# EMERGING ETHICAL CONSIDERATIONS FROM THE PERSPECTIVES OF THE ELDERLY

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**Abstract:** *The introduction of assistive technology for elderly no longer able to live independently has brought along a set of new ethical issues that deserves attention. Previous studies on similar topics mostly focus on certain groups of elderly or specific ethical issues rather than addressing ethical issues that apply to the majority of elderly regardless of their background. This paper reports from four methods of data gathering where we let elderly using assistive technology voice their own ethical considerations without having to speak within an ethical framework or only limited to one or few ethical issues. The data is gathered through four different methods at a local care home in Oslo over a period of 15 months. Rooted in a thematic analysis we present four identified problem areas, and we summarize and discuss our findings with regards to how we believe these issues should be dealt with in the future.*

## 1 Introduction

Through the increased focus on the rapidly expanding elderly population, an increasing number of elderly in Oslo are being introduced to assistive technology (AT). Introduction of AT brings forward ethical issues that must be taken into consideration, and in the midst of this discussion, it is important not to forget the elderly who have to live with this AT. As stated by the Directorate of Health (2012), *"welfare technology is not about technology, but about people"*. Our motivation is to bring attention to the ethical aspects from the perspective of the elderly, giving them a voice and chance to speak openly and freely from their own perspective.

Previous studies have addressed ethical challenges associated with the introduction of AT from various perspectives. However, most of this research aims at addressing ethical issues from a given starting point, i.e. with selected ethical issues in mind or with a predefined ethical lens or framework. At length, this narrows down the discussion of ethical challenges to a focused set of issues, which may not cover all the challenges in their entirety. It may also limit or prevent the elderly from bringing their own perspectives into the discussion. While these related studies provide us with great insight and address important issues, we still miss research focusing the broader ethical considerations that emerge when introducing AT. As we are witnessing AT being rolled out in heavy numbers in Norway, we argue that some attention should also be devoted to the ethical considerations that can reach beyond those issues only relevant for one or a few limited groups of users, e.g. elderly suffering from cognitive impairments.

Rather than approaching with a predefined ethical framework, we allowed the elderly and their caregivers to define issues they considered ethical.

We have extracted data targeting ethical issues from four different methods carried out at a local caring home in Oslo throughout the last 15 months. The goal of this paper is to shed light on some of the general ethical issues that emerged from the perspectives of the elderly living with AT, as well as discussing how we might handle them. Through a thematic analysis, we have elicited four problem areas, namely lack of information, privacy and safety, intrusion, and decision- making. We use these problem areas in our discussion of why we encourage *patience, adaptability* and *openness* with AT as a way of dealing with these issues.

## 1.1 Related work

An obvious underlying issue is the tension between privacy on one hand and safety on the other; how far can you stretch the breach of privacy using the argument of increased safety or security? The ongoing debates are mostly concerned with finding the optimal balance between safety and security, both from the views of the elderly and other involved actors, e.g. the home care service. As the Directorate of Health (2012) points out, ethical challenges and privacy issues with welfare technology are especially prominent when used where the technology is most needed, i.e. among the weakest of the elderly. We see clear traces of this in that most of the conducted research on ethical challenges with welfare technology links this to elderly suffering from cognitive impairment, e.g. (Batchelor, Bobrowicz, Mackenzie, & Milne, 2012; Kang et al., 2010; Lauriks et al., 2010; Martin, Bengtsson, & Dröes, 2010; Meiland, Dröes, Sävenstedt, Bergvall-Kåreborn, & Andersson, 2010; Rosenberg, Kottorp, & Nygård, 2012). All these researchers address the ethical issues that arise when dealing with cognitive deficiency, albeit from different standpoints and ethical perspectives, e.g. privacy, trust, intimacy, intrusion and autonomy. Their discussions mainly revolve around unveiling ethical aspects with AT, and include fruitful arguments on what constitutes as a correct balance between privacy and care, and the acceptable or non-acceptable violations of privacy. In addition to these studies, we also find studies dealing with ethical issues among elderly, although with slightly different perspectives, e.g. a generational perspective (Birkland, 2010), a sensor technology based perspective (Ding, Cooper, Pasquina, & Fici-Pasquina, 2011), future perceptions perspective (Harrefors, Axelsson, & Sävenstedt, 2010), medicalnperspective (Ziefle, Rocker, & Holzinger, 2011), and the significant other perspective (Rosenberg et al., 2012).

