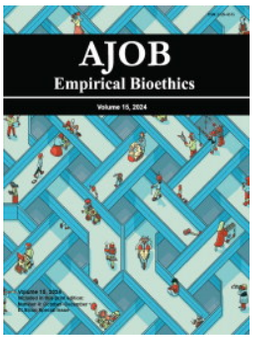

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Monitored and Cared for at Home? Privacy Concerns When Using Smart Home Health Technologies to Care for Older Persons

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ABSTRACT

Background: States and families are facing growing challenges provide adequate care for older persons. Smart home health technologies (SHHTs) in the forms of sensor or robotic devices have been discussed as technical solutions for caregiving. Ethical and social concerns are raised with the use of such technologies for caregiving purposes, a particularly prominent one being privacy. This paper contributes to the literature by distinguishing privacy concerns into both the type of technologies and conceptual dimensions.

Methods: Data for this paper stem from sixty semi-structured interviews with older persons, informal, and formal caregivers living in the German-speaking regions of Switzerland. All information related to privacy, that were initially inductively coded, were thematically sorted into four dimensions of privacy (physical, psychological, social, and informational) and by the type of technologies studied.

Results: Participants were especially concerned about privacy intrusions from smart wearables and ambient sensors than robotic technologies, which may be due to the relative lack of familiarity with the latter. Informational privacy was evident in the context of data collection capacities and potential for misuses of data. The installation and implementation of both visual and ambient sensors induced discomfort to their senses of physical space. Alerts of smart wearables and obtrusive sightings of SHHTs garnered worries related to stigmatization and manipulation, indicating intrusions into end-users' psychological privacy. Little discussions of social dimensions of privacy were evident in the data, even toward robotic technologies for their functions to promote social interactions for older persons.

Conclusions: This paper is one of the first that use the stratification approach on empirical data to highlight the multi-faceted privacy concerns when technologies may be implemented in elder care. Our paper could thus supports potential end-users in deciding which technologies to use and how to balance different privacy concerns against other values that they may hold important.

KEYWORDS
Caregiving; older persons; aging; gerontechnology; privacy; ethics

Introduction

Over the past decades, the global demographic has shifted toward population aging. The United Nations estimates that the worldwide population aged 65 years and above is expected to surpass 1.6 billion by 2050 (Wilmoth et al. 2023). Switzerland is not an exception with 1.7 million persons or 20% of the national population over the age of 65 in 2018, with these figures to respectively reach 2.7 million and 27% in 2045 (Kucera 2018). With increased longevity, older individuals are often confronted with physical and/or cognitive impairments making it difficult for them to independently manage their daily activities, emotional or physical distress (Novitzky et al. 2015). Consequently, the burgeoning need for healthcare resources places great strain on both informal caregivers as well as healthcare providers and state capacities to care for these older persons (Fleming, Evans, and Chutka 2003; Garlo et al. 2010; Haberkern and Szydlik 2010; Mello et al. 2017).

Technical solutions in the form of smart home health technologies (SHHTs) are proposed to alleviate caregiving burden and allow older persons to remain independent (Demiris and Hensel 2008; Turjamaa, Pehkonen, and Kangasniemi 2019). SHHTs for

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caregiving include sensors, actuators, and other interoperable health devices that could automatically alert caregivers to falls, or deviation from normal health and habit patterns. (Demiris and Hensel 2008; Moraitou, Pateli, and Fotiou 2017). Monitoring for vital parameters could increase the likelihood to prevent deteriorations of existing chronic conditions and assist in the diagnostic processes in formal care (Majumder et al. 2017; Wilson, Hargreaves, and Hauxwell-Baldwin 2015). Visual sensors for the home could not only provide more data to the current routines and conditions of older persons, but are developed with additional features such as fall prediction enabled by AI technologies (De Miguel et al. 2017; Shu and Shu 2021).

Despite these opportunities of SHHTs in caregiving, studies have also brought forth ethical considerations such as privacy, autonomy, stigma, fear of human replacement, and unclear boundaries of responsibilities and liabilities (Ienca et al. 2018; Schweda et al. 2019; Shafi and Mallinson 2023). Amongst them, privacy issues are one of, if not the most cited barriers for acceptance and use from end-users (Bian et al. 2021; Felber et al. 2023; Guhr et al. 2020; Ienca et al. 2018). According to Bian et al. (2021), privacy is "the biggest concern for the rejection of the standard camera," and resolving this concern may shift older persons' decisions in purchasing and adoption of emerging technologies (Bian et al. 2021, 10).

In existing literature, privacy is also not a homogenous concept. Daniel Solove (2002) speaks of privacy as a concept in disarray. Generally, privacy is the setting of boundaries from external influence or interference (Beauchamp and Childress 2019). There are four dimensions to privacy for typologizing user's concerns that most existing theoretical literature have converged toward (Hughes 2004; Jaschinski et al. 2020; Leino-Kilpi et al. 2001; Schomakers and Ziefle 2019), which are also those that we have recently built upon with our own conceptualization of privacy concerns in the use of smart home technologies for elder care (Tian and Wangmo 2024): 1) *Physical privacy,* includes the accessibility of a person's physical environment, including one's home, body, or any other objects that may be deemed attached (Hughes 2004; Mittelstadt 2013). *2) Psychological privacy,* or also called "decisional privacy", underscores that end-users should have the right to refuse access of technologies to read, control, or alter their thought processes, desires, responses that may be integral to the personal identity, despite the possible benefits for the cognitive or physical functioning of older persons or for science generally (Hughes 2004; Leino-Kilpi et al. 2001; Mittelstadt 2013). *3) Social privacy* delineates the boundaries of frequency, manner, and the counterpart of social interactions falls under the concept of social privacy (Burgoon 1982; Jaschinski et al. 2020). As a relational dimension, social privacy is also influenced by culture, in terms of how individuals desire to maintaining distance or social independence from one another, as well as to what extent individuals feel comfortable to control the frequency of interaction with another (Altman 1975; Leino-Kilpi et al. 2001). Finally, *4) Informational privacy* is what is most discussed in the literature in terms of data access, data protection and confidentiality. This dimension could also be referred to as "data privacy" (Yusif, Soar, and Hafeez-Baig 2016). Specifically, when SHHTs are introduced in caregiving, they collect a wealth of both personal identifiable information and health data such as vital signs, activity or sleep (Philip et al. 2021; Wang et al. 2021). Older persons may be concerned about the sharing of their data with various family members or professional caregivers; or the aspect of data transfer and storage, whether the data remain securely processed and treated (Chung, Demiris, and Thompson 2016).

