Designing Technologies to Facilitate Information Acquisition for the Remote Caregivers of Independently Living Elderly

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Abstract: As the elderly population grows, so too will the burden placed on the caregivers of the independent elderly. Many caregivers report difficulties communicating with the remote elderly that could be solved with the use of sensor-based care devices such as monitoring systems. Robotic care devices have often been criticised for not sufficiently incorporating the everyday problems that caregivers and the elderly face during the development phase, such as communication and privacy issues. The aim of this study is to uncover difficulties faced by the elderly and their informal caregivers in their remote communication with one another, and to develop a set of system guidelines for developers of monitoring systems from the findings to help solve these issues. Data from interviews conducted with nine informal caregivers for older adults living independently in their own homes was analysed using the SCAT qualitative data analysis method. The findings show that changes in their daily lives can indicate a decline in the functional capabilities of the elderly, while also increasing the risk of accidents within the home. In addition, the relationship between the elderly and their caregivers highly affected their willingness and desire to disclose certain kinds of information. Based on these findings, we establish design guidelines for monitoring systems capable of selectively disclosing information to caregivers.

Keywords: elder care, sensing technology, interview study

1. Introduction

The rising life expectancy and population ageing being witnessed in most countries around the world have led to a stark increase in the number of elderly people who require care in their daily lives. As the number of older adults requiring care increases, so too will the burden placed on formal and informal caregivers of the elderly.

Given this background, elderly people are being encouraged to live independently for longer in their own homes. Therefore, there has been increased interest shown in the development and use of assistive technologies to facilitate ageing in place. The development of these robotic applications should not be based on what is technically feasible, but rather on the actual needs of the elderly and their caregivers [1]. However, too much focus is currently placed on technological usefulness, and the practicality of developed systems has not yet been established [2].

As the country with the most developed country in the world [3], Japan has been heavily investing in and encouraging the development of robot technologies. In 2012, the Ministry of Economy, Trade and Industry (METI) and the Ministry of Health, Labour and Welfare (MHLW) revealed the "Priority Areas to Which Robot Technology is to be Introduced in Nursing Care" [4] with the goal of advancing the development of robotic care devices for the elderly. The six priority areas consist of lifting aids, mobility aids, toilets, monitoring and communications systems, bathing, and nursing-care services.

Communication with the remote elderly seems to be one of the hardest aspects of caregiving, as caregivers struggle to find and uphold appropriate communication channels and the elderly find it hard to use communication devices such as mobile phones to stay in contact with their family and caregivers.

The present research aims to determine the main difficulties faced by informal caregivers when communicating with the remote

elderly and to discover the difficulties they face in their daily lives. Based on the identified difficulties, we propose a solution to these problems through the use of assistive technology while considering the privacy of the elderly.

Following the principles of privacy by design and stakeholder integration, we analysed data from interviews conducted with the primary family caregivers of independent elderly in Japan using the Steps for Coding and Theorisation qualitative data analysis method. Through the analysis, the main difficulties faced by caregivers and the elderly were uncovered and used as the foundation for system guidelines which were established in the next step. The system guidelines propose the design of a monitoring system meant to detect changes in the elderly's daily lives and surroundings that could be used to indicate functional decline. Next, we proposed several possible applications that could be developed to follow these guidelines and finally developed a prototypical application that detects dangerous objects placed in the paths used within the home to prevent fall risk.

The remainder of this paper is organised as follows. Section 2 presents previous and related work in the fields of care devices for the remote elderly and interview studies conducted with them. In Section 3, the results of the interview study and the implications that follow from them will be described. Additionally, system guidelines will be derived from the result of the analysis. Finally, examples of possible applications that would satisfy the system guidelines are introduced in the application section.

2. Related Work

2.1 Monitoring systems for use within the home

In the domain of home-care robots, literature on devices to prevent and detect accidents within the home based on behavioural patterns in very rich. Researchers have found that wireless sensor networks seem to be effective for potentially detecting declines in the functional capabilities of the elderly [2]. They observe that

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single video monitoring systems have emerged as a new type of technology utilising computer vision techniques. This could be due to advances in the technology itself, but also due to policy changes as Japan re-allowed the usage of video cameras to monitor people after having prohibited it during the 2000s [5].

Cameras have already seen usage in applications to detect falls within the home [6]. While most vision-based fall detection systems use powerful and expensive equipment, some low-cost systems have been proposed that can obtain comparable results and could be a good commercial alternative to the many wearable devices that are currently on the market [6]. These systems are advantageous as they are simple to install compared to non-video sensor systems [2]. However, they neglect aspects such as privacy and have not seen much clinical or practical use [2, 6].

2.2 Ethical considerations

The Japanese population has repeatedly been shown to be more open towards the use of robotics compared to other countries [5, 7]. More recently, government policies encouraging the usage of robots in various sectors, with the aim of making Japan the "robot innovation hub" of the world [8], have led to increased awareness and acceptance of robots in the general populace.