Adaptability from an ethical point of view is an important part of the discussion in several previous studies. Birkland (2010) points out that research on older adults and ICT has mainly been based on age as the sampling criteria, rather than using the effect technology has on the individual as a basis. In their view, this has resulted in a *"conceptual, design and sampling gap"* (ibid). Martin et al. (2010) refer to previous studies focusing on a principle- based approach rather than a theoretical approach, in which individual autonomy stands as one of the key principles. Findings from Frennert, Forsberg, and Östlund (2013) indicate that AT should recognize individual parameters, while Rosenberg et al. (2012) also highlight a need to let technology adapt on an individual level in order to gracefully integrate with previous habits. In their study of tele-

care-in-use, Mort, Roberts, Pols, Domenech, and Moser (2013) also argue that customizability and adaptability are main components in an ethical practice of telecare. Findings from Harrefors et al. (2010) also support that elderly who believe they are able to make their own decision also trust themselves and their own judgmental ability. This indicates that elderly comfortable with making decision should not be deprived of this autonomy. Similarly, Rosenberg et al. (2012) mention how oversimplified technology may end up with an opposite effect if it automates and replaces physical and cognitive capabilities that are still intact, e.g. the ability to remember numbers. Their results also suggest that some elderly feel a strong motivation towards using assistive technology precisely because it allows their brain to get regular exercise.

There are also studies on more overall topics such as policies, practice and future implications of introducing AT. Martin et al. (2010) bring in paternalism to discuss whether or not it is justifiable to make decisions on behalf of the citizens, either because they are unable to make decisions for themselves, e.g. due to cognitive deficiency, or because the government believes they know what is best for the citizens. Coeckelbergh (2010) present studies on the ethical implications of replacing human care with artificial intelligence, as well as various ways of understanding and approaching care. Finally, there has been some discussion of assistive technologies using robots and the ethical consideration of a society in which current caregiving tasks are either supported by robots or completely carried out by robots (Coeckelbergh, 2010; Sharkey & Sharkey, 2012; Sparrow & Sparrow, 2006). They all provide interesting perspectives on future ethical challenges.


## 2 Methodology


### 2.1 Ethical perspective

Different researchers have applied different ethical perspectives in their studies of AT. There are examples of researchers, e.g. within dementia care, turning towards consequentialist theory (Martin et al., 2010). Another widely applied approach is to rely on deontological theory and use ethical values based on basic human rights as seen in (Coupland, Wakunuma, & Stahl, 2009; Martin et al., 2010; Sharkey & Sharkey, 2012), e.g. the European Convention on Human Rights. In our research, we choose to rely on this second deontological approach, where we consider ethical issues from the users' experience with regards to human rights rather than from an action-based or principle-based approach. Working with technology aiming to add value to the life and well-being of the elderly users, our ultimate goal with an ethical consideration is to address all issues that may prevent technology from contributing to the good of the user. This includes the impact and relevance of the technology, the expectations of the elderly, and the benefits and implications the technology has on the immediate surroundings (Coupland et al., 2009).

## 2.2 Research setting

Our empirical context is a local care home in Oslo administrated by Oslo Municipality, which is designed to include welfare technology as a part of the basic package delivered to all residents. The care home consists of 87 apartments, and the current average age is 83 years old. Through our collaboration with Oslo Municipality we have an arena at the care home where we can learn about elderly interacting with technology, as well as experiment with new technologies. All results presented in this paper were gathered at this local care home.

Our pool of participants is very close to equally distributed between the two genders, although there is a slight majority of women. All participants have had an active working life up until their retirement, although they have no clear similarities in their background. Some have partly relevant backgrounds which helps them relate to the discussion, e.g. nurses or engineers, although our previous studies have never demonstrated any significant difference in opinion due to prior professions. All participants have children, and all have been married at some point. However, due to their advanced age which spans from 74 to 98 years, most of them now live in widowhood. With a few exceptions, all apartments are built for single elderly, and rather than staying in a home which was once shared with children or former spouse, they now live in a new home tailored for their individual living. Most of the elderly are able to function relatively independently, although some residents require daily visits from the local home care unit as there is a variation amongst the participants considering their health situation. Common for all is that they are considered too healthy to move into a nursing home and that they have been cognitively cleared by the municipality office within the last year. However, some struggle with limited motor skills and rely on walkers or electric wheelchairs, while others suffer from dyspnea, e.g. chronic obstructive pulmonary disease. Due to their varying needs, different AT help them with their daily activities. Some use AT to help keep track of their medical history, while other rely on AT in order to stay safe.

Common for most residents is that they use AT to stay in touch with the outside world, e.g. long-distance relatives or friends outside the local care home. We have made strong efforts in order to ensure that our selection of participants includes all types of participants.

## 2.3 Studied technologies

In general, assistive technology (AT) is widely used to describe a set of technologies designed to help people with disabilities. The term is not tied to an age-specific group or to certain disabilities, and is often substituted with a more specific and contextually appropriate term, e.g. adaptive technology, rehabilitative technology or welfare technology. However, in the case of our empirical context, we have studied a set of technologies, ranging from commercially available assistive equipment to adaptive devices specifically designed for our particular context. The local care home is equipped with a wide range of devices and sensors, e.g. automated light-sensors, RFID-based door locks into private homes, motion sensors in living room and bedrooms, and prein-

stalled tablet devices in all apartments. Therefore, we use the umbrella term AT throughout the paper to emphasize how our results and findings are rooted in more than one type of technology. However, during our presentation of the data gathering, we refer to two particular studies, namely the task-based group evaluation of a tablet device and the usability testing of a future telecare system. The different technologies involved in these two particular studies are further explained in this section.

