2022 IEEE 30th International Requirements Engineering Conference Workshops (REW) | 978-1-6654-6000-2/22/$31.00 ©2022 IEEE | DOI: 10.1109/REW56159.2022.00016

A Participatory Design Methodology to Elicit Aging-in-Place Stakeholder Concerns with Ambient Assistive Living (AAL) Devices During COVID-19

Katherine-Marie Robinson
School of Engineering Design and Teaching Innovation
University of Ottawa
Ottawa, Canada
krobi064@uottawa.ca

Rachana Devkota
School of Engineering Design and Teaching Innovation
University of Ottawa
Ottawa, Canada
rdevkota@uottawa.ca

Jason Millar
School of Engineering Design and Teaching Innovation
University of Ottawa
Ottawa, Canada
jmillar@uottawa.ca

***Abstract*— For varying reasons, our world is experiencing increasing life expectancies and decreasing birth rates, which has led to a generational shift in population distribution. The Government of Canada predicts that in the year 2030, over 9.5 million (23%) Canadians will be 65 years or older. For this growing demographic of older adults, intelligent home health technologies have been proposed as one beneficial avenue to support and maintain an individual's health and wellness as they begin experiencing aging-related health effects. However, many ethical concerns have been raised regarding the design and deployment of intelligent home healthcare technologies in aging-in-place settings such as long-term care and nursing homes. This paper presents a revised participatory design methodology to identify aging-in-place stakeholders' ethical concerns with two Ambient Assistive Living (AAL) devices. The main objective of this paper is to develop and test a participatory design research method that is well suited for older adults living in long-term care settings, which is currently lacking. Developed by an interdisciplinary team of engineers and social science researchers, this paper presents the participatory method that was designed and tested in a long-term care facility by collaborating with a mix of aging-in-place stakeholders, including older adults and healthcare professionals. By interweaving interactive activities, hand-written tasks, and discussions throughout the data collection process, the methodology successfully identified stakeholders' ethical concerns with the devices.**

Keywords*— *Aging-in-place, Long-Term Care, Ambient assisted living technology, Ethical concerns, Participatory research design method.

I. INTRODUCTION

The Government of Canada predicts that by the year 2030, over 9.5 million (23%) Canadians will be 65 years or older [1]. Other countries such as the United States, Britain, Germany, and Japan are experiencing similar trends [2]. This has led to the United Nations (UN) prediction that by 2050, one out of every six people globally will be over the age of 60 [3]. Within this growing demographic of older adults, intelligent home health technologies are presented as an effective and innovative solution to support and maintain an individual's health and well-being as they begin to experience aging-related health effects. One area of intelligent home health technology proposed in recent years is Assistive Technology (AT) [4]. This paper focuses on an area of AT known as Ambient Assistive Living (AAL) technology. AAL technology blends AT with computational components such as Artificial Intelligence (AI) or Machine Learning (ML) [5]. AT is an umbrella term used to describe any tool that allows a person with a physical or cognitive impairment to complete a task they would otherwise be unable to perform [6]. Overall, AAL technology includes any device, software, or human-machine equipment that can aid older adults in everyday activities to live actively, healthily, and autonomously in their own homes, regardless of any physical, cognitive, or environmental impairments [7], [8]. While AAL technology is often considered a tool to support those with cognitive impairments, such as people who have dementia, it is important to note that it can be used to support anyone who is "aging-in-place." As defined by the Government of Canada [9] and the Center for Disease Control and Prevention (CDC) [10], aging-in-place is "*the ability to live in one's own home, space, and community safely, independently, and comfortably, regardless of age, income, or ability level*."

However, with the increased adoption of AAL technology, many ethical concerns have been raised regarding the design, deployment, and use of this technology for older adults who are aging-in-place [8], [11], [12]. Starting in 2006, researchers such as Sparrow & Sparrow [13] began to voice concerns about the technology. Many researchers believed that the reason for the increased research efforts in robotics and AI for healthcare was not so much due to the concern for older adults' needs, concerns, or desires, but instead the curiosity and interest of the researchers themselves [13]. Nearly two decades later, the ethical questions and concerns regarding the use of AAL technology for aging-in-place have only grown due to AI's advancements over the years [8], [14], [15].