However, lack of sufficient knowledge of possible ethical issues among the Japanese population has been criticised in a survey comparing the perceptions of home-care robots in Finland, Ireland, and Japan [5]. The authors stress that older people must be sufficiently informed of the possible risks and benefits that come with using robotic care devices.

Several guidelines have already been published that aim to guide developers as they design technologies for the elderly. Riek and Howard's code of ethics for human-robot interaction practitioners discuss various ethical principles that should be followed when dealing with robotic systems [9]. Körtner discusses similar ethical principles in the specific case of social service robots for the elderly [10]. In terms of privacy, Nordgren calls for the integration of privacy in the design process [11], while Periyasamy, Alagar, and Wan present a concrete design pattern for patient-centric systems using sensors [12]. Finally, Kuoppamäki, Tuncer, Eriksson, and McMillan present a set of design guidelines aimed at kitchen technologies for ageing in place [13].

Researchers have found that unobtrusive devices are most likely to be accepted by elderly people [14]. Additionally, the same researchers highlight the importance of empowering older adults to decide which information they would like to share, and incorporate this into their design implications, stating that devices should be configurable and provide elderly people with the control over the content and frequency of notifications sent to family members [14]. Monitoring devices should not reduce the direct communication between family members and the elderly, but rather serve to alleviate the anxiety felt by family members while preserving their autonomy [14], thereby functioning more as an extension to rather than a replacement for the direct social contact.

2.3 Qualitative data analysis

Analysing interviews conducted with the elderly can be an effective means of gaining new insight into their lives and daily struggles, as shown by Gustavsson, Jernbro, and Nilson, who

discovered that "there is more to life than risk avoidance" [15]. Interview data can be analysed using qualitative data analysis methods such as Grounded Theory Analysis (GTA) [16]. However, GTA requires a large amount of data and a long period of time in order to be utilised properly [17]. Studies based on grounded theory require advanced planning and prior integration into the study design. In addition, the generative coding used in GTA is not considered beginner-friendly. The Steps for Coding and Theorisation (SCAT) method was developed after identifying these weaknesses as an attempt to overcome or at least significantly reduce them [17].

In this study, we aim to achieve the practicality necessary in an effective system by integrating the results of a caregiver interview analysis into the design process of a prototypical sensor-based monitoring system. In contrast to previous studies, we focus specifically on sensor-based monitoring systems, but integrate the analysis of comprehensive interview data comprising more than 13 total hours of interview time will allow for an in-depth look into existing problems and needs.

The study utilises the method proposed by Ohtani, which is described in more detail in Section 3.2.5. The proposed device should be non-invasive and easy to install. In addition, a focus will be placed on an appropriate information disclosure framework that is built into the design of the system to give elderly control over their own privacy.

3. Interview Study

3.1 Aim of the Analysis

The aim of this study was to identify the daily problems experienced by independently living older adults as perceived by their primary family caregivers. The interviews focused on difficulties in information acquisition on the caregivers' side.

3.2 Research Methods

3.2.1 Respondents

Eleven Japanese women who held the primary responsibility for looking after an older family member were recruited for this study. The mean age of the participants was 52.1 years. Each participant was or had been a caregiver for an independently living family member aged 75 or older. A further criterion was that the older family member was certified as "requiring long-term care" by the Certification Committee of Needed Long-Term Care in Japan with Care Level 1 or above as defined by the Ministry of Health, Labour and Welfare of Japan [18].

While all interviewed caregivers were female, the gender of and their relationship to their older family member (hereafter referred to as the subject of the study) differed (see Table 1). All participants spoke Japanese.

The interview data for two of the eleven interviews were not able to be analysed for this study and were thus excluded from the analysis, resulting in a total of nine subjects.

3.2.2 Setting

The interviews took place in a small conference room at the Multimedia Data Engineering Lab in the Department of Multimedia Engineering, Graduate School of Information Science and Technology, Osaka University. This was done in order to

protect the participants' privacy.

Table 1: Respondent characteristics.

	_	Subject (n=9)
Sex	Male	1
	Female	8
Relationship	Blood relation	6
	In-law	3
Age (years)	75-79	6
	80-84	1
	85-90	2

3.2.3 Recruitment procedure

The participants were recruited through an external consumer marketing research company.

3.2.4 Data collection

The data were collected from semi-structured interviews that were conducted individually with each respondent between November 2013 and January 2014. Each interview took approximately 120 minutes and was recorded and subsequently transcribed.

Questions were mainly related to the daily activities, decline, and chronic diseases of the subject, in addition to communication with the remote elderly and questions related to visiting them in their homes.

3.2.5 Data analysis

The interview data were analysed using the Steps for Coding And Theorisation (SCAT) developed by Takashi Ohtani [17]. SCAT consists of two main procedures: 1) coding and 2) writing the storyline and theory.

