Exploring Multi-User Access Control Design in IoT-assisted In-Home Dementia Care

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Abstract

With dementia affecting 57 million people globally, the growing popularity of home IoT devices in recent years has garnered significant attention for their potential to support in-home dementia care. However, with the delicate power dynamics between people with dementia (PwD) and their caregivers, and the progressive nature of dementia, how home IoT devices can be designed and deployed with respect to PwD's privacy and autonomy, while also allowing easy oversight from caregivers to ensure the safety of PwD, remains unanswered. In this paper, we conducted an online survey of 267 older adults to investigate how they would like to share data with their caregivers at different stages of dementia and whether they would allow their caregivers to override their privacy settings when necessary. To our best knowledge, we are the first to explore the design of access control for in-home dementia care. The results revealed that, although one's preferences for data sharing vary in the mild dementia stage, their willingness to share markedly increases with dementia severity for all types of data, including privacy-sensitive data such as video monitoring. Our participants are also open to the idea of allowing their caregivers to override their privacy settings as their dementia progresses, but only with precautions (e.g., requiring auditing or allowing override only in an emergency). These findings suggest that to enable home IoT devices for in-home dementia care, a more dynamic, collaborative, and stage-aware access control model is needed.

CCS Concepts

• **Security and privacy → Human and societal aspects of security and privacy**.

Keywords

Access control, Smart homes, IoT, Dementia, Caregiving

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1 Introduction

Dementia is a syndrome of progressive loss of cognitive ability, including memory, problem-solving, language, and more [34]. The symptoms may be trivial first, such as forgetting important dates or events, getting lost in conversation, or feeling disoriented in familiar environments (e.g., their own neighbourhood). Over time, the symptoms can worsen dramatically, to the point where the person with dementia (PwD) may completely lose their ability to communicate verbally, cannot recognise their own home and loved ones, get confused about time, experience severe mood swings, and even hallucinate. According to the World Health Organisation (WHO), dementia affected 57 million people worldwide in 2025, with nearly 10 million new diagnoses each year [40].

Past literature has suggested using IoT devices, such as smart home devices (home IoT), to improve the quality of life for PwD and their caregivers [6, 7], but not without various challenges. First of all, obtaining a diagnosis of dementia is difficult in its earliest stage, as misdiagnoses are common and acceptance can be challenging [25], limiting the potential options one may be able to consider and use. Second, even if assistive technology is introduced, the progressive nature of the disease means that the preferred technology and its use and management can change over time. Early-stage PwD may desire more autonomy and privacy, while later-stage PwD may require enhanced safety and support from caregivers. Moreover, on top of the various dynamics PwD may have with their caregivers, with the progression of the disease, these power dynamics can also change, adding more complexity to the situation.

An intricate balance, the need for safety and support, and the desire for autonomy and privacy, is thus needed and must be constantly adapted to the stages of dementia. To enable this balance, assistive technology like smart homes should not only be easy to use, but also should provide access control that is adaptive enough to accommodate the changing needs of PwD and their caregivers. Despite extensive work on access control in smart homes, how it can be used for PwD and their caregivers is still underexplored.

We thus propose the following research questions.

RQ1 How does the progression of dementia affect people's data-sharing practices with their caregiver(s) in an in-home monitoring system?

RQ2 How does the progression of dementia affect people's willingness to let their caregiver(s) be their surrogate decision maker(s) and override their data-sharing settings?

To better understand how people's data-sharing preferences and openness to potential overrides vary with different dementia stages, we conducted an online survey with 267 older adults, which revealed that the intention to involve a caregiver increases markedly with dementia severity, from 15% in mild stages to almost 100% in severe cases (Figure 1). Similarly, comfort with data sharing also rises. For example, the percentage of participants who found it comfortable sharing video monitoring data increases from 38% to 78% (Figure 3), informing our stage-specific policy weights.

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2 Related Work

2.1 IoT Devices for Dementia Care

Dementia is a neurodegenerative syndrome with progressive impairment of memory, orientation, and decision-making [4]. Clinical guidelines distinguish *early, middle*, and *late* stages, each marked by escalating cognitive and functional decline [35, 39]. During **early-stage dementia**, most PwD remain at home, relying on informal caregivers for instrumental activities [38]. Continuous supervisory demands induce emotional distress [19] and even despair [12].

Home IoT devices are thus explored as a possibility for in-home care, either to ease the burden of caregiving or maintain the independence of PwD. For example, GPS tracking systems have long been used for managing wandering behaviours among PwD [28, 30, 32]. More recently, smart watches have also been used to keep track of PwD's health data and daily activities to ensure their quality of life [10]. Home IoT devices, such as voice assistants, are also actively explored for their potential to support more advanced in-home caring [6, 7, 13]. New IoT devices or systems are also developed to support the various needs and therapies of dementia [8, 20, 21].

Although new IoT technologies enable additional support for PwD, concerns remain. Most IoT systems rely heavily on sensors, raising concerns about privacy and disempowerment [28, 30, 32], especially if the data needs to be shared with caregivers.

