lived in an apartment within one of the four residential communities at the time of the study.

Data collection

Each focus group was held in private space at the residential community site where the participants resided between October 2013 and April 2014. Only participants and members of the research team attended focus groups. Focus groups began with introductions from all in attendance followed by discussion utilizing a semi-structured group interview guide designed by the research team to gather insights about how older adults view personal health and what information they use to manage their day-to-day health (Table 2). The research team included prompts to encourage discussion about information management practices, visits with healthcare providers, and involvement of informal caregivers, such as family and friends. One member of the research team with doctoral training in biomedical informatics facilitated group discussion, while another team member took notes. Care was taken to ensure that all participants had the opportunity to respond during the discussion. We audio-recorded focus group sessions for qualitative analysis.

Qualitative analysis

We applied affinity diagramming to inductively analyze data for emergent themes regarding older adults' perspectives on health and health information in everyday life. Affinity diagramming is a qualitative method for thematic analysis in which observations are written on index cards and then sorted by similarity into categories (52). Two coders from the research team (KO, AH) completed this process in two steps. For each focus group session,

the coders first independently noted key issues expressed by each participant as qualitative quotes. The coders compared notes to resolve discrepancies and document common issues identified across participants and focus group sessions on index cards. In the second step, the coders collaboratively synthesized themes by grouping index cards into the elements: individuals, tasks, tools, social organization, and physical environment, guided by the Balance Model (53) used to characterize PHIM in prior work (5). In the context of the Balance Model, we considered participants as *individuals* who complete *tasks* to manage personal health information using *tools* within the *social organization* and *physical environment* of everyday life. The coders then examined emergent themes that reflect relationships among these five elements.

Results

Participants

Twenty-five participants (P1–P25) took part in focus groups. Their reported age ranged from 60 to 97, and the majority were women (76%). During focus group sessions, most participants shared stories about their management of chronic conditions (e.g., diabetes, hypertension, arthritis, multiple sclerosis). Other health issues surfaced, such as hip replacement, heart stents, and managing cancer, medications, or symptoms (e.g., pain, sleeplessness). At least one participant from each site experienced limited mobility and used a walker or wheelchair.

Prominence of wellness in views of health and health information

When asked what comes to mind when they consider “personal health information,” most participants initially talked about the medical information they explicitly track and share with healthcare providers. For example, some participants described lists of medications, provider contacts, and even recent lab reports they kept in known locations, such as hung on the refrigerator, posted on the door, or left with residential community staff to direct caregivers during an emergency. As the discussion progressed, participants shared stories that reflected a broader conception of health and health information existing outside the clinic in their everyday personal lives, such as fitness logs, phone calls to family, clinic appointment schedules, and medical records kept by residential staff. From our analysis, three qualitative themes emerged that point to the prominence of *wellness* in the conceptualization of health and health information from the perspective of community-dwelling older adults: (1) staying healthy through personal health practices, (2) staying healthy through social network support, and (3) staying healthy through residential community engagement. Rather than focusing on deficits in physical function, these themes illustrate how participants talked about maximizing wellness through physical, cognitive, and social well-being in their pursuit of healthy aging. Below we describe each emergent theme, including challenges and opportunities that surfaced to better support these wellness activities through management of personal health information.

Staying healthy through personal health practices that foster well-being

The first key theme reflecting participants' perspectives on health and health information comprises personal health practices for staying healthy. This theme relates closely to *tasks* and *tools* participants described using to manage health and health information. When asked what they do to maintain health, participants described a range of physical, cognitive, and emotional aspects of a healthy lifestyle. Rather than framing health in terms of deficits (e.g., loss of mobility), participants expressed wellness from a position of personal strength by emphasizing physical, cognitive, and emotional well-being. In particular, they emphasized having personal agency and adapting personal health practices with age. For example, when asked about personal goals P3 told us:

...being able to move without walkers or whatever. We're pretty careful about exercise. We exercise on a regular basis at the gym or a person teaches us seated dance. We sit down and do all of these things. It's very important that you have structured exercise in your life.

P5 also reflects similar positive appraisal:

Another thing that makes us health conscious is exercise. We are in a group that was set up for 65 year olds and it's very strenuous but it does make you realize your age and also what you can do to improve your life. I think that is a major part of our lives.

Several participants explicitly connected their personal health practices with maintaining independence, such as moving without assistance in daily life within their residential community.

Physical well-being

Participants in all groups talked about the importance of staying physically fit, maintaining mobility, and "feeling strong" (P20). One participant enjoyed onsite Tai Chi and weight training classes that were not available to her before moving to the residential community. Another participant with mobility limitations advocated to "walk even if you're in your apartment" (P15). P7 told us he keeps track of miles he walks "in my head," but because of worsening memory became lost on one of his regular neighborhood walks. Even when physical activity was explicitly tracked, such as quarterly fitness assessments logged by the physical trainer at site 3, this information was not integrated into residents' health records kept at the residential community, nor was this information shared with residents' healthcare providers.