According to guidelines and frameworks in artificial intelligence, it is a priority to ensure privacy in the designs of ethically-conscious technical solutions for older care (Floridi and Cowls 2022; Hine, Nilforooshan, and Barnaghi 2022). This idea of ethically-conscious design has been cited in other ways, such as "ethical-by-design" or "ethically-mindful," all to encompass ways in which ethical concerns (particularly privacy) can be best suited in technological solutions to the needs and worries of their end-users (Morley and Floridi 2020; Mulvenna, Boger, et al. 2017; Mulvenna, Hutton, et al. 2017). There is also evidence to suggest that privacy concerns are not one-and-the-same across all technologies in older care, but vary contingent on their perceived benefits in a tradeoff relationship with their invasiveness (Mulvenna, Hutton, et al. 2017; Pol et al. 2016; Townsend, Knoefel, and Goubran 2011). For example, motion detectors and fuzzy logic based monitoring systems with RFID were seen as a "privacy-preserving alternative" to raw images, videos, or sounds collected by cameras in the care of older people (Park and Kautz 2008; Pol et al. 2016; Pramod 2023, 92). Nevertheless, carers still thought that the use of cameras in the home for persons with dementia to be ethically acceptable when considering beneficence and reassurance for their caregivers (Mulvenna, Hutton, et al. 2017). To our knowledge, there has yet to be an empirical article that distinguishes privacy concerns across its four dimensions and different types of technologies. Mapping the end-user attitudes in this way could contribute to a better understanding of the concept of privacy and pinpoint the specific reasons that trigger concern for privacy in greater detail, and may

further allow a preference-oriented caregiving solution supported by SHHTs. We seek to answer two research questions in this paper:

1. What are older persons' and their caregivers' attitudes toward the use of SHHTs for caregiving purposes?
2. How does privacy concerns vary with the use of different SHHTs (wearable, ambient and visual monitoring devices, and robotic technologies)?

Methods

This paper stems from the qualitative module of a larger project called Smart Homes, Older Adults, and Caregivers: Facilitating social acceptance and negotiating responsibilities [RESOURCE]. During the interviews, the study participants were shown a collection of SHHTs ranging from wearable monitoring technologies to visual sensors and robotic assistants, with their attitudes and impressions gathered using open-ended questions and probes.

Ethics approval

All empirical research within the project Smart Homes, Older Adults, and Caregivers: Facilitating social acceptance and negotiating responsibilities [RESOURCE] was reviewed and approved by the Ethics Committee of Northwestern and Central Switzerland. All participants were provided an information document in advance of scheduling the interview that contained the project aims, interview content, responsible person, and the data protection measures for the recorded interviews and transcribed data. Prior to the interview, the participants were briefed again on the content of the information document, encouraged to ask questions, and informed of the possibility to withdrawal from the study. Thereafter, written consent was obtained.

Interview guide

The research team developed an interview guide in English, which was then translated to German and back-translated to ensure consistency. The interview guide was divided into several sections to allow concentrated flows of reflection from the participant. The first section allows the participant to become comfortable with the interview process and invites them to share their current caregiving needs, challenges, tasks, and experiences. The second section begins with a list of SHHTs in order of ascending technological complexity and the level of perceived familiarity by the participants. Pictures of the technologies investigated were shown to ensure that participants are certain of the SHHTs that we referred to. In the case of Pepper, a video was shown as well. To allow participants to feel more comfortable with answering questions on technology, we began with a simple assistive emergency alarm button that has been introduced in the market for many years now and may thus be more familiar for the participants. Monitoring technologies were shown next, wearable sensors on the wrist (e.g. the Apple Watch), to ambient non-visual sensors, then finally ambient visual sensors. Thereafter, the virtual reality glasses were shown followed by two robotic technologies, Pepper and Paro. Open-ended questions were designed around their first impressions of the technologies, the benefits and barriers imagined for their personal use in caregiving situations, and any ethical dilemmas that they could think of. As privacy was anticipated to encompass a large portion of ethical concerns based on previous literature (Berridge and Wetle 2020; Chung, Demiris, and Thompson 2016; Felber et al. 2023; Sánchez, Taylor, and Bing-Jonsson 2017; Sundgren, Stolt, and Suhonen 2020), we took care to ask and probe further when privacy-related remarks such as those on data protection, control, sharing, or discomforts related to the use of such technologies raised by the participants. The last section concluded with general questions on their perspectives of SHHTs and the future of technology use in caregiving.

Participant recruitment

Participants were recruited using a purposive sampling method with an informative flyer containing the project aims, recruitment criteria, and the required contact information. Local and district nursing homes, home care organizations, as well as community care services (i.e., Meals on Wheels) were contacted as well in addition to the use of social media and online advertising channels. Formal caregivers and older persons were recruited primarily through a combination of these methods. Participants were also introduced through a snowball sampling method.

As we were interested to gather data from three populations involved in the caregiving of older persons, we had three sets of recruitment criteria and participants could be recruited if they fit at least one of them: 1) Older persons who are 65 years of older living in home settings (nursing homes, assisted living, or private residences). 2) Formal caregivers to an older person such as home carers – (employed in a home care organization called Spitex in Switzerland), healthcare providers, or nursing home personnel. 3) Informal caregivers such as family members or friends caring

for an older person. All participants have to be living in Switzerland during the time of data collection.

Data collection

Two female interviewers (VD and NF) trained in qualitative and interview methodology carried out the data collection. Both are native Swiss-German speakers, one was completing her Ph.D. education in biomedical ethics and the other her medical degree. Data for the project were collected between September 2021 to October 2022. Due to COVID restrictions, interviewers abided the concurrent regulations by the facilities and interview partners they met, in terms of mask-wearing, physical distancing, and allowing a virtual setting if necessary.