Therefore, in this paper, we aim to explore how home IoT systems could better support the data-sharing process among PwD and their caregivers. We map different data-sharing preferences and stages of dementia to identify what access control models are needed to support the varying needs throughout the progression of dementia.

2.2 Dementia and Early-Stage Planning

People with early-stage dementia often can live independently and make decisions for themselves. It is thus the best time to plan for future care needs, including setting up wills, advance statement, power of attorney, future-proof assistive technology, etc. [3, 5].

Although early-stage PwD need to plan for their future, they still have an independent life to live. However, biomedical ethics has historically *prioritised safety over self-determination* [18], reducing PwD to "bodies to be managed" [9] and passive "patients" to be treated rather than understood [11]. Some have expressed frustrations when they were first diagnosed, they were told to "give up their pre-diagnosed life and put all the planning in place" [37]. Understandably, many PwD with early-stage dementia prefer to be independent as much as possible [14]. However, it is also undeniable that PwD may need intensive care in late stages of dementia, which is also why one has advance statements and a lasting power of attorney in place. Therefore, we believe that when using home IoT systems for dementia care, they must support both independent living and extensive care, as introducing new devices or systems can be challenging in the later stages of dementia. Our work thus aims to better understand how one's privacy attitudes change across different stages of dementia.

2.3 Access Control for Home IoT

A home IoT system is a multi-user system inherently, which means access control is the centrepiece for maintaining the security and privacy among users. Past studies have shown that people's access control decisions in a home IoT system are often context-dependent, which means that an all-or-nothing access control model would not suffice, and a finer-grained access control mechanism is needed [16, 33, 41]. To build a finer-grained access control, one must consider how the access may be constrained. According to a study done by Alghamdi et al. in 2023, today's smart home systems often build their access control mechanisms around user roles, properties, devices, time, and geofencing [1], which provides more control for everyday users.

The unique challenge for access control of in-home dementia care is the progressive nature of the disease, where the person in control may shift, and the level of access shared between PwDs and their caregivers may change. To our best knowledge, we are the first to explore how one's desired access control policies may evolve in dementia care.

3 Methods

We investigate how the progression of dementia affects people's data-sharing preferences with their caregiver(s) when various IoT devices are used for caring and monitoring purposes. Each participant is randomly assigned one of the six data types that can potentially be used for informal caregiving. They then go through three different stages of dementia, from mild to severe.

3.1 Survey Design

Using stages of dementia [39] and contextual integrity framework [29] to guide the survey design, we examined three key factors for building an adaptive access control framework for dementia care: *dementia stage*, *data types*, and *access control methods (transmission principles)*. We assume the primary data subject and data sender are always the PwD in question. We also assume the data receiver to be the caregiver specified by participants. We made the choice because one's expected caregiver can vary, and imagining someone unexpected as the primary caregiver is challenging.

Additionally, when considering what may happen when PwD becomes unable to make data-sharing decisions, we introduced a new concept called *override options*, which allows caregivers to override PwD's data-sharing settings in certain situations. The idea is inspired by existing practices in dementia care regarding late-stage PwD's legal and financial decisions. As PwD may gradually lose their cognitive abilities to make decisions for themselves, it is recommended that PwD should appoint someone they trust as their lasting power of attorney and create an advance statement when they still can [3, 5]. Of course, such power can easily be abused and should be carefully guarded. The goal of this study is merely to investigate whether our participants may be open to the idea and how they may expect such overriding behaviours to be conducted.

We detail our design for the four selected factors below.

Dementia stages. Our survey adopted a widely used three-stage dementia progression model (full description in Appendix A.1), which dissects the progression of dementia into mild, moderate, and severe stages [20, 21, 35, 39]. As some argued that a three-stage model is too coarse-grained for practical technical solutions [36], we had also attempted a four-stage model when developing the survey [23]. However, the idea was discarded because our pilot participants struggled to differentiate between the stages.

Data types. We focused on six data types based on their relevance to dementia care and the potential for IoT devices to collect them: *health data (heart rate, breathing rate, medication reminders), safety data (real-time/historical location, camera feed), routine data (sleeping patterns, meal timings), and communication data (logs of phone calls, messages, social media).* These types were established through a literature review showing their clinical relevance and privacy implications in dementia care. Health data correlates with dementia severity and requires continuous monitoring [2, 26], while safety data enhances monitoring for vulnerable individuals [28]. Routine data helps identify behavioural changes indicating decline, with eating patterns and cooking behaviours serving as critical markers [26, 27]. Communication data, though less studied in dementia contexts, was included for its practical utility as a secondary means to ensure patient safety when primary monitoring systems fail. We list our descriptions of data types in Appendix A.2.

Access control methods (transmission principle). Transmission principles in the contextual integrity framework [29] were adapted to define how caregivers can access the data collected by smart home devices. Although caring for dementia creates new requirements for traditional smart home devices, how data can be shared among multiple users is still largely bound by smart home systems. Relying on past literature on access control for multi-user smart homes [1, 17], we defined the following six access levels for caregivers to access the data collected by smart home devices:

Full access (24/7). Caregivers can access the data at any time, including historical data.

