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How I want technology used in my care: Learning from documented choices of people living with dementia using a dyadic decision making tool

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Abstract

While technologies for aging in place are promoted to support care partners and people living with dementia, perspectives of people living with dementia are underrepresented in both use decisions among families and discussions within academia and industry. This mixed-methods study examined the use preferences of twenty-nine people living with mild Alzheimer's disease (AD) for four categories of technologies: location tracking, in-home sensors, web-cameras, and virtual companion robots. Participants completed a novel dyadic intervention, Let's Talk Tech, where they documented their preferences of the four technology categories for care planning purposes. Post-test interviews were thematically analyzed and provide insight into selection processes. Technology preferences varied considerably by and within participant living with mild AD. Excepting location tracking, non-technology and low-technology options were more desirable than the featured technologies. Control over technology use was of great importance to people living with AD. Considerations given to technology preference selection imperfectly fit within the new Health Technology Acceptance Model (H-TAM) developed for older adults. These findings underscore the importance of including people living with dementia in decision making about technologies to support care at home and the need for further personalization and tailorable technological devices to accommodate and align with their preferences.

Keywords

people living with dementia; care planning; technology preferences; decision aid; ethics

Introduction

For decades, research has sought to better understand what drives technology adoption among older adults, with the goal of helping them manage health conditions, maintain quality of life, and age in place (Peek et al. 2014). Much less work has been done to understand the perspectives of people living with dementia (PLWD) (van Boekel et al. 2019; Vermeer et al. 2019). Technologies for aging in place are increasingly viewed as a worthwhile and cost-effective option to assist care partners in supporting PLWD (Astell et

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al. 2019; Moyle 2019; Thordardottir et al. 2019), though a recent large clinical trial with PLWD found no effect on cost or prolonged ability to live at home (Howard et al. 2021). Use of various technologies used at home in dementia care can pose various risks such as threats to privacy and autonomy, data security, and information overload for caregivers (Berridge et al. 2021). Given this uncertainty in the context of strong momentum toward implementation, it is critical that research attends to the technology use preferences and concerns of PLWD.

Preferences of PLWD for technologies used in care

Few studies examine how PLWD make or contribute to decisions related to technology use in their care. Those that exist tend to focus on evaluating the acceptability of a specific technology (e.g., location tracking) by PLWD and/or their care partners (Wan et al. 2014; Thorpe et al. 2019; Stavropoulos et al. 2021). Studies have identified several factors that influence technology acceptability for PLWD- divided into external barriers, personal/perceptual barriers, and facilitators. External barriers include lack of formal support in accessing and using technology, cost, and technology infrastructure, (e.g., internet connectivity) (Gibson et al. 2015; Thordardottir et al. 2019; Vermeer et al. 2019). Personal/ perceptual barriers include a lack of awareness or experience with technology, extended time to learn the technology or perceive a benefit, high technology complexity, stigma, and data privacy issues (Holthe et al. 2018; Gibson et al. 2019; Thordardottir et al. 2019; van Boekel et al. 2019). Examples of facilitators of technology acceptability are technology design (e.g., size, appearance, style), reliability, convenience, affordability, ease of use, low complexity, familiarity with technology, perceived benefits, and care partners' encouragement (Wan et al. 2014; Holthe et al. 2018; Farina et al. 2019; Thordardottir et al. 2019; van Boekel et al. 2019; Vermeer et al. 2019; Lariviere et al. 2021; Stavropoulos et al. 2021). Perceived benefits of technology are largely centered around the care partner and their supportive roles. For instance, tracking PLWD's activity using a monitoring device may be accepted by PLWD for the sake of their care partners (Gibson et al. 2015).

Decisions surrounding technology use and acceptance are also affected by personal conceptions of values, such as privacy, autonomy, safety, restriction, and freedom. PLWD and their care partners consider how using a technology may serve to enhance or conflict with values important to them (Robillard et al., 2018; Wan et al., 2014). For instance, technologies that enhance feelings of autonomy and independence are considered more acceptable by PLWD (Godwin 2012; van Boekel et al. 2019), while experiences of technology infringing upon privacy or restricting autonomy may be undesirable (Godwin 2012). These determinations of value concordance with technology use are individualized and contextually dependent (Wan et al. 2014; Robillard et al. 2018). There is a need for flexibility in technology use that accommodates individual circumstances, and for discussions on use to consider personal values (Gibson et al. 2019; Berridge et al. 2021; Lariviere et al. 2021; Berridge, Turner, Liu, et al. 2022).

Studies also highlight the role of care partners in initiating and reinforcing technology use, sometimes without informing the PLWD (Wan et al. 2014; Gibson et al. 2019; Lariviere et al. 2021). Care partners often decide to use technology for peace of mind about the PLWD's safety (Wan et al. 2014; van Boekel et al. 2019; Lariviere et al. 2021). The benefits

care partners perceive could override potential concerns they may have about diminished autonomy or privacy for PLWD (Gibson et al. 2015; van Boekel et al. 2019) and may result in the exclusion of PLWD from decision making about components of their care (Miller et al. 2016). This underscores the need to better understand how PLWD evaluate and consider technology options, and for increased opportunities for communication between PLWD and their care partners about these options.

Study intervention

This study presents findings derived from preferences documented by PLWD while completing a dyadic intervention called Let's Talk Tech that is delivered as a web-application. Findings from the pilot study on desired outcomes of Let's Talk Tech are presented elsewhere (Berridge et al. 2022; Berridge, Turner, Liu et al. 2022). Let's Talk Tech is a self-administered dyadic intervention that supports education, comprehension, and within-dyad communication about a range of technologies that are used to in dementia care at home. Let's Talk Tech facilitates informed conversation that enables PLWD and care partners to talk about what matters to them and to create a technology use plan that aligns with the PLWD's values (Berridge et al. 2022; Berridge, Turner, Liu, et al. 2022). It is a forward-looking process to document the preferences of PLWD before dementia undermines informed preference formation and expression. After it is completed, the dyad is presented with the summary of the preferences the PLWD selected after facilitated discussion with their care partner for technology use.