Sixty interviews were completed with sixty-seven participants, as seven interviews were with two participants, either both older persons or an older person with their caregiver(s). The participants had no prior relationship with the interviewers. The older persons group was composed of a fairly even distribution of those living in private homes and assistive or nursing homes, with a slightly higher mean age for the female versus male breakdown. Most formal caregivers were female and provided either home visits or nursing home assistance. The gender distribution was similar for informal caregivers, with at least seven caring for an older person with dementia (PwD). Table 1 includes more detailed demographics.

The interviews averaged to be around 96 min (range: 46-189 min) in length. With the exception of one virtual interview, all other took place in-person, whereby either the interviewer traveled to the homes of the participants, or met at an agreed coffee shop, meeting area, or office space. Likewise, most interviews were completed in one sitting, and split into two sessions when the participants (formal caregivers in particular) had a time restriction.

Data analysis

The two interviewers transcribed all interviews verbatim into German. For the first few transcripts of each population group, several authors participated in roundtable meetings where in addition to gaining familiarity with the data, these transcripts were inductively coded as a team. Thereafter, two of the coauthors coded remaining interviews from the project and added new codes where appropriate. From the project dataset, we have prepared and published a few empirical papers, with some using an inductive and others an deductive approach of analysis (Felber et al. 2024; Martani et al. 2024; Wangmo et al. 2024).

For this paper, we focused on the monitoring and the robotic technology as they generated the most privacy-relevant concerns. The two first authors exported the codes relevant for privacy (e.g. "Sensors at home\Location of sensors", "Data sharing\relatives/close persons", and "Discomfort with eyes watching" etc) into a Microsoft Excel document. This privacy specific dataset was inductively analyzed again using applied thematic analysis (Braun and Clarke 2006; Guest, MacQueen, and Namey 2012) leading to codes such as "Feelings of being observed", "Data sharing to relatives ok" or "No surveillance in private rooms." These analyses were audited by the last author. Furthermore, data analysis continued throughout the writing process as themes were revised based on further reflections among the authors. As the aim of the paper was to differentiate the findings into the four dimensions of privary, toward the later stages of the analysis process, we sorted our results into the four dimensions of privacy. We nevertheless did not force findings to fit into the four dimensions of privacy and instead noticed that some issues were not restricted to one dimension of privacy but rather transcended multiple ones.

As a qualitative paper, the findings are not representative of a population but aims to inform the issues pertinent to the stakeholder groups explored in Switzerland. Therefore, we use illustrative terms such as "several, some, most, almost all" to provide comparative information where relevant and use quotes from the participants to substantiate the themes. The quotes have been translated from German to English and edited to ease comprehension.

Table 1. Participant demographics ($N = 67$).

	Older persons ($n = 27$)	Formal Caregivers ($n = 23$)	Informal caregivers ($n = 17$)
Gender ratio (F:M)	15 : 12	19 : 4	13 : 4
Mean age (F:M)	90.2 : 84.0	45.6 : 43.3	56.5 : 58.8
Setting of care	Homes: 13	Home Care: 9	–
	Nursing Homes: 10	Nursing Homes: 9	Nursing homes: 2
	Assisted Living: 4	Other: 5	–
Type of care	–	–	General caregiving: 8
	–	–	Caregiving for PwD: 7

Results

We first lay out the privacy concerns in a comprehensive table (Table 2) that aggregates the themes across all dimensions of privacy for monitoring and robotic technologies. Here we note up to four key concerns per technology type. Thereafter, we proceed in-depth into these privacy concerns in the following sections.

Physical privacy

In terms of physical privacy, participants focused only on the wearable and ambient sensors. Toward ambient sensors, participants related their tracking, locating, detecting, and alerting functions to be forms of surveillance. The home, likewise the body, was considered a private space that participants wanted to protect from intrusions. Only one professional caregiver commented on the filming function of Pepper, the companion assistive robot, which was similar to the discomfort elicited from the use of visual sensors.

Smart wearable devices

Some participants in all three groups expressed concern toward the wearable devices with their functions to GPS locate and monitor for health conditions. Namely, older persons related smart watches to the surveillance and loss of control in one's own space, generating negative feelings of being observed (Table 3, Quote 1). Professional caregivers added that the wearables could record information that may serve no purpose but still cause discomfort toward being constantly observed. One expressed that living at home should already encompass less surveillance as compared to other institutions, that: "*PCH2: There is a reason why so many people rather remain at home. They let the Spitex in to help them and everything. But still, one doesn't want to be observed*" and the use of watches could thus be counterproductive.

Whether locating technologies incorporated on the wearable devices was appreciated or not differed, concerns were raised on the slippery slope toward surveillance and control vs usefulness of having an exact location during emergency situations: *ICR5: "…if my grandma…falls somewhere in the forest or elsewhere, it would certainly be a great relief if her exact location can be tracked. But on the other hand, it is again very surveilling*" (Also see Table 3, Quote 2).

Ambient sensors (visual and non-visual)

Ambient sensors in the form of visual, audio, motion, movement, and pressure detectors were thought to be too invasive for participants in all groups. Participants thought ambient sensors would be excessive when implemented for safety and monitoring functions at home, that the amount of protection would not justify this level of surveillance. Negative feelings such as shame, fears of judgment, being observed by others were mentioned. Though non-visual sensors also elicited discomfort, it was only exacerbated by the use of cameras and thought to be completely off-limits in terms of physical privacy.

Several older persons imagined feeling a sense of shame if an "eye" is constantly watching them at home, particularly objecting against the possibility to be surveilled naked: "*OPN3: And I don't necessarily want to be surveilled. It makes me feel like…yeah one could say, a dangerous criminal.*" This was echoed by

Table 2. Key concerns per privacy dimension by type of SHHT.