Cognitive well-being

Other participants tied personal goals to maintenance of cognitive health: "Reading—I'm an avid reader so keeping information helps my brain" (P10). Personal health practices to stay cognitively active were also common across sites, including cognitive exercises to maintain mental acuity, such as reading, knitting, word games, puzzles, or poetry. Some participants described social games they played, such as bridge. For example, several participants from site 3 described the "brain fitness program" offered at their residential community. Other

participants described individual activities, like reading or crossword puzzles to stay cognitively active: “Anything where you have to concentrate. Even though I don’t have time, I take the time” (P22). P6 told us: “I watch ‘Wheel’ [of Fortune] and ‘Jeopardy’ every night! Sometimes it’s fun to see what you had stored in your mind that you didn’t know you knew.” Other participants described memory games they devise themselves. For instance, P8 told us: “memorizing poetry is good exercise for the mind.”

Emotional well-being

Although less common than physical and cognitive health, a few participants raised emotional well-being as a personal goal for staying healthy, such as relaxation, stress reduction, and laughter: “The relaxed state is one of my goals in my health profile”(P13). P15 told us about the stress she often feels walking outside in the densely populated urban area in which her residential community (i.e., site 4) is situated. P12, who is also from site 4, discovered a remedy for stress reduction. He told us that he finds “some good relaxation in the summer by catching the ferry across the [Puget] Sound” (P12). P8 shared: “I think a sense of humor is important and frame of mind...laughing and a sense of humor is important for good health.”

Staying healthy through social network support

A second key theme reflecting participants’ conceptions of health and health information was the value of supportive interpersonal relationships with family caregivers, residential community staff, and healthcare providers. This theme reflects common issues that emerged regarding health and health information within the *social organization* of a support network. Across focus groups, most participants benefited from a range of social support through these relationships, including instrumental (e.g., taking to medical appointments or providing ‘a second pair of ears’ at clinic visits), informational (e.g., obtaining tips and advice), and emotional support (e.g., contact with family members and close friends when facing a new diagnosis).

Family caregivers

Relationships with family caregivers were integral to conceptions of health. Participants described a spectrum of such relationships. At one end, a few participants described having authorized a sibling or adult child to act on their behalf through power of attorney, including complete management of health information and decisions. At the other end of the spectrum, a few participants preferred not to involve family in their health because they did not want to create worry or believed their family was unavailable or uninterested. Most participants fell in the middle of the spectrum and shared health information, typically with specific family members. For example, P9 told us: “My daughter is a registered nurse and sometimes I call her to ask her about things.” Sharing personal health information with friends and family centered largely on face-to-face interaction or phone calls. Deciding when, with whom, and how much personal health information to share was a challenge for many participants. For instance, P18 remarked: “You have a dichotomy. If you complain a lot, they stop listening.” Limited family support was acknowledged by a majority of participants at site 4, but the

community itself was seen to substitute—as P13 reported: “Our community is a metaphor for an extended family.”

Residential community staff

Residential community staff also played a role in management of personal health information. A common practice described by participants across sites was to keep residential community staff updated with contacts, insurance, and other health information. Emergency information, such as a “list of people to contact if I’m sick” (P9), was a particularly important type of information kept by residential community staff. P25 shared the frustrating experience of having out of date information:

We have a list we are supposed to fill out and we keep at the front desk. It is a list of our medications, our PCP, our hospital, so if the fire department is called. I had a frustrating experience because the medical records were not up to date with the front desk and my husband had a problem. I have now updated that.

Several participants also described providing residential community staff with a copy of their medical records when they moved in. With access to those records, onsite nurses can provide regular healthcare services, such as diabetic foot checks or blood pressure monitoring. At site 4, which did not offer onsite nursing services, visiting nursing students provided basic services, such as documenting blood pressure in log books kept by residents. However, it was unclear the extent to which personal health information managed by residential community staff onsite was exchanged with participants’ family caregivers or healthcare providers outside of emergencies.

Healthcare providers

Participants expressed strong preferences in characteristics they sought in healthcare providers, such as offering sufficient time for clinic visits and listening so that patients feel heard. Several participants raised the importance of familiarity, rapport, and mutual respect that develop over long-term relationships. For example, P4 told us that her healthcare provider “is very open and we have long talks—we talk family and problems and I feel pretty good about what I’m getting in terms of health care.” Another participant described her strategy to maximize time with her provider: “I find that if you have the first appointment of either the morning or afternoon, you have a better chance of getting your questions answered and hearing what your doctor has to say.” (P19). Thus, supportive communication and interpersonal connection with providers were important components of participants’ conception of health and health information.

Although eight participants talked about using PHRs and secure messaging to share personal health information with healthcare providers, most participants relied on face-to-face interaction and phone calls. Most participants also tracked health and questions for their provider by memory or on paper logs brought to clinic visits. A few participants shared challenges they encountered when acting as “information couriers” to coordinate medical records among their multiple providers. Rapport was important in these provider relationships, and a number of participants experienced challenges with new healthcare providers after changes in living location or insurance.

