What Is Privacy? Perceptions of Older Adults in the South of Spain About the Concept of Privacy and in Terms of Video-Based AAL Technologies

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Abstract: Privacy is a very complex concept that concerns all areas of human activity. Even more so, it has acquired whole new importance and has become a hot-button topic in the era of ubiquitous computing. The emergence of Active and Assisted Living (AAL) technologies is offering the improvement of the quality of life and maintaining the independence of older adults in their preferred environment. Especially with the advancement of computer vision, video-based technological solutions are giving us promising results but bring along significant risks of privacy violation. With this qualitative study, we aim to explore older adults' understanding of privacy as a construct and their privacy considerations for technology-based monitoring applications in eldercare, for video-based systems among them. Exploratory interview sessions were conducted with 12 older adults 66 and plus of age living in care homes and in private households. Findings indicate that the concept of privacy is indeed difficult to understand and define for older adults. However, the context of video monitoring elicits clear privacy concerns. The nudity aspect of privacy was proved to be the most important among the participants, yet, the attitudinal shift in the perception of nudity was observed in older adults living in care homes. Eight out of 12 interviewed older adults did not like the idea of having a camera-based assistive technology, however, some of their worries were alleviated after explaining to them the possible technology's inherent privacy-preserving techniques.

1 INTRODUCTION

Privacy is a basic human need (Altman, 1976; Doyal, 1997) and it spans all areas of human activity. For that the concept of privacy is notoriously known as very difficult to define (Price and Cohen, 2019). Even more so, the technological era has given a whole new meaning to privacy (Hartmann et al., 2022; Koo et al., 2020). Modern technological solutions, such as Active Assisted Living technologies, provide great benefits in healthcare and at the same time posit a risk of violating privacy. Computer vision advancements gave rise to visual sensing based AAL solu-

tions which are further advanced as they register a great deal of information compared to other sensors, and allow the analysis of complex scenarios. Hence, camera-based technologies offer way more flexible and adaptive solutions to providing care (Colantonio et al., 2018). With the great benefits of visual data processing, risks for privacy and data security come into play, as visual information can be quite sensitive from a technology user perspective. In response to this, privacy-preserving smart solutions are emerging. The Privacy by Design paradigm in technology allows data protection through inherent technology design (Schaar, 2010). Under this framework different visual privacy preservation filters are being developed for video-based AAL technologies (Climent-Pérez and Florez-Revuelta, 2021; Ravi et al., 2021).

On the other side of these technological advancements is the user perspective. Privacy concerns are

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thought to be one of the main factors affecting the acceptance of the AAL or technology for aging in place (Peek et al., 2014; Schomakers and Ziefle, 2018; Wang et al., 2019). However, this statement is a rather simplification of this matter as there are far too many variables playing a role in this process. A recent study carried out on 1296 Dutch older adults demonstrated that participants appraise aging in their preferred home environment as a valid trade-off for some loss of privacy, despite having significant privacy concerns (Jaschinski et al., 2020). Another recent study went even further demonstrating that privacy concerns are not as prominent as are benefits of assistive technology use and revealed its less impact on acceptance.(Schomakers and Ziefle, 2019). However, there is a big variety of key factors playing a role in these findings, such as age, cultural background and necessity for assistance in the participants, as well as the technology in the focus of these studies, and the investigated dimensions of privacy. Understanding and measuring the concept of privacy already presents a big challenge in the technological context (Hartmann et al., 2022).

The aim of the study is to execute primary exploratory interviews to understand what privacy means for older adults, and what implications it has in relation to active assisted living technology in a Spanish population. We are specifically interested in knowing how older adults define privacy as a concept, in relation to their lives, and in relation to AAL technology; What are their attitudes toward AAL technology and Video-based AAL technology (VAAL) specifically and how does it affect their privacy?

2 METHODS

In order to explore the research questions under the topic of privacy, a qualitative methodological framework was developed, encompassing primary exploratory interview sessions with older adults. The study was approved by the ethical committee of the University of Alicante.

2.0.1 The Sample

The interview sessions were conducted with 12 older adults, 66 and plus of age in the southeast of Spain. The recruitment of the participants was organized using the help of the case manager from a healthcare center in Alicante, Spain. A purposive sampling technique was used to identify respondents in a way that fitted the different sociodemographic profiles. Half of the respondents were from care homes and half were from private households in the Valencian province of Spain. Further sociodemographic characteristics of participants are displayed in Table 1.