All residents at the local care home have been equipped with an 11-inch tablet with custom software tailored for their context. The municipality refers to this tablet as welfare technology, and the tablet assists them with their daily tasks, e.g. ordering food from the in- house cantina or providing overviews of internal and external events. It also includes social features that allow the elderly to make phone calls, have video conversations, use the Internet, and listen to the radio. The tablet can also serve as a hub for attachable health-monitoring equipment, e.g. pulse oximeter, blood glucose meter or medical thermometer, although these features are not yet made available at the local care home. The tablet is also used by the staff at the local care home to communicate with the residents. In a Nordic context, no similar acquisition has ever before been made by any municipal or governmental unit. As a result, there are no systems immediately available for comparison. While each individual technology may be compared to similar studies, we believe it is the ethical issues emerging from this combination of interacting technologies that is of interest. It also provides us with a highly unique empirical context and allows us to discuss ethical matters with residents, staff and external caretakers through the same piece of AT.

The second study we refer to during our data gathering, is our usability study of a future telecare system. This usability study is a part of an ongoing collaborative change experiment and includes the district home care unit, the staff at the local care home, and elderly residents who are dependent on daily visits. A set of tasks traditionally given through home visits, are now being delivered through the television. The elderly participants use their own televisions with a provided wide-screen camera to receive home care services, e.g. medical dosages, follow-up conversations and food instructions, at pre-scheduled times without having to rely on unscheduled home visit.

In contrast to these two studies focusing on a particular piece of technology, the open- ended inquiry methods, e.g. the group interview with the daytime staff, did not revolve around one specific implementation. Instead, the interviewees were told to discuss freely and voice their concerns independent of existing technological implementations, and consequently, these methods yielded ethical issues related to cases or examples that were not necessarily present at the local care home.

## 2.4 Data gathering

The study of already existing AT at the local care home provides perspectives on existing ethical issues. However, our ongoing experimentation with new and alternative AT involves elderly participants as evaluators, experts and co-designers, and allows us to capture their opinions regarding future AT as

well. We believe providing the elderly with an opportunity to voice ethical matters through evaluation of existing AT, as well as during the design of currently non-existing AT, strengthens the discussion. Certain ethical issues are directly rooted in the development process and the developers' underlying ethical views. By discovering ethical issues during the development process, improvement can be made to the development process which in turn may contribute to avoiding unfortunate side effects once deployed (Coupland et al., 2009).

The empirical data used in this study was gathered over a period of 15 months through four different methods as shown in Table 1. These methods are a part of a larger set of data gatherings during our ongoing long-term work in collaboration with Oslo Municipality. These four methods are based on four different approaches to data gathering, although they all allowed the participants to discuss issues they perceived as ethical. Our goal was not to give them a definition of ethical issues or present our own opinions on what constitutes as an ethical issue, but rather allow them to use their own experience and their own perspective as a starting point.

Table 1: Overview of methods

| # | Method | N | Collected data | Inquiry method |
|---|--------|---|---------------|----------------|
| A | **Task-based group evaluation** | 21 | Photographs, field notes, problem grading | Categorical labeling and grading |
| B | **Group interview with daytime staff** | 5 | Audio recording of interview, field notes | Open-ended questions |
| C | **Usability testing of a future telecare system** | 8 | Photographs, field notes, usability grading | Post-interview and observation |
| D | **Questionnaire on use of welfare technology** | 51 | Results from questionnaire | Employee summary |

The task-based group evaluation was conducted on the tablet device distributed to all residents of the local care home. The evaluation included a total of six sessions, three sessions with groups of elderly, two sessions with groups of employees, and one session with a group of HCI-experts. In each session, the participants were taken through steps of representative tasks and were given time to discuss each step in each task. They identified and graded the severity of each issue individually before engaging in a plenary discussion. Finally, all identified issues were labeled from a predefined set of categories, out of which one was labeled as "ethical". What issues that constituted as ethical were individually determined. In this method, we only presented the tasks, and we did not partake in the discussion or express any personal opinions; however, our presence allowed us to capture tension or disagreements that arose during the discussions. Altogether, this involved 21 participants, namely 11 elderly, 7 employees and 4 HCI-experts. We draw our results from all six sessions, as they all either elicited user problems regarding ethical issues or expressed privacy concerns during discussions.

The *group interview* was held with the five key employees at the care home, namely the daytime staff. They all interact with the elderly on a daily basis and serve as a first-line support for all issues the elderly encounter, including those of a technical nature. The employees were given a demonstration of the system by a representative from the vendor, and were then engaged in an open un-

structured group interview where they could elaborate on topics brought up during the demonstration, as well as other issues. This was done early after the introduction of AT in this care home, and the goal of the discussion was to collect and summarize issues reported so far. The open-ended questions allowed the employees to direct the discussion based on the feedback from the elderly, as well as issues they deemed important from their own perspective.

