

Multifaceted perspectives about digital home assistants and privacy from older adults with mobility disabilities

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Abstract

Background: Digital home assistants (DHAs) can provide support for a wide range of everyday activities. They may be particularly useful for people who are aging, especially those with mobility disabilities, as they are voice-activated. However, barriers such as concerns about privacy could prevent older users from taking advantage of the full potential of DHAs.

Research Aim: Understanding the attitudes of those aging with mobility disabilities regarding privacy and DHAs.

Methods: Participants were 14 community-dwelling older adults who self-identified as having a long-term mobility disability (i.e., 10 years or more). This mixed-method study included questionnaires and a semi-structured interview administered after 10 weeks of using a DHA.

Results: Participants reported using their DHAs for a range of activities, including supporting leisure, hobby, entertainment, and health monitoring and maintenance activities. Most had at least some knowledge about how their device worked and how it stored and used their data. Most participants held the belief that control over their personal information was important and that privacy was highly valued. They expressed nuanced attitudes about privacy issues related to their DHAs. Privacy themes included the idea that their data was not of interest or value; there are no conspiracies directed toward data; there is a need to build confidence or trust with a device and an acknowledgement and acceptance of some risk. A common theme among participants was their appreciation for the benefits of using DHAs despite concerns about privacy risks.

Conclusions: Older adults with long-term mobility disabilities reported using their DHAs for a wide variety of activities and perceived benefits from doing so. They reported a range of attitudes about privacy, from a lack of concern to some strong concerns. The findings suggest that increased education and training about privacy risks and protective strategies could facilitate use, given the high value participants placed on privacy.

Keywords: Echo, Alexa, digital home assistant, aging, mobility disability, technology acceptance, privacy

INTRODUCTION

Digital home assistants (DHAs) hold great potential to provide holistic and accessible support for older adults, especially those aging with disabilities. DHAs can be used for a variety of daily activities, including Instrumental Activities of Daily Living (IADLs) and Enhanced Activities of Daily Living (EADLs), by providing information access, organizational aids, and memory support. IADLs are important for maintaining independence, such as cooking, financial management, and medication adherence (Lawton, 1990). EADLs are related to one's ability to adapt to changes, accept new challenges, and learn, such as acquiring novel skills, engaging in entertainment and social opportunities, participating in the community, and partaking in hobbies (Rogers et al., 1998; 2020). IADLs and EADLs are crucial components of an individual's independence and quality of life.

As the aging population continues to increase, so does the population of older adults who are aging with disabilities. Mobility disability is most prevalent, accounting for approximately 21% of the population 65 years of age and older (Administration for Community Living, 2024). Mobility disability can create challenges for aging in place (National Institute on Aging, 2020), defined as a preference to live in one's chosen home and community with autonomy (Rogers et al., 2020). Many adults aging with mobility disabilities may need support for IADLs and EADLs to age in place and, therefore, may benefit from adopting DHAs.

Research has shown that older adults do find DHA technologies useful and can benefit from them, and studies that included users with disabilities found that voice-activated interfaces facilitated their use of technology as well (Corbett et al., 2021; Kim & Choudhury, 2021; Koon et al.,

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2019; Pradhan, Mehta, & Findlater, 2018). DHAs remove a barrier imposed by typical screen-based technologies requiring basic typing skills, as one participant shared, "I don't have to type into it, which I am not good at" (Kim & Choudhury, 2021). Additionally, DHAs offer a variety of functions that older adults have reported finding particularly useful, such as keeping lists, setting reminders, and allowing for easy communication with family and friends (Corbett et al., 2021; Koon et al., 2019). Moreover, Kang et al. (2024) found that adults aging with mobility disabilities reported that DHAs were not only useful and beneficial but expressed satisfaction and enjoyment in using them in their daily lives. Participants reported that these technologies improved their functional independence by enabling them to control their home environment remotely, increase their safety, and enable them to access up-to-date information.

