"If Alexa knew the state I was in, it would cry": Older Adults' Perspectives of Voice Assistants for Health

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ABSTRACT

AI-powered technologies are increasingly being leveraged in health and care practices for aging populations. However, we lack research about older adults perceptions of AI-driven health in long-term care settings. This paper investigates older adults' perceptions of how one AI-powered technology, voice assistants, should be used for personal health management. We interviewed 10 older adults living in an assisted living community in the U.S. to explore their values around AI for health. Findings show that they value technologies that generate and share positive and relational health information. We use this emphasis on positive health representations to speculate on a critical refusal of negative health representations. We highlight this preference in contrast to existing deficit-based health tracking technologies for aging and discuss how researchers, developers, and designers can engage in better approaches to AI-driven health for older adults and other historically marginalized populations.

CCS CONCEPTS

• Human-centered computing → Empirical studies in ubiquitous and mobile computing; Human computer interaction (HCI); Accessibility; • Information systems → Information retrieval.

KEYWORDS

older adults, voice assistants, AI, health, critical refusal, data

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1 INTRODUCTION

Age-related disability is common amongst older adults (ages 65+), and people are twice as likely to develop moderate to severe health conditions and disabilities over the age of 65 [1, 2]. Most HCI research to support older adults' health focuses on technologies for

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older adults living in their homes. Yet, age, lack of social support networks, and disability are correlated with a higher likelihood of older adults living in assisted and skilled care residential communities [25, 65]. In this paper, we investigate health and data preferences of older adults in an assisted living community.

Older adult residents in assistance-based long-term care (i.e., assisted living, memory care, skilled nursing homes), their family members, care staff, and medical professionals collaboratively engage in information and data sharing to address older adults' health needs and answer their health questions. Traditionally, this collaborative data work happens through in-person visits to primary care physicians or check-ins with care staff. Yet, health care professionals and long-term care staff are increasingly using technology to support data management and sharing amongst older adult residents. For example, ambient, monitoring technologies such as wearable activity trackers and biosensors can be used to track and predict adverse behaviors [24, 58]. Video conferencing with physicians and personal health informatics dashboards can support patient-provider communication and meaningful reflection [7, 18, 53]. Recently, researchers have explored how artificial intelligence (AI)-powered technologies such as voice assistants can be used to support health for older adults [50, 51, 56, 60, 63, 64]. Yet, a complex relationship with technology exists between older adults, care providers, and technology developers as digital tools can be seen as useful and as forms of surveillance [8]. In this paper, we extend prior work to investigate how AI-powered technology can support health-related data and personal health management with older adults who live in assisted living communities, and tensions that arise.

We choose to focus on voice assistants, which are a type of AI-powered technology. Recently, researchers have discussed the potential for voice assistants (i.e., Siri, Alexa, Google Assistant) to be one component of the personal health management ecosystem for their ease of use, natural input/output interactions, and availability compared to medical professionals [68]. For example, natural language processing can enable conversations between primary care physicians and patients, generating a summary of the visit for one's medical chart or for older adults to review outside of medical settings [3, 34, 64]. Voice assistants can also be helpful in one's home, by providing verbal access to symptom checkers to receive a diagnosis [68] or analyzing speech data to monitor health conditions [40]. As much of this research focuses on older adults' perceptions of voice assistants who age-in-place (in their homes) [51, 56, 63], we lack a thorough understanding of older adults' perceptions of voice assistant use in long-term care communities for personal health management.

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The primary goals of this work are to (1) understand perceptions of AI-powered personal health management tools for data and sharing by older adults in an assisted living community and (2) propose design recommendations for technologies that support older adults' visions of AI-driven health. We explore these values and design futures through the lens of one AI-technology - voice assistants - for its pervasiveness, low cost, and widespread availability. To address these goals, we conducted interviews with 10 older adults residing in a assisted living community in the United States to explore their values around AI technologies for health. Findings show that they value technologies that generate and share a positive perspective about their health. We use this emphasis on positive health representations to speculate on a critical refusal of negative health representations. We highlight this preference in contrast to existing health tracking technologies for older adults [46] and use critical, feminist epistemology to discuss how the research and design community can engage in more positive and participatory approaches to AI-driven health for older adults and other historically marginalized populations.