The *usability testing of a future telecare system* was conducted as a part of a collaborative change experiment where a two-way usability study was applied to capture the inter-dependency between the elderly and the homecare nurses. This involved making parallel observations on both sides of the interaction simultaneously. This data gathering presented the elderly with modifications to existing solutions and they were asked to grade certain aspects of the interaction, e.g. quality and experience of the service. In addition, they were engaged in an informal post-interview where they were asked to comment on the service's challenges and potential for medical and social care. We only asked for their opinions on general issues, and they themselves chose what elements to include. 8 elderly participants contributed to our study, and we also had one home care nurse assist us in the study.

The *questionnaire* was created by the administrative leader of the care home in collaboration with the employees. The answers were collected by going from door to door rather than using an electronic survey. The intention behind the questionnaire was to capture the experience and opinions on the residents regarding the use of all AT after one year of residency. The questionnaire mainly included closed-ended questions about their experience so far, e.g. use, training and knowledge, although it did allow the elderly to comment freely on each question. This yielded many interesting perspectives on issues that were not directly covered through the questionnaire, e.g. ethical aspects. The employees who collected the data processed and summarized the qualitative data from the questionnaire. Out of the 74 people who reside at the local care home, 51 elderly agreed to answer.

## 3 Results

The four methods presented in Table 1 yielded different types of data, ranging from structured severity-graded usability issues to informal comments captured during observations. Common for all the extracted data was that it included issues that elderly in one way or another perceived as ethical issues. Not surprisingly, the openness of our approach, i.e. not providing the elderly with any definitions, guidelines or frameworks, generated a highly unstructured data set from various sources. In order to organize our results, we analyzed the data thematically and then categorized our identified issues into four problem areas.

### 3.1 Data

The task-based group evaluation generated a list of 39 unique issues with the existing technology. Issues not labeled as ethical were discarded and we also cross-examined their identified issues with our observational data in order to correct for potential mistakes. All these issues were included in the analysis as related issues. However, some issues mainly labeled as something other than ethical, still generated discussions indicating it also being an ethical concern. Despite not being tagged as an ethical issue by the users themselves, we still found these apparent non-ethical issues to represent unforeseen ethical side effects of the introduction of AT, and as a result we chose to include these issues as partly related. The group interview was mainly captured through audio recordings and field notes. This generated a transcribed interview that in combination with our observational data was coded. The usability study of a future telecare system generated a list of 16 task-related usability issues, out of which none covered ethical issues. It also generated 14 non-task related issues where most of the issues were of an ethical nature. The post-interview after the usability testing revealed additional ethical issues. In the case of the questionnaire, the data from the 51 participants yielded a quantitative dataset with a summary of the comments from the elderly. We only kept the results from questions with unambiguously response; elements of uncertainty, i.e. questions with ambivalent answers, were not included. Data from this questionnaire was only used to support or contradict results from the three other methods, thereby serving as secondary data for primary data grounded in qualitatively verified results.
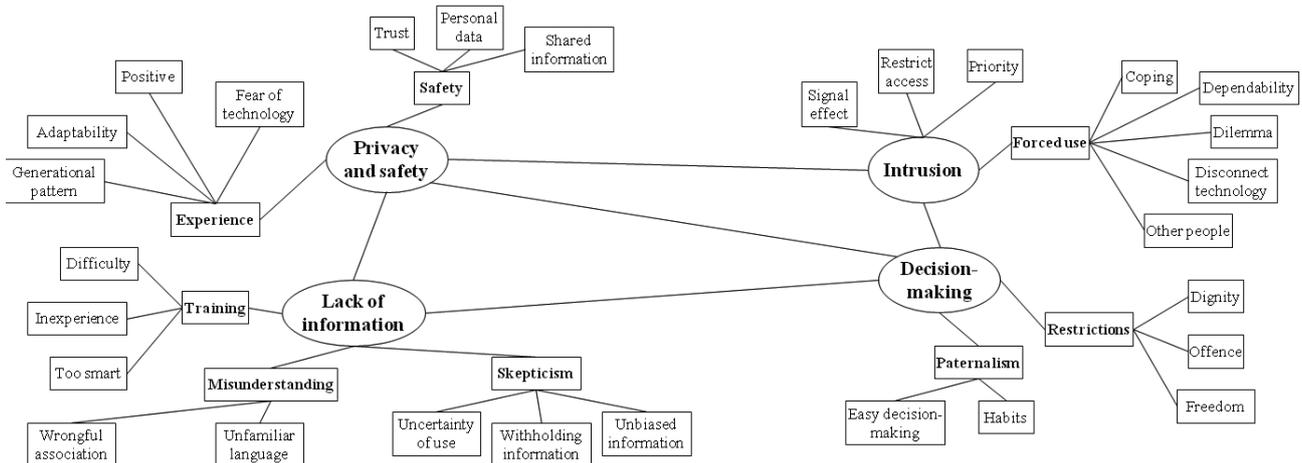
### 3.2 Analysis