The first of the two main procedures when analysing data using SCAT is the coding procedure. This is also referred to as a "decontextualisation process" in which the data are segmented into matrix form and assigned codes that summarise the most important concepts found within them. Codes are added in the following order:

- (1) Important words or phrases from within the data.
- (2) Paraphrases of (1) using words or phrases not included in the data.
- (3) Words or phrases that help explain the concepts from (2).
- (4) Topics or constructs that emerge after rereading all notes from (1) to (3).

It is important that the notes be as impactful and simple as possible, particularly in the final step. In an additional optional step, questions and tasks that have revealed themselves during the analysis so far can be noted down.

The second main procedure consists of two steps: storyline and theory writing. The results from (4) above are used to write a storyline from which a theory can be constructed. The storyline is described as "the result of combining the topics noted in (4) with the potential meaning within the happenings described in the data" [17]. The words noted down in the final coding step must be used in combination with appropriate connectives in order to "recontextualise" the data. Following this, a theory can be constructed by fragmenting the storyline from the previous step.

Ohtani provides a sample Excel sheet which can be used to aid the analysis [19]. The template can be filled out either by analysing the entries corresponding to steps 1, 2, and 3 in order vertically (by column) and then finally filling in step 4 or from step 1 to step 4 horizontally one row at a time, before proceeding to the storyline and theory writing.

Finally, any doubts or remaining questions can be noted down. Additionally, points to be checked if a follow-up interview is conducted should also be written down in the "Further investigation" section.

For the study at hand, the data from the interviews were analysed in chronological order using Ohtani's SCAT method. Due to the nature of the interviews, only the answers given by the respondents were analysed in full, while notes were taken from the questions posed by the interviewer only when necessary for clarifying purposes. Different themes were identified that were confirmed and summarised over the course of the analysis. A special focus was placed on identifying difficulties faced by the subjects in their daily lives and the fears that the interviewed caregivers most often addressed during the interviews.

3.3 Research Findings

The data analysis led to the identification of various theories for each interview. These theories were aggregated into four main categories: "Changes in and around the elderly" defined changes that led to difficulties and risks that the elderly dealt with in their daily lives and the consequences thereof; "Comfort over safety" focused on the prioritisation of different aspects in their daily lives that could lead to further problems; "Problems regarding information acquisition" defined issues faced by caregivers as they tried to care for their family members, and "Technology acceptance" summarised the opinions of the caregivers and the elderly towards new technologies that could be used to monitor the elderly.

3.3.1 Changes in and around the elderly

Changes in the elderly's behaviour and in their surrounding environment were found to greatly increase the perceived risk they faced while living independently. Both the cognitive and the physical decline of the elderly were identified as risk factors.

A decline in the physical capabilities of the elderly was quite common across all interviews and affected them in different ways. In general, many caregivers mentioned that they were able to tell whether the subject was in a good physical state or not through simple observation. For example, sudden and rapid weight loss was taken as an indication that something was wrong and led the caregiver to seek further assistance from external sources.

Physical factors are far easier to determine than mental ones, even though the mental well-being of the subjects might affect them far more greatly than their physical well-being.

Although there is no direct and completely accurate method to see how the subjects were doing mentally, caregivers said that they paid attention to their tone of voice, mood, changes in their daily routines, conversational skills, and hygiene levels to gauge the mental well-being of their elderly family members.

Feeling anxious was a common theme, as subjects would reduce the frequency with which they left the house or refuse to take part in social activities because they would worry that something would go wrong.

Thus, subjects would often lack the intrinsic motivation to go outside, even if they were physically capable of doing so. Sometimes, subjects' cognitive abilities were not able to keep up with their physical ones, such as struggling to remember tasks that they had successfully completed.

These declines made it harder for the elderly to adapt to changes in their environment. In addition, they displayed an inability to react to changes in behaviour or environment, so were more prone to accidents in general. Respondents worried about the risk of fires, falls, loneliness caused by social isolation, and the incorrect intake of medicine. Another consequence was that the initial decline would cause a further decline in other abilities, resulting in a vicious cycle that was hard to combat.

In short, the elderly were faced with both physical and cognitive declines that led to a heightened inability to react and adapt to changes in their daily lives. This is supported by further studies that found that physical or cognitive declines in the elderly had negative effects on their ability to carry out activities of daily living [20, 21]. Caregivers were able to witness some, but not all, of these declines through observation.

3.3.2 Comfort over safety

In many of the interviews, a dichotomy between stability and boredom could be witnessed that was brought about by the rigid routines followed by the elderly. Having set chores could help subjects to get out of bed in the morning and was an important part of being able to function in their daily lives:

Interviewer: Does [the subject] wake up in the mornings to eat breakfast, even when it's cold?

Respondent: She says she tries to at least get up in the morning or else she'd spend the whole day in bed so she tries to get up even when it's cold. And it wouldn't do to have the newspaper in the postbox all day so she says she wakes up to get the newspaper but I'm not sure whether that means she goes outside in her pajamas or gets changed properly [...]. I can't really ask her this kind of stuff so I don't know.