Live-only access. Caregivers can view the data in real-time, but they do not have access to historical data.

Emergency access. Caregivers can access the data without prior approval during emergencies.

Access with periodical review. Caregivers' access to the data is subject to regular assessments of the need for continued access.

Access with explicit review. Caregivers must obtain explicit approval for access requests to the data.

No access. Caregivers cannot access the data at all.

Override options. When considering the override options, we focused on how caregivers can override the data-sharing settings set by PwD in different dementia stages. Ranging from permissive to restrictive, five conditions were examined:

Whenever. Caregivers can override PwD's data-sharing settings at any time.

Optimistic. Inspired by the optimistic access control proposed by Malkin et al. [24], we specify that caregivers can override PwD's data-sharing settings at any time, but PwD can audit and revoke such power.

Prior approval. Caregivers must first request to override PwD's data-sharing settings, and they are only allowed to do so if explicit approval is acquired.

Emergency-only. Caregivers can override PwD's data-sharing settings only in emergencies.

Never. Caregivers *cannot* override PwD's data-sharing settings under any circumstances.

3.2 Survey Instrument

The finalised survey instrument employed a systematic structure designed to maximise data quality whilst minimising participant burden. The instrument began with a comprehensive Participant Information Sheet and Consent Form, ensuring ethical compliance and establishing informed consent for all data collection. This was followed by an educational component providing participants with contextual information about dementia and the potential role of technology-mediated data collection in supporting patient autonomy and caregiver assistance. Following the between-subjects design, participants were randomly assigned to different data type conditions, ensuring methodological rigour whilst controlling for potential order and exposure effects.

The survey consisted of three distinct scenario-based sections, each presenting participants with carefully constructed vignettes that depicted progressively severe stages of dementia. Within each scenario, participants responded to a set of questions addressing (1) perceived need for a caregiver, (2) preferred caregiver relationship type, (3) comfort levels regarding access to the specific data type under consideration, (4) appropriate data access modalities, and (5) suitable override mechanisms for each context. This consistent questioning framework, applied across scenarios, systematically compared how preferences evolve with disease progression.

Attention check questions were strategically embedded throughout the instrument to identify inattentive responses and ensure data integrity. The survey concluded with demographic questions to enable analysis of response patterns across population subgroups and assess potential moderating factors.

3.3 Recruitment

We recruited our participants from Prolific [31]. We screened participants based on their country of residence (UK only), age (50+ years old), and approval rate (above 95%). All screening is done through Prolific's platform. The participants received an information sheet and a consent form before participating in the study. The participants spent an average of 9.6 minutes on the survey, with a median of 8.7 minutes. Each participant was compensated with £1.4 for their time. We obtained approval from the university's ethical committee prior to conducting the online survey.

3.4 Limitations

The survey's design and implementation have several limitations that should be acknowledged before interpreting the results.

First, the vignettes are artificial scenarios, and we did not recruit participants with dementia, which limits the generalizability to real-world situations. However, past studies have shown that PwD are usually not diagnosed until they reach the moderate stage, while self-management systems are best adopted in early-stage dementia [25]. Studying older participants in general gives us a better understanding of how they perceive the use of IoT devices in dementia care, which can be a good indicator of how early-stage PwD may plan for their future usage and management of smart home devices for caring purposes, especially when almost 40% of participants have cared for dementia patients before.

Second, the survey uses a within-subject design for the dementia stages without randomisation, which may introduce an anchoring effect. Although we believe it reflects the real-world situation where people plan for their future dementia care, it does not account for potential preference changes PwD or their caregivers may experience in later-stage dementia, which needs further study.

Third, the survey was conducted in the UK. The results may not be generalised to other countries with different cultural and social contexts. We decided to limit the sample to the UK only because different countries have different healthcare systems, which may affect how people seek in-home and professional care. The different cultural background may also affect how one values their privacy and familial involvement. A much larger-scale study is thus needed to examine these national or cultural factors properly.

4 Results

In this section, we aim to answer the following questions.

- When do the participants plan to involve caregivers in dementia care? Who do they expect to be their caregiver? (Section 4.2)
- How do the participants' comfort with sharing data with their caregivers vary by data types and dementia stages? (Section 4.3)
- How do the participants prefer to share access with their caregivers? (Section 4.4)
- How would the participants like their caregivers to override their data-sharing settings? (Section 4.5)

Table 1: Survey demographics

Gender		**Household (excl. participant)**	
Woman	138	0 (live alone)	51
Man	127	1–2	160
Prefer not to say	2	3–4	51
		5+	2
Age		Prefer not to say	4
45–54	76		
55–64	134	**Dementia caring expr.**	
65–74	43	Yes	96
75–84	12	No	165
Prefer not to say	2	Not sure	4
		Prefer not to say	2
Education			
No formal qual.	5	**Elderly care expr.**	
GCSEs or equivalent	50	Yes	171
A Levels or equivalent	30	No	92
Apprenticeship/ vocational qual.	32	Not sure	2
Foundation degree/ HNC/HND	20	Prefer not to say	2
Bachelor's degree	72		
Master's degree	36		
Professional qual.	10		
Doctorate	9		
Prefer not to say	3		

4.1 Participants

We recruited a total of 278 UK-based participants from Prolific. Eleven participants were excluded from further analysis due to failed attention checks (4), self-reported being in the unqualified age groups (3), or finishing the survey too fast (4, finished in less than 4 minutes). The final sample consisted of 267 participants.