Staying healthy through residential community engagement

Staying socially connected through engagement within the residential community was a third key theme in participants' conceptions of health and related health information. This theme reflects common issues that emerged regarding health and health information within the *physical environment* of community living. Highlighting the value attributed to their residential community, participants described opportunities for community engagement, including both formal and informal programs that support personal health and social connectedness. Although some community activities involved health information (e.g., fitness logs, clinic appointment schedules), participants explicitly managed very little of this information. Most participants expressed a strong value for the social cohesion they experienced in their residential community. One participant summed up her value of community living for maintaining independence: "The whole thing [residential community] is just coordinated to help us choose what we want to do to be healthy and live our lives happily in a social setting that we get to choose how much we want to participate in. So it's independent living." (P17).

Formal community programs

At three of the four sites, personal health and activities of daily living were supported through daily meal programs, fitness classes, transportation, and other formal community programs. For instance, P20 commented on the value of the fitness program at site 3:

I'm in much better condition than I was a year ago when I moved in. because I always had good intentions to exercise on my own and rarely if ever did. I moved in here and started going down to the basement three days a week for exercise classes" (P20).

P3, who was in her late 80's, talked about exercise logs kept by onsite personal trainers: "We have little tests that we take when we start the [fitness] program and we'll see if we can improve. At three month intervals, they [personal trainers] will measure us again." Other formal community programs connected residents with local services. For instance, participants from two sites told us about their mobile library programs in which a van transports books checked out from the public library. A private van service was available at three of the sites for transportation to and from shopping, church, and medical appointments and thus managed information about residents' medical appointment schedules.

Informal community activities

At site 4, which lacked formal community programs, residents self-organized by gathering regularly for group activities, such as communal potlucks and "high tea." P16 told us "I love to cook. It's the best thing I could do...I bring cookies or cakes to our events." She also enjoyed the community garden "to work in and reap the benefits from." Another participant from site 4 often walked across the street to the senior center to play pool with friends. Another participant from site 4 described how he and a friend developed a routine as regular "walking buddies." Although site 4 offered no transportation services like the other sites, this residential community was located within close walking distance to shopping,

healthcare services, and bus lines. Thus at site 4, many participants met their personal health needs through informal community opportunities.

Social connectedness

Across sites, participants described a range of social activities they engaged in through their residential communities. Participants took part in special interest groups (e.g., book club, poetry club, bridge group) and social outings (e.g., field trips, plays, museums). Less formally, participants enjoyed “movie night” and working on the computer or playing console games together in communal living areas. Some sites provided formal offerings to promote cognitive acuity, such as a “brain vitality” program. At site 3, participants took part in Sudoku and crossword contests in which winners received free lunch. Throughout the examples shared, social connectedness was an important thread in how participants talked about staying healthy through engagement within the residential community. Referring to the social activities at her site for example, P2 told us: “These are the kinds of things that keep you healthy and keep you here.”

Discussion

Principal findings

To guide PHIM efforts in the context of healthy aging, we explored the perspectives of older adults on health and health information used in their everyday lives. Through focus groups, we found that *wellness* plays a prominent role in how community-dwelling older adults think about health and manage personal health information. In contrast to focusing on physical deficits, wellness considers maximizing potential across the holistic and multiple dimensions of health and well-being (54, 55). Participants expressed wellness from a position of personal strength, rather than health-related deficits, by focusing on personal health practices, social network support, and residential community engagement as *wellness activities* for healthy aging. By capturing the perspectives of older adults, these findings expand our understanding of PHIM needs, particularly in the context of healthy aging.

Most existing HIT designed for older adults focus on disease self-management, leaving a persisting support gap for tools that incorporate support for wellness to promote healthy aging more broadly (22, 28). Beyond support for medication management (11–13, 39) and information sharing with healthcare providers (38), tools that can support wellness activities we identified have merit. Halbert Dunn defined *wellness* as an “integrated method of functioning which is oriented toward maximizing the potential to which an individual is capable. It requires that the individual maintains a continuum of balance and purposeful direction within the environment in which he/she is functioning” (54). Dunn uses the term “integrated” to indicate that wellness involves multiple interrelated components. The multidimensional nature of wellness emphasizes the need to examine the whole person in their environment by addressing physical well-being, mental and cognitive health, social well-being, and spiritual well-being (55). Since its inception, the Dunn framework of wellness has been tested and informed several health promotion initiatives for older adults (56, 57). However, HIT that addresses the holistic and multidimensional nature of wellness has been slow to develop (58). Design of new technologies that can assist older adults in

management of personal health information has the potential to facilitate healthy aging by better supporting wellness activities. Future work on design of interventions and technologies should address this “wellness support gap” for older adults.