We addressed the openness of our approach by applying a thematic analysis, and we followed the guidelines presented in (Braun & Clarke, 2006). Our data was not rooted in any predefined focus area, nor was it scoped down. As a result, we chose an inductive approach to the analysis. This provided us with the necessary freedom and flexibility to categorize the data. While it would be interesting to study the underlying views shaping the ethical standpoints of the participants, we did not consider our data material appropriate for a latent theme analysis; without a defined focus area or any in-depth data gatherings on particular ethical issues, we chose to limit the analysis to a semantic level.

Following the recommendations of Braun & Clarke (2006), we did not use quantifiable measures in order to determine our themes, nor did we require a minimum prevalence. Instead, we looked for the reported issues that the elderly themselves had labeled as ethical. The data from method [A] and [C] was already labeled, and all labeled feedbacks were gathered and filtered before the issues were clustered solely based on this labeling. The data from method [B] and [D] was coded and later added to the appropriate clusters. Since we wanted the meanings to emerge from the data, we chose an open coding rather than axial or selective coding. We did not look for any underlying ideas as one would expect from a thematic analysis at the latent level, but instead

focused on grouping the responses mainly to summarize the issues. As recommended by (ibid), we progressed from this descriptive grouping of issues to an interpretative theorizing of their broader meaning. As Figure 1 shows, four top-level themes hereafter referred to as four problem areas, emerged from this theorizing. All issues were categorized under the four problem areas, and they were labeled with the methods that brought forward the particular issue. The presentation of our findings revolves around these four problem areas.

Figure 1: Thematic analysis of the data



## 4 Findings

Table 2 gives an overview of the four problem areas elicited through the thematic analysis, as well as the main findings, from which of the four methods the data was gathered, and finally key observations or quotes.

Table 2: Overview of problem areas and findings

| Problem area | Main findings | Source method | Key observations or quotes |
|---|---|---|---|
| **Lack of information** | Do not understand own privacy concerns due to technological inexperience | [A], [C], [D] | Certain words (e.g. camera, sensor, monitoring) are associated with surveillance |
| | Have not been given enough training | [B], [D] | The language used is unfamiliar and confuse or misinform them |
| | Feel unwelcome to use | [A], [C] | *"The technology is too smart for me"* |
| | They believed the system may withhold important information | [B], [C] | *"Does the system know about the fire alarm before I hear it"* |
| **Privacy and safety** | Fear of certain aspects prevents use of the whole system | [A], [D] | Elderly taping over cameras with black tape |
| | Safety overrules privacy | [A], [C] | Safety and trust issues are perceived as more important than privacy issues |
| | Desire to turn off the system at a given time | [B], [C] | *"I want to turn off the device at night in the same way I turn off my cell phone"* |
| | Feel safer with the technology once they master it | [B], [D] | 50 out of 51 respondents in [D] expressed increased safety due to technology |

Table continues on next page.

| Intrusion | Fear of surveillance of personal information | [A], [B] | Many feel forced to choose between having contact with distant relatives and storing personal information in the tablet |
|---|---|---|---|
| | Lack the option to block outside calls or contact when no relatives | [A] | Miss option to disconnect the technology from the outside world |
| | Afraid of people not wanting to visit due to cameras in apartment | [A], [B] | *"Do I need to have a surveillance sign in outside my door"* |
| Decision-making | Does not facilitate for easy decision making | [A], [B], [C] | Often certain options are withheld from elderly who want those settings available |
| | Do not like it when other decide for them | [B], [D] | *"I was told that I have to have this option, even though I did not want it and will not use it"* |
| | Prevented from using old familiar technology | [A], [C] | The elderly are not given an option to choose devices themselves, and several people with familiar devices are unable to use them |

## 4.1 Lack of information

As some of the elderly more familiar with technology explained, the majority of the residents at the local care home were unaware of the consequences of using the technology due to their inexperience. They were mainly presented with the positive aspects of technology, and many elderly desired unbiased presentations that allowed them to consider their own privacy preferences with full information. Several elderly claimed that more training would increase their knowledge of technology, including security and privacy. We observed some confusion about privacy concerns based on either misinformation or wrongful understanding of technology. Firstly, some elderly wrongfully believed the AT to collect and store more information than it actually did, e.g. what data the sensors recorded, and secondly, there were some wrongful understandings about the difference between monitoring-on-demand and surveillance.

The AT in the care home was pre-installed for the elderly as a part of the basis delivery to all residents. While their intentions were to introduce the technology early in order to give the elderly time to adapt, this also deprived the elderly the opportunity to assess their own privacy concerns before using the AT. Since all systems were also set to one universal predefined setting, there were no guarantees of each resident being truly informed. For many elderly who were new to technology, discovering personal privacy preferences took time and they did not feel mature enough to make important decisions regarding privacy. We also saw cases of elderly having very clear opinions about sharing personal information or monitoring of activity, without being able to articulate their views from a technological standpoint.

