Northumbria Research Link

Northumbria
University
NEWCASTLE

University Library

Functional privacy concerns of older adults about pervasive health-monitoring systems

Andrew McNeill, Pam Briggs, Jake Pywell, Lynne Coventry

Northumbria University

Newcastle upon Tyne

{andrew.mcneill, p.briggs, jake.pywell, lynne.coventry}@northumbria.ac.uk

ABSTRACT

Technologies designed to support ageing can be deemed to be ageist in that they often exhibit a benevolent paternalism that tries to 'protect' older people. Often this involves gathering extensive data to monitor physical and cognitive decline at the expense of an individual's privacy, with an underlying, often implicit, assumption that older adults no longer need much privacy. We consider such issues in the context of a project which seeks to promote the well-being of older adults. We conducted interviews with 20 older adults (10 males, 10 females, mean age=73) to ask, under what health and wellbeing circumstances would they wish to protect their privacy?

Using thematic analysis, we uncovered six distinct reasons why older adults want to maintain privacy: protection from harm, autonomy, to present a positive social identity, to break free from social norms, to protect others, and to protect their own self-concept. We conclude that privacy is a highly valued resource for older adults and one that enables them to live fulfilling lives. We consider the design implications of our findings, noting that designers should aim to protect privacy from the outset, rather than viewing privacy as a 'bolt-on' that would inhibit data collection under specific circumstances. These concerns speak to the 'paternalism' agenda, in that older adults should be considered as active agents in the management of their own data disclosures.

CCS Concepts

• **Security and privacy~Social aspects of security and privacy** • **Social and professional topics~Seniors**

Keywords

Privacy; older adults; online social network systems; ageing; health

1. INTRODUCTION

Pervasive health-monitoring systems are an increasingly viable way of observing the health of older adults. This is especially the case when older adults live alone and friends or family seek to ensure their wellbeing. Family members or caregivers may wish to keep track of the wellbeing of their relatives or patients and the ready availability of devices such as smart watches, wireless video cameras, and location trackers means that there is no shortage of technologies to do this. Researchers continue to explore the potential of smart homes [6, 7], for example, as they look to a future where the living environment continuously monitors health information.

Nevertheless, in the desire to help older adults, designers may inadvertently be paternalistic in their approach to the needs of older adults. One of the ways this is manifest is in the design of systems that fail to consider the concerns of older adults. If information systems can be "racist", then it is fully possible that systems can be "ageist" in similar ways. In the case of "Tay", the bot that ended up tweeting racist statements, the issue of agency and who was responsible was brought to the fore and some argued that the system developers were at least partly responsible [16]. Others have argued that algorithms used in information systems can be intrinsically unethical [21]. So, can a system be ageist? Well, if the designers of such systems do not pay attention to the concerns of older adults, or worse, design systems that treat them in discriminatory ways, then there is grave cause for concern.

Our concern is that some developers assume, sometimes without asking, that while older adults desire to live independently, there is a need for some kind of health supervision in order protect them from harm. Further, that this need for protection outweighs any need for privacy. This results in the design and implementation of technologies which inadequately protect the privacy of older adults. While such technologies might have the best of intentions (i.e. promoting the wellbeing of older people), they can end up treating them as merely passive subjects whose privacy can be disregarded. Various technologies, from smart homes to location and fitness trackers, now exist to monitor and hopefully improve the wellbeing of older adults. Many of these technologies requires extensive tracking of user data to assess the wellbeing of the user. However, this can assume a very passive role for the older adult user in the sense that they provide all their data to the system without any active role in managing that data. We argue that older adults need to be considered as people with a real interest in continuing to preserve their privacy. They want to have control over their own information.

1.1 Research context and system

In the ACANTO project, we are developing an online social network for older adults that will link together people with similar interests. The aim of this system is to support older adults to live independently but maintain their social contacts through physical and cognitive exercises, thereby improving their quality of life. When using the network it will collect a variety of information about the user which will form their profile. The system will use this profile to recommend personalised activities with recommended users with whom they can connect based on shared interests, location, age, etc. The system will suggest things to do together and will suggest places to go. The aim is to design a system that is easy to interact with that will help people to be

more physically active and socially engaged. The system also acts as a means of safe introduction to new people before meeting face to face.