At the same time, some deeply ingrained habits could cause health problems, such as in the case of one subject who had the habit of not using the air conditioning even with a high risk of heatstroke or dehydration.

Following the same paradigm of comfort over safety, one subject had the habit of gathering many objects around himself in order to be able to live comfortably. This caused the caregiver to worry a lot:

Every time I went, there would be a lot of stuff all over the floor. My father would place it there so he could reach it more easily and live more comfortably. But, from my point of view, when he moves stuff from one place to another, he has to reach over it and that is very dangerous. I told him to clean it up many times, but even so he kept on spreading items out so they were in his

This is an example of a subject who prioritised his own comfort over his safety. Although having many items cluttered on the floor could lead to a higher risk of falling, the subject preferred this in order to be able to live more comfortably. In the case of this interview, the respondent subsequently moved a hall hanger to the room he spent the most of his time in in an effort to make life more convenient for her father. This, however, had the opposite effect, as her father ended up tripping over the hanger and breaking two ribs. This shows how a lack of knowledge on the caregiver's side can also be a risk factor that should be taken into consideration.

In summary, the elderly often prioritised living comfortably over living safely, for example by sticking to old habits that could prove harmful to them or pose greater risks of accidents within the home. Simultaneously, the monotony of their daily lives was perceived as unpleasant and boring, so some elderly would actively try to make life more comfortable by creating diversity within their day-to-day, such as by cooking by themselves. Previous research has theorised that older adults may show more risk-taking tendencies if a task demands more than their cognitive abilities permit [22]. In some cases, a physical or mental decline caused changes in their daily routine. As they struggled to adapt to external changes, these disturbances obstructed their ability to live independently, potentially impacting sleep quality [23] and nutritional status [24].

3.3.3 Problems regarding information acquisition

There were some situations discussed in the interviews where conflicts or difficulties arose due to the caregivers' behaviour around and assumptions about the elderly.

Many caregivers used indirect signs as an indicator of changes. These signs included availability by phone, changes in cleaning or toilet habits, tone of voice, television volume, changes in priorities (e.g., not prioritising hygiene as much as before) and observing the amount of usage of daily products such as soap.

Caregivers preferred to observe rather than ask their elderly family members directly so as not to upset them and in order to respect their sensitivities. In one interview, while the subject was aware of limitations she had completing certain tasks and could ask for direct help, she was sometimes frustrated when her daughter-in-law would keep on pressing her to drink and stay hydrated. Caregivers therefore also have to consider the pride of the elderly person they are taking care of and handle sensitive topics without embarrassing them.

However, caregivers often complained of gaps in their knowledge as they did not know exactly how the elderly person behaved when they were not around. In addition, actions that were not directly witnessed by the caregiver were suspected to be possible exaggerations and the respondents generally found it hard to trust what the subject reported to them. Indeed, this mental instability disturbed not only the caregivers, but the subjects themselves as well, as they sometimes found themselves being physically capable of completing certain tasks, but having no recollection of the fact afterwards.

The conflict most felt by caregivers was the difficulty they had in balancing their desire to provide a stable environment for the elderly person with their desire to keep the elderly person safe, which in some cases meant that their environment had to be changed or limited in some way.

Furthermore, some caregivers reported that small worries could spiral into panic if they were not able to quickly confirm the safety of their elderly family members. Caregivers have to be able to accept that living alone means the subjects must do things they might consider dangerous at times, such as carrying heavy items:

I have told her that I want to her to avoid carrying heavy things as much as possible, but she lives alone so she goes grocery shopping on her own and if she buys too much she says she is exhausted [from carrying heavy items]. When I am there, I go with her and carry the heavy items. I have told her to not overdo it.

Interestingly, a caregiver's relation to the elderly person was seen to make a big difference in terms of what information the elderly person may be willing to reveal. In cases where the caregiver was the subject's daughter-in-law, the subject was reported to be unwilling to complain quite as much or to be cared for. She did not want to show too much weakness to someone who was not her own child. In yet other cases, subjects did not want to cause too much worry for their own children as this could in turn also lead to fights. Family dynamics are very important when considering who should be the primary caregiver for an elderly person.

Altogether, caregivers could be said to be faced with the inverse problem presented in Section 3.3.2. Where elderly people were often shown to prioritise their comfort over their safety, caregivers cared more about the elderly's safety, even if it meant that they would be more restricted in their freedoms and may consequently experience a long-term cognitive or physical decline. This overprotective behaviour could also make older adults more dependent in the long run [25]. This concern was largely due to the knowledge gaps the caregivers faced as they could mostly only use indirect signs to gauge the elderly's health condition while being aware of and preserving their pride and dignity. This is supported by previous research showing the difficulty caregivers experience in reaching peace of mind due to their emotional investment [26]. Additionally, the relationship between caregiver and care receiver played an extremely important role, as children and children-inlaw face different problems while providing care for their elderly family members [27].