	Smart wearables	Ambient sensors (visual and non-visual)	Robots
1. Physical privacy	• Feeling observed and controlled • Location data still surveillance	• Visual sensor evokes feelings of shame and imprisonment • Delineating boundaries by rooms in home • Being monitored in their client's homes is not acceptable • Invasion by human compared with visual sensors	–
2. Psychological privacy	• Manipulation and pressure to change behavior • Reminders may be too obtrusive • Induces self-doubt and questioning	• Manipulation to control end-users • Sight of sensors may be obtrusive	• Appearance and activation may be obtrusive and overwhelm end-user
3. Social privacy	• Disruptions from obtrusive alerts in social settings • Positive effects to social isolation	• Disruptions from caregivers to engage socially • Visual information disrupts social relationships	–
4. Informational privacy	*Common across all tech* • Data can be misused and lost • Data should be collected purposefully for health reasons • Not all data is appropriate to collect • GPS data useful for wandering behaviors	• Need to protect visual information against misuse and general storage • Persons other than the direct end-user should not be surveilled	

Table 3. Physical privacy concerns for monitoring technologies.

Type of technology	Quote no.	Quotation
Smart wearables	1.	OPH13: Yes, I think the disadvantage of those … things is the risk of feeling observed. That's a general thing. I mean, one does not know what else is interpreted afterwards. This is somehow also an inhibition. One wants to be free and does not want to be surveilled, and I think that's a big problem. I mean, If I wore this watch and our children know exactly where I am, it's none of their business where I want to go to. Yes, somehow one loses a piece of freedom.
	2.	OPN6: So, I wouldn't allow too much control because then we are a police state. And this isn't good either, this certainly isn't good either. You know, it's kind of a limit, a limit I cannot exactly define what to do.
Ambient sensors (visual and non-visual)	3.	ICR8: And for her the look [how she appears to others] must be right. Even if she has an appointment in the morning at 9, then she already wakes up at 7 and gets ready. And if a hygienic accident happens then she takes a shower herself, with all the risks coming along, she absolutely wants that. It's so important to her that it's like that. And total surveillance, that would not be something for her.
	4.	PCH5: Like in a prison where everything is filmed. That is someone who… if one films someone, that is why I cannot understand that relatives film their father with dementia because this is such an invasion of the privacy, even if someone cognitively does not understand it anymore, it is an invasion nonetheless. It is a calming for the relatives but in the end it is a violation of the fundamental rights.
	5.	OPH4: No, I don't want to have it in the entire apartment. No need for everyone to see when I come out of the shower or go in. (laughs) There are boundaries where I say, no, I don't need that. Neither do I want this in the bedroom.
	6.	PCH3: And with Spitex one really enters as a guest into a house or apartment. And if all this is visible on video, well…
	7.	PCN4: Video surveillance according to… In my opinion, how it is regulated outside in diverse large cities, I find it really ok because there it is about the safety of anyone. Here at this home, the resident's room is a no-go because it's the privacy we preserve, …, what we do in nursing is already borderline because it is extremely invasive to the privacy….. If one solely looks at the privacy this is why I think it does not need to be presented visually somewhere in addition. Video surveillance is simultaneously a recording. There one needs it? And do I need this? No. No.
	8.	PCN5: Yes, however, in my opinion, the threshold [of privacy] of older persons decreases enormously once they settle in a nursing home because they know someone can come into the room at anytime. It's also true that they generally have less privacy left because one briefly knocks and then enters. Basically, the patient doesn't have the opportunity at all to open the door themselves and to say "no"…That's why I think because of such a camera, that this won't be a severe cut into their privacy anymore.

around half of the informal caregivers, who were concerned that the older person under their care would feel uncomfortable, embarrassed, and judged, irrespective by strangers or their children (Table 3, Quote 3). For older persons with dementia, a professional home caregiver alluded to the potential problem of an unconscious invasion of privacy in a family's use of cameras (Table 3, Quote 4).

A way to protect one's environment from external intrusions is to delineate temporal and geographic boundaries. When considering the type or location of sensors installed, or the time to allow activation of these sensors, participants in all groups had a variety of opinions. A few participants in each group declared that no sensors, especially no visual sensors should be installed everywhere, neither outside on the streets for fear of public surveillance nor inside the home. In contrast to the privateness of the home, participants thought that the sensors were more associated with hospitals and nursing homes, which may also rationalized the rejection to include sensors in the home that may remind them of the latter. Participants often explicated on the discomfort with an invasion of privacy with the issue of private zones: "*ICR3: Yes, so I think that I would not want this done in the home, so generally the rooms, dining rooms, and entrances. It is just because they are private zones…*" An agreement was still to be reached whether sensors should be built into high-risk but high-privacy invasive areas, such as bathrooms and bedrooms (Table 3, Quotes 5). Nevertheless, two professional caregivers also mentioned that sensors on the entrances to the rooms or homes could allow early detection of wandering behaviors for persons with dementia*: "PCN2: So, we have door sensors. When the door opens. We have that for people at risk of running away. Or at the door downstairs where the sensor is somewhere, this is also again the button or so.*"

Particularly, professional caregivers spoke about the physical privacy invasions in their work experiences and when imagining the consequences of having smart technologies installed in their client's homes. On the one hand, one professional caregiver pointed out that they are visitors in the home of the older person to provide care and would not like to be filmed (Table 3, Quote 6). Another agreed that surveillance in this manner would be very difficult for care workers to accept and likewise should not be forced upon them, "*We repeatedly have the topic in Spitex for coworkers also very, very hard to accept…this is very difficult for people.*"

While one professional caregiver mentioned that the human care is already invasive enough to the older persons' physical privacy, and would thus be against the use of visual sensors (Table 3, Quote 7). However, another expressed that there are constant privacy invasions, particularly in nursing homes, with caregivers carrying out their tasks around the clock as well as the presence of other co-residents. In this context, this formal caregiver stated that one's threshold for privacy would be lessened and the use of visual sensor may be deemed to not cause any further damage than is already done (Table 3, Quote 8).

Psychological privacy

Members from each population group mentioned some aspect of psychological privacy, especially in relation to wearables, mainly in reference to their features to provide feedback and reminders. Feedback, recommendations, alerts, and evaluations may shift, steer, or lead older persons to doubt their own decisions and capacity to carry out certain behaviors. These alerts and prompts from the SHHTs risk affecting and intruding into the formation and fluidity of thought processes that are integral to a person's identity, which falls under the dimension of psychological privacy.