Implications for the design of PHIM tools

Although lifestyle behaviors help people of all ages stay healthy, older adults in particular viewed these personal health practices as critical to their physical, cognitive, and emotional well-being. PHIM tools for these kinds of wellness tasks may be particularly important for healthy aging, but represent a gap less explored than HIT for disease self-management (22). Social and emotional aspects of health have not traditionally been the focus of patient-facing HIT, but tools like PHRs could be extended with features to support healthy aging, such as physical activity, social activities, and community engagement. Examples might target social isolation (59), leisure and occupational activities (60, 61), memory (62, 63), or even the built environment (64, 65). Although older adults express interest in wellness tools for health and health information, some find existing tools lack requisite support (22, 66). Since healthy aging can coexist with disease and functional limitations through compensatory psychological and social mechanisms (67), PHIM tools should provide support across the multiple dimensions of health.

Given the importance of social support provided through interpersonal relationships in the social organization of older adults (68), considering social networks in the design of PHIM tools may be especially important for preventing social isolation. Tools that promote relationship building and social connections may be especially useful among older adults who live independently with limited or no family support. Concurrently, PHIM tools are needed to facilitate sharing of personal health information among family caregivers, residential community staff, and healthcare providers. Information fragmentation led to breakdowns for some participants who may have benefited from PHIM systems that support health information exchange to keep data updated, complete, and accessible across stakeholders. Prior work lays important groundwork, such as telehealth wellness programs integrated within the unique setting of residential communities (69).

In addition to providing a rich context for social support, residential living offered a physical environment to stay healthy and connected within the social fabric of the residential community. Community engagement was prominent in the way participants perceived of health. While health information could be tied to several community-based activities for healthy aging, participants did not emphasize explicit management of this information. Although community engagement appears critical to the personal health of community-dwelling older adults, there are many unexplored opportunities for designing supportive PHIM systems that leverage the social context of community living. Examples might include HIT that facilitates peer support connections (70) or volunteerism that stimulates social cohesion and personal well-being (71).

Study contributions

Strengths of this work include both its theoretical and practical contributions. The voices of our participants extend our understanding of the needs of older adults for healthy aging in

the context of community living. Findings support a patient-centered perspective on healthy aging (2, 72, 73) that reflects wellness (54). The social context of the community living environment illustrated rich interactions among the physiological and psychological dimensions of health and well-being, including peer exercise programs and social activities (e.g., book club, bridge group). Our findings align with Young et al.'s (67) multidimensional framework of successful aging, which places just as much emphasis on psychological and sociological dimensions of health as physiological health. Such frameworks may be particularly useful for grounding future research to understand and address the PHIM needs of older adults. Observing PHIM practices devised by older adults themselves can also teach us many ways to promote personal health practices and supportive relationships (19).

Our study also illustrates the practical value of engaging older adults to understand and meet their diverse needs. Although many health and wellness programs align support services with traditional models of “successful aging” (1), older adults often view themselves as aging successfully despite having chronic illnesses and disabilities (74). Patient-centered perspectives demonstrate how the perceptions of older adults can shape services by focusing on gains rather than losses (75), well-being (76, 77), adaptive behaviors (78, 79), wisdom and reliance (80–82), and housing (83, 84). As we gain a deeper understanding of how PHIM technology can better support wellness activities that promote healthy aging, it is critical that we continue this tradition of engaging older adults in the formative design process to ensure that the tools and services we develop will meet their diverse and significant needs (19, 26).

Study limitations

Despite these contributions, our findings have some limitations. The focus groups were exploratory and engaged a convenience sample of community-dwelling older adults. Thus, findings may have limited generalizability. Because residential community settings may offer services to promote well-being of older adults, findings may be limited to this context. It is possible that wellness may not have been as pronounced in a sample of participants from other settings. We purposively sampled diverse residential community sites for representation of local socioeconomic diversity of older adults. Participants at each site represent a convenience sample of older adults who may have a greater interest in health and well-being than residents who chose not to participate in focus groups. We did not collect detailed on demographics or extent of experience with technology, which could have impacted the results. Because the focus of discussion was health and not disease, emergent themes about wellness may have been more likely than medical deficits. Thus, our findings may be limited in scope and reflect the exploratory nature of the focus groups. Older adults with different living situations, personal characteristics, or geographic locations may have provided different perspectives.

Conclusion

Older adults apply various strategies to pursue healthy aging, but we have known little about their views and use of personal health information to accomplish those ends. Understanding health information needs is critical as our aging population grows. Through focus groups,

we learned that wellness plays a prominent role in how older adults think about health and health information. Participants expressed wellness from a position of personal strength, rather than health-related deficits, by focusing on personal health practices, social network support, and community engagement for healthy aging. Although social and emotional aspects of health have not traditionally been the focus of patient-facing HIT, PHIM tools have the potential to be tailored to the personal health needs of older adults and allow for tracking information associated with wellness, such as physical activity, social activities, and community engagement. Our findings have implications for both the design of future wellness technologies and interventions that support healthy aging and methods that engage older adults as active participants and co-producers of these critical programs.