As shown in Table 1, our sample is mostly gender-balanced, with 51.7% self-identified as women and 47.6% as men. Due to the design of the study (only recruiting participants over 50 years old), the majority of the participants (50.8%) reported being between 55 and 64 years old. Typical of most online surveys, our participants are more educated than the general UK population, with almost half (47.6%) of our participants reporting an equivalent degree to a bachelor's degree or higher. Interestingly, as our participants are generally older (over 50 years old), 64% of our participants reported having cared for an older adult before, and 36% of our participants have cared for a PwD before.

4.2 Caring Needs

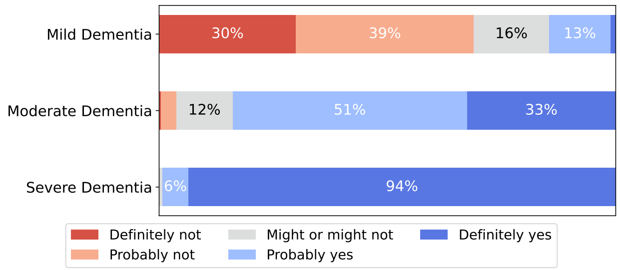

Figure 1: Participants' intention to use a caregiver when they face different dementia stages.

Figure 1 shows that older adults overwhelmingly postpone seeking informal or professional care at the *mild* stage. 69% of the participants stated that they definitely or probably don't need a caregiver in the mild dementia stage when their independence is largely intact. However, when dementia progresses to moderate (i.e., one's independence is partially impaired), the need for care quickly increases. After being presented with typical symptoms of moderate dementia, 84% of participants admitted that they probably or definitely need a caregiver. When reaching the final stage, 95% of participants stated that they definitely need a caregiver.

As mentioned in Section 2, assistive technologies, such as smart homes, are mostly recommended to be introduced when symptoms are mild. However, our results indicate that people typically plan to seek care when they reach the moderate stage, suggesting that assistive technologies, such as smart homes, should be utilized both independently and collectively, depending on the stage of dementia.

If participants responded positively or neutrally to the "need-of-care" question for the given dementia stage, we followed up by asking who they believed would be the most likely caregiver. The results are shown in Figure 2. It turns out that close family members (e.g., spouse, children) and professional caregivers (e.g., nurses, therapists) are the go-to options for the majority of our participants. Over 70% of participants choose to rely on their close family members instead of professional caregivers until the final stage, when their choice of caregiver shifts to a professional one.

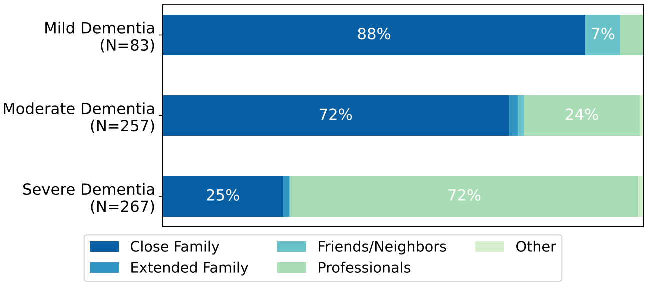

Figure 2: Participants' expected caregiver across different dementia stages, if they *at least* believe they might or might not need care ($N_{mild} = 83, N_{moderate} = 257, N_{severe} = 267$).

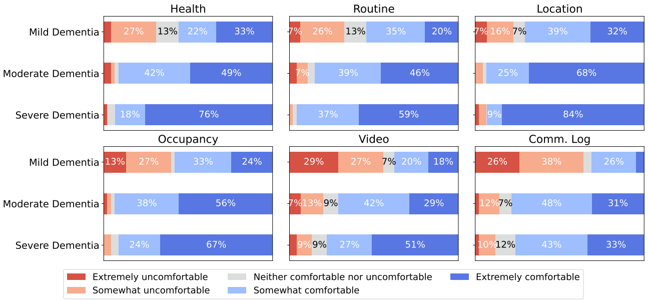

Figure 3: Comfort level with sharing different data types, by dementia stage.

4.3 Comfort with Data Sharing

As Figure 3 shows, participants' comfort with sharing personal data increases greatly with dementia progression while varying across data types.