2 RELATED WORK

2.1 Personal Health Technologies

Over the last 20 years, there have been significant advances in personal health informatics research. Previous studies have shown how personal health data is a collaborative process, with people often sharing information with their medical providers (e.g., [7, 53]). Yet, boundaries between health and non-health data are often blurred and patient-generated data can be indirectly related to one's health [18]. Research has shown how people wanted medical providers to have a better sense of their daily life so that physicians could customize their health plans, to enable better accountability, to ask questions, and for additional emotional support. Data sharing could also support health behavior reflection, which prior work has shown to be correlated with more informed health decision-making [18].

To investigate what impacts the sharing process, researchers have studied the types of health data older adults share and want to share about themselves. Prior work describes how older adults may conceal or modify information about themselves to be perceived as more favorable to a medical professional [10]. Similarly, Lim et al. (2016) show how older people focused more on reporting symptoms than activity-based behaviors that could contextualize their symptoms, arguing for better ways to support patients sharing qualitative information to inform the patient-provider relationship and life outside of the doctor's visit [42]. To better support sharing such contextual data, researchers have suggested that sharing information by audio or speech may be more accessible, intelligible, and would limit the need for recall, which is often inaccurate [49]. Extending research on health sharing preferences, we investigate what older adults value about voice-based personal health data.

2.2 Older Adults and Voice Technologies

Researchers agree that voice technologies can be more accessible forms of interaction for older adults (e.g., [15]) and are more preferred over screen or keyboard-based technologies [66]. When asked about their perceptions of smart speaker voice interfaces (e.g., Siri, Alexa, Google Assistant), older adults specified that they liked the accessibility of smart speaker devices because they could engage using natural language interaction and did not need to use a mouse) [39]. While voice technologies may be less accessible for hard-of-hearing older adults, research describes how these accessibility concerns can be mitigated by providing more options for customization screen-based feedback [12].

Beyond accessibility benefits, older adults have indicated what they value about using voice technologies. For example, interviews with older adults in long-term care who use(d) voice assistants show how some thought it would help them be more independent, social, and help to provide companionship or connect with others [55, 67]. Additionally, voice assistants were perceived to be easier to use than visual technologies and could be used as a form of memory support [56]. However, concerns remain over how to structure conversation to a voice assistant, recall commands, address privacy concerns, avoid being overly reliant on technology, and how to appropriately include a visual component [39, 56, 61, 66, 67]. In this paper, we investigate health and well-being opportunities and concerns of voice assistant use.

2.3 Voice Assistants for Health

Older adults often use technology to supplement their health needs, and are increasingly exploring how voice assistants can be part of their health ecosystem. In a study of older adults' health information seeking behaviors on a computer, participants faced challenges with complex search queries [32] and described how voice assistants would be ideal for engaging with and sharing health information [45]. By using voice assistants, older adults envisioned how it would be easier to receive personalized health information, track daily activities, and would provide a better "holistic health" summary [45, 56]. Older adults also valued being able to listen to their health progress [30]. In a literature review of research about conversational agents and chatbots for health [35], researchers highlight how conversational agents can reduce health literacy barriers [33, 62] and stigma of disclosing personal information [44].

Researchers agree that conversational technologies should supplement, not replace, human interaction in health settings, yet there remains a call to understand concerns at the intersection of trust, health, and voice technologies [35]. Prior work suggests that older adults perceive voice interfaces to be more trustworthy than younger adults, [31], which is a challenge in high-risk contexts such as health. One study [11] examined how people evaluate health information with voice assistants. Findings show how many participants misinterpreted the voice assistants' responses to health questions. Pradhan's work (2020) also provides evidence of older adults facing difficulty verifying information or trusting health information from a voice assistant [56]. Other challenges include how to mitigate comprehension conflicts where there are "troubles in understanding" [38] and designing for increased autonomy. While probing how to design an intelligent health assistant for older adults, participants described wanting agency in health data management and decision-making, and increased transparency in how data is being used [60]. Understanding the role of transparency is particularly important as older adults may have other stakeholders involved in their health, well-being, and care practices, and these stakeholders

may have different values around using voice assistants for health [69]. Such research highlights a critical need to better understand how voice assistants can be used for older adult's health. In this paper, we focus on older adults' values around voice assistants for health-related data collection, presentation, and sharing.