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References

1. Rowe JW, Kahn RL. Successful aging. *Gerontologist*. 1997; 37(4):433–440. [PubMed: 9279031]
2. Depp C, Vahia IV, Jeste D. Successful aging: Focus on cognitive and emotional health. *Annual Review of Clinical Psychology*. 2010; 6:527–550.
3. Pratt W, Unruh K, Civan A, Skeels MM. Personal health information management. *Communications of the ACM Special Issue on Personal Information Management*. 2006; 49(1):51–55.
4. Civan A, Skeels MM, Stolyar A, Pratt W. Personal health information management: Consumers' perspectives. *AMIA Annual Symposium Proceedings*. 2006:156–160. [PubMed: 17238322]
5. Moen A, Brennan PF. Health@Home: The work of health information management in the household (HIMH): Implications for consumer health informatics (CHI) innovations. *Journal of the American Medical Informatics Association*. 2005; 12(6):648–656. [PubMed: 16049230]
6. Agarwal, R., Khuntia, J. Personal health information and the design of consumer health information technology: Background report. Rockville, MD: Agency for Health care Research and Quality; Jun. 2009 (Prepared by Insight Policy Research under Contract No. HHS290200710072T). AHRQ Publication No 09-0075-EF
7. Hansen-Kyle L. A concept analysis of healthy aging. *Nursing Forum*. 2005; 40(2):45–57. [PubMed: 16053504]
8. Choi N. Relationship between health service use and health information technology use among older adults: Analysis of the US National Health Interview Survey. *Journal of Medical Internet Research*. 2011; 13(2):e33. [PubMed: 21752784]
9. Kim EH, Stolyar A, Lober WB, Herbaugh AL, Shinstrom SE, Zierler BK, et al. Challenges to using an electronic personal health record by a low-income elderly population. *Journal of Medical Internet Research*. 2009; 11(4):e44. [PubMed: 19861298]
10. Kim K, Nahm E. Benefits of and barriers to the use of personal health records (PHR) for health management among adults. *Online Journal of Nursing Informatics (OJNI)*. 2012; 16(3) [cited 2017 Feb 2]; Available from: <http://ojni.org/issues/?p=1995>.
11. Lakey SL, Gray SL, Borson S. Assessment of older adults' knowledge of and preferences for medication management tools and support systems. *Annals of Pharmacotherapy*. 2009; 43(6): 1011–1019. [PubMed: 19470855]

12. Haverhals LM, Lee CA, Siek KA, et al. Older adults with multi-morbidity: Medication management processes and design implications for personal health applications. *Journal of Medical Internet Research*. 2011; 13(2):e44. [PubMed: 21715286]
13. Siek KA, Ross SE, Khan DU, Haverhals LM, Cali SR, Meyers J. Colorado Care Tablet: the design of an interoperable personal health application to help older adults with multimorbidity manage their medications. *Journal of Biomedical Informatics*. 2010; 43(5 Suppl):S22–S26. [PubMed: 20937480]
14. Mynatt ED, Melenhorst A-S, Fisk A-D, Rogers WA. Aware technologies for aging in place: Understanding user needs and attitudes. *IEEE Pervasive Computing*. 2004; 3(2):36–41.
15. Demiris G, Hensel BK, Skubic M, Rantz M. Senior residents' perceived need of and preferences for "smart home" sensor technologies. *International Journal of Technology Assessment in Health Care*. 2008; 24(1):120–124. [PubMed: 18218177]
16. Caine KE, Fisk AD, Rogers WA. Benefits and privacy concerns of a home equipped with a visual sensing system: A perspective from older adults. *Proceedings of the Human Factors and Ergonomics Society Annual Meeting*. 2006; 50(2):180–184.
17. Haux R, Hein A, Kolb G, Künemund H, Eichelberg M, Appell J-E, et al. Information and communication technologies for promoting and sustaining quality of life, health and self-sufficiency in ageing societies -outcomes of the Lower Saxony Research Network Design of Environments for Ageing (GAL). *Informatics for Health and Social Care*. 2014; 39(3–4):166–187. [PubMed: 25148556]
18. Hein A, Winkelbach S, Martens B, Wilken O, Eichelberg M, Spehr J, et al. Monitoring systems for the support of home care. *Informatics for Health and Social Care*. 2010; 35(3–4):157–176. [PubMed: 21133770]
19. Procter R, Greenhalgh T, Wherton J, Sugarhood P, Rouncefield M, Dewsbury G. The ATHENE Project: The importance of bricolage in personalising assisted living technologies. *International Journal of Integrated Care*. 2013; 13(7):1.
20. Daniel, K., Cason, CL., Ferrell, S. Assistive technologies for use in the home to prolong independence; *Proceedings of the 2nd International Conference on Pervasive Technologies Related to Assistive Environments*; 2009. article 26
21. Harte RP, Glynn LG, Broderick BJ, Rodriguez-Molinero A, Baker PM, McGuinness B, et al. Human centred design considerations for connected health devices for the older adult. *Journal of Personalized Medicine*. 2014; 4(2):245–281. [PubMed: 25563225]
22. Joe J, Demiris G. Older adults and mobile phones for health: A review. *Journal of Biomedical Informatics*. 2013; 46(5):6–13.
23. Caine KE, Zimmerman CY, Schall-Zimmerman Z, Hazlewood WR, Camp LJ, Connelly KH, et al. DigiSwitch: A device to allow older adults to monitor and direct the collection and transmission of health information collected at home. *Journal of Medical Systems*. 2011; 35(5):1181–1195. [PubMed: 22038195]
24. Bickmore, TW., Caruso, Lisa, Clough-Gorr, Kerri. Acceptance and usability of a relational agent interface by urban older adults; *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, Extended Abstracts*; p. 1212-1215.
25. Liu W-T, Wang C-H, Lin H-C, et al. Efficacy of a cell phone-based exercise programme for COPD. *European Respiratory Society*. 2008; 32(3):651–659.
26. Thielke S, Harniss M, Thompson H, Patel S, Demiris G, Johnson K. Maslow's hierarchy of human needs and the adoption of health-related technologies for older adults. *Ageing International*. 2012; 37(4):470–488.
27. Rowan J, Mynatt ED. Digital family portrait field trial: Support for aging in place. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 2005:521–530.
28. Dishman E. Inventing wellness systems for aging in place. *Computer*. 2004; 37(5):34–41.
29. Kueider AM, Parisi JM, Gross AL, Rebok GW. Computerized cognitive training with older adults: A systematic review. *PLoS One*. 2012; 7:e40588. [PubMed: 22792378]
30. Jimison, H., Gorman, P., Woods, S., Nygren, P., Walker, M., Norris, S., Hersh, W. Barriers and drivers of health information technology use for the elderly, chronically ill, and underserved. Rockville, MD: Agency for Healthcare Research and Quality; Nov. 2008 Evidence Report/