4.3.1 Across dementia stages. When considering how dementia stages would impact their comfort with data sharing, over 70% of participants reported being comfortable sharing data once dementia had progressed to the moderate stage, regardless of the type of data. As discussed in Section 4.2, moderate dementia is also the stage when most participants start to seek care from their caregivers, which may partially explain the shift in comfort with data sharing.

When reaching the stage of severe dementia, over half of the participants stated that they are extremely comfortable sharing all types of data, except for communication logs with their caregivers. It indicates that although our participants are happy to share data with their caregivers, the permissiveness is not unlimited. Some may still hesitate, even in the worst situations, which further underscores the importance of discussing PwD's preferences early on, so that their privacy and autonomy can be respected later.

4.3.2 Across data types. Location data, surprisingly, shows the highest level of comfort with sharing, ranging from 70.5% in the mild dementia stage to 93.2% in the severe stage, with 84.1% reporting being extremely comfortable sharing their location data with their caregivers. Sharing data about one's health, routine, and home occupancy with caregivers is also welcomed by the participants. For these three types of data, over half of the participants (54.4%–57.8%) responded positively towards sharing when the dementia symptoms are mild. The percentage increases to over 90% (91.1%–95.7%) when dementia progresses to the severe stage, with less than 5% participants still expressing unwillingness to share.

At the same time, communication logs remain consistently the most sensitive category, even more so than video monitoring. When dementia symptoms are mild, 64.3% of participants reported that they are uncomfortable sharing their communication logs, even though we specified that the logs only contain information about who and when they have contacted and no conversations would be shared. The percentage is only 55.6% for video monitoring. Despite being the data type that participants are most unwilling to share, acceptance still increases dramatically from mild (30.1%) to severe (76.2%). The percentage of participants found sharing video data comfortable is around the same (77.8%), but the composition is completely different. 51.1% of participants found sharing video data extremely comfortable, while only 33.3% of participants said the same for sharing communication logs.

4.4 Access Control Preferences

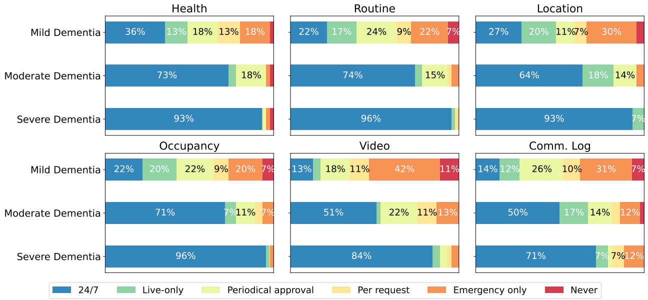

Figure 4: Participants preferred access control methods of sharing different data types, by dementia stage.

Figure 4 shows that participants' access control preferences evolve dramatically across dementia stages while varying between data types.

4.4.1 Across dementia stages. In mild dementia, preferences are highly diversified, with "emergency only" access predominating for sensitive categories like communication logs (31%) and video monitoring (42%). For all other types of data except for health data, our participants' opinions split. For example, for location data, 27% of participants are fine with their caregiver having access to their current and historical location 24/7. At the same time, 30% of participants expressed that they believe such data should only be accessed in an emergency, showing a staggering contrast.

As cognitive decline progresses, acceptance of continuous "24/7" access increases dramatically for all data types. The most substantial increases occur between the mild and moderate stages, rather than between the moderate and severe stages. For instance, routine data shows a distinctive jump in "24/7" acceptance from 22% (mild) to 74% (moderate), ultimately reaching 96% in severe stages. Video data shows the smallest increase from mild to moderate stages (13% to 51%), likely reflecting its perceived intrusiveness.

4.4.2 Across data types. Video data consistently remains the most protected data type across all stages, with the lowest "24/7" acceptance in mild dementia (13%) and the highest "never" rating (11%). Communication logs exhibit similar patterns to video data in the mild dementia stage. However, in severe stages, communication logs have the lowest continuous access acceptance (71%, 13% lower than video data) and the highest emergency-only access acceptance (11%, 7% higher than video data). Conversely, health data begin with relatively high "24/7" acceptance (36%) even in mild stages, suggesting recognition of its importance in care contexts.

The findings suggest that default settings should be highly restrictive in the early stages, while progressively relaxing as cognitive decline progresses, with data type sensitivity dictating the protection levels.

4.5 Overriding Access Control

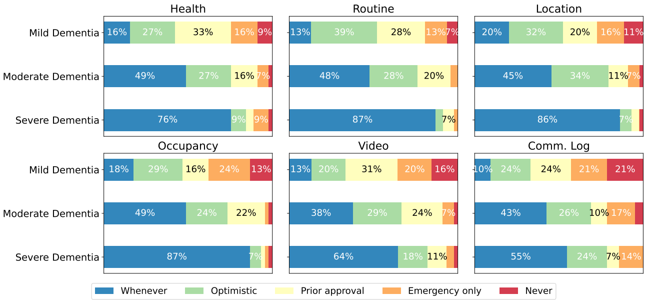

Figure 5: How participants allow the caregiver to override their settings for various data types, by dementia stages.