To begin the facilitated dyadic conversation, Let's Talk Tech asks PLWD to rate the importance they place on key values that are implicated in technology use decisions: privacy, feeling free to do as I want, continuing to live where I am, and feeling safe. It then provides education about each of four categories of technologies used in dementia homecare: location tracking, in-home activity sensing (with 4 different locations specified), home webcameras, and virtual companion robots that employ artificial intelligence. These data-diverse technologies were selected based on the literature and Delphi survey process with domain experts who identified technologies that will be most prevalent in dementia homecare in the next five years (Berridge et al. 2021). The general function of each technology is presented in a clear and concise manner for participants to understand what data the technology uses and its primary purposes, followed by education about both the research-based values and risks of use. Let's Talk Tech facilitates within-dyad communication about each technology category through a series of discussion and question prompts before asking the PLWD to document their use preferences. In addition to questions on preferences for the seven technologies, dyads are presented with non-technology and low-tech options to support care, such as having more phone calls with friends or family or having more frequent visits. PLWD are then asked about the desirability of these options (Table 3). Finally, Let's Talk Tech asks PLWD to select among five control options related to technology use in general, derived from Berridge et al. (2021) and Berridge, Zhou et al. (2021). These options include the ability to try out a technology before deciding to keep it, to pause a technology, to stop using a technology, to know if a technology is being used, and to be asked again about using the technology to see if feelings change (Table 4). The goal of these questions is to help the PLWD consider their preference for these and to communicate those to the care partner.

The Healthcare Technology Acceptance Model (H-TAM)

One way researchers seek to make sense of proclivities influencing acceptance of technology is through technology acceptance models. The Healthcare Technology Acceptance Model (H-TAM) was recently developed to understand older adults' considerations when presented with new healthcare technology (Harris and Rogers 2021). We focus on H-TAM as a framework because of its unique targeted focus on technologies used to manage older adults' health conditions (here, Alzheimer's disease).

H-TAM includes four predictors of technology acceptance: ease of use, perceived usefulness, social influence, and facilitating conditions. The model identifies specific factors older adults consider when presented with healthcare technology that influence those predictors. Privacy, trust in the technology, technology complexity, and familiarity are hypothesized to influence perceived ease of use. Perceived benefit, perceived need, and relative advantage of the technology are predicted to influence perceived usefulness. Trust in the person recommending the technology and advice acceptance are predicted to affect social influence. Finally, price value and perceived compatibility of the technology with one's current context influence facilitating conditions (Harris and Rogers 2021). We use H-TAM to organize our findings and clarify considerations important to PLWD when contemplating technology use. Using H-TAM as an organizational frame also serves to situate our findings within the current research on technology acceptance and inform the model's refinement.

Study aims

We used a convergent mixed methods study design (Fetters et al. 2013) to answer the following research questions: What are the choices people with mild AD make a technology use planning process and why? And further, how well do these explanations given by people living with mild AD fit the H-TAM? Data are the documented preferences from the Let's Talk Tech intervention paired with dyadic interviews that explain decision-making processes and considerations. Our interview findings are presented by each predictor used in the H-TAM. We discuss findings that did not fit this model and recommend potential adjustments.

Methods

Participants and recruitment

The study took place in the United States. Twenty-nine dyads comprising people living with mild Alzheimer's disease (here, 'people living with dementia'/PWLD) and their care partners completed Let's Talk Tech. The larger pilot study's inclusion criteria were: 1) member of the University of Washington Alzheimer's Disease Research Center (ADRC) clinical core or research registry with an ADRC diagnosis of mild Alzheimer's disease dementia; 2) 55+ years of age; 3) English-speaking; and 4) has a co-participant acting as the primary support person for the PLWD willing to participate in the study who is 18+ years of age and English-speaking. To meet diagnostic criteria of mild Alzheimer's disease, older adults needed a Clinical Dementia Rating (CDR) of 1 and a probable/possible Alzheimer's Disease diagnosis as determined by the University of Washington ADRC. Dyads needed to

be able to complete Let's Talk Tech together and one member needed to be able to access a device with Internet connection.

The ADRC identified 110 possible participants living with mild AD, all of whom were contacted via phone or email. Of these, 33 consented to participate in the study, 30 did not respond to the invitation, and others declined to participate. In total, 29 dyads completed the study (completion rate: 88%). All participants completed the informed consent process and all PLWD had capacity to sign informed consent. All 29 dyads completed 100% of the Let's Talk Tech modules and, as a group, answered 98.5% of the preference questions. Each participant who completed the study received a \$150 Visa gift card for their time and effort. See Berridge, Turner, Liu et al. (2022) for additional details on participant recruitment and completion. The University of Washington Human Subjects Division approved this study.

Procedures

Let's Talk Tech presents four categories of technologies (location tracking, 4 locations for in-home sensors, web-camera, virtual companion robot) in four modules, one at a time, with prompts to discuss how each member of the dyad feels about each. The dyad is then prompted to move on to the next questions where the PLWD is asked to select their preference. Within the technology modules, PLWD are asked to document their preferences on a total of seven technologies with the prompt, 'Select the option that best reflects how you currently feel: I want [technology] used with me/ I don't want [technology] used with me/ I'm not sure if I want [technology] used with me.' Open comment boxes are provided for additional explanation. Participants are then asked questions about the desirability of non-technology and low-tech options to support their care. At the end, PLWD document whether they would want each of five options to enable control over technologies used in their care in general, marking either 'yes,' 'no,' or 'unsure.' Only the PLWD is asked to document their preferences so that the care partner will have the PLWD's preferences to refer back to for consideration should they become a surrogate decision maker. After completing Let's Talk Tech, participants completed a dyadic interview via Zoom or inperson according to participant preference (average interview length was 33 minutes, range: 15–75). Dyads were given the opportunity to be interviewed together or separately. All but one dyad chose to be interviewed together. Two care partners requested time to be interviewed separately in addition to the dyadic interview. Interviews centered around their experience using Let's Talk Tech, including questions on whether the intervention was helpful, what it helped them to think about, and which technologies dyads had differing opinions on. Dyads also provided explanations for the preferences selected by PLWD, including concerns and perceived benefits.