Smart wearable devices

Though smart watches could provide positive motivation for health-promoting behaviors like exercise, diet, and sleep reminders, it also provides interferences to the end-user's own thoughts and behaviors (Table 4, Quote 1). Concerned that this could interfere with their own perception of their health, some older participants preferred to rely on themselves to be healthy. As one older person indicated, technology should not try to replace common sense, "*One also doesn't make a sensor do, "Yes, you've had enough. You shouldn't eat that much." Hey, I realize this myself. If I'm not doing well anymore […] there's the human instinct which is built like, "Ah, hot, ouch.*" Particularly when participants may not be fit to carry out a recommendation, it may cause feelings of insecurity and questions to their self-confidence that is another example of an invasion to psychological privacy (Table 4, Quote 2). The arrival of sudden alerts or recommendations from the wearable can also be obtrusive during unwelcome times and settings, interfering with streams of consciousness or disrupting existing patterns of behavior (Table 4, Quote 3). To avoid further intrusions into psychological privacy and as some participants still valued the health-promoting benefits brought by wearable devices, older persons suggest to adopt more unobtrusive reminders.

Ambient sensors (visual and non-visual)

Likewise, ambient sensors also provoked concerns for manipulation in all three participant groups. A few older persons were specifically critical toward the control from the state if monitoring sensors could become widespread in society and that "*This certainly*

Table 4. Psychological privacy concerns for monitoring technologies.

Type of technology	Quote no.	Quotation
Smart wearables	1.	PCN8: It would be terrible – it happened before with my insurance where basically, if one does not smoke and not drink and [walks] this and this many kilometers and then you can even connect a step counter to an insurance app, and then you receive a reduction of the costs. I have – there is my limit – I find this a little… I live relatively healthy and there I sometimes think, "No, I don't go along with this.", this is too…
	2.	OPH9: And on the age. Like a young person, if you are jogging and then such a notification appears, now you need to do this and this many steps, or I don't know what appears, then one might still try to do it, if one is in shape and healthy and so…
		Interviewer: Hmm-hmm, yes…Whereas if you're not doing so well…then you think, oh no, not again, now I even have to do this, and I can't anymore or I can't do it anymore.
	3.	OPN4: No, one should be able to decide for oneself: Do I want now or I don't want this now. If I'm hiking somewhere, yes, if I want some peace, then I don't necessarily need any further "Beep, you have a heart rate of beep", no… (laughs)
Ambient sensors (visual and non-visual)	4.	ICR2: I find it difficult that there's just this control…then the data would be analyzed, perhaps also by the insurance, and then one might say, "Ok, they have to pay more for the insurance", which I understand, someone who smokes a lot, for example my father his entire life, he has a higher risk of getting ill, then again he's 88 by now. Well, yes. On the other hand, I think that our society is going, the longer the more, toward this direction. How people are assessed, how much meat they eat, how much they fly, that's just the reality. But well. I am for keeping the control as wide as possible. But it can be a help for older people. If it is a help, it's good, if it's about controlling them, how they behave, then I think it's not only positive.
	5.	PCH2: Well, the camera. There you had a good clue (laughs). Yes, I simply have these, it also seems like if one knows that there is a camera on the ceiling, also for people, then one doesn't move the same anymore. Then sometimes the risks of falls are even higher almost. So then, there is simply a restriction of life, of how one lives.

is not good either. You know. This is a limit…" A couple of informal caregivers also had similar thoughts and believed that, whilst helpful, visual sensors could control and manipulate (Table 4, Quote 4).

Some were also concerned that the use of visual sensors could put pressure on the user to behave in a certain way (Table 4, Quote 5). The knowledge of having a visual sensor or suddenly noticing sensors around the home may distract and conversely increase fall risks. An older person said: "*OPN5: I think because there are more and more [visual sensors everywhere and in every corner], then they look and see one there and there, and then they might fall because of this.*"

Robots

One older person feels that robots should also be controllable and unobtrusive to avoid overwhelming the end-user. For example, an obtrusive robot draws attention to oneself or approaches the end-user with reminders and alerts at unexpected or unwelcome times. *"OPN3: In any case, install it with a sensor inside that says, "Not good now" that it simply turns off so there's no risk of overwhelming, […] then perhaps one might even entrust the robot with something."*

Social privacy

Social privacy included participants' concerns on the impact of SHHTs in relation to relationships, social settings or contexts, and issues with social isolation. Technologies that provide feedback and alerts could be disruptive and induce feelings of stigmatization and prejudices from others around the end-user. However, any social interactions enabled by technologies could also be welcome in some cases of social isolation.

Smart wearable devices

Only older persons voiced social privacy concerns with respect to wearable technologies. The preferences for unobtrusiveness follow from the previous section on psychological privacy, whereby this section focuses on the disruptions in social settings. For example, an older person expressed annoyance at sudden unwelcome notifications: "*OPH6: So, it annoys me when I have guests over and they have a phone next to the plate or whatever they have on the table and the phone beeps frequently […]*" Another older person preferred to have no reminders when out in public, where a reminder for a medical visit could be particularly uncomfortable (Table 5, Quote 1). Furthermore, some older persons suggested particular time-specific or form-specific boundaries to limit these disruptions, or simply through having full-control of turning off the device whenever needed. Nevertheless, an older participant valued the feedback function stating that these could reduce loneliness (Table 5, Quote 2).

Ambient sensors (visual and non-visual)

A minority of caregivers believed that the home should be free from unwanted social interruptions. For example, one formal caregiver imagined a scenario where the camera could allow family members to connect during mealtimes, but was uncertain whether this possibility to socially engage at any time was desired (Table 5, Quote 3). Another formal caregiver expressed that cameras could offer more information about the older person and could induce others to form prejudices about this person, subsequently affecting their relationships (Table 5, Quote 4).

Table 5. Social privacy concerns related to monitoring technologies.