3.3.4 Technology acceptance

This category defines the degree of openness the caregivers displayed towards the usage of technology to help them and their elderly family members in their daily lives.

Most caregivers seemed quite open towards assistive care devices in general, with some already making use of special nursing care beds or renovations within the home to make life easier for the elderly.

Technologies would have to be both easy to install and to use, as caregivers feared that they would just buy them and not be put properly to use otherwise. Having to renovate the house to accommodate devices or register a user account were seen as further hurdles.

In addition, caregivers wondered whether it would be worth it to purchase new appliances in the first place since the elderly may not use them or be able to learn how to use them. This could be seen in the case previously mentioned in Section 3.3.2, where a caregiver purchased an induction stove for her mother, who continued using the gas stove because she could not learn how to

cook using the induction stove.

Thus, functions added to technologies to make them "easier to use" often result in the opposite effect. Elderly people should be introduced to these technologies earlier on while they are still able to learn how to operate them, but developers should also focus on keeping the devices as simple as possible so elderly people and caregivers can easily learn how to operate them.

A common subject mentioned by caregivers was their desire to be notified of abnormalities or changes in the lives of the subjects, rather than an all-encompassing, uninterrupted surveillance. Technologies that would allow them to continue to indirectly observe and infer from their observations while away from the elderly's home were preferred. Technology was seen as a means to fill in their knowledge gaps instead of as a way to replace them in their role as the primary caregiver.

All in all, the interviewees were generally open to using technologies that would complement their caregiving rather than serving as a complete replacement. Caregivers have been shown to be receptive to familiar assistive devices that can serve as a supplement to their caregiving [26]. As time is of the essence in aging, it is important that caregivers introduce assistive systems before it is too late for the elderly to properly learn how to use them. At the same time, developers of these systems must not overcomplicate them and should instead focus on a simple and easy-to-learn design.

3.4 Implications

In this section we will present the main implications from the results of the interview data analysis. The findings from the study show that the environment surrounding the elderly greatly influences them as they go about their daily lives. Declines in physical capabilities, as discussed in Section 3.3.1, could include an inability to complete tasks that could previously be completed due to physical weakness or pain. Cognitive decline was indicated by memory loss or illogical conversation flow, among others. These declines could inhibit an elderly person's reaction time or understanding of events in their surroundings, leading to higher risk of events such as falls or fires. In summary, functional capabilities greatly affect the elderly's ability to continue living independently.

Declines in both the physical and the cognitive abilities of the elderly were responsible for two big risks:

- Accidents caused by changes in the elderly's behaviour or in their environment are more likely.
- The elderly experience greater difficulty in adapting to changes in their environment.

There were also problems on the caregivers' side, such as cases where the elderly person displayed an unwillingness or an uneasiness at the prospect of disclosing certain kinds of information to their caregiver. This was highly dependent on the relationship that the elderly person had to their caregiver, such as if they were blood relations or in-laws. Moreover, caregivers showed that they were open to using new technologies if they could help them to provide better care, especially in moments when they could not be in the same location as their elderly family members.

The implications from the interview analysis are as follows:

- The elderly's level of willingness to disclose certain kinds of information to their caregiver is highly dependent on the relationship between the elderly person and the caregiver.
- Monitoring systems should take into consideration the relationship between the caregiver and the elderly person, and give the elderly control over how and how much information is disclosed to caregivers.
- Monitoring systems should reassure caregivers and allow them to fill the gaps in their knowledge regarding the elderly's daily activities that they are not able to witness from a distance.

3.5 System Guidelines

The analysis revealed that changes in and around the elderly are extremely important and relevant to family members who wish to provide good care to the independent elderly. Being able to detect changes would allow a monitoring system to avoid disclosing all information gathered. In this way, caregivers would not have to be overwhelmed by receiving the plethora of data that is available, thereby causing a disturbance in their lives. Based on this, we propose a set of guidelines that a system facilitating the acquisition of information regarding changes in the daily lives of the independent elderly should follow.

3.5.1 Types of changes

We found that there are several different types of changes that a monitoring system could detect:

- (1) Behavioural changes, such as changes in the frequency of daily activities or dietary changes. These could be used to identify whether the older adult's ability to perform activities of daily living is inhibited.
- (2) Environmental changes, such as objects placed in new locations or an unexpected change in room temperature. These could indicate cognitive declines such as the onset of dementia.
- (3) Physical changes, such as changes in gait or outer appearance that could indicate pain or illness that the caregiver could then respond to accordingly.

3.5.2 Presentation of changes

Monitoring systems must adequately balance an older person's fundamental right to privacy and autonomy [9] with their caregiver's need to know about their daily routine in order to be able to provide sufficient care. Information should be filtered so that only information related to important and relevant changes is disclosed to the caregiver. Additionally, systems should also include feedback loops so they can respond and adapt to changing needs over time [29].