Data & Analysis

The data for this analysis are PLWDs' choices documented as part of Let's Talk Tech and post-intervention dyadic interviews. This source of data is unique for two reasons: 1) it is inclusive of multiple categories of technologies and 2) unlike technology acceptance studies, participants learned about, discussed, and documented together with their care partner their choices for technology use in the form of a decision making and planning tool (Berridge, Turner, & Liu et al. 2022). While Let's Talk Tech enables communication between the care

partner and PLWD, the preferences documented are those of the PWLD. The development of the intervention and preliminary feasibility, acceptability and efficacy findings from the pilot study are reported in Berridge, Turner & Liu 2022; Berridge, Turner, & Liu et al. 2022)

Mixed methods approach—We used a convergent mixed methods study design (Fetters et al. 2013). Technology preferences documented by PLWD within Let's Talk Tech are the quantitative data. Post-test structured dyadic interviews contextualize quantitative findings. Analyses of the quantitative and qualitative data were conducted in parallel, with each analysis procedure described below. Findings were then merged so the qualitative findings could be used to expand upon the reasons for preference selection. Results from the quantitative and qualitative are integrated in the results section.

Quantitative analysis of documented preferences—Descriptive statistics and frequency counts were used to summarize the technology preferences, technology control options, and other desired care options documented by participants living with dementia. Bivariate analyses were conducted to examine relationships between participant characteristics and technology preference. Descriptive and bivariate analyses were performed in R, mainly utilizing the dplyr () and tidyr () functions (R core 2020).

Qualitative analysis of interviews—The twenty-nine dyadic interviews and all freetext qualitative comments within Let's Talk Tech were thematically analyzed. Transcribed interviews were coded and analyzed within Dedoose version 9.0.46 (2022) (Nowell et al. 2017; Deterding and Waters 2021). Codes were first generated deductively based on the interview guide. For example, the interview guide included questions on what Let's Talk Tech helped dyads to consider and which technologies they had differing opinions on, and so deductive codes included aspects of their discussion content. A primary coder coded the transcripts. The codebook was refined as additional codes were generated inductively during the coding process. Previously coded transcripts were updated to incorporate these new codes. Then, a secondary coder reviewed the coding decisions. The primary and secondary coder met to discuss and resolve the minimal discrepancies (Nowell et al. 2017). Codes relative to technology preferences and the typed-in qualitative comments from Let's Talk Tech were used to identify themes that describe reasons for preference selection. After coding was completed and themes were generated, results were mapped onto H-TAM as a way to organize findings related to preference selection. While this study focuses on PLWDs' preferences, care partners sometimes summarized discussions or filled in when the PLWD had difficulty remembering their experiences using Let's Talk Tech. For this reason, we include statements from PLWD and their care partners.

Results

After presenting participant characteristics, results are presented in two sections. First, both quantitative and qualitative findings on preferences for technology and non-technology options and responses to enable control are presented. Second, we present qualitative findings that describe explanations for these preferences, organized by the components of the H-TAM.

Participant characteristics

Table 1 provides participant characteristics. All dyads were living together, and all care partners were spouses, except one who was the PLWD's daughter. PLWDs' ages ranged from 59 to 82 years (Mean = 70; SD = 6.73), and care partners' ages ranged from 55 to 83 years (Mean = 68; SD = 7.06). Participants were asked to write in their gender. Over half (62%) of PLWD identified as male, with the remaining identifying as female. For care partners, 38% identified as male and 62% as female. The majority of our sample (94.8%) identified as white, with one PLWD identifying as African American and two care partners identifying as Asian. The majority of PLWD (79%) received their Alzheimer's disease diagnosis more than one year ago.

Let's Talk Tech preference selection

Diversity of preferences of the featured technologies and other independent living supports—Table 2 displays the technology preferences response totals for each technology. People living with mild AD had diverse preferences across technologies. Only one participant did not want any of the technologies, and no one wanted to use all the technologies. The remaining 28 PLWD selected a mix of preferences across the technologies. While there were diverse preference responses across participants, overall, there were more 'no' responses than 'yes' or 'unsure' responses. Of the seven technologies, location tracking was the most desired (18), while sensors in the kitchen were the least desired (2). The bathroom and bedroom sensors generated slightly more 'no' responses than all other technologies (20 and 21, respectively). Eighteen PLWD selected they would not want sensors in the living room. Cameras garnered the most uncertainty (12 'unsure' responses). The virtual companion was rated similar to the living room senor. PLWD indicated they wanted to specify in which rooms a camera should or should not be placed and at what times it should be used.

Preference for non-technology options—Let's Talk Tech also captured preferences for additional or alternative non-technology options that PLWD may want to use. Participants could mark that they 'may want' any of these options in any combination with the featured technologies presented in Table 2; that is, none of the options were mutually exclusive. Table 3 presents how often each of these options were selected. Participants were then asked about their selections during the interviews. Based on selections and interviews, these options, especially those involving friends and family (e.g., more phone calls, social outings, increased visits), were preferable to the featured technologies. However, based on interviews, these options were not always viewed as accessible or reliable, especially during COVID. For example, one care partner stated,

With COVID for starters...you can have a caregiver that you really like taking care of your person and all of the sudden they're down with COVID and they're out for two weeks and you're scrambling to replace them. Whereas some of these technologies would be probably a little more reliable.