A further aspect of the project is an intelligent walker which aims to improve the physical health of older adults. It will do this by monitoring a wide variety of physical aspects, such as balance and walking speed, to see how well that individual is walking. If walking ability declines (i.e. if balance becomes decentralised, gait shortens or walking speed reduces) then the system can notify a health care professional in order to suggest an early intervention to reverse the decline perhaps through the use of exercise activities, or feedback.

This pervasive health system thus collects extensive data about the user – data about their interests (for recommendations), data about their health and walking, data about their activities with others, and so on. This data is then shared via the social network with relevant parties. Because so much data is collected, the need for privacy is highly salient for the designers and potential users. Understanding why users want privacy helps us to understand how to design the system to enable privacy.

1.2 Objectives

Our aim in this paper is to highlight the importance of understanding the functions of privacy in a pervasive health system. In the rest of the paper we explain how we discussed with participants why they would want privacy around the types of information the system would collect with a view to understanding how the system can fulfil or frustrate everyday functions of privacy.

1.3 Related work

1.3.1 The need for privacy

Thankfully, some researchers have paid attention to the need of addressing the privacy concerns of older adults in the context of pervasive health-monitoring systems. Shankar and colleagues [22] survey a range of in-home technologies to assist older adults (such as an ambient plant to monitor the presence of an older relative for family members and a portal mirror which provides a photo of anyone who rings the doorbell or who enters the door) and propose a design framework which emphasizes the need for product usefulness, appropriate granularity of data collection, appropriate recipients of the information, and privacy for sensitive activities. Similarly, Ziefle et al. [29] point out the importance of distinguishing different types of rooms inasmuch as they are associated with different sensitivities of activities (e.g. toilets and bedrooms are particularly sensitive). Other researchers point out the need for appropriate ethics such as informed consent and codes of conduct so that privacy is maintained [6, 13].

However, such research has often had a relatively static conception of privacy and tends to think privacy is only about intimate activities. But seminal work on privacy has argued that privacy is dynamic [1] and functional [27]. In other words, privacy is *for doing things;* it has "uses" [24]. Rather than seeing privacy as a state in which the technology has no role and has to "back-off", privacy can be seen as an area where the technology helps the user fulfil a desired function by handling disclosure of data in specific ways. Crucially, privacy enables a person to engage in the creation of "self" [19] and fulfils a variety of psychological needs.

Furthermore, this functional perspective of privacy is more concerned with the end value or goal of achieving privacy rather than the means of achieving privacy [11]. While some research seeks to explore the optimal data collection strategies of a system

in order to maintain privacy, a functional perspective also seeks to understand the reasons behind those arrangements. Understanding the reasons for privacy enables a deeper understanding of the user experience of a system and how it can enable the accomplishment of privacy-related functions that are valuable to the user.

1.3.2 Functions of privacy

The literature on the functions of privacy is well-known. Westin [27] suggested four purposes of privacy that explain why it is needed. *Personal autonomy* refers to the desire to avoid being manipulated, dominated or exposed by others. *Emotional release* refers to release from the tensions of social life such as role demands, emotional states, minor deviances and the management of losses and of bodily functions. Privacy, whether alone or with supportive others, provides the 'time out' from social demands. *Self-evaluation* refers to integrating experiences into meaningful patterns and exerting individuality on events. It includes processing information, supporting the planning process, integrating experiences and allowing moral and religious contemplation. Finally, *limited and protected communication* has two facets: limited communication sets boundaries and protected communication allows for sharing personal information with trusted others [12, 27].

Pedersen [17, 18] has contributed functions of privacy which are: contemplation, autonomy, rejuvenation, confiding, creativity, disapproved consumptions, recovery, catharsis, and concealment. Essentially these are a refinement of Westin's model but driven by empirical data rather than theoretical reflection. *Contemplation* as a privacy function refers to the extent people can think about who they want to be and reflect how they have approached situations. *Autonomy* describes the extent to which someone can be himself or herself and do their own thing. *Rejuvenation* describes how people can recover from social interactions and make plans for future social interactions. *Confiding* can be described as trusting others not to disclose the expressed emotions or disclosed information. *Creativity* refers primarily to being creative – expressing oneself, but also to relaxing. *Disapproved consumptions* can be described as hedonistic behaviours, for instance, eating or drinking whatever someone wants to. The function *recovery* is very similar to rejuvenation, but it involves a greater sense of refuge and relaxation. *Catharsis* is also very similar to confiding. *Concealment* refers to doing things without being seen by others or having to take social norms into account.