Technology Assessment No. 175 (Prepared by the Oregon Evidence-based Practice Center under Contract No. 290-02-0024). AHRQ Publication No. 09-E004

31. Young R, Willis E, Cameron G, Geana M. Willing but unwilling: Attitudinal barriers to adoption of home-based health information technology among older adults. *Health Informatics Journal*. 2014; 20(2):127–135. [PubMed: 24056750]
32. Xie B. Effects of an eHealth literacy intervention for older adults. *Journal of Medical Internet Research*. 2011 Nov 3.13(4):e90. [PubMed: 22052161]
33. Echt, KV. Designing Web-based health information for older adults: Visual considerations and design directives. In: Morrell, RW., editor. *Older Adults, Health Information, and the World Wide Web*. Vol. 2002. Mahwah, NJ: Lawrence Erlbaum Assoc Inc; p. 61-88.
34. Smith, A. Older adults and technology use. Pew Research Center. *Older Adults and Technology Use*. Apr. 2014 [cited 2017 Feb 2]; Available from: <http://www.pewinternet.org/2014/04/03/older-adults-and-technology-use/>
35. Fischer SH, David D, Crotty BH, Dierks M, Safran C. Acceptance and use of health information technology by community-dwelling elders. *International Journal of Medical Informatics*. 2014; 83(9):624–635. [PubMed: 24996581]
36. Peek ST, Wouters EJ, van Hoof J, Luijkx KG, Boeije HR, Vrijhoef HJ. Factors influencing acceptance of technology for aging in place: A systematic review. *International Journal of Medical Informatics*. 2014; 83(4):235–248. [PubMed: 24529817]
37. Chaudhuri S, Lee ST, White C, Thompson H, Demiris G. Examining health information seeking behaviors of older adults. *Computers, Informatics, Nursing*. 2013; 31(11):547–553.
38. Ancker JS, Witteman HO, Hafeez B, Provencher T, Van de Graaf M, Wei E. The invisible work of personal health information management among people with multiple chronic conditions: Qualitative interview study among patients and providers. *Journal of Medical Internet Research*. 2015; 17(6):e137. [PubMed: 26043709]
39. Palen, L., Aaløkke, S. Of pill boxes and piano benches : Home-made methods for managing medication; Proceedings of the 2006 20th anniversary conference on Computer Supported Cooperative Work; 2006. p. 79-88.
40. Zayas-Cabán T. Health information management in the home: A human factors assessment. *Work*. 2012; 41(3):315–328. [PubMed: 22398501]
41. Unruh KT, Pratt W. The Invisible work of being a patient and implications for health care: [the doctor is] my business partner in the most important business in my life, staying alive. In *Ethnographic Praxis in Industry Conference Proceedings*. 2008:40–50.
42. Piras EM, Zanutto A. Prescriptions, x-rays and grocery lists. Designing a Personal Health Record to support (the invisible work of) health information management in the household. *Computer Supported Cooperative Work*. 2010; 19(6):585–613.
43. Wilson, C., Peterson, A. *Managing Personal Health Information: An Action Agenda*. Rockville, MD: Agency for Health care Research and Quality; Mar. 2010 (Prepared by Insight Policy Research under Contract No. HHS290200710072T.) AHRQ Publication No. 10-0048-EF
44. Pratt W, Unruh K, Civan A, Skeels MM. Personal health information management. *Communications of the ACM*. 2006 Jan; 49(1):1. 51–55.
45. Klasnja P, Hartzler A, Powell C, Phan G, Pratt W. HealthWeaver Mobile: Designing a mobile tool for managing personal health information during cancer care. *AMIA Annual Symposium Proceedings*. 2010:392–396. [PubMed: 21347007]
46. Jacobs, ML., Clawson, J., Mynatt, ED. My journey compass: A preliminary investigation of a mobile tool for cancer patients; Proceedings of the SIGCHI Conference on Human Factors in Computing Systems; 2014. p. 663-672.
47. Sun S, Belkin NJ. Managing personal health information in the home: Strategies of diabetes patients in the US and China. *Proceedings of the Association for Information Science and Technology*. 2015; 52(1):1–4.
48. Turner AM, Osterhage K, Hartzler AL, Beeson T, Thielke SM, Phelan EA, Demiris G. Addressing the personal health information management needs of older adults: The SOARING Project. *Gerontologist*. 2014; 54:115–116.