PLWD desired options to enable control over technologies—The five technology control options presented to participants were desired by PLWD (Table 4). The majority of

PLWD wanted to know if a technology was being used to monitor them (27), to stop using a technology if they became uncomfortable with it (26) to be able to pause a technology in their home for privacy (25), try out a technology before deciding to keep it (24), and to be asked again about these technologies to see if their feelings changed (21). When asked about reasons for technology preference selection during interviews, PLWD also reported a high desire for autonomy and control. Some PLWD associated using technologies with a lack of control over their life. When explaining why he did not want location tracking, one PLWD said, 'you know it's over when that happens. Control of your own life.'

Values of privacy, feeling free to do as I want, continuing to live where I am, and feeling safe were all ranked highly on a scale of zero to ten. On average, PLWD rated continuing living where I live as the most important (M = 9.53; SD = 1.14), followed by feeling safe (M = 8.96; SD = 1.71), feeling free to do as I want (M = 8.74; SD = 1.54) and privacy (M = 7.59; SD = 1.67). We assessed possible relationships between preferences for each technology and how participants rated each of these values and found no association for any of them.

Explanations for preferences

Understanding uncertainty—Interviews revealed three explanations for PLWD selecting they were unsure if they wanted to use a given technology.

Unsure as a dyadic compromise.: In some cases, marking unsure represented a compromise between PLWD and care partner preferences for that technology. Unsure as a dyadic compromise reflected instances in which during the interview the PLWD conveyed not wanting to use a technology that the care partner did express interest in using. In these cases, the PLWD expressed not wanting to use a technology, while the care partner conveyed wanting to use the technology or seeing its benefits. For example, in a dyad in which the virtual companion was the only 'unsure' option selected, the members of the dyad explained:

CP: The one about the companion, she was like 'I don't know about that.' PLWD: It sounds a little creepy. CP: But you know when we talked about some of the things that they put in that section, one of which was maintaining proficiency and language, it's like well, I can actually make sense.

In another case, the dyad described their disagreement over being monitored in the kitchen, as the PLWD did not want to get caught baking cookies, an activity the care partner did not want the PLWD doing. Reflecting a compromise, the PLWD selected 'unsure' for having activity sensors in the kitchen.

Unsure as ambivalence or not applicable.: Selecting unsure was also used to represent 'not applicable' or ambivalence toward a technology. Unsure as ambivalence or not applicable represented times where the PLWD or care partner indicated this technology was not relevant to them or they had no preference, yet the PLWD selected 'unsure.' One care partner explained the PLWD 'doesn't care generally if she is monitored which wasn't really given as a choice. 'I'm not sure' is not the same as "I don't care."'

<u>Unsure to convey openness to considering it in the future.</u>: Unsure was also selected when PLWD did not want to use the technology but might be open to use later in their progression. The care partner of a PLWD who selected 'unsure' for location tracking, explained, 'He was willing to consider a tracker or things like that later if needed and he's willing to come back and talk about those.'

How do participants' priorities map onto the Healthcare Technology

Acceptance Model?—Participants spoke directly to each predictor of H-TAM during interviews. Below we map our findings onto each of H-TAM's predictors of technology acceptance. We start each section with a brief description of factors that influence each predictor, as identified in H-TAM. We then provide exemplar quotes illustrating how dyads considered each factor.

Ease of use.: H-TAM posits that ease of use is affected by technology familiarity, complexity, privacy, and trust in the technology (Harris and Rogers 2021), all of which were discussed by participants during interviews. Dyads spoke of their familiarity with the technologies featured in Let's Talk Tech, such as using phone apps to track the PLWD's location. One PLWD explained, 'The tracking the phone is fine, and we've always done it. You know we do it with the kids so it's not an issue of privacy for us.' In another case, a care partner explained that a smart speaker responded to conversations in their home inappropriately and alarmed them, so they selected 'no' for the virtual companion. We found that dyads also considered what technologies would be the most feasible for the PLWD to use, illustrating considerations of H-TAM's technology complexity. One PLWD explained she was open to 'whatever I can understand and use.' Another PLWD explained that while she might see the benefits in using a virtual companion, she was concerned when her condition progressed it would scare her as she would not be able to rationalize who was talking to her. Dyads discussed privacy concerns during the interviews, citing both concerns over personal privacy (e.g., feeling watched or monitored) and data security (e.g., who has access to feed). When thinking about security and access issues, one care partner said,

Who makes this? Amazon? And where is it connected? Is it connected to the cell phone system and the internet? Okay, who's listening? I could see hey there's just a lot of issues here. And trust and so on.

Usefulness.: According to H-TAM, three factors influence perceived usefulness: perceived benefit, perceived need, and relative advantage. The PLWD and care partners in our study discussed all three factors relating to usefulness. Care partners and PLWD discussed perceived benefits of technology during interviews, such as an improved sense of safety, security, and peace of mind. Participants also discussed instances in which they could envision wanting or needing to use the technologies, which represented H-TAM's perceived need. Finally, relative advantage in H-TAM is 'the degree to which a technological factor is perceived as providing greater benefit' compared to the current strategies (Harris & Rogers, 2021 p. 10).

During interviews, dyads discussed how using technology might give peace of mind, which we found to represent a perceived benefit. For example, one PLWD wrote in the Let's Talk

Tech comment area under location tracking, 'would give me peace of mind knowing that my caregiver would know where I am especially if I were to get lost.' One care partner indicated that using technology might enable her to feel more comfortable leaving her spouse at home alone saying, 'I don't leave very much, and it kind of helped me to think about, okay, if I were to be gone for six hours, what would that look like.' People living with dementia also noted that they would be open to using a technology if it benefited their care partner. For example, one said, 'I certainly feel that if it's needed for my care and if it helps whoever, whether it's [care partner name] taking care of me or someone else, then I am fine with that.'

With the virtual companion, dyads discussed the benefit of having something to answer questions or to maintain the PLWD's language functions. One PLWD commented that they would use a virtual companion, 'to have someone to talk to if [care partner name] runs a short errand. Or someone to answer a question.' Another care partner explained their interest in the virtual companion to converse with the PLWD in multiple languages: 'So if she wants it to do, like, her Portuguese, which she's fluent in, you would be able to talk to it. She can't do that with me.' An additional perceived benefit identified during interviews was using technology to answer questions related to health. For example, one care partner explained they could envision using sensors at night to monitor for possible sleep issues.