This rather intimidating list has been made more simple and coherent in the Privacy Framework for Information Systems Development [5] in which nine functions are outlined: self-identity, personal growth, autonomy, contemplation, self-protection, confiding, emotional release, rejuvenation, and creativity. Various studies show that autonomy [23], personal growth [10] and creativity [14] are seen as psychological needs and contribute to wellbeing. Satisfaction of these privacy functions therefore fulfil important human needs [10, 17]. Users seek a state of privacy to satisfy their needs and privacy provides a positive experience offering opportunity for cognitive, emotional and physical rejuvenation [11].

The importance of considering these different functions of privacy is that by exploring the functions, we open up a design space where we can think about how systems can help users fulfil these functions as part of their experience with the system. If user experience is interested in understanding the needs and desires of users, then one should consider why privacy is sought and the needs it fulfils.

2. Method

2.1 Participants

30 older adults were contacted by email to participate in this study through a database of older adults in the North-East of England. Of the thirty contacted, 20 replied who formed the sample for the current study (66% response rate). The sample consisted of 10 males, 10 females who were all over sixty years of age and all lived in the north-east of England. Twelve participants had been involved in previous studies conducted within the project and so had prior knowledge of the project and the system.

2.2 Materials

Participants were guided through an interview schedule during which different scenarios were discussed where the system would gather and use their information for different purposes. To reduce the number of scenarios given to each participant and to reduce the time of the interviews, three scenario lists were produced, each including nine scenarios. Each scenario considered a specific type of information: general information, health information or location information. For example, one scenario read, "Through the use of games for entertainment, the system will record your memory and attention scores in order to provide more targeted and appropriate tasks."

2.3 Procedure

Semi-structured interviews were conducted on a one to one basis with each participant. Participants were presented with one of the scenario lists, one scenario at a time, and were told that the proposed system would collect the piece of information mentioned in the scenario. They were then asked to think about the potential positive and negative consequences of other people having access to this information. Following this, participants were asked how much of the information they would disclose, to whom they would disclose it and under what circumstances. This indirectly caused the participants to consider what type of privacy functions they would use for each piece of information. For each question the interviewer asked for reasons or justifications behind each decision the participants made. Interviews lasted no longer than 80 minutes.

2.4 Analytic approach

The transcripts were analysed using thematic analysis [4] and coded with a focus on privacy functions. The analysis was conducted inductively to begin with and identified 58 initial nodes. These were identified by reading the interviews and identifying places where participants explained why they wanted privacy. Using the Privacy Framework Factors Model [5] these 58 codes were then deductively mapped onto existing categories of privacy function. Some additional categories were added to adequately account for the data. This led to a set of seven over-arching functions of privacy (Table 1).

3. Results

An overview of the seven functions identified is given below in Table 1. These are then discussed in more detail below to explain the implications each has for the design of pervasive health-monitoring systems.

Table 1: Functions of privacy identified in interviews. Items in italics are added to the existing Privacy Framework Factors Model [5].

Function	Definition
Self-protection	Protection from the disclosure of sensitive information or information that could cause harm.
Autonomy	The ability to make independent decisions.
Emotional release	Being able to relax from social norms and roles without fear of consequences.
Confiding	Control over the extent of information disclosed and to whom it is disclosed.
Social identity	Protecting information to manage the social image that is portrayed.
Self-concept	Managing information that would affect how an individual views their own self
Protecting others	Withholding information to protect others.

3.1 Self-protection

Protection from the disclosure of harmful information or sensitive information is one of the most commonly noted functions of privacy, often to the extent that it is focused on exclusively as the reason why older adults want privacy in a health-monitoring system. Trust in the system and data-recipients is thus seen as an important factor in understanding whether users will allow a system to monitor their activities at home [28]. If those who see the data are trust-worthy, then they can be relied on not to use the data to harm or cause shame to the user. In the context of the system we propose, because of the diversity of information being collected (such as social activities and interests), the potential for information to cause harm or embarrassment increases. Consequently, it was the most commonly observed theme in our data.