3 METHODS

To understand older adults' digital health data monitoring and sharing perceptions, we conducted semi-structured interviews with older adult residents living in an assisted living community in a large city in the Northeastern region of the United States, which had partnered with a start-up to provide its residents with access to Amazon Alexa devices. We focused our interviews on health perceptions of voice assistants because of their increasing adoption amongst older adults and accessibility for older people with disabilities [52, 57]. In the interviews, we asked about prior experience with voice assistants and engaged older adults in scenarios to understand how these devices could be used for health and well-being. In this paper, we chose to focus on a section of the interviews in which we engaged participants in a speculative inquiry exercise to understand their perceptions of health-related data use, reporting, and sharing. Specifically we asked about:

- Data use and reporting: If Alexa could create a report or summary about you based on what you say to it, would you want it to? (if yes) What would you want this report to include?
- **Health:** If Alexa could create a report or summary about your health based on what you say to it, would you want it to? (if yes) What would you want this report to include?
- Emotional well-being: If Alexa could create a report or summary about your mood based on what you say to it, would you want it to? What would you want this report to include?
- Trust: How would you know whether to trust the report?
- Accuracy: How would it be able to capture or describe your health accurately?

To date, voice assistants have been known to produce undesired realities in health contexts with younger [11] and older adults [16]. As such, speculative inquiry is an ideal approach since it is often used as means for "eliciting tech futures" in contexts where desired realities have not yet been designed, where alternate realities are desired, or to critique existing realities [6, 22, 29]. In this part of the interview, we asked participants about their *desires for data reporting* to themselves and others, *what* data they would want shared, *how* the data would be shared, and *perceptions* of such data.

After receiving approval from our university Institutional Review Board, we partnered with an assisted living community to recruit older adults using paper flyers, with help from the community's activity director. The activity director shared the flyer with residents over the age of 65 who had Alexa devices in their rooms due to the start-up's Alexa device program. We did not restrict inclusion criteria by active voice assistant use to recruit older adults with a range of voice assistant experiences as perspectives between novice and expert users can differ. We recruited 10 older adults (73-86 years old, average age = 78 years old, 5 male, 5 female, see Table 1). As is common in research with marginalized older adults [4, 29], our sample size is small. Yet, we highlight how this study is a starting point to understanding health representation preferences in long-term care settings.

P#	PseudonymGender Age			Voice Assistant Percep-
				tions and Use
1	Bruce	Male	77	Uses to play games or lis- ten to music, good for liv- ing alone
2	David	Male	74	Uses for music, community schedule updates, time, date, weather
3	Betty	Female	73	Describes as "polite"; uses for music, for community menu updates, jokes, daily affirmations, weather
4	Gerald	Male	86	Uses for music, games
5	James	Male	73	Describes as "information center"; uses for date, time, weather
6	Carolyn	Female	79	Describes as "somebody smart", "clever"'; uses for alarm, news, the weather, to play music
7	Janet	Female	76	Uses for alarms, news, meditation, and to play mu- sic
8	Marilyn	Female	83	Describes as "my friend"; asks about weather, news, movies, facts; plays music
9	Susan	Female	84	Describes as "a little ro- bot", uses for music, games, and to learn about the daily menu; no longer uses reg- ularly
10	Robert	Male	70	Uses regularly for timers, the weather, and facts

 Table 1: Participant demographics and summary of their

 Amazon Alexa usage

After verbal consent, we recorded each interview and used a third-party service for interview transcription. To analyze our data, one member of the research team used an inductive thematic analysis approach to identify patterns across the interview transcripts [14]. To do so, the researcher read the transcripts to become familiar with the data. After doing so, they developed codes for the interview section that focused on health data use. Lastly, the researcher generated initial themes from the codes that aligned with broader patterns in the data, iteratively refining and reviewing themes. The final set of themes include: (1) positive reporting, (2) trust, (3) accuracy, (4) privacy, and (5) comprehension. In this paper, we focus on two of these themes, positive reporting and comprehension. Due to our small sample size, we do not quantitatively report findings, yet we indicate whether patterns were identified by one or multiple

participants. Future work could apply our themes with a larger sample size for a quantitative indication of their salience.

4 FINDINGS

In the following section, we report on how older adults wanted to be represented in health data from AI technologies. We find that they overwhelmingly wanted more positive representations of their health and social well-being. We also describe comprehension concerns they have with voice-based health AI technologies.

4.1 Positive Health and Aging Representations

Participants had mixed reactions to using AI technologies for health in assisted living, reacting positively and negatively. Some participants were optimistic about voice assistants being one component of their health data ecosystem. For example, Marilyn wanted data to be shared not only to medical professionals, but also to herself, saying, "...you'll see the improvement [...] in other words, they're showing you." This shows a desire to be more involved in understanding her own health progress.