Although DHAs may offer the potential to support IADIs and EADLs, older adults can experience barriers to technology adoption, such as lack of trust and concerns about privacy (Knight et al., 2024). For example, privacy concerns such as the fear of DHAs being hacked, someone accessing user's data, or the fear that DHAs are 'always listening' could prevent older adults from adopting DHAs (Bonilla & Martin-Hammond, 2020). In a focus group study of older adults, most participants indicated that privacy was important to older adults and identified themselves as 'privacy pragmatics and fundamentalists' (Wang, Bolling, Mao, Reichstadt, Jeste, Kim, & Nebeker, 2019). To harness the full potential of DHAs for older users we must assess attitudinal barriers related to privacy.

The purpose of this study was to evaluate older adults' understanding of how their DHA works, such as their knowledge of the technology and how their information is used, their attitudes about privacy, and what privacy protective strategies they used when engaging with this technology. This analysis is part of a larger study in which older adults with disabilities were provided a specific type of DHA (Amazon Echo Show 8) and related environmental control technologies (i.e., Amazon Smart Plug, Phillips Hue Smart Lightbulb) along with instructional materials to support setup and usage of the technologies (Kang et al., 2024). The present analysis and results are from an interview conducted after participants used a DHA for 10 weeks.

METHODS

Participants

Participants were 14 community-dwelling older adults (61-91 years; $M = 71$, $SD = 7.6$) who self-identified as having a mobility disability for at least 10 years (i.e., having serious difficulty walking or climbing stairs). All participants were novice users

of the study technologies prior to their participation and used a mobile device compatible with the Alexa application. *Table 1* provides participant characteristics and technology experience.

This study was approved by the Institutional Review Board Office for Protection of Research Subjects at the University of Illinois Urbana-Champaign. Potential participants were recruited and screened via telephone from a variety of sources, such as a participant registry housed at the Rehabilitation Engineering Research Center on Technologies to Support Aging among People with Long-Term Disabilities (RERC TechSage) and the Illinois Disability and Education Services (DRES) research registry. Recruitment also included word of mouth, the use of social media, and distribution of study flyers locally. All participants provided informed consent prior to participation.

Materials

Participants received the Digital Assistance in a Box technology suite we designed specifically for older adults with mobility disabilities [omitted for anonymity] that included technologies (i.e., Amazon Echo Show 8, Smart Light, Smart Plug), instructional user manuals created by the research team with older adults in mind, and postcards to help onboard participants to the technologies. The five user guides covered Echo Setup, Echo Basic Uses, Environmental Control, Social Communication, and Health Applications.

This mixed-method study included questionnaires and a semi-structured interview. Questionnaires included: TechSage Background Questionnaire (TSBQ; Remillard et al., 2020), Technology Readiness Index 2.0 (TRI 2.0; Parasuraman & Colby, 2015), Mobile Device Proficiency Questionnaire (MDPQ; Roque & Boot, 2018), Wireless Network Proficiency Questionnaire (WNPQ; Roque & Boot, 2021), System Usability Scale (SUS; Brooke, 1996), Perceived Competence Scale (PCS; Williams et al., 2006), UCLA Loneliness Scale (Hays & DiMatteo, 1987), and Echo Show Usage Scale (Koon et al., 2020). For more details on the questionnaires and for the questionnaire results from the larger study, see Kang et al. (2024).

Semi-structured interview scripts were developed for four data collection time points (i.e., initial setup, 1-week follow-up, 5-week follow-up, 10-week follow-up); all interview scripts can be found in Blocker et al. (2023). Each set of questions was created with a specific purpose tailored to the corresponding phase of the study. The current analysis focused on a 10-week follow-up interview that investigated participants' attitudes toward privacy when using the study technologies (See *Table 2* for Interview questions).