Urgent changes, such as a detected fall or a change in the location of a daily object, should be notified as soon as possible. Clearly, a fall within the home could lead to severe injuries, while a change in the location of an object an elderly person uses every day could cause severe confusion or difficulties in their day-to-day life.

Conversely, long-term changes in behaviour need not be notified immediately as they may simply signal a gradual change in habits. These changes could be relayed to caregivers after a set period of time. Similarly, changes that do not pose a great risk do not need to be disclosed urgently.

Older adults should be included in the design process of a system as much and as early as possible, for example by conducting interviews with them to form concrete theories and find underlying trends. They should also be extensively enlightened about the way that their data is processed by these systems and should be given several options when it comes to what should be monitored and to what extent their relatives and caregivers can access their data. The elderly person and their caregiver should be given the opportunity to decide which cases should warrant a notification, and which detected changes should not be marked by the system. By gathering the input from both parties, a compromise can be reached that will satisfy the needs of both. It is important that default settings also be provided to minimise the need to customise the system, while providing this as an option so that individuals can adapt the system to suit their own definition of privacy. Ultimately, the older adult will decide to what degree they want to share their data with their caregivers.

Similarly, the system should provide a mechanism to define different access levels for different types of caregivers. This can be controlled using mechanisms such as the one discussed in Periyasamy, Alagar and Wan [12]. For instance, if an elderly person feels uncomfortable if their primary family caregiver is made privy to certain health-related data, but would like to share these data with their general practitioner, then the two could be assigned different levels of access that would allow the general practitioner to view the health data, while restricting access for the family caregiver, and vice versa.

Information based on detected changes can be selectively disclosed in such a manner that would empower the elderly person and give them control over their own data. They would therefore feel comfortable with the information that is disclosed to each caregiver as it would be something they had agreed on and chosen of their own volition. At the same time, caregivers would have access to enough information so that they feel reassured that accidents or declines can be prevented before the fact or reacted to in a timely manner. Developers, engineers, researchers, and all people involved in the design process, should work to provide older adults with technologies that respect them as individuals and protect their right to privacy.

3.6 Limitations

This study has some limitations that must be taken into consideration. First of all, the interview data was collected in 2013. Since then, there have been many advancements in technology, especially in the field of care robotics. Thus, the perception and usage rates of robotic devices for the elderly may have changed drastically. Nevertheless, the study provides an insight into problems faced by a population group that may still be less likely to be well-acquainted with and well-versed in the usage of technologies such as mobile phones that would allow for easier communication.

Additionally, all interviewed caregivers were female. Although the majority of family caregivers tends to be female, the number of male caregivers is increasing and their struggles may differ from

Figure 1: Detecting dangerous objects on paths within the home.



those of their female counterparts [28]. Nevertheless, the fact that robot technologies aimed at domains in which women – as caregivers or as care recipients – are the key players, are developed in fields that are dominated by male experts must be taken into account when implementing these new technologies [1]. Therefore, the inclusion of only women in this study is not too severe.

Additionally, due to time limitations and the data size being larger than anticipated, the data analysis using the SCAT method was found to be quite time-consuming. Consequently, not all interviews could be fully analysed using all the necessary steps involved in SCAT. However, we believe that enough significant data has been analysed to show the greatest problem areas faced by caregivers and elderly people.

4. Applications

Different types of systems were considered that could satisfy the system guidelines.

These included applications such as a monitoring system that would track changes in daily objects of the elderly. These could be items that the elderly person used on a daily basis. As previously mentioned, these objects can pose a risk if the elderly person places them in a new location that might be on a path that they frequently use. If these kinds of changes in daily objects can be detected, then the system could send an alert to the caregiver saying that there is a dangerous object placed on a path that could cause falls. This would enable the propagation of information and making the caregiver aware of the problem before an accident occurs.

Changes in activity and movement patterns could be detected by monitoring the activities an elderly person completes during the course of a day and detecting whether any one activity, such as eating or cooking, deviates from the norm. If the person usually spends a certain amount of time per day cooking, and the system detects that they have not cooked at all, then it could send a warning saying that it has detected some abnormal behaviour that might be a cause for concern.

After detecting these changes, the system guidelines propose the selective disclosure of information based on the changes that were previously detected. This could be done in several different ways depending on what kind of application was built.

If a room is being monitored within the home, then the footage could be blurred in order to preserve the privacy of the elderly person. Once a dangerous object is detected, then the object is revealed to the caregiver by selectively unblurring only the object within the image and sending an alert that a dangerous object has been detected (see Figure 1).

For the second example, time expenditure for daily activities could be displayed in a chart, where the content of the graph is

Figure 2: Detecting changes in time expenditure for daily activities.



blurred until a drastic change in time expenditure is detected. Only then would the activity where the deviation was detected be uncovered so that the caregiver can see what activity has undergone a change (see Figure 2).