Type of technology	Quote no.	Quotation
Smart wearables	1.	OPN7: Of course it is, considering the fact that it will be on the arm or a small device somewhere and this is, it depends, certainly of help, but it can also be negative if you sit in a concert or if you're at the theater or in the church or anywhere with people around and it rings or there's someone saying, 'You need to go to the doctor now' (laughs).
	2.	OPH9: Yes, it simply needs to like…so, this apartment is almost too big for one person…if he is alone, then at a certain age there simply is a certain emptiness and then one is glad to have something that sends a reminder. And one is not depending on the youngsters to call in the evening and ask, "Did you?".
Ambient sensors (Visual and non-visual)	3.	PCN1: And they could for example, that was as we imagined the model, and for example while the resident or a relative was having a meal, one could participate through the camera. And then seeing what he was eating and being able to talk to him, and there I was very ambivalent. So, for me that was, on the one hand, again surveillance, there I wondered, would I want this? (laughs) I don't think so.
	4.	PCN9: But camera, if I can see everything of this person, then I perhaps create a prejudice for myself. Well, she always answers like this even though she didn't mean it and so… Perhaps I create a prejudice for myself and maybe this influences the relationship, maybe.

Informational privacy

Concerning all included technologies, some older persons and formal caregivers took a neutral and function-specific approach to the collection of data. One older person felt that, *"OPSH1: notes on data protection [are] exaggerated anyway. With everything that is, data protection always comes along, in the past it also worked without it."* In particular, some older persons expressed that their collected data would not be interesting or necessary to hide from other people, especially if already anonymized, or that the overprotection of data could become political (Table 6, Quote 1). On the other hand, there were also concerns toward the data security and possibility of misuse. When asked about conditions where it would be wrong to use technologies for caregiving, one formal caregiver thought of the misuse of data: "*PCH4: If it leads to negative consequences for the people and if the data is misused or used for things that are not meant for originally.*" Others believed that data should be not only under one's own control, but also be securely stored and transferred.

Participants emphasized that data collection must be purposeful and needs-based. This meant that only health-related data were acceptable to collect (with the exclusion of genetic or financial data, and conversations between people). An older person valued the use of technologies to report health abnormalities, "*OPSH1: It wouldn't seem bad to me. […] And if someone has large deviations and this goes to a medical center, I would find this positive. […] If something like this was transmitted and someone will be alarmed, then I would have nothing against it.*" In addition, data collection could be acceptable for end-users with preexisting health conditions, such as diabetes or rare diseases, prior history or risks of atrial fibrillation, heightened risks of falls, or in post-operative states.

The collected data then should only be shared with trustworthy individuals who had been given prior consent. These usually included healthcare providers, formal caregivers, police officers, family members with whom a good relationship existed, and for some participants, even researchers if data were anonymized. Strangers, private companies, insurance, churches, banks, and the general public were deemed unsuitable to access older persons' data. The reasoning was generally connected with the concerns for misuse. In the context of Swiss medical insurance, one informal caregiver said, "*ICR6: Yes, simply if it suddenly turns into a disadvantage […] So really, especially the insurance companies, it is already like this, you want to get a supplementary insurance, forget it. Because of some previous illness that you had, And that's it.*"

Most informal caregivers, who were all family members of older persons, agreed that it would be acceptable that informal caregivers have access to the data. Nevertheless, one informal caregiver felt that, whilst the access to information could be beneficial, older parents would nevertheless keep their children updated on their health status in communicative exchanges. However, this caregiver also added: "*It would be good for sure if one could briefly look into it, but this is again such a grey zone because it is none of my business in general.*"

Smart wearable devices

Most points regarding smart wearable devices were also included in the aforementioned general concerns, such as data misuse and protection, the need for purposeful data collection, and data sharing permissions. For instance, a formal caregiver expressed that there

Table 6. Informational privacy and monitoring technologies.

Type of technology	Quote no.	Quotation
Smart wearables	1.	PCH4: Horror (laughs). So no, I think, complete surveillance over 24h, like my pulse, the deepness of my sleep, both my children also have such a thing, I don't know if they still have it, don't know….I clearly find it questionable. It may be interesting, can be, if someone has problems. But the question is "What's done with these data?" I mean, if they are only recorded but for example not causing anything…So let's say, it measures the pulse and the pulse is always at 40 and that's why people feel dizzy and are at risk of falls, but nothing happens with this, it only records, then there is no sense nor purpose.
	2.	ICD5: Where do we get to if one knows everything? But people with dementia disappear at some point. Then you want to know where they are. And I mean, people with dementia receive care at least 3 times a day, but still, you must find them within 24 h, or latest 48 h. This is why, yes.
Ambient sensors (Visual and non-visual)	3.	ICR4: Yes and you know, I mean, who could tell her or how does she know that despite everything, [the system] could be suddenly activated.
	4.	OPN7: Yes, I would say so, I don't see it [visual sensors] for everywhere. I see it mainly for the police and this is also important for their work but otherwise I don't see as much and I think, if everything is visually recorded… this would go too far for me.
	5.	ICR1: But…no, I couldn't imagine that there would be a camera in every corner or so. No, this would drive me crazy. Yes, I would be, I think, I couldn't be calm. And how is it when guests are coming over? Will everything be recorded? Oh god, no.

would be a waste of resources if the device only records and nothing happens (Table 6, Quote 1). This points again to a need-based or purposeful data collection, such as those targeted toward fall risks, promotion of safety, or under medical indication. Due to the locational functions of the wearable device, participants thought that GPS data were useful to find older persons with risks of wandering behaviors and getting lost (Table 6, Quote 2).

Ambient sensors (visual and non-visual)

Visual sensor technologies were particularly concerning for reasons of data misuse and security. When asked about shadow images manipulated to anonymize the identity of older end-users, one older person and an informal caregiver still expressed mistrust: *"OPH13: And who tells me that this is only a shadow image?"* (Also see Table 6, Quote 3)

Visual sensors were thought to collect too much information, especially those placed in spaces that may be particularly unpleasant or sensitive, and raised more concerns about the possibility of hacking. One formal caregiver paused for a while before expressing: *"PCN9: I think, camera is actually sensitive because of data protection and so…"* An older person elaborated on the discomfort with visual sensors by dissociating them from caregiving uses, instead more with security and crime. Data collection here is hence more relevant for the police for investigation purposes, rather than for caregivers or family (Table 6, Quote 4).

A couple of informal caregivers raised the concern about the data collected by ambient sensors on other people. "*ICR6: But then other people who live in the house could be observed too, theoretically. So…yes, it's again about what happens to these data? This is a little…*" Or alternatively when guests come for visits (Table 6, Quote 5).