## 4.2 Privacy and safety

For most of our participants, privacy concerns were not among the issues that directed the decision on whether to adapt new technology. Rather, safety and trust issues drove the decision; privacy was not regarded as a noteworthy concern. For most of the elderly, it was not a matter of being observed or not, rather who the observer was. They regarded monitoring as something positive

and safety enhancing. In most cases, they perceive the monitoring devices as something friendly rather than scary. If a worried daughter was watching over her old father's movement outside when it was cold and slippery, they understood that as care rather than surveillance. There were also cases where the necessity of the device claimed superiority over privacy concerns. Several of our participants had passed 90 years and safety issues were so prominent that they overshadowed ethical aspects. When introduced with

alarm mechanisms or alert systems, the elderly began to ask questions about who sat in the other end to respond to the alarm. Firstly, they needed confirmation that all alarms would be immediately answered, but secondly, and more importantly, they needed to know that the person responding was a trustworthy person. We have found trust to be such a strong factor in the decision making of the elderly, and we see clear signs of elderly regarding trust and safety as much more important than privacy concerns.

While the abovementioned case reflected the view of the majority, our results also indicates contradicting views and preferences, namely from those who were able to articulate their own privacy concerns. One of the participants who expressed a concern regarding breach of privacy claimed that the elderly as a generation were unable to understand privacy violations, and therefore had no particular opinion on the matter. Lack of system control was the one common issue among those who expressed concerns regarding privacy violation; it did not allow them to use the AT as they desired. Firstly, lack of control prevented them from having any explicit way to turn off the system, something many preferred to do at nighttime. Secondly, the two ATs tested in [A] and [C] from Table 1 did not allow the users to regulate individual aspects of the system. Both solutions included a camera, and several elderly did not want to use the camera, which they perceived as obtrusive. As there were no options labeled "disable camera" in either of the systems, they felt that they had no control over when the camera was turned on. However, this was not only a concern for the non-users of the camera feature; it was also an evident concern among some of those who did use it. One participant explained how he after use would cover his camera lens with black tape to "turn it off". We hold their argument as valid; when engaging in a real-time video dialogue, e.g. with the home care service, the elderly can no longer control which information is being shared and not.

## 4.3 Intrusion

Besides issues concerning matters of privacy when using the system, there were also issues reported on forced use, i.e. not having an option to withstand from using the technology. This was experienced as an intrusion as several elderly reported that they felt the technology forced itself upon them, even into their own homes. The elderly expressed concerns with the inability to isolate themselves from undesired technology. It was preinstalled in their homes, and some of the technology could not be physically removed, e.g. the sensors and the wall- mounted chargers. In addition, several services at the local care home were built around the technology, thereby forcing the elderly to cope with the technology. The elderly who felt forced to use the technology said that they had

no option to "disconnect" from the technology. Several elderly also mentioned that they were forced to accept undesirable circumstances during their involuntary use, and that they were forced not only to use the technology, but also to accept privacy violations they felt uncomfortable with.

Firstly, some elderly did not have any close relatives from whom they expected to receive calls. As a result, they did not want their assistive technology to be accessible for anyone outside. They expressed a desire to use the technology to help them with their daily activities without exposing their presence to the outside world. As the system depended on remote services, it was not possible to restrict connections only to local facilities. Since the whole residency was built around this system, it became difficult for them, for some even impossible, to refrain from using the AT. They felt compelled to use it on terms to which they did not agree.

Secondly, several elderly strongly disliked that the system gathered information about them, e.g. their whereabouts and their activities, even when they specifically did not want the system to do so. However, they were very aware of the fact that if they chose not to share their private information, they would not be able to use the system for communication purposes, most notably calling and video conferencing with their distant family. In the previous case of elderly having a positive outlook on privacy concerns, it did not matter that the elderly chose to prioritize trust and safety over privacy, because there were no contradictory or conflicting circumstances. In this case, the elderly had obvious privacy concerns, and suddenly it became a forced dilemma. Common for this case was that the need for privacy was overshadowed by the need for communication; consequently, most of the participants reported that they held the need for communication of such a high importance, that they would accept their privacy being violated. This exemplifies how elderly using AT often cope with privacy concerns because these important concerns are overruled by other, even more important, considerations; and when forced to choose between "our way or the highway", they silently accept.

A final observation is that elderly might have an opinion on privacy issues rooted in other factors than a sense of personal violation. One elderly woman asked us whether she needed to put up a surveillance sign outside of her door; she worried that her neighbors would stop visiting because of the sign.

## 4.4 Decision-making

Several elderly desired more freedom than what the system currently allowed. They felt competent enough to make decisions, although expressed concerns with the system not allowing them to do so; this made them feel restricted regarding both freedom and challenge. Several elderly had previous experiences with technology as regular users rather than as marginalized elderly users.