Dyads also discussed a perceived need for technology in the future as the disease progresses or for others with dementia who live alone. In this way, we found that perceived need was linked to disease progression. One PLWD wrote in the Let's Talk Tech comments on location tracking, 'In the future, if I am more at risk of getting lost, I'm willing to have my spouse arrange it.' Another care partner described their discussion with the PLWD saying, 'I think the biggest one that we both felt he would possibly be open to in the future, that would be beneficial, would be some kind of monitor... and I think we put on there, [in] the garage because that's where he's most likely to get into trouble.' In both cases dyads are considering how the disease may affect the PLWD in the future, such as by increasing the risk of getting lost or the risk of falling in the garage. Their consideration of disease progression influenced their thoughts on whether they might need to use a particular technology, which demonstrates perceived need as described by H-TAM.

Our findings illustrate that insights into perceived need for the technologies were often attributed to a perceived utility of the technology. Conversely, we found that selecting 'no' was attributed to a dyad not seeing the technology as useful, particularly because of the presence of a cohabitating care partner. One PLWD explained, 'At this time, my husband lives with me and I don't feel a need to use these instruments.' This finding can be linked to H-TAM's concept of relative advantage. Our findings indicated that if a PLWD had consistent support, such as through the presence of a care partner, or did not perceive a need for the technologies given their functioning, then there was no perceived advantage to using them. For instance, one PLWD who selected unsure or no for each technology commented, 'No problem calling people if I want to visit. I can still drive to familiar places and so I am not trapped. I can entertain myself.' There was no perceived additional advantage to using a technology to complete these tasks since the PLWD could still do them herself.

Social influence.: H-TAM indicates that trusted relationships can influence an individual's preference for technology (Harris and Rogers 2021). In line with this, interviews indicated that social influence was exerted by care partners on PLWD while documenting their preferences in Let's Talk Tech. Dyads participated in discussion and negotiation around the PLWD's expressed preferences. In cases where a PLWD selected 'unsure' as a compromise with their care partners when there was a difference in opinion, the PLWD was not inclined to use the technology but took the care partner's feelings into account. Dyads also noted the need for striking a balance between values. Some discussed negotiating concerns of peace of mind with ensuring the PLWD's safety. For example, one care partner explained,

...there may be some stuff that I need maybe more than you need, as far as my peace of mind, and I think that was really helpful to see it, to talk. You're already really considerate and you want me to be out there, doing stuff and that might mean maybe some of the three other [technologies] that we're not interested in, maybe that there's space for you to think about that from that perspective.

Let's Talk Tech is designed to elicit preferences from the PLWD, and the preferences selected reflect those of the PLWD. However, dyads reported engaging in rich discussion and negotiation that allowed them to 'iron out' plans related to use. This kind of back-and-forth interaction highlights the influence of the care partner's thoughts on PLWD's preferences.

Facilitating conditions.: Price value and perceived compatibility of the technology with one's current lifestyle are facilitating conditions in H-TAM, which were raised by participants. Participants discussed their concerns about not knowing what models/brands to buy, where to buy the technology, and how to find assistance in setting up or using the technology. One care partner said,

After it was done, I started realizing that we're in the ozone, as far as no info on cost or installation. Costs of the basic electronics that are required, your iPhone, your pad, your whatever, whether it's covered by Medicare and Medicaid or grants. No idea of the training.

Lack of training and support with technologies were concerning for dyads. Even those spousal dyads with adult children found that those adult children were not always able or willing to help set up technology. For example, one dyad wanted to use a smartwatch as a tracking device but had not been able to receive assistance from their daughter or the manufacturer in setting it up, so they were unable to use it. These experiences highlight the need for external or instructional support.

Discussion

Our findings indicate that PLWDs' desire for technologies used to monitor and support care is not necessarily consistent across devices or data collection purposes. Preferences were technology specific. No participant desired all the featured technologies. Participants were more likely to not want than to want to use most of the featured technologies. When featured technologies and alternatives to technology options presented to participants are examined together, featured technologies except location tracking ranked lower in desirability than

other options, with more opportunities for social engagement rising to the top. Some care partners commented in interviews about how access to these desirable supports are not within their power to control; that is, family and friends may not be available or willing to help with these activities. This supports an understanding that preferences are likely to be shaped by personal circumstances, needs, values in context, and negotiations with care partners.

Location tracking was by far the most appealing technology of four featured technology categories, though nine PLWD were still unsure if they wanted it used with them. The appeal of this technology was linked to clarity about its perceived usefulness. Desirability of each of four locations for sensors in the home varied by location, supporting the need for tailored device options. While cameras in the home were the best understood by PLWD, it also brought the most uncertainty about use. The option 'unsure' was used at times as a compromise with a care partner when the PLWD did not want to select 'yes.' Cameras may be considered potentially more invasive because of their use of audio and visual data. This finding, that the potentially more invasive of the featured technologies triggering the most disagreement within dyads, is consistent with findings from another dyadic study with older adults (not living with dementia) (Berridge and Wetle 2020). Cameras are being widely used for a variety of purposes, both with and without the permission of people in range of view or audio capture (Tan et al. 2022). These findings point to the importance of understanding and respecting the boundaries PLWD might wish to draw when a camera at home is under consideration.

Value ratings

We found no relationship between technology preferences and value rankings; however, most rated each value as very important with little variation. This may contribute to our finding of no association with specific technology preferences. It is also highly possible that simple value ratings are not adequate to reflect context-embedded preferences, relationship context, previous experiences or associations with a given technology, and the variety of meanings people attach to values like privacy. This lends further support for personalized and tailored approaches to discussing technology use.