49. Turner A, Osterhage K, Joe J, Hartzler A, Lin L, Demiris G. Use of patient portals: Personal health information management in older adults. *Studies in Health Technology and Informatics*. 2014; 216:978–978.
50. World Health Organization. Definition of an older or elderly person. Geneva, Switzerland; WHO: 2010. [cite 2017 Feb 2]; Available from: <http://www.who.int/healthinfo/survey/ageingdefnolder/en/index.html>
51. Kemper EA, Stringfield S, Teddlie C. Mixed methods sampling strategies in social science research. *Handbook of Mixed Methods in Social and Behavioral Research*. 2003:273–296.
52. Beyer, H., Holtzblatt, K. *Contextual Design*. San Francisco, CA: Morgan Kaufman; 1998.
53. Carayon P. The balance theory and the work system model. Twenty years later *International Journal of Human–Computer Interaction*. 2009; 25(5):313–327.
54. Dunn, HL. *High-Level Wellness*. Arlington, VA: Beatty Press; 1961.
55. Hoyman HS. Rethinking an ecologic-system model of man’s health, disease, aging, death. *Journal of School Health*. 1975; 45(9):509–518. [PubMed: 1042431]
56. Miller, CA. *Nursing for Wellness in Older Adults*. Philadelphia, PA: Lippincott Williams & Wilkins; 2012.
57. Kleffel D. Rethinking the environment as a domain of nursing knowledge. *ANS Advances in Nursing Science*. 1991; 14(1):40–51. [PubMed: 1929235]
58. Demiris G, Thompson HJ, Reeder B, Wilamowska K, Zaslavsky O. Using informatics to capture older adults’ wellness. *Int J Med Inform*. 2013 Nov; 82(11):e232–e241. [PubMed: 21482182]
59. Findlay RA. Interventions to reduce social isolation amongst older people: Where is the evidence? *Ageing & Society*. 2003; 23:647–658.
60. Silverstein M, Parker MG. Leisure activities and quality of life among the oldest old in Sweden. *Res Aging*. 2002; 24(5):528–547.
61. Stevens-Ratchford RG. Occupational engagement: Motivation for older adult participation. *Topics in Geriatric Rehabilitation*. 2005; 21(3):171–181.
62. Boll S, Heuten W, Meyer EM, Meis M. Development of a multimodal reminder system for older persons in their residential home. *Informatics for Health and Social Care*. 2010; 35(3–4):104–124. [PubMed: 21133767]
63. Anguera JA, Boccanfuso J, Rintoul JL, Al-Hashimi O, Faraji F, Janowich J, et al. Video game training enhances cognitive control in older adults. *Nature*. 2003; 501(7465):97–101.
64. Li F, Fisher KJ, Brownson RC, Bosworth M. Multilevel modelling of built environment characteristics related to neighbourhood walking activity in older adults. *Journal of Epidemiology and Community Health*. 2005; 59(7):558–564. [PubMed: 15965138]
65. Rosenberg DE, Huang DL, Simonovich SD, Belza B. Outdoor built environment barriers and facilitators to activity among midlife and older adults with mobility disabilities. *Gerontologist*. 2013; 53(2):268–279. [PubMed: 23010096]
66. Huh J, Le T, Reeder B, Thompson HJ, Demiris G. Perspectives on wellness self-monitoring tools for older adults. *International Journal of Medical Informatics*. 2013; 82:1092–1103. [PubMed: 24041452]
67. Young Y, Frick KD, Phelan EA. Can successful aging and chronic illness coexist in the same individual? A multidimensional concept of successful aging *Journal of the American Medical Directors Association*. 2009; 10(2):87–92. [PubMed: 19187875]
68. Berkman LF, Glass T, Brissette I, Seeman TE. From social integration to health: Durkheim in the new millennium. *Social Science & Medicine*. 2000; 51(6):843–857. [PubMed: 10972429]
69. Demiris G, Thompson H, Boquet J, Le T, Chaudhuri S, Chung J. Older adults’ acceptance of a community-based telehealth wellness system. *Informatics for Health and Social Care*. 2012; 38(1): 27–36. [PubMed: 22571733]
70. Heisler M, Piette JD. “I Help You, and You Help Me” Facilitated telephone peer support among patients with diabetes. *The Diabetes Educator*. 2005; 31(6):869–879. [PubMed: 16288094]
71. Gorey KM. The beneficial effects of volunteering for older volunteers and the people they serve: A meta-analysis. *The International Journal of Aging and Human Development*. 1998; 47(1):69–79. [PubMed: 9718488]