2.0.2 Data Collection and Analysis

Potential respondents from private households were contacted by their health center case manager and were informed about the aim of the study. The contact information of those who agreed to participate was forwarded to the researcher who then followed them up to schedule interview sessions. Respondents were visited in their own living spaces by the interviewer. With the consent of the care home manager researcher also visited the care home to interview older adults living there. Each interview session started with the introduction of the study aim, reading the information sheet and was followed by the signing of the consent form. All interview sessions were audio-recorded. Each session lasted from 30 to 45 minutes. Interview sessions were then transcripted and the obtained data were analyzed with thematic analysis (Vaismoradi et al., 2013) using a MAXQDA 2022 qualitative analysis software package (VERBI Software,).

2.0.3 The Interview Guide

The interview guide was divided into two category questions: Privacy and Assistive Technology.

In the first part, questions about the concept of privacy were asked and different aspects of privacy were discussed. Respondents were presented with different dimensions of privacy (Physical, Psychological, Social, and Informational Privacy) originally described

Table 1: Sociodemographic characteristics of the participants (n=12).

Age: Median [Min, Max]	77 [66 to 88 years]
Sex	8 Females
Education	3 University graduates, 9 high school graduates
Comfort with Technology: Median [Min, Max]	1 [1, 3]
Health Condition: Median [Min, Max]	4.5 [1, 8]

Comfort with Technology and the Health Condition were measured with simple Likert-like self-assessment scales from 1 to 10.

by Burgoon and Parrott (Burgoon, 1982; Parrott et al., 1989), and were asked to define them. These dimensions with the author-provided definition are given in Table 2. We decided to add Nudity as a separate aspect of the Physical Privacy dimension as nudity seems to be a very important aspect of privacy, especially in the AAL and medical care context (Maidhof et al., 2022; Pupulim and Sawada, 2010), and it shall not be integrated into general Physical Privacy. Apart from the four dimensions of privacy we also added Bystander privacy as the fifth construct, as it comes as an important player in terms of video-based AAL technologies (Chowdhury et al., 2016). After the initial discussion about privacy dimensions, respondents were provided with the author's definition for each dimension and were asked to rate on a Likert-like scale (Jebb et al., 2021) how important each aspect is for them from 1 to 5, where 1 means "it is not important at all" and 5 means "It is very important".

In the second, part participants' attitudes toward AAL technology (camera-based among them) in terms of privacy were investigated. Participants were asked about their knowledge and experience with AAL technologies. The description and examples of these technologies were given to the participants when necessary, from simple emergency alarm buttons to highly elaborated video-monitoring systems. Their attitudes about privacy were studied and the privacy-preserving filter mechanisms in the case of the video-monitoring system were explained to them.

At the end of the interview, together with the sociodemographic data, respondents' comfort with technology and their health conditions were measured with simple Likert-like self-assessment scales (Jebb et al., 2021): "How would you evaluate your comfort with technology in general (e.g., Smartphone, Laptop, PC, tablet) on a scale from 1 to 10, where 1 means - I am very uncomfortable and 10 means - I am very comfortable"; "How would you evaluate your current health condition on a scale from 1 to 10, where 1 means - I am in very poor health and 10 means - I am in very good health". Participants were also asked to indicate if they had any previous experience with AAL technology.

3 RESULTS

Participants' characteristics are summarised in Table 1. We have used medians for descriptive statistics, as medians are likely to be more appropriate than means in a qualitative study reporting (Bazeley, 2004). Comfort with technology, measured with simple Likert-like self-assessment scales (from 1 to 10, where 1 means - I am very uncomfortable and 10 means - I am very comfortable) was quite low, (M=1.8; Sd=0.8) in the sample. Three out of 12 respondents have had previous experience with the Red Cross Alarm Button, none of them had any previous experience with video-based AAL monitoring systems and one participant knew someone who has had such an experience. Findings from the interview sessions are summarized in the two sections below.

3.0.1 What Is Privacy?

Most of the participants had a hard time answering the question – "What is privacy for you, how would you define it?". Eight out of 12 participants could not understand what is privacy at first and needed further explanations for it. Three participants (P.1, P.3, P.8) have mistaken the word "privacy" for "deprivation" ("Privacidad" for "Privar" in Spanish) and required more clarifications as well. Then again, after further explanations, they came up with their way of defining privacy: "Privacy for me is that no one from the street gets into my private things" – P.11. Some participants came up with even more elaborate definitions of it: "For me, privacy means that my personal data is not

Table 2: Privacy Dimensions (Burgoon, 1982; Parrott et al., 1989).