The importance of control options

Our findings align strongly with the responses from a large survey of people who are not living with dementia that examined the importance of the same options that enable control over elder care technologies (Berridge, Zhou, et al. 2022). That study also found that control options for technologies were important to the majority of older adult participants. While the current study is based on a much smaller sample, the finding that these options matter equally to people living with mild AD indicates that enabling control and privacy options even in technologies for use with dementia care may be needed for person-centered care. Importantly, 28 PLWD reported they did want to know if a technology is being used to monitor them. This is of particular relevance to implementation practices in which the assumption is more likely to be made that awareness is not important to PLWD. It is possible that dementia may increase some peoples' sensitivity to the possibility of deception, however well intended, that could impact their sense of dignity or control. Both larger

studies with more diverse samples and more in-depth qualitative studies are needed to better understand this need.

Alignment with the H-TAM

Many but not all the considerations raised by PLWD in our study fit within the H-TAM, developed by Harris and Rogers (2021). Dyads considered all 'predictors' of technology acceptance in the H-TAM when discussing technology preferences: ease of use, perceived usefulness, social influences, and facilitating conditions. In considering ease of use and technology complexity, dyads discussed what technology would be most feasible for the PLWD given their cognitive abilities. This finding extends the considerations of complexity described by Harris and Rogers (2021) beyond complexity in technology design to personal perspectives of complexity due to cognitive ability.

Harris and Rogers (2021) hypothesize that privacy concerns influence perceived ease of use. While their conceptualization includes concerns for both personal privacy and data security, the model does not include privacy's multifaceted, contextual nature, which has been articulated in other studies of remote monitoring with older adults (Berridge 2016). Hensel et al. (2006) use a multifaceted conceptualization of privacy within their related concept of obtrusiveness. Their definition of privacy includes controlling the sharing of personal information and the accessibility of one's person to others (Hensel et al. 2006). Using this conceptualization, Reeder et al. (2016) found that both aspects of privacy were of concern to older adults using in-home sensors. This mirrors our finding that dyads considered multiple aspects of privacy, particularly personal privacy for both the care partner and PLWD, as well as data security. The increasing use of devices with automation, such as algorithmically-mediated decision making, is likely to heighten the importance of privacy, transparency, and other data flow considerations for consumers (FakhrHosseini 2022).

One of the main perceived benefits of these technologies was peace of mind for the care partner. The H-TAM primarily focuses on perceived benefit for the person using the technology (Harris and Rogers 2021). Refinement of the model might take into account the complex user component of decisions around technology (i.e., used with or on in addition to by an older adult). The model does posit that trust in the person recommending technology are predictors of acceptance. However, this does not encapsulate the idea that PLWD are considering both benefits to themselves and their care partners when making decisions around technology. As evidenced through multiple themes (unsure as a compromise, perceived benefit, and social influence under H-TAM), the opinion of the care partner plays an important role in the development of the PLWD's preferences. Given the importance of the care dyad in supporting someone living with dementia (in addition to many other conditions (Lyons and Lee 2018)), use of the H-TAM for PLWD may require expanding the idea of perceived benefits to better reflect the decision-making power dynamics of dyadic partnerships.

Dyads also spoke to the importance of some non-technology options and their preference for these options over the featured technology. While these non-technology or low-technology options may be preferable, they may not be available or reliable. Such environmental/ resource constraints may affect decisions to use technology by contributing to perceived

need. The facilitating conditions predictor of H-TAM does not quite capture these external constraints that fall outside of technology-specific considerations. Focusing more on individualized environmental and external constraints may be beneficial for identifying and addressing external conditions that are potentially modifiable.

Finally, H-TAM does not incorporate considerations of autonomy and control, yet we found that participants expressed a high desire for control options and autonomy in their own lives. PLWD felt as though using these technologies signified a lack of autonomy and control over their life. The potential for technology used in care to negatively impact personal autonomy may be of particular importance to PLWD. Given the importance placed on maintaining autonomy and control and the stress that their loss can cause (Shelton et al. 2018), incorporating these constructs could enhance this new model's capacity to capture factors that matter to many older adults, including those living with dementia.

Limitations

A limitation of this study is the small and racially homogenous sample of primarily spousal dyads. We are not able to generalize technology preferences to the general population of dementia care dyads. This is particularly relevant given what prior research has found with adult children. For example, consistent with a small body of research (Berridge, 2016; Godwin, 2012; Lariviere et al., 2021; Mort et al., 2013), a small dyadic study found that adult children consistently favored the use of monitoring technologies more than their parent (Berridge & Wetle, 2020). Adult children were also more confident they could persuade their parent to use the technology and underestimated their ability to understand the technology and the importance of engaging their parent in the decision making process. It may therefore be even more critical to facilitate conversations with PLWD on technology use preferences among care dyads with adult children. Additionally, dyadic interviews were conducted with both PLWD and care partners present, meaning responses from the PLWD may have been influenced by care partner presence. Future studies may want to consider separate interviews, while bearing in mind challenges with memory and recall.

Conclusion

The preferences documented by participants living with mild AD regarding technologies that employ a range of types of data about them were dynamic and relationally embedded. Preferences within and across participants were diverse; acceptance or rejection of one technology did not necessarily predict preferences for others. All five options that enable a form of control were desired by most participants. Findings lend further support for individualized and person-centered approaches to technology use in dementia care (Godwin 2012; Novitzky et al. 2015; Meiland et al. 2017; Ienca et al. 2018; Robillard et al. 2018; Berridge et al. 2021). Considerations expressed by dyads partially mapped onto H-TAM, the most well-targeted technology acceptance model available for dementia care technologies. Unaddressed factors that may be considered for model refinement include the value of control, a multifaced conceptualization of privacy, and the shared nature of decision-making with PLWD.