5. Conclusion

We developed system guidelines to aid in the design of technologies for independently living older adults as the primary result of this study. The guidelines would facilitate information acquisition for the informal caregivers of the remote elderly. The question being pursued was what the main difficulties faced by older adults and their informal caregivers were during their communication with one another in their daily lives.

To develop the guidelines, we analysed data from interviews conducted with nine informal caregivers of the elderly using the SCAT method to uncover the biggest struggles they faced in their daily lives while communicating with the remote elderly. The analysis uncovered four distinct categories: "Changes in and around the elderly", "Comfort over safety", "Problems regarding information acquisition", and "Technology acceptance". The main takeaways were that changes in their daily lives could indicate a decline in both the physical and cognitive capabilities of the elderly. Functional capabilities were found to be factors that influenced the risk of falls, accidents, and further declines. Additionally, older adults sometimes behaved in ways that could put them at risk because they prioritised their comfort over their safety. The wants of their informal caregivers were found to conflict with this behaviour. This was further exacerbated by the fact that caregivers face a huge knowledge gap when dealing with the elderly. They desired to protect them, but could not communicate effectively with them. Additionally, some older adults do not want to share certain kinds of information with their caregivers. However, most caregivers were open to the use of technologies, indicating a need to lay out concrete guidelines during the development of these assistive systems. Using the results from the analysis, we then developed guidelines for assistive system aimed at independently living elderly that would also take information disclosure into consideration.

The system guidelines attempt to tackle the identified issues by selectively disclosing information based on changes detected within elderly people's homes. These changes could include behavioural, environmental, and physical changes and could indicate a decline in the functional capabilities of the elderly. The guidelines prescribe the filtering of information so that not all of the older adult's data is exposed to their caregiver. Instead, systems should only notify the caregiver of important and relevant changes in their daily routines that could be indicative of risks or functional

decline. In addition, the guidelines advocate a mechanism that would provide different caregivers with different access levels. In this way, the relationship between older adults and each caregiver can be considered so that both parties feel comfortable and safe.

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References

- [1] German Ethics Council. Robotik fuer gute Pflege [Robotics for Good Nursing]. https://www.ethikrat.org/fileadmin/Publikationen/ Stellungnahmen/deutsch/stellungnahme-robotik-fuer-gutepflege.pdf. Published March 10, 2020. Accessed October 4, 2021.
- [2] Lenouvel, E. et al.. Advances in Monitoring Effectiveness and Applicability: A Systematic Review and Update. The Gerontologist. 2019; vol. 60 (4), pp. e299-e308. doi:10.1093/geront/gnz049.
- [3] D'Ambrogio, E.. Japan's Ageing Society. https://www.europar l.europa.eu/thinktank/en/document.html?reference=EPRS_BRI(202 0)659419. Published December 15, 2020. Accessed October 4, 2021.
- [4] Ministry of Economy, Trade and Industry. Revision of the Priority Areas to Which Robot Technology is to be Introduced in Nursing Care. https://www.meti.go.jp/english/press/2017/1012_002.html. Published October 12, 2017. Accessed August 29, 2021.
- [5] Suwa, S. et al.. Exploring Perceptions Towards Home-Care Robots for Older People in Finland, Ireland, and Japan: A Comparative Questionnaire Study. Archives of Gerontology and Geriatrics. 2020; vol. 91. doi:10.1016/j.archger.2020.104178.
- [6] De Miguel, K. et al.. Home Camera-Based Fall Detection System for the Elderly. Sensors. 2017, vol. 17(12), p. 2864. doi:10.3390/s17 122864
- [7] Nitto, H., Taniyama, D., and Inagaki, H.. Social Acceptance and Impact of Robots and Artificial Intelligence. https://www.nri.com/en/knowledge/report/lst/2017/cc/papers/0201. Published February 1, 2017. Accessed August 3, 2021.
- [8] METI. New Robot Strategy. https://www.meti.go.jp/english/press/20 15/pdf/0123_01b.pdf. Published October 2015. Accessed August 27, 2021.
- [9] Riek, L. D. and Howard, D. A.. A Code of Ethics for the Human-Robot Interaction Profession. Paper presented at: We Robot; April 4, 2014. https://ssrn.com/abstract=2757805. Accessed September 28, 2021.
- [10] Körtner, T.. Ethical Challenges in the Use of Social Service Robots for Elderly People. Zeitschrift für Gerontologie und Geriatrie. 2016; vol. 49, pp. 303-307. doi:10.1007/s00391-016-1066-5.
- [11] Nordgren, A. Privacy by Design in Personal Health Monitoring. Health Care Analysis. 2013; vol. 23, pp. 148-164. doi:10.1007/s1072 8-013-0262-3.
- [12] Periyasamy, K., Alagar, V., and Wan, K.. Dependable Design for Elderly Health Care. Paper presented at: 2017 Federated Conference on Computer Science and Information Systems; 2017; vol 11, pp. 803-806. doi:10.15439/2017F261.
- [13] Kuoppamäki et al.. Designing Kitchen Technologies for Ageing in Place: A Video Study of Older Adults' Cooking at Home. Paper presented at: ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies; 2021; vol. 5(2), no. 69, pp. 1-19. doi:10.1145/346351
- [14] Sas, C. et al.. Communication Needs of Elderly at Risk of Falls and their Remote Family. Paper presented at: 2017 CHI Conference Extended Abstracts on Human Factors in Computing Systems; May 6, 2017, pp. 2900-2908. Denver, Colorado, US. doi:10.1145/30 27063.3053274.
- [15] Gustavsson, J., Jernbro, C., and Nilson, F.. There is more to life than risk avoidance – elderly people's experiences of falls, fall-injuries