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Table 1. Participant demographic characteristics and technology experience (N=14)

Demographic characteristics	N	%
Gender		
Male	5	36
Female	9	64
Race		
Black or African American	1	7
White	13	93
Education level		
High school graduate/GED	1	7
Bachelor's degree	5	36
Master's degree	6	43
Doctoral degree	2	14
Health condition*		
Arthritis	5	36
Cancer	3	21
Depression	4	29
High blood pressure/hypertension	5	36
High cholesterol/hyperlipidemia	6	43
Osteoporosis	5	36
Overweight	4	29
Stroke/transient ischemic attack	1	7
Multiple sclerosis	10	71
Overall health rating		
Poor	1	7
Fair	5	36
Good	5	36
Very good	3	21
Frequency of health problems interfering with desired activities		
Never	1	7
Seldom	3	21
Sometimes	4	29
Often	6	43
Having serious difficulty walking or climbing stairs	21	87.50
Using any supportive aids for mobility**		
Grab bars	17	70.83
Grabber or reacher	15	62.50
Cane	11	45.83
Manual wheelchair	10	41.67
Power wheelchair	8	33.33
Scooter	7	29.17
Walker	7	29.17
Unable to walk independently without using a walking aid	20	83.33
Technology experience	M	SD
Technology readiness index 2.0***	3.21	1.11

*Participants could have multiple health conditions so the total percentage may exceed 100%

**Participants could have multiple health conditions or use multiple aids, so the total percentage may exceed 100%.

***Response scale from 1 (strongly disagree) to 5 (strongly agree). The lowest possible score is 1.0 and the highest is 5.0. A higher score indicates higher technology readiness.

Procedure

During the 10-week study visit, the interviewer first ran the developed algorithm to collect the command history from the participant's Echo Show (Kadylak et al., 2021). This was followed by the interview (see Table 2 for interview questions), after which the questionnaires were administered using REDCap. After all questionnaires were completed, the survey was submitted, and the interviewer confirmed the email address to send the final compensation. At the end of this encounter, participants were

debriefed and informed that the technologies were theirs to keep and compensated for their participation.

RESULTS

Data analysis

Thematic analyses were conducted on the qualitative data from the interviews (Braun & Clarke, 2006). Three coders used a combination of inductive and deductive approaches. One coder generated an initial set of themes based on the research questions and those that emerged from the data. Two additional coders then reviewed and refined the identified themes. Throughout the analysis process, codes and themes were adjusted, edited, or added as new patterns emerged from repeated readings of the transcripts until a consensus was reached on a final set of themes in the categories of using the Echo, Knowledge of the Echo, Attitudes about Privacy, and Privacy Protective Strategies.

Using the Echo

Participants reported using the Echo for a wide range of activities during the 10 weeks of the study. Figure 1 shows the activities in the categories of leisure and entertainment, information retrieval, environment control, and memory support.

Knowledge of the Echo

When asked to describe how the Echo worked, some participants gave simplistic descriptions, such as, "I have no idea. I assume it goes over the wires, just like a telephone call goes over the wires through the air, and she responds back to you." Others demonstrated a more complex understanding, with one participant sharing, "...I would explain to them that the voice recognition software allows it to take what you say and in a blink of an eye report that to a computer or a server somewhere off in space, which then sends back the instructions to implement what you've asked for. Which is, I think, how it actually works."

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Table 2. Privacy interview questions

Interview questions

Were you the primary person who used your Echo Show? If no: who else used your echo show?

What types of commands did they give to your Echo Show?

What types of commands did you primarily ask your Echo Show?

Did other people in your home, or visitors, use your Echo Show? If yes: who?

What types of commands did they give to your Echo Show?

How would you explain how your Echo Show works to another person?

When you give your Echo Show a command, how do you think it works? In other words, what do you think is the “journey” of a voice request?

What comes to mind when you think of the word “privacy” in the context of technology?

Let's talk about technology and privacy. What is your opinion of the relationship between technology and privacy? Has your opinion changed over time?

Privacy can be defined as the right of a person to maintain control over and confidentiality of information about themselves. How did you feel about your privacy with the digital home assistant? Did your feelings change over the course of the 10 weeks?