Participants wanted to protect their information, specifically location information, for protection of their property:

"yeah well we're living in a world where we're living in a lot of crime and so forth and fraud cases and all those sort of things. So it's best not to advertise everything about your home address. Where you'll be in or where you won't be in and everything"

Older adults view their houses as a place of safety and security and to divulge information about it could place them in a position of physical vulnerability. Furthermore, older adults expressed their need for psychological self-protection, specifically with regards to health information. The need to protect their information to avoid verbal conflict, discrimination, insults, judgement and to protect themselves from others taking advantage if they are in a vulnerable state were all identified. The concept of memory loss emerges as a salient factor within this theme for fear of being taken advantage of:

*"pffff, again there's the potential of 'you can borrow £20 off him because his memory is declining' *laughs* y'know people might want to take advantage of your lack of memory, or lack of attention span"*

Participants also mentioned the fear of social exclusion:

"Yes, they might think, "It's not worthwhile having him in the group. (Laughter) Anything we tell him he'll forget the following day," which he will."

And they also mentioned the fear of being the topic of gossip:

"Other than the gossip factor, that, 'Do you know such-and-such? I see he's, yes, looks like his memory's fading.'"

This suggests that older adults view disclosing information about their cognitive functioning as only having negative consequences, which they wish to avoid.

3.2 Autonomy

This was the second most common theme in our data and like this previous one, is commonly noted in literature on privacy. Many researchers are aware that preserving the autonomy of users is vital [30], even in the case of older adults who use home-based monitoring systems [22]. The importance of this needs to be continually stressed in the case of older adults. In a similar project to the current one, researchers noted that loss of autonomy was one of the key barriers to using ambient-assisted living technology [9].

Participants were concerned that the very idea of a health-monitoring system jeopardised autonomy:

"I must be basically very luddite. I think that the idea of a system monitoring you reduces your autonomy"

Part of this reduction of autonomy is because of a feeling that they are being deprived of owning their own experiences:

"It would make me feel that I wasn't owning my own history and experience. It's sort of like an invasion of privacy, yes"

For such participants, more would need to be done to make the participant feel that they owned the data. Privacy, in the sense of not sharing the data with people that they do not choose, enables a sense of ownership and can promote autonomy. The important thing is that the user needs to feel in control of how the data is collected and disseminated. Designing for privacy then, must go beyond simply avoiding the collection or sharing of data and must seek to actively promote a sense of autonomy by engaging users in how the data is collected and disseminated [10]. In a practical way, this may involve letting users choose what sensors they want to enable as well as letting them choose how that information is used.

3.3 Emotional release

Moving beyond the more obvious privacy functions of self-protection and autonomy, our data shows the independent and counter-stereotypical nature of older adults' lives. The need for emotional release refers to the need of people to relax from social norms and pressures without the fear of others looking on. This is the kind of privacy one needs when having a lazy day at home – freedom from being observed by others who might expect us to be doing something:

"The negative is that I can't be allowed to be a slouch, just for a little while even if I want to, without people knowing that I'm being."

This is the problem with constantly-aware systems that collect data about the user's habits – even mundane habits like walking patterns. If such data is available to others, then the privacy need for emotional release is encroached. Perhaps this requires the system to be able to be paused for selected periods – or perhaps other creative solutions may be plausible. Either way, the need for emotional release is vital for the well-being of users and their adoption of the system.

Beyond being able to be lazy, older adults are not always rigid social conformists. Counter-stereotypically, they may have interests that are not socially acceptable and they want the freedom to be able to engage in them. Location patterns or specific interests may be collected from a system like the ACANTO system and these may compromise privacy:

Respondent: "If they had an interest in something that was erh not quite socially acceptable then they might want to have that hidden"

Designing for older adults must avoid the kind of paternalism that expects them to submit their lives to open scrutiny and must allow them the freedom to break social conventions. More controversially, emotional release may conflict with other priorities. While system designers may want to collect data to ensure accuracy of data, users do not always want to share accurate data:

Respondent: Actually, then the downside is you can't lie to your doctor then about, "I've done it, really."

Interviewer: Would you want to lie to your doctor?