Robots

Participants were not in agreement regarding the capabilities for Pepper to collect and share data about their end-users. The robots would theoretically be used intimately in caregiving settings and collect sensitive data that should neither be shared to insurance companies or the state, nor misused and leaked. However, older persons themselves may not be worried or be relatively more concerned about their healthcare than about the collection of data itself, which echoes the finding at the beginning of this section regarding neutral or needs-based position that some participants took about data privacy. As one informal caregiver posed the hypothetical question to the older person about recording and collecting of their health data through a robot, the older person said simply without further comment, *"OPH15: Well, it won't be bad."*

Discussion

From our findings above, it is clear that the four dimensions of privacy concerns were associated especially with smart wearable and ambient sensor technologies. We elaborate and reflect with existing literature on the following five key findings of this study: 1) Participants were most familiar with and spoke most about informational privacy, which reveal that potential end-users were still concerned and unsure about the protection of their data, especially toward the misuse and misapplication for non-health reasons; 2) Delineating social boundaries was not mentioned by many participants in great detail, and surprising absent for the robot, which is primarily used to promote social activities; 3) Any kind of ambient sensors were perceived to be physically intrusive, particularly when installed in their own homes; 4) Participants were worried about behavior-manipulating or health-promoting features from technologies, particularly the automatic feedback or alerts from the wearable devices as a part of psychological privacy; 5) Obtrusiveness was perceived to be relevant to multiple dimensions of privacy, thus focusing on the unobtrusiveness in future designs may be the most efficient approach to improve adoption.

To begin with, our findings in the informational privacy dimension largely confirmed previous research on concerns in health data sharing, data security and misuse, as well as the emphasis on purposeful data collection (Leikas and Kulju 2018; Lie, Lindsay, and Brittain 2016; Zhu et al. 2022). Boise et al. (2013)'s study revealed a temporally-stable level of acceptance toward the sharing of information with family members and physicians. This finding was by-in-large echoed in our study, which hints at the perennial nature of end-users' anxieties to sufficiently protect their data and reconcile with the tradeoff with that these data may bring for their health. Trepte et al. (2015) examined a knowledge gap between people's stated concerns about privacy and the actual behaviors to suit these concerns: While users seem concerned about their online privacy, there is a lack of literacy and knowledge that prevents actual behaviors to protect their privacy in ways that they desire. Extending this to our study, participants could be aware that they should exercise caution to protect their data, but

there could still exist a gap where the knowledge has not translated to concrete behaviors.

Social privacy was a relatively smaller concern compared to the other dimensions of privacy for our study participants. This low emphasis on social privacy could be explained by the general limited access to and unfamiliarity with technologies. For example, participants' unfamiliarity with robotic technologies could have translated into the lack of its association as a social tool, which then impacts their relevance for social privacy concerns. Likewise, the lack of concerns for the monitoring technologies could be associated with participants seeing their functions in relation to deteriorating physical health and failing to see that these technologies *could* impact the end-user's socially. Furthermore, among others, Hughes (2004) and Leino-Kilpi et al. (2001) outlined important connections between social privacy and technologies, specifically in the control and need for boundaries in social interactions from cultural influences and comparisons. We thus reflect that the dearth of relevant data in the social privacy dimension may also stem from the lack of cultural comparisons in this study. On the one hand, despite the concerns for social isolation and need for independence, it remains necessary to clarify boundaries for social interactions as one continues onto their older ages. On the other hand, end-users with varying cultural backgrounds may also demand a certain amount and manner of social interactions that differ depending on societal expectations and social roles, which also affects their concerns for social privacy (Low, Lee, and Chan 2007). This emphasis on and complex management of social-cultural relationships inevitably influences older persons' understanding of social privacy and should thus be evaluated with contextualized and culturally-sensitive lenses.

The extensive installation of ambient sensors (visual and non-visual) made SHHTs for caregiving off-limits for most participants in all three groups, despite efforts to blur or anonymize the identity of the observed. This is a finding that may nuance previous findings in the empirical literature that the camera is the most privacy-invasive, and the ambient sensors may be a suitable alternative (Bian et al. 2021; Pramod 2023). As the home is seen and valued as a private sphere, participants pondered at and some rejected to being monitored in (specific locations of) their homes, which offset the technologies' benefits for caregiving. Specifically, the installation and use of ambient sensors at home during toileting, sleeping, and grooming are deemed especially problematic. These concerns thus contribute to the existing literature that points to the particular privacy concerns that these spaces at home bring to the user (Chung et al. 2017; Jaschinski et al. 2020; Niemeijer et al. 2015). In our results, it shows that if people knew that staying at home might come with the installation of SHHTs especially in these spaces, they may prefer a nursing home when they encounter greater health needs. As one formal caregiver indicated in the dimension of physical privacy, the threshold for privacy would be lessened when an older person enters the nursing home by frequent intrusions from formal caregivers and may not be damaged further by visual sensors. The use of SHHTs may thus indicate a shift of boundaries between public and private (Burrows, Coyle, and Gooberman-Hill 2018), which was echoed by some participants in our study with an association of ambient sensors with relatively public spaces such as prisons and hospitals, rather than private homes. Most importantly, the shift toward a preference for institutionalized caregiving contributes a different perspective to existing literature that document the prioritization of aging-in-place from older adults for as long as possible (Peek et al. 2016; Van Dijk et al. 2015; Wang et al. 2019). This may also emphasize the feeling of discomfort that potential end-users feel toward the use of ambient sensor, and would reject them even if it may enable more independence or time at home.