Did you have any specific concerns about your privacy? If yes: what concerns were they? If no: why do you feel that way?

Do you feel that you have control over your personal information that you share with the Echo Show? To what degree? Is having control over your own data important to you?

Privacy and convenience can sometimes be viewed as two opposing ideas — the more you have one, the less you may have of the other. With that in mind, what is generally more important to you: Convenience, or, Privacy?

Did you read the Echo Show's Terms of Use regarding privacy for your device? If yes: What are some of the points you remember from it? Did you think it was important? If no: why not?

Did you explore the privacy settings and controls in the Echo Show when you owned the device? If yes: What were your overall thoughts about the controls? Did you change any of the settings to better match your preferences? If yes: What did you change? If no: why not?

Did you ever try to prevent your Echo Show from listening to you? *If they mention mute button:* How often do you use this button? When did you last use this feature? Do you find this feature useful? *If they do not mention mute button:* Did you know that you can mute your Echo Show, so it stops listening? If yes: Is there a reason you have not used this feature? If no: Now that you do know, would you utilize this feature? Why do you feel that way?

Did you ever adjust your conversations when near the Echo Show?

Have you looked up your command history, or log of commands to your Echo Show device? Why or why not?

Your Echo Show device allows you to delete all your command history. This means that it can delete every command you have ever given it. What do you think about this feature?

Let's design the ideal Alexa device that you would be most comfortable with. Currently, in order to capture the attention of your Echo Show, you need to say “Alexa.” Is there any feature you would add or edit to change how you get your device's attention?

Have you heard of the concept that the Echo Show is ‘always listening?’ How do you feel about this?

Do you have any recommendations for changes to the Echo Show that would make you more comfortable when using it?

Finally, are there any other privacy controls that you wish the Echo Show had?

One way to learn about how the Echo works would be to read the terms of use. The Echo's terms of use explain the different functionalities of the device, such as how interactions between the Echo and the user work, how the environment is monitored, and how data are stored. Almost all participants (n=10) reported reading the terms of use and stated that they

thought they were important. In sum, most participants were at least somewhat informed about how their device worked and how it stored and used their data.

With many technologies, the user has some control over how their data is used and stored. When asked how important it was to control the per-

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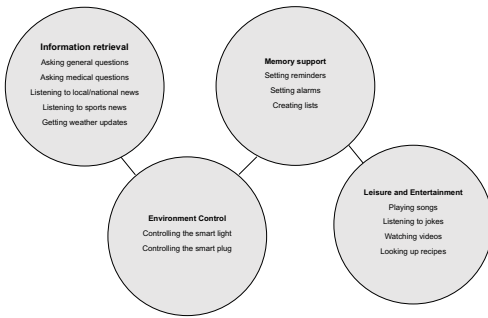


Figure 1. Participants' use of their Echos

sonal information they shared with their Echo, all participants stated it was important. Furthermore, all participants stated they felt they had control over the personal information they shared with their Echo. As one participant stated, "I do [have control] because I decide what I will use it for."

Attitudes about privacy

When asked if they had concerns about privacy when using the Echo, four participants shared they had specific concerns such as the Echo listening to their conversations or watching their environment. Ten participants stated they held no specific concerns about their privacy when using the Echo.

One theme was the idea of needing to build confidence or trust in the technologies. When discussing how they felt using the Echo, one participant stated, "...being in the older generation that we are. That's a huge concern. I don't think the young people are as concerned about it, as we folks are, because we grew up without all this techy stuff...I think it's the same with all these technologies now that us older folks have to get used to the way it is. And be assured that it's not affecting our privacy, that she [Echo] is not listening in to everything that we're saying...and that's a big adjustment." This theme highlights the willingness to embrace new technologies while emphasizing the importance of building trust for continued use.