However, one participant strongly objected to data from voice assistants being used for health because his many health conditions are complex. Robert said, "I don't need that. My health is a mess. You have no idea all the problems I got. My eyesight is going. I've got glaucoma. I just had a cataract removed [...] I've got dental work that needs to be done. I've got bad kidneys for the last 25 years [...] I can go on. I'm a physical mess. If Alexa knew the state I was in, the tower would weep. It would cry." We interpret this last statement as this participant's means of describing how age-related health needs can negatively impact one's mood and be depressing. Although there are benefits of reflecting upon one's health, this refusal of voice assistants aligns with prior work in health informatics, which suggests that personal health technologies can lead to rumination and "negative self-attention" [23] for older adults with more critical health needs.

These quotes suggest that voice assistant data could be used for more accessible personal health management, yet raise questions about how the data should be presented to be useful and how to appropriately share data if someone has multiple health conditions. When asked how they wanted data about themselves to be presented, nearly one-third of participants described wanting AI technologies to report positive aspects of their health and wellbeing. Several participants wanted medical professionals to know that they are being active, social and have a positive personality. For example, David said, "*I'd like to* [...] *tell whoever that I'm a happy person. I like interaction. And like being out and about*," showing how he would want reports to include social activity and well-being, reinforcing positive relational behaviors. This could also indicate a preference for reporting information about interactions outside the home.

Others wanted reports to share about their personality rather than health. For example, Carolyn said the voice assistant "should know that I have a nice personality, nice with people and get along with everybody." Similarly, Susan said that any report should share that she is "a very friendly person. Very positive. I am well-liked and I try very hard to give the same in return to my residents. I talk a lot because I am very opinionated... I am all in good health. I am still cognizant, I wake up happy. I try to use all the facilities around me so I can keep healthy." Although speculative, the focus on mood could be in reference to the high frequency of mood disorders amongst older adults or depressive symptoms impacting people with dementia [13, 48].

Each of these responses seems to be in stark contrast with how data about older adults is currently presented in health-related technologies [9, 43]. For example, smart-home technologies and wearable devices targeted towards older adults often focus on monitoring the absence of positive behaviors or indicators of health such as falls, high-blood pressure, or irregular heartbeats. However, our findings show how older adults prefer fewer deficit-based forms of health data being presented and more positive, strengths-based forms of health data. We return to this more in the discussion.

4.2 Comprehending health information

Participants expressed concern over understanding health data and information from voice assistants. Two participants stated they would not want health data shared with anyone because it would be too difficult to interpret medical information. Bruce said, "A report? What kind of report would I have at this stage?...I told you...I have no formal education... So why should I confuse the hell out of myself even more than I'm confused to begin with?" Throughout the interview, he compared health and medical information to a foreign language and needing a healthcare professional to interpret health information in a more accessible format. Bruce also expressed skepticism of learning new information about his health from a voice assistant, saying, "Why if I ask the girl over there [referring to Alexa] what's the matter with me was [sic]? What am I going to get? I'm going to get basically what I know. You know? What's already been said to me, she's not going to give you anything new." In this quote, Bruce is showing how it is not only important to understand information, but to be able to process and learn new information from Alexa.

When asked about sharing health data with others in their care network, participants were concerned about how they would confirm voice-generated health data prior to sharing. For example, Janet said, "*I don't know... Well, I can't see it. I can't read it.*" These quotes raise questions, not only about the content, but also the modality of AI-generated health reports. In the discussion, we discuss strategies that designers and developers could use to present voice assistant and other AI-generated health data in ways that are comprehensible and trustworthy.

5 DISCUSSION AND CONCLUSION

Our findings highlight older adults' concerns about how their health data is being represented. They wanted more positive and social representations of their health data and ways to make data easily interpretable. In this discussion section, we (1) reflect on aging and data representation through the lens of feminist epistemology and critical refusal and (2) suggest recommendations for designers and developers of voice assistants and other AI-powered health tools.

5.1 Aging and data representation

Older adults explicitly expressed concerns about how a voice assistant would share and describe their personal health data, often describing a future of positive and social health representations. This imagined future of better health and age representation in AI technologies aligns with prior work that cautions against positioning older adults as disinterested in technology, instead inviting researchers to engage with underlying narratives of use [37]. Building from our findings, we argue that understanding critical refusal (of AI-based technologies that report negative information) and alternative forms of representation are important for future research. Feminist data scholars such as D'Ignazio and Klein [21] describe the need to "examine and challenge power", "rethink binaries and hierarchies", and "embrace pluralism" [41]. Feminist data and HCI scholars have been instrumental in highlighting "new data futures" and the harms of data practices that seek to normalize an idealized representation of society in ways that do not consider the needs of marginalized or oft-excluded communities such as older adults in care settings (e.g., [19, 21, 59]). For example, the Feminist Data Manifest-No [19] describes 32 aspects of critical data refusal, describing refusal as a valid approach to data practices that further marginalize communities such as Black and Indigenous communities, disabled people, and low-income people.