Figure 5 illustrates how participants would allow caregivers to override their data-sharing settings across dementia progression. During mild stages, controlled override mechanisms dominate, with "optimistic" approaches (allowing changes with subsequent review [24]) reaching 39% for routine data and "prior approval" requirements peaking at 33% for health data.

Location, routine, and occupancy data all show a high acceptance of unrestricted overrides in severe dementia (86.3%–87%). Simultaneously, communication logs remain the most protected, with only 54.8% accepting unrestricted access and the highest "never" rating (21.4%) in mild stages. By comparison, routine data show minimal resistance. Only 6.5% select "never, " even in mild stages.

The findings reveal a sophisticated understanding of context-dependent privacy needs. Participants distinguish between direct data access and override authority, with stricter controls persisting for communication data even as physical safety monitoring becomes more freely accessible. We thus envision that a home IoT system for dementia care must implement these nuanced override preferences through stage-specific meta-permission settings that adjust authorisation requirements as cognitive decline progresses.

5 Discussion

5.1 Dementia-Friendly vs. Dementia-Specific

Past discussion of using home IoT devices for dementia care often focuses on what technologies or devices are needed by PwD and their caregivers. Although such discussion is critical to address the unique needs of dementia care, we would like to argue that making existing technologies friendly towards PwD is equally essential.

As mentioned in previous studies, misdiagnoses are common among PwD, and even with the diagnosis, it takes time to be accepted by PwD and their family [25]. When PwD are unaware of or in denial about their condition, they are less likely to engage with dementia-specific interventions that could benefit them in the future. However, non-dementia-specific solutions, such as home IoT devices for ageing in place, may be more acceptable. Introducing such interventions early can facilitate their gradual integration into daily life and allow for later customisation to better support dementia care once the diagnosis is acknowledged or accepted.

Home IoT devices are not naturally dementia-friendly [6, 7, 36]. Most home IoT devices employ a centralised control model with a primary user (owner/admin) who is rarely changed [1, 15, 22]. Such a model violates two essential requirements for a dementia-friendly home IoT system, as suggested by our studies: (1) allowing shifts of who is in control of the system, and (2) facilitate conversations about when and how such shifts should happen.

5.1.1 Allowing Control Shifts. In Section 4, we found that our participants believe their need for care and data sharing practices (both comforts and methods) are likely to change when transitioning from mild dementia to moderate dementia. Their attitudes towards caregivers' power to override PwD's previous data-sharing settings also become increasingly permissive throughout the entire progression process. This implies that to create a dementia-friendly home IoT system, a more dynamic, collaborative, and decentralised access control model is necessary.

5.1.2 Facilitating Conversations around Control Shifts. We have also found that people's preferences for access control models and override options vary from person to person, especially when dementia symptoms are mild (Section 4.4 and 4.5). For overriding options, even at the most severe stage of dementia, some may feel uncomfortable if their caregivers can override their settings. The variances in our participants' attitudes suggest the necessity and importance of communicating one's privacy preferences early on, with considerations for worsening symptoms and emergencies in the future. PwD should also be fully disclosed, with existing access control options available in their home IoT systems.

5.2 Data Exposure and Helpfulness

In Section 4, we demonstrated how data types influence participants' preferences for sharing data with caregivers. Video data and communication logs are considered the least accepted for data sharing among our participants, even in the severe dementia stage.

However, we would like to acknowledge that although we established the data types based on past literature, we did not examine whether these data offer the same level of helpfulness. It is possible that the perceived helpfulness varies from person to person, and the types of data that are most helpful in different stages of dementia may also differ. Such variances create another design opportunity for future in-home designers, with which one can potentially minimize data exposure but maximize its effectiveness. Future research is needed to explore this opportunity further.

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A Survey Instruments

A.1 Dementia Stages Descriptions

The survey presented participants with the following scenarios describing different stages of dementia.

- **Mild dementia:** Please imagine that lately, you have started experiencing mild but noticeable changes in your cognitive abilities. It becomes more likely for you to forget recent events and misplace items like keys and glasses. Concentration becomes more challenging than usual, making it hard to plan and organise things ahead. Sometimes, you get disoriented in places where you are supposed to know well. You sometimes lose track of visual cues (e.g., signs), and your perception of distances is slightly off. When communicating, it also becomes harder to find the right words than before. Although nothing major has happened so far, these changes have started to impact your daily life.

- **Moderate dementia:** Please imagine that lately, you noticed that you begin to have moments of severe confusion and sometimes do not recognize familiar places or people. You may get lost in your own neighbourhood. Sometimes, you may even fail to notice the time of the day (e.g., getting dressed in the middle of the night). You have also been told by others that you are repeating the same sentence or some activities over and over again. You may forget what you are saying mid-sentence. Following what others are saying also becomes more challenging. You also feel more paranoid than usual.
- **Severe dementia:** Please imagine that lately, you've experienced a significant decline in memory and cognitive abilities. Most of the time, you cannot recognize close friends or family members and communicate effectively. You sometimes do not even recognize your own reflections in the mirror. You believe you are in an earlier period of your life, and sometimes you would even try to go to your childhood home, as that is what you remember as home. Communication with others is very difficult. You often can only say a few words, and rely more on non-verbal communication (e.g., gestures). These experiences distress you and can cause severe anxiety.