- and compliant flooring. International Journal of Qualitative Studies on Health and Well-being. 2018; vol. 13 (1), p. 1479586. doi:10.108 0/17482631.2018.1479586.
- [16] Glaser, B. G. and Strauss, A. L.. The Discovery of Grounded Theory: Strategies for Qualitative Research. New York, NY: Aldine de Gruyter; 1967.
- [17] Ohtani, T.. SCAT: Steps for Coding and Theorization: 明示的手続きしやすく小規模データに適用可能な質的データ分析手法. 日本感性工学会. 2011; vol. 10 (3), pp. 155-160. http://hdl.handle.net/2237/15075. Published July 15, 2011. Accessed January 7, 2021.
- [18] Ministry of Health, Labour and Welfare. 要介護認定はどのように行われるか [How the Required Long-Term Care Level is Determined]. https://www.mhlw.go.jp/topics/kaigo/nintei/gaiyo 2.html. Published 2009. Accesses July 15, 2021.
- [19] Ohtani, T.. SCAT: Steps for Coding and Theorization. Nagoya University. https://www.educa.nagoya-u.ac.jp/~otani/scat/index e.html. Updated November 4, 2015. Accessed July 25, 2021.
- [20] Mioshi, E. et al.. Activities of daily living in frontotemporal dementia and Alzheimer disease. Neurology. 2007; vol. 68 (24), pp. 2077-2084. doi:10.1212/01.wnl.0000264897.13722.53.
- [21] Seidel, D. et al.. Patterns of Functional Loss Among Older People: A Prospective Analysis. Human Factors. 2009; vol. 51 (5), pp. 669-680. doi:10.1177/0018720809353597.
- [22] Shao, R. and Lee, T. MC.. Aging and risk taking: toward an integration of cognitive, emotional, and neurobiological perspectives. Neuroscience and Neuroeconomics. 2014; vol. 2014 (3), pp. 47-62. doi:10.2147/NAN.S35914.
- [23] Zisberg, A., Gur-Yaish, N., and Shochat, T.. Contribution of Routine to Sleep Quality in Community Elderly. Sleep. 2010; vol. 33 (4), pp. 509-514. doi:10.1093/sleep/33.4.509.
- [24] Nurhayati, I. and Hiadayat, A. R.. Age, intellectuall functions and activity contributions to elderly nutritional status. International Journal of Public Health Science. 2020; vol. 9, no. 3, pp. 216-223. doi: 10.11591/ijphs.v9i3.20464.
- [25] Nakken, N. et al.. Informal caregivers of patients with COPD: Home Sweet Home?. European Respiratory Review. 2015; vol. 24, pp. 498-504. doi:10.1183/16000617.00010114.
- [26] Jaschinski, C. and Allouch, S.. Listening to the ones who care: exploring the perceptions of informal caregivers towards ambient assisted living applications. Journal of Ambient Intelligence and Humanized Computing. 2019; vol. 10, pp. 1-18. doi:10.1007/s12652-018-0856-6.
- [27] Pinquart, M. and Sörensen, S.. Spouses, adult children, and childrenin-law as caregivers of older adults: a meta-analytic comparison. Psychology and Aging. 2011; vol. 26 (1), pp. 1-14. doi:10.1037/a0021863.
- [28] Saito, M.. Current issues regarding family caregiving and gender equality in Japan: male caregivers and the interplay between caregiving and masculinities. Japan Labor Review. 2016; vol. 14 (1), pp. 92-111. https://www.jil.go.jp/english/JLR/documents/2017/JLR53 _saito.pdf. Published 2016. Accessed August 31, 2021.
- [29] Hassan, A. Y. I.. Challenges and Recommendations for the Deployment of Information and Communication Technology Solutions for Informal Caregivers: Scoping Review. JMIR Aging. 2020; vol. 3 (2), p. e20310. doi:10.2196/20310.
- [30] Newell, A. et al.. Methodologies for Involving Older Adults in the Design Process. In Stephanidis C. (eds) Universal Access in Human Computer Interaction. Coping With Diversity. UAHCI 2007. Lecture Notes in Computer Science. 2007; vol. 4554. Springer, Berlin, Heidelberg. doi:10.1007/978-3-540-73279-2_110.