Respondent: (Laughter) People do. I'm diabetic, I sometimes make things up to my doctor. Maybe not so truthful about the alcohol consumption or whatever, or trying to work that out.

Designing systems to be accurate and comprehensive is commendable. But if it comes at the expense of acceptability or continued use of the system, then it fails to address the problem at all. Users may want to lie about, or at least blur, certain aspects of their lives, and while a designer may not want to facilitate deception by users, neither do they want to create a system that operates as a functional lie-detector for a medical professional.

3.4 Confiding

Possibly one of the more obvious functions of privacy is the ability to be able to control who gets to know some information and when. It has both positive and negative aspects: sometimes people will want privacy to confide information to a friend or trusted other, and this implies the hiding of information from others. It was the hiding (the inverse of confiding) that came up most often with our participants. Often, they want to hide information to allow more controlled disclosure by themselves:

You've got to be careful, a general thing you could put on, but no specifics. It's too much personal information, erh whichever way you want to do it. If you put too much personal information on it can alter your relationship with friends and acquaintances, never mind the bad guys or anything like that.

Disclosing too much information had the potential to alter relationships with friends and participants wanted to be able to control the flow of information. Even in the case of sharing information with medical professionals, who were often one of the most trusted groups discussed, older adults often wanted to control the flow of their data; to be able to confide when they chose:

Respondent: Well, I don't mind anybody knowing, but I want to be the agent that engages with the exchange of information with the doctor. I mean, this says, "It may inform your doctor." That's amazingly Brave New World-y, isn't it?

Interviewer: So you wouldn't want it to automatically tell your doctor?

Respondent: No, no. I would want it to tell me.

In this case, privacy is about more than who gets to see the information – the participant says that she does not "mind anybody knowing" – but it is also about when to confide.

Of course, this desire to control when and where information is disclosed is instrumental in itself. One participant said,

"If I was a widower living by myself and my family lived a little way away and they could log onto the site and see how I'm getting on that's great that. Erh the only thing against that is of course that is saves them phoning me up or coming to visit me so you lose a bit of personal contact that way"

In this case, being able to avoid disclosure via the system would allow the user to stay in control of the communication and even manipulate people to contact them directly.

Understanding this function of privacy enables us to see that privacy is not just about a decision to share or not share information, but it is also a decision about how information should be shared. Privacy in one medium (the health-monitoring networked system) enables confiding in another medium (personal phone calls or visits). In the context of design, this suggests the need for a system that will not only collect information, but only release it to others in ways that facilitate social contact.

3.5 Social identity
The Privacy Framework [5] refers to self-identity as the development of the self-ego with a view to achieving self-actualisation. However, we felt the need to divide this idea into two components: (1) social identity refers to the outward-facing self-presented by means of impression management, and (2) self-concept refers to the inward-facing self in which the individual possesses their own understanding of who they are as a unique individual.

Social identity then, is about the importance of privacy in maintaining the image of the self that a user intends to convey to others. Whereas social media is often implicitly narcissistic in its emphasis on "likes", older adults are often concerned about being seen as bragging. In relation to sharing the nature of his friendships, one participant said,

"If I was to tell them everything about me, put it on the website, as I say some people wouldn't believe it, some people would hate me and say I was bragging and showing off, nobody would be envious of me but no, it's not the kind of stuff you put on."

Nevertheless, while there is a desire not to appear boastful, social image is important for older adults. Participants spoke about how they would want to carefully manage their photograph privacy because others might think they look older than they are. But the biggest area of concern was around physical and mental health. If physical health information is shared with others on the system, even in general ways, this can be enough to cause embarrassment:

"You know, just don't want people to be thinking, "Oh, I didn't know that he had a walking problem," Or such-and-such."

This is particularly acute with reference to mental health where the stigma can be very real:

Respondent: Mental illness is a different thing to physical illness and I, like the rest of people, think, if you can, if it's controllable, mental illness should be quietly kept a secret.

Interviewer: Why's that?

Respondent: People react badly to it. They expect anyone with any kind of mental illness… I don't mean depression, but learning

problems. They half expect the patient to do something wild or something they can't cope with, and because they're expecting it, I think sometimes the person with the mental disorder falls into role.

A system that stores and shares information about a person's mental health has the potential then, to cause real damage to the user's social image. Privacy needs to be understood in the context of social relationships and the design of health-monitoring systems need to manage the sharing of information carefully in order to enable the user to present the image that they want to convey to others.