Other themes emerged when we asked participants specifically about privacy issues relating to using their Echo. The theme of the high value of privacy and the human right to privacy reflected participants' comments about privacy being very important to them. One person shared, "With technology, it can tap into all of your information, and with that being said, it's important if you're sharing information about that person to get that person's permission." This theme highlighted an individual's desire for their individual right to privacy and their attention to the right of privacy for others. When participants were

specifically asked about the concept of the Echo 'always listening,' they expressed concerns over it, with one person sharing, "I am not completely comfortable with it 'always listening'...I don't know that my life is that exciting, but it doesn't need to be listening, why would it ever need to be listening I guess is the point." This highlights the concerns of the participants when using the Echo as they value their privacy and want to ensure that is not infringed upon.

Despite privacy being of high value, some participants did not view the data collected and stored by the Echo as important. This theme reflects the perception that the data were not personal in nature or would not be of interest to others. As one participant stated, "Well, I guess I am talking to them. And they can see my interests. And they could get a pretty good profile of me. But I think Amazon has a lot better things to do with their time [than] analyze my privacy." When asked about the concept of the Echo 'always listening,' some responded that they were not concerned and one stated, "I don't care. There's nothing I say or do that they can't hear... it doesn't worry me." This theme reflects a belief that the data that the Echo has access to is not considered valuable to the degree that it would need to be protected.

No conspiracy or ulterior motives was another emergent theme. In response to the idea of the Echo 'always listening,' participants shared that they did not feel it was and there was no ulterior motive to the technologies. One said "I don't really worry about that ... I do remember somebody saying somebody can listen to everything that you're saying to the Echo, And I thought, I don't think so. So, I really don't worry about that too much. Or maybe I should, but I don't." In this case, even though the participant stated they maybe should worry about the Echo 'always listening,' they did not believe that to be the case.

Some participants expressed that they understood using technology comes with risk and there is no way to completely prevent that risk. This reflects an acknowledgement of risk and that it is unrealistic to control some malicious activity. Comments were that some amount of risk is inevitable, and there will always be malicious people/behavior. One participant shared, "...it's worrisome because there are people who can access information that you don't want them to get to. So...you have to be very careful." Another stated, "Technology is a big risk factor for privacy. Whenever you put yourself out there... the same thing with the computer. If you're on Facebook or Twitter or anything like that, you're discoverable. And who knows what hackers can

find out once you're on those devices." Another participant shared, "I am more concerned about people hacking into my accounts or that kind of stealing [of] things. I'm more concerned about that, than privacy. I'm not too worried about privacy. I know it's important, but I think sometimes it gets carried a little overboard." These quotes exemplify participants' understanding of a certain amount of risk in using the Echo.

Many participants discussed the benefit of convenience gained from using their Echo. And for some, that convenience outweighed the cost of the effort to protect their privacy: "I've had to give up privacy from the beginning of having a disability. And convenience wins out [over] privacy for me for that. I'd rather be able to live a life that's easier. I don't want to have to struggle so hard. And so, if I can have the technology to make things easier, I'll take that over privacy." This theme highlights that some participants are aware there is a risk when using these technologies, but that they also perceive the benefits the technology provides.

Privacy protective strategies

When asked if they explored the privacy settings and controls in their Echo, eight participants stated they did not, while six said they did. When asked if they tried to prevent Echo from listening to them, most said they did not and that they did not adjust their conversations in the presence of the Echo. Upon being told that a function of the Echo is that you can mute it as an extra privacy precaution, most participants shared they did not know of this feature. However, when asked if they would use it now that they know about it, eight said they would. Additionally, when participants were told they had the ability to delete their command history, most responded that they thought it was a good feature to have access to. One person said, "That's a nice feature, as long as it doesn't impact use."

Some participants did share privacy protective strategies they used, ranging from turning the camera off to limiting what was said around it or adjusting their conversations. One person stated, "I think [privacy concerns are] one of the reasons why I've used the device for such limited uses. I don't want to put myself out there with the device having more information than I want it to." Another participant shared, "If we said something in confidence...we have a couple of friends with major health issues they do not want the information shared...I'm thinking if I'm talking to my husband about this [health issues] and she [Echo] hears it, can she [Echo] pick that up and do something with it...that was a huge concern." These quotes reflect that some participants used a variety of privacy-protective strategies to maximize their privacy when using the technology.