Physical privacy	The degree to which one is physically accessible to others.
Social privacy	Individual's ability and effort to control social contacts.
Psychological privacy	The ability of human beings to control cognitive and affective inputs and outputs, to form values, and the right to determine with whom and under what circumstances they will share thoughts or reveal intimate information.
Informational privacy	Individual's right to determine how, when, and to what extent information about the self will be released to another person or to an organisation.

used in an opportunistic way so that people can not take advantage of certain things, that nobody interferes too much in my life... so that it is respected and so on..." – P.12. P.6 gave us a very interesting perspective: "Privacy means that I am independent, but actually I am not anymore, my privacy would be to do things by myself, but I can not anymore, they [care home nurses] have to help me - I can't take a shower by myself."

Respondents were also asked to define different privacy dimensions i.e. Physical (Nudity as a separate dimension of it), Psychological, Social, Informational Privacy, and Bystander Privacy. Just like about privacy definitions, most of the participants had a hard time thinking of what could mean each dimension of privacy and coming up with examples around it. After the initial discussion about privacy dimensions, respondents were provided with the author's definition for each dimension. The median ratings of the importance of each dimension (measured on a Likert-like scale from 1 to 5, where 1 means "it is not important at all" and 5 means "It is very important") are presented in Table 3. Nudity was rated as the most important across the participants among the presented dimensions and Bystander Privacy was rated as the least important. Because of the qualitative nature of the study and the small sample size, it was not possible to calculate if there was a significant difference in the ratings of privacy dimensions between the participants from a care home and the ones living in private households. However, it is key to note that there was a big difference between those two groups of participants in attitudes towards privacy dimensions and privacy in general, as expressed in the conversations: five out of six participants from care homes noted their perception shift about nudity and physical privacy since they moved to the care home: "What can I say about nudity, here they [care home nurses] wash you every day - the girls, the boys [nurses]. Do not think I liked it so much at first! but then I got used to it, now I don't even pay attention to it"- P.3. "There is no privacy here"- P.4.

3.0.2 Privacy in VAAL Technologies

The second set of questions of the interview was dedicated to understanding the participants' attitudes toward AAL technologies - video-based ones among them. Participants were asked if they knew what is assistive technology, after which further explanations and examples were given on the AAL technologies, and inquiries about their perceptions were made.

All participants saw assistive technologies as a generally positive thing, however, two of them raised trust and data security concerns: P.1 - "I don't like it when they tell me one thing and do another, it happens in every system, in banks too, what if this is the same", P.12 - "As long as data is used for good it [assistive technology] is fine, but if they take advantage of the data then no. For example, you pay for internet and then they use your data you don't know how". P.12 also raised a concern about the fact that access to assistive technologies can be problematic: - "Sometimes you have to go through so many bureaucratic procedures that in the end, it is not worth it".

Speaking of camera-based ALL technology, eight of 12 participants did not like the idea of having a video-based assistive technology for themselves. However, some interesting trends came out in the conversation. Three of those eight participants saw camera-based systems as favorable in general, but they said they do not need it just yet. P.1. – "The camera is a good technology, nothing against it, emergency help possibility is the biggest advantage of it in case something happens to someone, but I don't need it". Participants' reasons for not wanting to have a camera-based assistive technology were mostly privacy associated: P.2. - "Cameras are seeing everything, I don't like it"; P8. - "I prefer not to have the camera in my room, for example, if I am taking a bath and they are always looking at me, no, no, in my private space they do not interfere!"; P9. - "In a camera, everything is shown"; P.11 - "What I don't like is that they know who you are, it scares me, cameras take away your privacy"; P.12 - "It takes away a lot of your intimacy, they can see if you are taking a shower, if you are dressing". P1. Also raised a concern about

Table 3: Ratings of each privacy dimension (How important is it for you from 1 to 5).

Privacy Dimension	Median	[Min, Max]
Physical Privacy	3	[2, 5]
Nudity	4.5	[2, 5]
Social Privacy	3	[2, 4]
Psychological Privacy	4	[2, 5]
Informational Privacy	3.5	[1, 5]
Bystander Privacy	2.5	[2, 4]

feeling ashamed of having a camera: - "It [camera] would be a shame for me, what do I tell others?!".