3.6 Self-concept
One of the more intriguing aspects of a health-monitoring system is that it can reveal details about health and behaviour to the user that he or she does not know (see also [15]). Perhaps the user is not aware that their health is in decline; in such a case, the system may reveal to the user something that will affect their self-concept. And if self-concept is affected, this may cause further health decline [25, 26].

As one aspect of the system, we suggested games that could monitor the user's cognitive abilities and changes. But this was met with some concern:

Respondent: "well I like games that challenge my memory, like quizzes, but I wouldn't like a game that said ooh you're falling here dear, watch it, you're going downhill."

Interviewer: "So what about that makes you uneasy?"

Respondent: "Well, it's what it is, isn't it? It's someone out there monitoring me and seeing my decline, really. I suppose at my age, it's that bit about knowing I will start to decline."

Even in the context of physical decline, participants were uneasy:

"I think it's quite unhealthy to be told, 'You didn't walk quite as far this week as you did last.'"

Because information about decline can feed a negative self-concept, participants were concerned about the effect this would have on them. In the context of design this opens up new questions about how to present information about decline in a way that does not harm the user's self-concept – or whether it should be presented at all.

3.7 Protecting others
One function of privacy that also does not appear in the other literature on privacy functions, to the best of our knowledge, is that of protecting others. In some ways, this makes sense because privacy is often considered in relation to the self. But if information about the self contains links to others, then others could be compromised by information disclosed about the self. More concretely, to give an example, if someone knows that you are friends with someone else and they have an unfavourable impression of you, this could cause them to have an unfavourable impression of your friend. So even something as simple as a friends list is subject to privacy concerns by some participants:

Interviewer: yeah so if the system has got your friends list, and then it made that public.

Respondent: no I wouldn't like that for my friend's sake. They may not want that known. I can only sort of allow openness for me. I can't speak for other people; that would be naughty wouldn't it.

Another aspect of protecting others is not wanting them to see information about you that would cause alarm. Health information may be subject to privacy concerns for this reason:

Respondent: "My family are not reliable. I've got no siblings. They're 10 miles, away and they've got bigger problems than I have at the moment. So, I would not want to burden them with unnecessary stuff if I'm okay. I'm doing it myself and coping."

Similarly, another participant said,

"I just don't burden my family with things like that. I think that is a burden to them. I'm not saying they would say it was a burden. I would feel it's a burden. It's just giving them too much information about me that they may not need to know."

While privacy concerns are often in relation to protecting the self from harm, for older adults discussing a health monitoring system, the well-being of others is also a concern. This is an issue that would inevitably affect adoption of such a system and unless users can control the information for the protection of others, they may avoid using it.

4. Discussion

Drawing on psychological literature on the functions of privacy [5, 18, 27] we identified seven reasons why older adults want privacy in the context of a proposed system to improve the well-being of older adults. The evaluation of our data shows that older adults seek to play an active role in the maintenance of their own privacy while using social network sites, and are not merely passive subjects. While other researchers have argued for this [3, 8, 9], we have argued specifically that the reasons why older adults wants privacy need to be carefully considered. While considering when and how older adults would like to see privacy implemented is important, we have focused here on why older adults want privacy in order to uncover the user experience needs of users.

Within the context of Ambient Assisted Living (AAL) these findings have important implications. AAL technologies improve quality of life by empowering older adults and assisting them with independent living. However, if AAL technologies are a success at the expense of the individual's privacy then to what extent is the AAL really empowering or improving the well-being of the elderly? Such technologies need for focus on the needs of the users [2], particularly with regards to privacy.

4.1 Implications

The functions identified have numerous design implications for pervasive health-monitoring systems. Given that privacy is a psychological need, satisfaction of the privacy functions that potential users of the system require, provides concrete conclusions for design implications.

Self-protection: In the context of the system we propose, because so much of the information could expose the user to potential harm (e.g. location information and sensitive health information), it is vital to ensure that the safety and well-being of the user is protected. Because the overriding concern of users in this theme is to be safe, one potential design solution is to have some form of vetting for users to try to keep users safe – something that users themselves suggested. While not a foolproof solution, it may be a way of preventing more flagrant abuses of privacy.