There were also cases of elderly reporting offensive built-in limitations. One of the elderly even described the system as downgraded to a restricted level of access similar to childproofed systems. For many elderly, being active was central in retaining their voice in society. While the elderly often refrained from using equipment that openly signaled fragility or dependability, we ex-

perienced the AT to discourage use on a personal level. The elderly residing in the care home are very aware of their own capabilities, and some felt insulted when the AT assumes them to be either cognitively weaker or less familiar with technology then they actually were. For systems that rely on one or few levels of user capability, the threshold is usually set very low, thereby ignoring those who want to use the system like regular users.

## 5 Discussion

The elderly participating in our research reported a vast amount of issues on privacy. However, they all seemed to have very different perspectives on what constituted as a violation, and how severe they deemed it. Issues characterized as a severe problem by some was not mentioned at all by others. Rather than looking at privacy in the traditional definition, i.e. a *"state in which one is not observed or disturbed by others"* (Zwijsen, Niemeijer, & Hertogh, 2011), we will look at privacy as something more nuanced in our discussion; something not objectively measured, but instead something unique and personal to each user. Our findings indicate that rather than being bound to the technology or rather than being tied to the cognitive or medical condition of the user, the privacy issues are bound to the context in which they are used. Instead of guaranteeing that the state is keeping a secret or out of reach of others, we should instead aim for an *"appropriate flow of personal information"* (Nissenbaum, 2009). With this understanding of privacy in context in mind, we use our empirical findings and related work to discuss why we believe considering *adaptability*, *patience* and *openness* might help us tackle some of the current ethical challenges with AT.

### 5.1 Encouraging patience

As our findings show, it took a while for the elderly to identify and articulate their own needs concerning privacy. Having lived at the local care home for less than a year, they still needed time to adapt to their new everyday life. In our understanding of privacy issues being tied to the context, we see why they needed time to discover these needs. Through our 15 months of fieldwork, we have witnessed many elderly slowly recognizing and finding the ability to articulate their needs own needs from a contextual perspective. Gramstad, Storli, and Hamran (2013) describe a similar process from their own research as a "prolonged and subtle" process. We also see elderly approaching AT very carefully and hesitantly as they try to find the appropriate balance between the technology and their own vulnerabilities. Luckily, we experienced early adapters having a positive effect on the more hesitant users as it gave them a sense of relief that their peers adapted so easily. Besides this, we also need to maintain patience in order to prevent rushing or forcing the technology on the elderly. In a rushed situation, caregivers or other involved parts may be the ones "un-silencing" and articulating the needs on behalf of the elderly (Gramstad et al., 2013). While this is often perceived as positive as it gives a voice to unaddressed needs, the caregivers might not be able to interpret the needs

correctly, and their proxy voice might not articulate the needs entirely. This may eventually disturb this appropriate flow needed to ensure that personal information is handled correctly. Other elderly felt that the pre-installed technology was being forced on them before they were ready. This resulted in them refusing to use the AT, and we have seen examples of elderly stowing away AT in cupboards and drawers. A final reason for encouraging patience, as well as adaptability, is that as time goes by, new ethical considerations emerge. Over time, the gradually declining cognitive and somatic abilities of the elderly will eventually bring forward new circumstances that might influence their privacy preferences, or alter their ability to express or even have such preferences. Acute short-time care include different ethical considerations than long-term care; the former focuses on medical treatment and healing, while the latter face challenges related to deterioration rather than cure (Van der Dam, Abma, Kardol, & Widdershoven, 2012).

## 5.2 Encouraging adaptability

In our empirical context, most elderly are expected to live with AT for at least a decade. We consider adaptability to be an extremely important factor in guaranteeing that ethical concerns are continuously protected throughout the period, where needs and preferences is expected to change over the coming years. As the people and the technology change, the context in which privacy issues are assessed also changes. Elderly who might seem satisfied with the technology today, might not feel the same once the surrounding circumstances changes. Regardless of the perspective and focus, common for all related work presented in this paper is that they all support our idea of adaptability as a necessity in well-designed AT.

However, most of them bring in adaptability in order to adjust to declining somatic, cognitive or medical conditions, and they do not discuss the personal ethical preferences of the elderly. We encourage adaptability in order to ensure that elderly can use AT depending on their own preferences, rooted in the context of use.