Interestingly, two of the eight participants who did not like the idea of having a camera-based assistive technology at first, changed their ideas after having explained to them about so-called Privacy Filters, which anonymize obtained visual information: P.10 - "I would accept cameras that cover my body, but that is very difficult to do right?! But I would accept this". Participants felt more secure about using camera-based technology with privacy filters, however, trust issues were also raised: P.11 - "I would always have doubts if they are really doing what they have told me [in terms of using privacy filters] or if they are using your data. You can tell me that I see this [anonymized images], but how can one be sure?". Two participants noted the difficulty of reasoning about such technologies when they have never seen it: P.3 - "But here there are no such systems and how do I imagine it". P.9. - "If I have never touched it, I have never seen it, what do you want me to tell you".

Four of the eight participants found camera-based assistive technology acceptable from the beginning, even if one of them (P.4) said that: "The feeling that you are being watched is uncomfortable". Interestingly, all those four participants live in care homes and are above 80 years old. P.5 had a previous history of falls and had an experience of using an emergency button. She found the fall detection ability of the camera-based system very advantageous: "Camera will be for good, if I fall, I don't have to think about anything". P.7 expressed that he would not mind being watched with a camera because: "They [cameras] are watching me to help me". P.6 from the care home also shared with us an interesting view in terms of privacy: "I do not see anything wrong with cameras, I no longer have the freedom of no one seeing me in the bathroom, for example, so cameras would not violate my privacy". It is important to note that a contrasting view also was presented by the P.3, when he noted that: "Here there are always the same girls or boys [nurses at the care home] and you are already used to it and with cameras, I wouldn't be at ease because everybody sees you".

4 DISCUSSION

Findings indicate that the concept of privacy is not readily understandable for older adults, however when mentioned in the context of video-based monitoring systems, then they do get alarmed. Hence researchers shall be very cautious when measuring this construct. It was very surprising when three respondents mistook the word "privacy" for "deprivation" ("Privacidad" for "Privar" in Spanish), however, interestingly enough, the etymology of the term "privacy" can be traced back to the Latin words "privatus" (Curtin, 1981) and "privo", meaning "to deprive" (Rawnsley, 1980). Its original usage pertained to the military term "private," which denoted the act of being deprived of status or rank '(Leino-Kilpi et al., 2001). This has been a very thought-provoking coincidence (or not a coincidence) which has led us to think that one´s privacy is indeed a very sensitive matter which can lead to a loss of power and status ("to be deprived of status or rank") when compromised. This historical connotation of the term prompts contemplation on the nature of privacy and the potential consequences of unwanted access. The concept of privacy is closely intertwined with the notions of autonomy, influence, and independence. With further studies, we wish to inquire whether privacy and independence lie on the same continuum or are oppositional in terms of AAL technologies. On one hand, participants stated that privacy for them means independence, but they no longer have the autonomy of privacy. On the other hand, modern technologies seem to be offering us increased independence at the expense of risking privacy. Hence, the question is, can technologies guarantee data security and privacy together with increased independence.

Interview sessions demonstrated that nudity can be one of the most important aspects of privacy for older people, however, perceptions of nudity defer between people living in their private households and care homes - with the latter group stating that they already do not have the physical privacy. Likewise, people from care homes tend to be more accepting of video-based AAL technologies, which again could be associated with the existing lack of privacy in care homes. However, we need to be very careful with this statement and further studies need to be done to closely understand this matter. Findings indicate that data security and trust are the main issues with the AAL technology and admittedly in the VAAL systems privacy comes into play. Interviews also showed a positive attitudinal shift for VAAL once visual anonymization was offered to the respondents. However, they reasonably stated that it is very difficult to imagine mentioned privacy filters without at hand experience.

This exploratory qualitative study comes with a lot of limitations associated with the chosen study design and not only. The sample size is fairly small (n=12), even if this was a pilot study and we conducted the interviews until the saturation of informa-

tion was reached. The sample is from a small urban area in the south of Spain and cannot be generalized to a bigger population and cross-culturally. Participants of the interviews did not have any direct contact or experience with the AAL technology they were interviewed about, nor about the proposed privacy filters, they were simply given explanations of it. However, this study has been insightful in grasping what older adults understand about the concept of privacy and AAL technology as the first stage. This leads us to future studies with a more sophisticated methodology and integrated at-hand experience with the proposed AAL technologies.

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