Smart wearables were thought to be invasive to the bodily environment from a physical privacy perspective, as well as manipulative from a psychological dimension. Participants associated the wearable device with feelings of control and restraint, which aligned with Dunne and Smyth (2007) description of devices within one's "peripersonal space" and could thus be intrusive to one's feeling of their private space. For psychological privacy, participants were worried about health recommendations and the rewarding of certain behaviors that was by-in-large common among monitoring technologies. These manipulative effects were even more problematic when understood within the concepts of mental privacy and forming personal identities, from the perspective of interfering self-narratives, the confidence to independently make decisions and the trust in self-judgment (Wajnerman Paz 2021). Moreover, this fear toward the promotion of certain externally established health ideals is echoed by Schomakers, Biermann, and Ziefle (2020), who compared the home to a prison and standards for behavior are then set by others. Specifically, the dimension of psychological privacy and the application of boundaries to prevent interference to one's ideologies, thought-processes, and decision-making could inform the research on neuroethics and AI (Schicktanz

et al. 2023; Wajnerman Paz 2021). Whether cognitive declines and memory deficits in older ages should be augmented with wearable technologies is an issue that is closely related to this dimension of privacy, in terms of the justifications to balance the principle of beneficence with the needs to set boundaries for one's psychological privacy and freedom of thought (Wajnerman Paz 2021). The fact that these concerns are already originating from the use of health alerts and recommendations based on everyday data analysis highlights to the need for further consideration to protect the rights and desires of persons in later ages. Furthermore, some participants even feared that the alarms on these wearables could be a distraction and thus reduce the wearer's safety. From this perspective, privacy and safety appear to be complementary considerations rather than being presented as a tradeoff for the wearable, which offers a different perspective to the literature on nature of balancing the ethical values of privacy and security for smart technologies (Schomakers and Ziefle 2023)

The aspect of unobtrusiveness may serve as a solution to resolving social, physical, and psychological privacy concerns for older persons when such technologies are used to ensure their safety and well-being. Hensel, Demiris, and Courtney (2006) emphasized the notion of undesirably noticeable or prominent in obtrusiveness, which generates feelings of discomfort that could be physically or psychological felt by the user. In other words, a device or event that is desired or unnoticeable would be conversely unobtrusive. Taking this back to our study, participants thought that unwelcome or conspicuous reminders from and the sight of SHHTs within their physical or peripersonal spaces could be distracting to both older persons and any bystanders. When only considering older persons, these distractions may not only be overwhelming, but also risk being manipulative, or even negatively impacting their self-esteem from the psychological dimension. Compared to other participant groups in our findings, only older participants mentioned discomfort with obtrusive reminders from wearable sensors in social settings, which also contributes to the perspective of "affectedness" as a criterion for the perception of social privacy intrusions (Schicktanz 2009). In other words, because the reminder or alert from the wearable watch is provided to older persons in a social situation, they are naturally the most affected person in a social situation and may feel most affected by stigma or embarrassment. This finding highlighted the importance of empirical research with older persons, as they would be the most affected by any technologies used in their care. While obtrusiveness is typically considered as a usability or esthetic concern (Felber et al. 2024; Pietrzak, Cotea, and Pullman 2014), we believe that our findings may expand this into the concept of privacy. Because SHHTs not only collect data, but also transmit information to third parties *via* perceptible signals, this aspect could also be interpreted as an intrusion in informational privacy. For example, a noticeable signal or alert could inform third parties in the public about the use of a SHHT, which may be associated with shame and a sense of loss of control over personal data for the users. At the same time, older people and persons with dementia in the early stages of their illnesses are particularly concerned about regulating information about their own need for help (Buhr and Schweda 2022). As the negative impacts associated with obtrusiveness spills across several dimensions of privacy, this may highlight the need for future design of SHHTs to consider unobtrusiveness as a parameter in order to improve adoption and usability for end-users.

Study limitations

There exist several limitations with our study. Firstly, our data collection took place during the pandemic between September 2021 to October 2022. We were inevitably influenced by the COVID-19 restrictions that were intermittently present in Swiss nursing homes, state policies, and the University regulations during that period. This may have led to the self-selection of participants who were comfortable and able to be interviewed in-person. The factors of mask-wearing and physical distancing measures may have also impacted the interview style. Although previous literature has pointed to the potential benefits of digital tools to improve issues of social isolation and caregiving burdens during the pandemic, our study was designed prior to the first outbreak and unfortunately does not allow a comparative approach to the privacy concerns from end-users before and after the COVID-19 pandemic (Akabayashi et al. 2021; Sturm et al. 2023). Secondly, our research was limited to perspectives of people from a Western European culture but provides rich and informative data for the development of hypotheses for quantitative work. However, our findings are not generalizable. Thirdly, not all participants had experiences with all the introduced SHHTs, with the robot Pepper being the most foreign. To ensure that participants were comfortable and knew exactly what they were giving opinion about, we showed them pictures of the technologies and described those to them as well. As we did not provide

the opportunities for participants to experience the technologies before their attitudes were gathered, this could be a limitation to our findings. However, many studies have used similar methodology, where they have shown pictures or a demonstrative video to participants, followed by verbal explanations provided by the interviewer (Klawunn, Albrecht, and Dierks 2023; Shin et al. 2022). We also acknowledge Ghorayeb, Comber, and Gooberman-Hill (2021)'s finding, that participants with prior experience with smart homes were more accepting of the technologies, more concerned about its utility and less about privacy compared to the non-users. Lastly, the novelty of the technologies that were discussed during the interviews may have affected the quality of discussions on privacy, which may explain limited privacy concerns found in the case of robotic technologies. Thus, we cannot exclude the effect of social desirability in our data despite the assurances that the study was anonymous and the topic of discussion being of less sensitive nature.

Conclusions

The use of remote monitoring and robotic technologies have been framed to support caregiving needs and the health of older persons at home. Switzerland, like many other nations with demographics of an increasing aging population, has looked toward the benefits and opportunities of these solutions. Nevertheless, as a main barrier and ethical concern, SHHTs bring forth discomfort relevant to privacy and its related concepts of data sharing, and the issues of control or manipulation. From the discussions with sixty-seven study participants, we found that all SHHTs that enabled collection and sharing of data generated informational privacy concerns for the participants interviewed, whilst wearable and sensors at home were associated with social, physical, and psychological dimensions of privacy. When isolated by technology, the participants were most uncomfortable with the use of ambient and visual sensors out of all SHHTs. With inputs from participants in a diverse set of caregiving roles, this article holistically contributes to the array of privacy concerns toward SHHTs used for caregiving purposes. The stratification of privacy concerns from potential end-users into dimensions and type of technology offers a novel perspective in the empirical literature on ethical concerns for elder care technologies that allows researchers, end-users, and product designers to better determine the point of concern and find target-oriented solutions to resolve them.

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