72. Phelan EA, Larson EB. "Successful aging"—where next? *Journal of the American Geriatrics Society*. 2002; 50(7):1306–1308. [PubMed: 12133032]
73. Depp CA, Jeste DV. Definitions and predictors of successful aging: A comprehensive review of large quantitative studies. *The American Journal of Geriatric Psychiatry*. 2006; 14(1):6–20. [PubMed: 16407577]
74. Montross LP, Depp C, Daly J, Reichstadt J, Golshan S, Moore D, Sitzer D, Jeste DV. Correlates of self-rated successful aging among community-dwelling older adults. *The American Journal of Geriatric Psychiatry*. 2006; 14(1):43–51. [PubMed: 16407581]
75. Phelan EA, Anderson LA, Lacroix AZ, Larson EB. Older adults' views of "successful aging"—how do they compare with researchers' definitions? *The American Journal of Geriatric Society*. 2004; 52(2):211–216.
76. von Faber M, Bootsma–van der Wiel A, van Exel E, Gussekloo J, Lagaay AM, van Dongen E, Knook DL, van der Geest S, Westendorp RG. Successful aging in the oldest old: Who can be characterized as successfully aged? *Archives of Internal Medicine*. 2001; 161(22):2694–2700. [PubMed: 11732934]
77. Ryff CD. In the eye of the beholder: Views of psychological well-being among middle-aged and older adults. *Psychology and Aging*. 1989; 4(2):195–210. [PubMed: 2789747]
78. Reichstadt J, Depp CA, Palinkas LA, Jeste DV. Building blocks of successful aging: A focus group study of older adults' perceived contributors to successful aging. *The American Journal of Geriatric Society*. 2007; 15(3):194–201.
79. Baltes, PB., Baltes, MM. Psychological perspectives on successful aging: The model of selective optimization with compensation. In: Baltes, PB., Baltes, MM., editors. *Successful aging: Perspectives from the behavioral sciences*. Cambridge, UK: Cambridge University Press; 1990. p. 1-34.
80. Reichstadt J, Sengupta G, Depp CA, Palinkas LA, Jeste DV. Older adults' perspectives on successful aging: Qualitative interviews. *The American Journal of Geriatric Society*. 2010; 18(7): 567–575.
81. Wiles JL, Wild K, Kerse N, Allen RE. Resilience from the point of view of older people: 'There's still life beyond a funny knee'. *Social Science & Medicine*. 2012; 74(3):416–424. [PubMed: 22204841]
82. Jeste DV, Savla GN, Thompson WK, Vahia IV, Glorioso DK, Palmer BW, Rock D, Golshan S, Kraemer HC, Depp CA. Association between older age and more successful aging: Critical role of resilience and depression. *The American Journal of Geriatric Society*. 2013; 170(2):188–196.
83. Mack R, Salmoni A, Viverais-Dressler G, Porter E, Garg R. Perceived risks to independent living: The views of older, community-dwelling adults. *Gerontologist*. 1997; 37(6):729–736. [PubMed: 9432989]
84. Oswald F, Wahl HW, Schilling O, Nygren C, Fänge A, Sixsmith A, Sixsmith J, Szeman Z, Tomsone S, Iwarsson S. Relationships between housing and healthy aging in very old age. *Gerontologist*. 2007; 47(1):96–107. [PubMed: 17327545]

Table 1

Residential community sites.

| | Site 1 (n = 5) | Site 2 (n = 5) | Site 3 (n = 9) | Site 4 (n = 6) |
|---|---|---|---|--|
| Type of housing | Urban senior housing | Suburban senior housing | Below market senior housing | Subsidized senior housing |
| Size of residence | 155 units | 102 units | 194 units | 60 units |
| Meal program | Yes | Yes | Yes | No |
| Transportation | Yes | Yes | Yes | No |
| Healthcare services | Onsite nursing staff | Onsite nursing staff | Onsite nursing staff | Visiting nursing students |
| Examples of amenities that promote personal health and well-being | Saltwater pool Computer center Social clubs and outings | “Silver sneakers” class “Brain vitality” program Activity center with piano | Tai Chi class Library and computer lab Social games and local tours | Offsite billiards at community center Computer room Monthly pot luck |

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Table 2

Focus group interview guide.

| |
|---|
| How do you define health? |
| What kinds of things do you do to maintain your health? |
| What comes to mind when you hear “personal health information”? |
| How does personal health information help you reach your personal goals? |
| What are the hardest things about staying on top of your personal health information? |
| What kinds of things could make managing personal health information easier? |

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