Our findings suggest that the privacy issues do not lie in the observation itself, but rather in who the observer is. The questions should not be of a binary kind, e.g. whether they are observed or not, but instead more nuanced, e.g. when it is acceptable to be observed or who the observer is. Most elderly felt comfortable with being observed in some scenarios, e.g. with safety alarms, even though that involved monitoring. In fact, observing itself might be perceived as something positive in some cases, like in the case with the safety alarms or as exemplified through the literature (Essén, 2008; Zwijsen et al., 2011). Similarly, the question of whether one is disturbed or not is decided on a subjective level in a given context, and we need to recognize individual thresholds of what constitutes as privacy. In order to do so, it requires us to shape technology in such a way that it can adapt to personal and circumstantial preferences. When privacy is implemented as something reacting to individually-bound contextual preferences, we may create new use scenarios that would otherwise constitute as privacy violations. This will also allow those who are truly dependent of technology to use it in a way that would otherwise consti-

tute as a privacy violation, e.g. by allowing family members to monitor outdoor activities. Correspondingly, literature also claims that for some elderly, safety aspect may claim superiority over any ethical dilemmas, e.g. privacy concerns or restriction of integrity (Rosenberg et al., 2012; Zwijsen et al., 2011).

Bringing in contextual integrity also allows us to understand why some elderly reported an imminent danger of non-adaptable AT not meeting them on the level of autonomy best suited from both an ethical and medical perspective. Some reported the AT as very complicated, while others claimed it to be oversimplified and insulting. Common for these participants was that they missed working with a system that was suited for them, namely their cognitive and bodily capabilities. Even though they did not mentioned it explicitly themselves, their concerns are similar to those of Rosenberg et al. (2012), who discuss the potential negative effects of oversimplified technology, where stigmatization is a possible consequence of directing, limiting or forcing decisions. This also became an autonomy issue, as the elderly felt they were not given enough freedom and challenges to keep functioning as active and independent citizens. As many of the elderly stated, they were used to getting daily brain exercise from the systems they were used to, and they had to bring in their own equipment, e.g. a laptop, because the assistive technology was too oversimplified for them. Also from the perspective of paternalism discussed by Martin et al. (2010) and Harrefors et al. (2010), AT should aim not to make decisions on behalf of fully competent elderly.

## 5.3 Encouraging openness

Honesty and righteousness are both fundamental principles, as is keeping a promise. This implies that we avoid giving illusions about how AT inevitably will make their life better. Several elderly mentioned not being able to make informed, un-coerced, decision by themselves due to limited and one-sided information. Others said they felt that decisions and regulations that affected their lives were being partly hided from them. This was an important part of maintaining independence and influencing their lives. We encourage openness to help elderly understand AT not from the moment it is presented to them as users, but instead from when the decision to acquire AT is being made. Allowing them to partake in the decision, or at least being informed about it, may create forces of mutual learning where the openness help those accountable of the technology to understand from the perspective of the elderly.

As we experienced, some of the elderly being directly confronted with questions about ethics had very clear opinions on e.g. privacy or safety, similar to the research of Ziefle et al. (2011), although they had no channel to speak through. In one case, an elderly woman claimed that privacy needs assess on her behalf, i.e. who should have access to her personal information, were not to her preferences; it was just closest to her preferences. As pointed out by Zwijsen et al. (2011), the most preferred option for the elderly is not necessarily the ethically correct choice, it might just be the least bad option; sometimes the privacy context brings forth a willingness to sacrifice privacy for safety. And that was also the case with woman who wanted her to share information with her family because she believed it increased safety. However, the main ar-

gument for encouraging openness should still be the opportunity to influence your own life; as Eek and Wressle (2011) mention, maintaining dignity and integrity are of uttermost important to the elderly. Wright (2011) points out that to maintain dignity, the elderly must be given the opportunity to directly influence the policies that eventually affect their lives.

Many elderly also express concerns about ending their days in a dystopia where human contact was replaced by sensors and systems. As providers of technology, we also have a responsibility to be open about potential privacy and trust issues that may arise along with the new technology in the future. While not removing human contact, they might still find themselves in situations where their autonomy or privacy is being compromised or violated, e.g. shift of agency from the elderly to sensor data over which the elderly possess no control over or are not necessarily aware of (Mort et al., 2013). Similarly, information about ourselves that we currently do not regard as private or sensitive could suddenly become so the moment it is combined with other seemingly innocent information about us. As more and more information about us is gathered, the imminent danger of compiling all this information also increases.

## 6 Conclusion

There are still many general ethical challenges remaining with AT, and as the development of technology moves on, new ethical issues are likely to emerge. We experience that while the elderly might misunderstand aspects of the technology, and thereby believe it to be more in violation than it actually is, the resulting feeling of violations is still real; they experience it in the same way as if they were correct in their claims. We encourage a continuous focus on ethical challenges when introducing AT, because the moment we lose focus on the ethical aspect of AT, we might just experience how close it is from a state of delight to a state of harm.

In this paper, we have reported from a study where we gave the elderly a chance to express ethical concern from their own perspectives, and thereby brought attention to some of the challenges currently experienced with AT. We have based our findings on data from four different methods being thematically interpreted and analyzed. Rooted in our empirical data, we have discussed four problem areas concerning some of the ethical consideration with AT, and we have discussed how we believe these should be handled. By encouraging patience, adaptability and openness around AT, we believe that the technology will be better suited to tackle some of the ethical challenges presented in this paper.

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