It is important to note that acceptance is not the same as satisfied actual use, and a model of acceptance will always be limited in its capacity to predict beyond that. The goal of our work with Let's Talk Tech is facilitating technology practices that work for all of those involved, and our pilot research suggests that educating and talking with a person living with dementia holds promise as an intervention and method to achieve that (Berridge, Turner, & Liu 2022; Berridge, Turner, Liu et al. 2022). Our finding of no association between values ratings and technology use preferences may indicate problems with attempts to automate predictions of satisfied technology use by mapping implicated value weights to technology choices. Perhaps what is most needed for personalized, control-enabling technology use in dementia care is conversations directly with the person one is tailoring to, whenever possible before dementia undermines preference models target, could help families better navigate technology use decisions.

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References

- Astell Arlene J, Bouranis N, Hoey J, Lindauer A, Mihailidis A, Nugent C, Robillard Julie M. 2019. Technology and dementia: The future is now. Dementia and Geriatric Cognitive Disorders 47(3):131–139. [PubMed: 31247624]
- Berridge C. 2016. Breathing room in monitored space: The impact of passive monitoring technology on privacy in independent living. The Gerontologist 56(5):807–816. [PubMed: 26035900]
- Berridge C, Demiris G, Kaye J. 2021. Domain experts on dementia-care technologies: Mitigating risk in design and implementation. Science and Engineering Ethics 27(1):14-14. [PubMed: 33599847]
- Berridge C, Turner NR, Liu L. 2022. Pilot study of a self-administered advance planning tool for technology use with dementia care dyads Innovation in Aging. 6(Suppl 1):253.
- Berridge C, Turner NR, Liu L, Karras SW, Chen A, Fredriksen-Goldsen K, Demiris G. 2022. Advance planning for technology use in dementia care: Development, design, and feasibility of a novel self-administered decision-making tool. JMIR Aging 5(3):e39335-e39335. [PubMed: 35896014]
- Berridge C, Wetle TF. 2020. Why older adults and their children disagree about in-home surveillance technology, sensors, and tracking. The Gerontologist 60(5):926–934. [PubMed: 31102442]
- Berridge C, Zhou Y, Lazar A, Porwal A, Mattek N, Gothard S, Kaye J Control matters in elder care technology: evidence and direction for designing it. In Designing Interactive Systems Conference; 2022. 1831–48. 10.1145/3532106.3533471
- Deterding NM, Waters MC. 2021. Flexible coding of in-depth interviews: A twenty-first-century approach. Sociological Methods & Research 50(2):708–739.
- FakhrHosseini S. 2022. Do we need a new technology acceptance model? MIT AgeLab Blog [accessed]. https://agelab.mit.edu/home-logistics-and-services/blog/do-we-need-new-technology-adoption-model/.
- Farina N, Sherlock G, Thomas S, Lowry RG, Banerjee S. 2019. Acceptability and feasibility of wearing activity monitors in community-dwelling older adults with dementia. International Journal of Geriatric Psychiatry 34(4):617–624. [PubMed: 30701592]
- Fetters MD, Curry LA, Creswell JW. 2013. Achieving integration in mixed methods designs-principles and practices. Health Services Research. 48(6pt2):2134–2156. [PubMed: 24279835]
- Gibson G, Dickinson C, Brittain K, Robinson L. 2015. The everyday use of assistive technology by people with dementia and their family carers: A qualitative study. BMC Geriatrics 15(1):89-89. [PubMed: 26205957]

- Gibson G, Dickinson C, Brittain K, Robinson L. 2019. Personalisation, customisation and bricolage: How people with dementia and their families make assistive technology work for them. Ageing and Society 39(11):2502–2519.
- Godwin B. 2012. The ethical evaluation of assistive technology for practitioners: A checklist arising from a participatory study with people with dementia, family and professionals. Journal of Assistive Technologies 6(2):123–135.
- Harris MT, Rogers WA. 2021. Developing a Healthcare Technology Acceptance Model (H-TAM) for older adults with hypertension. Ageing and Society.1–21.
- Hensel BK, Demiris G, Courtney KL. 2006. Defining obtrusiveness in home telehealth technologies: A conceptual framework. Journal of the American Medical Informatics Association: JAMIA 13(4):428–431. [PubMed: 16622166]
- Holthe T, Halvorsrud L, Karterud D, Hoel K-A, Lund A. 2018. Usability and acceptability of technology for community-dwelling older adults with mild cognitive impairment and dementia: A systematic literature review. Clinical Interventions in Aging 13:863–886. [PubMed: 29765211]
- Howard R, Gathercole R, Bradley R, Harper E, Davis L, Pank L, Lam N, Talbot E, Hooper E, Winson R et al. 2021. The effectiveness and cost-effectiveness of assistive technology and telecare for independent living in dementia: A randomised controlled trial. Age and Ageing 50(3):882–890. [PubMed: 33492349]
- Ienca M, Wangmo T, Jotterand F, Kressig RW, Elger B. 2018. Ethical design of intelligent assistive technologies for dementia: A descriptive review. Science and Engineering Ethics 24(4):1035– 1055. [PubMed: 28940133]
- Lariviere M, Poland F, Woolham J, Newman S, Fox C. 2021. Placing assistive technology and telecare in everyday practices of people with dementia and their caregivers: Findings from an embedded ethnography of a national dementia trial. BMC Geriatrics 21(1):121-121. [PubMed: 33588768]
- Lyons KS, Lee CS. 2018. The theory of dyadic illness management. Journal of Family Nursing 24(1):8–28. [PubMed: 29353528]
- Meiland F, Innes A, Mountain G, Robinson L, van der Roest H, García-Casal JA, Gove D, Thyrian JR, Evans S, Droes R-M et al. 2017. Technologies to support community-dwelling persons with dementia: A position paper on issues regarding development, usability, effectiveness and cost-effectiveness, deployment, and ethics. JMIR Rehabilitation and Assistive Technologies 4(1):e1-e1. [PubMed: 28582262]
- Miller LM, Whitlatch CJ, Lyons KS. 2016. Shared decision-making in dementia: A review of patient and family carer involvement. Dementia (London, England) 15(5):1141–1157. [PubMed: 25370075]
- Mort M, Roberts C, & Callén B. (2013). Ageing with telecare: care or coercion in austerity? Sociology of Health & Illness 35(6):799–812.
- Moyle W. 2019. The promise of technology in the future of dementia care. Nature Reviews Neurology 15(6):353–359.
- Novitzky P, Smeaton AF, Chen C, Irving K, Jacquemard T, O'Brolcháin F, O'Mathúna D, Gordijn B. 2015. A review of contemporary work on the ethics of ambient assisted living technologies for people with dementia. Science and Engineering Ethics 21(3):707–765. [PubMed: 24942810]
- Nowell LS, Norris JM, White DE, Moules NJ. 2017. Thematic analysis: Striving to meet the trustworthiness criteria. International Journal of Qualitative Methods 16(1):1–13.
- Peek STM, Wouters EJM, van Hoof J, Luijkx KG, Boeije HR, Vrijhoef HJM. 2014. Factors influencing acceptance of technology for aging in place: A systematic review. International Journal of Medical Informatics (Shannon, Ireland) 83(4):235–248.
- Reeder B, Chung J, Joe J, Lazar A, Thompson HJ, Demiris G. 2016. Understanding older adults' perceptions of in-home sensors using an obtrusiveness framework. In International Conference on Augmented Cognition. Cham. Springer International Publishing.
- Robillard JM, Cleland I, Hoey J, Nugent C. 2018. Ethical adoption: A new imperative in the development of technology for dementia. Alzheimer's & Dementia 14(9):1104–1113.
- Shelton EG, Orsulic-Jeras S, Whitlatch CJ, Szabo SM. 2018. Does it matter if we disagree? The impact of incongruent care preferences on persons with dementia and their care partners. The Gerontologist 58(3):556–566. [PubMed: 28077452]