Autonomy: Because users want to be in control of their own information and because they sometimes feel that they lose possession of their own history and experiences through pervasive systems, it may be wise to allow users to enable and disable different sensors at different times depending on their preferences.

This may enable a greater sense that they are in control of the data being collected and distributed about them. Because autonomy is a human need, facilitating it has positive implications for well-being [20].

Emotional release: Older adults, as much as anyone else, want the freedom to break social conventions without the fear of being observed. They want to be able to lie to others about their habits without those lies being uncovered. This is dilemmatic insofar as we want to design a system that will accurately represent, for example, the number of steps a user takes. But sometimes all that is required is for the system to be able to be paused to enable solitude for the user. The system would need to learn to handle incomplete data when assessing progress or making recommendations, but this may be better than a system that deprives the user of any form of emotional release.

Confiding: With the desire of older adults to be able to confidentially disclose information to others, systems need to take account of this. One finding was that older adults may prefer not to share certain information via the network because they prefer personal contact to confide with others. To design for this, systems may be able to require personal contact in order to obtain desired information. For example, a short video call or phone call may be required from the caregiver by the system in order to access desired data about the wellbeing of the user. This may be able to satisfy the desire for personal confiding as well as providing the data that the caregiver desires.

Social identity: Since older adults seek to portray a positive identity via the system, care needs to be taken to let users see how others see their profiles or information. If they can preview what others see, impression management can be handled more effectively.

Self-concept: Since users desire to maintain a positive self-concept, the system should avoid presenting information about decline which is irreversible. Where change is possible, it may be possible to encourage users to be more active or involved providing encouraging feedback is provided. The important thing is that the system should make the user feel good about themselves where possible.

Protecting others: Older adults sometimes do not want to share information about health problems with their friends or relatives for fear of burdening them. This desire ought to be respected by the system if it is to avoid paternalism or breaches of trust in the system. But the availability of anonymous support forums may be a possibility for older adults seeking support and advice and this may help the older adult user while avoiding their concerns about burdening friends and family.

4.2 Limitations

There are some limitations to this research. Firstly, we focused only on privacy in relation to our system. Talking with participants about privacy in the context of everyday life could have opened up more functions of privacy that afford design possibilities. Secondly, we did not discuss design solutions with participants. In further work, we intend to discuss some design solutions with participants to explore whether they find the solutions plausible.

4.3 Conclusion

In this paper, we have argued that the privacy concerns of older adults need to be addressed when designing pervasive health-monitoring systems. We conclude by stressing the importance of understanding the reasons why older adults want privacy in the

context of pervasive health-monitoring systems. It is important, but not enough to understand the issues around how much and when and to whom users want information disclosure or privacy. Understanding functions of privacy effectively uncovers the user needs underlying the design of an effective system that the user will enjoy.

5. ACKNOWLEDGMENTS

6. REFERENCES

[1] Altman, I. 1976. Privacy: "A Conceptual Analysis." *Environment and behavior*. 8, 1 (1976), 7–31.

[2] Bannon, L.J. 2011. Reimagining HCI: toward a more human-centered perspective. *Interactions*. 18, 4 (2011), 50–57.

[3] Boise, L. et al. 2013. Willingness of older adults to share data and privacy concerns after exposure to unobtrusive home monitoring. *Gerontechnology*. 11, 3 (2013), 428–435.

[4] Braun, V. and Clarke, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 3, 2 (Jan. 2006), 77–101.

[5] Carew, P.J. and Stapleton, L. 2005. Towards a Privacy Framework for Information Systems Development. *Information Systems Development Advance in Theory, Practice, and Education*. (2005), 77–88.

[6] Cheek, P. et al. 2005. Aging well with smart technology. *Nursing administration quarterly*. 29, 4 (2005), 329–338.

[7] Demiris, G. et al. 2004. Older adults' attitudes towards and perceptions of "smart home" technologies: a pilot study. *Med. Inform*. 29, 2 (2004), 87–94.

[8] Demiris, G. et al. 2009. Older adults' privacy considerations for vision based recognition methods of eldercare applications. *Technology and Health Care*. 17, 1 (2009), 41–48.