In the remainder of this section, we draw upon two key themes from feminist data scholars [19] as they have direct connections to older adult participants' AI data concerns and historical representations of aging - subjectivitiy, and intelligibility. In doing so, we extend feminist data literature into a new context - aging - and contribute a nuanced understanding of older adult participants' AI data concerns. Our findings build upon recent work about aging and representation in AI [54], showing how alternative forms of representing data about older adults are valuable in health contexts. We argue similar conversations about data, representation, and feminist approaches to AI are important to continue having with other marginalized communities such as children or people with disabilities.

5.1.1 Subjectivity. "We refuse data logics that hyper-value the quantitative, the "objective," and the "generalizable." We commit to developing, adopting, and advancing methodologies that draw insight from the subjective, embodied, contingent, political, and affective in ways that transcend traditional boundaries between qualitative and quantitative." [19]

Older adult participants often described alternative data values that are typically shared. Specifically, they wanted a summary of their health to include positive, social activities - communicating with others in their assisted living community, establishing relationships with residents, keeping in touch with family members. This desire for relational health representations directly aligns with the Data Manifest-No's statement to transcend data boundaries beyond physiological metrics to also include the relationship between one's affective state and relationships with others. Prior work in personal health informatics and aging has described values that younger and older adults value in health data including alternative data representations [5], holistic health [30], stress tracking and mitigation [20], goal customization [30], and result personalization based on health history [45]. In our study, we expand prior work about aging and objective forms of data representation to more subjective and relational data about social well-being, acknowledging that such representation advocates for strength-based approaches to health data.

While we acknowledge that there are critiques of whether to use AI for health and well-being (e.g., [26, 47]), we argue that there are benefits of AI in health contexts, if implemented appropriately. We encourage AI technology designers and developers to consider data logics that "transcend traditional boundaries" and present positive representations of health, which may include social well-being data about daily social interaction with others in a community, new friendships established, friendships maintained, and connections with family members. As older adults are at high risk of social isolation due to changes in social networks, there may also be opportunities for AI-powered health tools to recommend new connections or events in one's care community or neighborhood to improve social well-being. Future research could also explore how older adults' perceptions towards using AI technologies for health changes if they are represented in the data is more subjective.

5.1.2 Intelligibility. "...We commit to seek to make systems and data intelligible, tangible, and controllable." [19]

Our findings show how there were concerns about comprehending health-related data provided by a voice assistant. These concerns included understanding medical jargon, being provided with new information about their health, and presenting data in an intelligible format prior to sharing with others, each of which are concerns related to digital and non-digital health literacy. Intelligibility is a known challenge in home-based health monitoring literature (e.g., [28]) and in conversation with medical professionals (e.g., [27]). Prior work has shown how older adults want an intelligent assistant to "explain things in plain language" when they are searching for information, providing opportunities for follow-up conversations [45]. In our study, we see a similar hesitation, but with an intelligent voice assistant generating a summary about their health, which may be shared with medical professionals. Sharing voicegenerated data with others presents new intelligibility challenges as older adults want to ensure that they not only understand information for comprehension purposes, but also to verify information accuracy and be able to correct or confirm data summaries prior to sharing [36].

With visual or text-based data, users may have access to an 'edit' feature to correct inaccurate information or add text notes to contextualize behaviors. Researchers have studied similar approaches to audio-only editing [17], which can be used for editing voice-based AI-generated health reports based on speech data. Also, voice notes or memos can be used for older adults to contextualize information from health summaries.

5.2 Limitations and Future Work

We acknowledge that the demographics of participants in our sample were not representative of all older adults, rather most closely associated with the demographics of the assisted living community in each we recruited, which skewed towards older, older adults. Future work may include survey data of older adults across different living communities (e.g., independent living, nursing homes) and those aging-in-place to understand whether these perceptions scale to older adults in other contexts (e.g., wearables) and with other voice technologies (e.g., Google Assistant, Apple's Siri) . We also encourage researchers to have similar conversations about health and data representation with other vulnerable populations such as children, adolescents, disabled people, incarcerated people, etc. As advocates of human-centered approaches throughout the research and design process, we plan to conduct co-design sessions with older adults to design health summaries generated from voice assistant data, probing for more social and relational data representations and how design and health data disclosure preferences would vary by audience.

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