A.2 Data Types Descriptions

The survey randomly assigned participants with one of the following types of data:

- **Health data** (e.g., heart rate, breathing rate, medication reminders)
- **Home occupancy data** (e.g., smart lock logs, motion sensor activity)
- **Video data** (security cameras feeds from shared areas, e.g., living room, front door)
- **Routine data** (e.g., sleep patterns, meal timings)
- **Communication log data** (e.g., phone call logs, messages, social media—only logs, no content)
- **Location data** (e.g., GPS location)

A.3 Survey Questions

Introduction According to the NHS, dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of brain functioning. In the UK, 1 in 11 people over 65 years old have dementia.

Introducing technologies to the patient's home is common advice for helping PwD stay independent and live well.

For example, smart watches or smart home devices (electronic devices that connect to the internet) allow people to keep track of their daily routines. The data helps remind patients in case they forget their medication or other daily activities.

Caregivers can also access these data remotely, making it easier for them to stay informed about the patient's well-being.

Examples of Smart Home Devices:

- **Home assistants** like Amazon Echo or Google Home can play music, control other devices, or answer questions using voice commands.
- **Smart watches** track health metrics such as heart rate, step count, and sleep patterns, while also keeping users updated with notifications from their phone.
- **Smart security systems** include devices like video doorbells, security cameras, and smart locks. These enhance home safety by providing real-time surveillance and remote access control.

In the next section, several hypothetical scenarios will be presented. We will ask you to imagine yourself experiencing symptoms of **dementia with various severities**.

There are 3 scenarios in total. Please consider each scenario independently. There will be attention checks. Failing attention checks may disqualify you from the study.

There are no right or wrong answers to any of the questions. Your honesty will help us the most in designing systems for people with dementia.

The following use the example "Location data (e.g., GPS location)", "Close family members (spouse, children)", and a dementia stage for the specified scenario.

The survey implemented a randomiser to vary the specific data type presented across all scenarios while keeping the other elements constant. The conditional logic displayed follow-up questions based on participants' initial responses.

Scenario X (out of Y) - [Dementia Stage]
[Scenario Description]

For the given scenario, do you think you need a caregiver?

A caregiver is someone who could help you manage your medications, attend medical appointments, and maintain your daily routines. They could be a close family member (e.g., a spouse, or an adult kid), or a professional hired to assist you. They don't necessarily live with you or always be around. Still, you can safely assume that they are genuinely concerned about your well-being and would like to stay informed and help.

○ Definitely not
○ Probably not
○ Might or might not
○ Probably yes
○ Definitely yes

A.3.1 Caregiver Selection. *Display if: Might or might not, Probably yes, or Definitely yes selected*

Scenario X (out of Y) - [Dementia Stage]
[Scenario Description]

In the above scenario, who would you **most** likely choose as your primary caregiver?

○ Close family members (spouse, children)
○ Extended family members (cousins, uncles/aunts, in-laws)
○ Professional caregivers (nurse, therapist)
○ Friends/Neighbors

○ Other (please specify)

A.3.2 Comfort with Caregiver Access (Selected Caregiver). Display if: Might or might not, Probably yes, or Definitely yes selected

Scenario X (out of Y) - [Dementia Stage]
[Scenario Description]

For your chosen caregiver (Close family members (spouse, children)), how comfortable would you be if they had access to your **Location data (e.g., GPS location)**?

Please consider your answer based on the given scenario on this page.

○ Extremely uncomfortable
○ Somewhat uncomfortable
○ Neither comfortable nor uncomfortable
○ Somewhat comfortable
○ Extremely comfortable

A.3.3 Comfort with Caregiver Access (Hypothetical). Display if: Probably not or Definitely not selected

Scenario X (out of Y) - [Dementia Stage]
[Scenario Description]

Assuming you do have a caregiver at this particular stage, how comfortable would you be if they had access to your **Location data (e.g., GPS location)**?

Please consider your answer based on the given scenario on this page.

○ Extremely uncomfortable
○ Somewhat uncomfortable
○ Neither comfortable nor uncomfortable
○ Somewhat comfortable
○ Extremely comfortable

A.3.4 Attention Check (Mild Dementia). Display if: Mild dementia scenario is presented

We are going to ask you about your music taste. When being asked about your favourite music genre, please select "Rock". This is an attention check.

Based on the text you read above, what music genre have you been asked to enter?

○ Blues
○ Punk
○ Indie
○ Rock
○ Jazz

A.3.5 Caregiver Access Level (No Caregiver Selected). Display if: Definitely not or Probably not selected

Scenario X (out of Y) - [Dementia Stage]
[Scenario Description]

As mentioned in the introduction, your smart home system allows you to share data with your caregiver.