- Stavropoulos TG, Lazarou I, Diaz A, Gove D, Georges J, Manyakov NV, Pich EM, Hinds C, Tsolaki M, Nikolopoulos S et al. 2021. Wearable devices for assessing function in Alzheimer's disease: A European public involvement activity about the features and preferences of patients and caregivers. Frontiers in Aging Neuroscience 13:643135–643135.
- Tan N, Wong R, Desjardins AA, Munson S, Pierce J Monitoring pets, deterring intruders, and casually spying on neighbors: everyday uses of smart home cameras. Proceedings of the CHI Conference on Human Factors in Computing Systems; 2022. 10.1145/3491102.3517617
- Thordardottir B, Malmgren Fänge A, Lethin C, Rodriguez Gatta D, Chiatti C. 2019. Acceptance and use of innovative assistive technologies among people with cognitive impairment and their caregivers: A systematic review. BioMed Research International 2019:9196729–9196718.
- Thorpe J, Forchhammer BH, Maier AM. 2019. Adapting mobile and wearable technology to provide support and monitoring in rehabilitation for dementia: Feasibility case series. JMIR Formative Research 3(4):e12346-e12346. [PubMed: 31625951]
- van Boekel LC, Wouters EJM, Grimberg BM, van der Meer NJM, Luijkx KG. 2019. Perspectives of stakeholders on technology use in the care of community-living older adults with dementia: A systematic literature review. Healthcare (Basel). 7(2):73. [PubMed: 31141999]
- Vermeer Y, Higgs P, Charlesworth G. 2019. What do we require from surveillance technology? A review of the needs of people with dementia and informal caregivers. Journal of Rehabilitation and Assistive Technologies Engineering 6:2055668319869517–2055668319869517.
- Wan L, Müller C, Wulf V, Randall DW. Addressing the subtleties in dementia care. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems; 2014: 3987–96. 10.1145/2556288.2557307

Table 1.

Participant characteristics

Demographics (n, %)	Care partner Person living with dement	
Age (Mean, SD)	68 (6.73)	70 (7.06)
Gender		
Male	11 (38)	18 (62)
Female	18 (62)	11 (38)
Race		
White	27 (93)	28 (97)
African American	0	1 (3)
Asian	2 (7)	0
Hispanic/Latino Ethnicity (missing 7 care partners)	0	0
Sexuality (missing 2 PLWD)		
Gay or lesbian	0	0
Bisexual	0	0
Straight or heterosexual	28 (97)	27 (100)
Queer	0	0
Not listed here	1 (3)	0
Time since dementia diagnosis		
Within past 12 months	6 (21)	-
More than one and less than two years	4 (17)	-
More than two and less than three years	4 (17)	-
More than three and less than four years	8 (35)	-
More than four years	7 (30)	-

Notes: Care partner N = 29, Person living with dementia N = 29. SD: standard deviation

Table 2.

Frequencies of technology preferences for each of the seven technologies

Technology		No	Unsure
Location tracking	18	2	9
Sensor			
In the bedroom to tell if someone is restless at night and when they get up		20	1
On the bathroom door to count how many times they are going into the bathroom	5	21	3
In the kitchen to tell how much time they may have spent preparing meals		18	9
In the living room to tell for how long they are sitting at a time		18	5
Camera in their home		13	12
Virtual companion that talks and listens		18	6

Note: N = 29

Table 3.

Desirability of alternatives to the featured technologies

Alternatives to technologies presented Number selecting they 'may want' eac	
Have more phone calls with friends or family	20
Wear a medical alert bracelet that has my emergency contact and medical conditions on it	19
Have more social outings and activities with other people	19
Have more frequent visits by others	19
Have a personal emergency response system (with a button to push, like LifeAlert)	16
Go on walks with others so I don't get lost	11
Have an alarm on my home's door so someone knows when I'm coming and going	6

Note: N = 29

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Table 4.

Frequencies for selection of technology control options

Option		No	Unsure
I want to try out a technology that is used in my care before deciding to keep it	24	0	5
I want to be able to pause a technology in my home when I want privacy		0	4
I want to stop using a technology if I become uncomfortable with it	26	1	2
I want to know if a technology is being used to monitor me (1 missing)		1	0
I want to be asked again about these technologies to see if my feelings change		5	3

Note: N = 29