[9] Hammer, S. et al. 2015. Design of a Lifestyle Recommender system for the Elderly: Requirement Gatherings in Germany and Greece. *PETRA 2015, Affective Computing for Biological Activity Recognition in Assistive Environments Workshop,1-3 July*. (2015).

[10] Lindenberger, U. et al. 2008. Psychological Principles of Successful Aging Technologies: A Mini-Review. *Gerontology*. 54, 1 (2008), 59–68.

[11] Lombardi, D.B. and Ciceri, M.R. 2016. More than defense in daily experience of privacy: The functions of privacy in digital and physical environments. *Europe's Journal of Psychology*. 12, 1 (2016), 115–136.

[12] Margulis, S.T. 2003. On the status and contribution of Westin's and Altman's theories of privacy. *Journal of Social Issues*. 59, 2 (2003), 411–429.

[13] Marziali, E. et al. 2005. A Systematic Review of Practice Standards and Research Ethics in Technology-Based Home Health Care Intervention Programs for Older Adults. *Journal of Aging and Health*. 17, 6 (Dec. 2005), 679–696.

[14] Maslow, A. 1962. *Toward a psychology of being*. D Van Nostrand.

[15] McNeill, A. et al. 2017. Privacy Considerations when Designing Social Network Systems to Support Successful Ageing. *Proceeding of CHI 2017* (2017).

[16] Neff, G. and Nagy, P. 2016. Automation, Algorithms, and Politics| Talking to Bots: Symbiotic Agency and the Case of Tay. *International Journal of Communication*. 10, 0 (2016), 17.

[17] Pedersen, D.M. 1999. Model for Types of Privacy By Privacy Functions. *Journal of Environmental Psychology*. 19, 4 (1999), 397–405.

[18] Pedersen, D.M. 1997. Psychological functions of privacy. *Journal of Environmental Psychology*. 17, 2 (1997), 147–156.

[19] Reiman, J.H. 1976. Privacy, Intimacy, and Personhood. *Philosophy & Public Affairs*. 6, 1 (1976), 26–44.

[20] Rogers, W.A. and Mitzner, T.L. 2016. Envisioning the future for older adults: Autonomy, health, well-being, and social connectedness with technology support. *Futures*. (Jul. 2016).

[21] Sandvig, C. et al. 2016. When the Algorithm Itself is a Racist: Diagnosing Ethical Harm in the Basic Components of Software. *International Journal of Communication*. 10, 0 (2016), 19.

[22] Shankar, K. et al. 2012. Aging, Privacy, and Home-Based Computing: Developing a Design Framework. *IEEE Pervasive Computing*. 11, 4 (Oct. 2012), 46–54.

[23] Sheldon, K.M. and Gunz, A. 2009. Psychological needs as basic motives, not just experiential requirements. *Journal of Personality*. 77, 5 (2009), 1467–1492.

[24] Taddicken, M. and Jers, C. 2011. The Uses of Privacy Online: Trading a Loss of Privacy for Social Web Gratifications? *Privacy Online*. Springer Berlin Heidelberg. 143–156.

[25] Taylor, S.E. and Brown, J.D. 1988. Illusion and well-being: a social psychological perspective on mental health. *Psychological bulletin*. 103, 2 (1988), 193–210.

[26] Westerhof, G.J. and Barrett, A.E. 2005. Age Identity and Subjective Well-Being: A Comparison of the United States and Germany. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*. 60, 3 (May 2005), S129–S136.

[27] Westin, A.F. 1967. *Privacy and Freedom*. Atheneum.

[28] Ziefle, M. et al. 2011. Medical Technology in Smart Homes: Exploring the User's Perspective on Privacy, Intimacy and Trust. *2011 IEEE 35th Annual Computer Software and Applications Conference Workshops* (Jul. 2011), 410–415.

[29] Ziefle, M. et al. 2011. When Your Living Space Knows What You Do: Acceptance of Medical Home Monitoring by Different Technologies. *Proceedings of the 7th Conference of the Workgroup Human-Computer Interaction and Usability Engineering of the Austrian Computer Siciety (USAB'11)* (2011), 607–624.

[30] Zwijsen, S.A. et al. 2011. Ethics of using assistive technology in the care for community-dwelling elderly people: An overview of the literature. *Aging & Mental Health*. 15, 4 (2011), 419–427.