At this dementia stage, if you do have a caregiver, what kind of access do you believe they should have for your **Location data (e.g., GPS location)**?

○ **Full access 24/7**
Once you add the caregiver to the system, they can see both current and historical activities or data at any time.
○ **Access only in emergencies**
The added caregiver can have access only during urgent or life-threatening situations (e.g., when the fire alarm is triggered).
○ **Access with periodical approval**
The added caregiver needs to obtain your permission periodically (e.g., every week/month) before they can see the data.
○ **Current data only**
The added caregiver can only access current information (i.e., when they open the dashboard), such as current location, instead of current and historical.
○ **Request for approval every time**
The added caregiver can only see the data once after approval. If they need to see the data again, they need to obtain your approval again.
○ **Never / I do not want to share data**
The added caregiver can never see the data.

A.3.6 Caregiver Access Level (Caregiver Selected). Display if: Might or might not, Probably yes, or Definitely yes selected

Scenario X (out of Y) - [Dementia Stage]
[Scenario Description]

As mentioned in the introduction, your smart home system allows you to share data with your caregiver.

At this dementia stage, for your selected caregiver (Close family members (spouse, children)), what kind of access do you believe they should have for your **Location data (e.g., GPS location)**?

○ **Full access 24/7**
Once you add the caregiver to the system, they can see both current and historical activities or data at any time.
○ **Access only in emergencies**
The added caregiver can have access only during urgent or life-threatening situations (e.g., when the fire alarm is triggered).
○ **Access with periodical approval**
The added caregiver needs to obtain your permission periodically (e.g., every week/month) before they can see the data.

- **Current data only**
  The added caregiver can only access current information (i.e., when they open the dashboard), such as current location, instead of current and historical.
- **Request for approval every time**
  The added caregiver can only see the data once after approval. If they need to see the data again, they need to obtain your approval again.
- **Never / I do not want to share data**
  The added caregiver can never see the data.

A.3.7 *Attention Check (Severe Dementia). Display if: Severe dementia scenario is presented*

We are going to ask you about some soft drinks. When being asked about your favourite soft drink, please select "Fanta". This is an attention check.

Based on the text you read above, which soft drink have you been asked to enter?

- ○ Sprite
- ○ Pepsi Cola
- ○ 7up
- ○ Fanta
- ○ Coca Cola

A.3.8 *Changing Data-Sharing Settings (Caregiver Selected). Display if: Might or might not, Probably yes, or Definitely yes selected*

> **Scenario X (out of Y) - [Dementia Stage]**
> [Scenario Description]

A dementia patient may gradually lose the capability to make calculated decisions. If they would like to change their data sharing practices with their caregivers, they may not be able to.

The system thus provides an option for patients to *allow the caregiver to make data-sharing decisions on their behalf.* For example, the caregiver may change how much data they can see or whether someone else (e.g., the doctor) can see the data as well.

At this dementia stage, when would you be comfortable allowing your caregiver(s) (Close family members (spouse, children)) to change your data-sharing settings about your **Location data (e.g., GPS location)**?

- **Only during emergencies**
  If there is an emergency, then the caregiver can change the settings without prior approval.
- **Allow the change, but you will be notified**
  The caregiver can change the settings, but you will be notified about any changes made. If dissatisfied, you can also revoke their capability to change settings afterward.
- **With prior approval set in advance**
  The caregiver can change the settings only after obtaining your prior approval. No changes can be made until you give your approval.
- **Whenever they feel it is necessary**
  You trust the caregiver to decide when access is needed without any additional approvals.
- **Never / I do not want them to change the settings**
  There are no circumstances where the caregiver should be able to change such settings.

A.3.9 *Changing Data-Sharing Settings (No Caregiver Selected). Display if: Definitely not or Probably not selected*

> **Scenario X (out of Y) - [Dementia Stage]**
> [Scenario Description]

A dementia patient may gradually lose the capability to make calculated decisions. If they would like to change their data sharing practices with their caregivers, they may not be able to.

The system thus provides an option for patients to *allow the caregiver to make data-sharing decisions on their behalf.* For example, the caregiver may change how much data they can see or whether someone else (e.g., the doctor) can see the data as well.

If you do have a caregiver at this dementia stage, when would you be comfortable allowing them to change your data-sharing settings about your **Location data (e.g., GPS location)**?

- **Only during emergencies**
  If there is an emergency, then the caregiver can change the settings without prior approval.
- **Allow the change, but you will be notified**
  The caregiver can change the settings, but you will be notified about any changes made. If dissatisfied, you can also revoke their capability to change settings afterward.
- **With prior approval set in advance**
  The caregiver can change the settings only after obtaining your prior approval. No changes can be made until you give your approval.
- **Whenever they feel it is necessary**
  You trust the caregiver to decide when access is needed without any additional approvals.
- **Never / I do not want them to change the settings**
  There are no circumstances where the caregiver should be able to change such settings.