DISCUSSION

Smart home technologies can serve as a valuable tool for helping adults aging with disabilities age in place, providing assistance for daily tasks. However, adoption of these technologies may be inhibited by one's understanding of how these technologies work and how their privacy may be impacted. Our goal was to evaluate the perspectives of adults aging with mobility disabilities regarding privacy and DHAs.

A user's attitudes about technology can impact their use and adoption of that technology (Mitzner et al., 2018). If perceived risks outweigh perceived benefits, users are less likely to adopt the technology long-term (Melenhorst et al., 2006). Some participants voiced their concerns about privacy when using their DHA, sharing that they felt they had privacy exposure when interacting with the device. Some also expressed concern that those who enter their homes or whom they speak about when near the DHA would also lose privacy. These concerns were consistent with their expressed values that the right to privacy is very important for themselves as well as others. Increasing older adults' knowledge about how their data are used could help to guide them about how to use their DHA and foster trust in the technology.

Several themes reflected nuanced and contextualized attitudes about privacy and DHA use. Despite the acknowledgement of some privacy risks, participants did not believe there was a conspiracy to do harm against them, such as by the device manufacturer. Some participants did not find the information they shared with their DHA to be of interest or importance, stating that they did not consider it to be "personal" (e.g., banking info, health records). Nevertheless, some did engage in behaviors to reduce privacy risks (e.g., privacy protective strategies).

These results show older adults' openness and willingness to use DHAs and perceptions of benefits for supporting everyday activities. However, their concerns about privacy did impact their use and could inhibit them from gaining the full benefits of the technology. Providing interventions such as training and educational materials can decrease concern and increase confidence in users. Research using an interactive simulation to teach older adult users how to spot phishing emails resulted in an increase in detection strategies and increased confidence in interacting with their email platform, as well as using the computer and engaging in an online presence in general (Kazamia et al., 2024). Educational materials and training programs could reduce some of the privacy concerns to facilitate the use and adoption of these devices.

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Areas of emphasis would be how data are monitored and stored, privacy-protective strategies, using features of the system, and how the user interacts with the device.

Limitations and future directions

Despite valuable insights into the perspectives of older adults aging with mobility disability perspectives on privacy when using the Echo, our sample size was small with limited demographic generalizability (e.g., race, technology proficiency). Given the interview data that were analyzed were from an optional follow-up to a larger study, those who participated had chosen to use it long-term. Additional research is needed to both qualitatively and quantitatively assess the use of DHAs for IADLs (e.g., following the stock market, getting recipes, using alarms for medication reminders) and EADLs (e.g., learning about current events and news, listening to music, videoconferencing with friends

Acknowledgments

This study was supported by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR Grant No. 90REGE0006-01-00) under the auspices of the Rehabilitation and Engineering Research Center on Technologies to Support Aging-in-Place for People with Long-Term Disabilities (TechSAGE; www.TechSAGERERC.org). We appreciate the considerable support of Kenneth Blocker, Travis Kadylak, Lyndsie Koon, RS Sreenivas, Ki Lim, Maya Malecki, and Widya Ramadhani on this project. Portions of this project were included in Husna Hussaini's Senior Honors Thesis at Illinois.

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and family) with larger and more representative samples, including those with more diverse racial and ethnic backgrounds and those who have less technology experience.

CONCLUSIONS

Digital assistants have the potential to enhance the ability to age in place by assisting with daily activities. We found that older adults with long-term mobility disabilities used their DHAs for a wide variety of activities and perceived benefits of such use and discussed varied levels of concern about privacy. Concerns about privacy when interacting with technology can become a barrier that inhibits the user from gaining the full benefits of the technology. Therefore, increased education and training about privacy risks and protective strategies could facilitate use, given the high value participants placed on privacy.

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