In an unpublished systematic literature review (SLR) [16], the authors investigated the ethical concerns that aging-in-place stakeholders, such as older adults, caregivers, and healthcare

2770-6834/22/$31.00 ©2022 IEEE
DOI 10.1109/REW56159.2022.00016

Authorized licensed use limited to: University of Ottawa. Downloaded on November 03,2024 at 05:07:28 UTC from IEEE Xplore. Restrictions apply.

professionals (HCPs), have with AAL technology. The SLR also investigated the ethical design and engineering frameworks used or created to design and develop new AAL technology that attempts to address the ethical concerns of direct stakeholders. From the SLR, six main themes of ethical concerns were identified:

- Autonomy: The ability to make decisions for oneself
- Comfort: Something that provides physical ease and relaxation
- Data Privacy: Control one has over information that is personal to them
- Independence: One's ability to complete a task without help from others or machinery
- Personal Privacy: Control one has over their physical self or space
- Social Connectedness: The experience of feeling close or connected to others. It is a sense of belonging to a social relationship

The main goal of this research project was to document the ethical concerns of long-term care (LTC) stakeholders (i.e., older adults, caregivers, and HCPs) so that the researchers can develop an ethical design tool to help with the design and development of AAL technology. The ethical design tool aims to inform direct and indirect stakeholders (older adult end-users, caregivers, HCPs, engineers, designers, and industry partners) of the ethical implications that must be considered before, during, and after designing, developing and using AAL technology.

This research aims to address the issue of inclusion for AAL technology development by focusing on older adults living in LTC, who are often an underrepresented and underserved segment of Canadian society. Looking through the literature, there is a lack of participatory research design and data collection methods to document the ethical concerns that older adults living in LTC have with AAL technologies. To address this limitation, this research aims to develop and test a participatory design research method that is well suited for aging-in-place populations in LTC settings. Therefore, this paper presents the participatory method that was designed and tested with older adults who are living in an LTC setting.

II. Why Participatory Research Design

The recent unpublished SLR conducted by Robinson *et al.* [16] provided insight into the concerns that ageing-in-place stakeholders have with AAL technology and identified various ethical design and engineering frameworks utilized when designing and developing the technology. While researchers such as Curumsing *et al.* [17] and Mincolelli *et al.* [18] have put forth new frameworks that may potentially do a better job at identifying and addressing stakeholder needs and requirements, these frameworks are still very new and have only been vetted by the same people that proposed them. On the other hand, many researchers used well-known frameworks (e.g., User-Centered and Participatory Design) to design and develop new AAL technology [7], [19]. Both frameworks center around the stakeholders that will be impacted the most by a proposed idea or solution and try to identify and address any needs or concerns throughout the design process to develop a device that is well-accepted by its intended audience.

Even though User-Centered Design is the more often utilized framework from the literature collected in the SLR, a Participatory Design methodology was chosen as the guiding principle for the data collection for this research. The reason for this choice is that User-Centered Design focuses heavily on the end-user of a device, while Participatory Design aims to include as many impacted stakeholders as possible.

Therefore, even though much of the focus of this study was on learning more about the thoughts, opinions, and concerns of the end-users who will be primarily impacted by the AAL technologies (i.e., older adults living in LTC), it is also essential to consider other stakeholders, such as caregivers and HCPs, who would have their own thoughts, opinions, and concerns regarding the devices as well.

Finally, as the outcome of this research aims to propose a tool to communicate the thoughts, opinions, and concerns that impacted stakeholders have with AAL technology, it is crucial to make stakeholders feel as though they have contributed to the tool by being actively involved in the research. By using a Participatory Design approach, which allows for interactive elements as a means of data collection, stakeholders can participate in the research, share or bounce their thoughts or opinions with other participants or the researchers, and understand what the next steps are with the data they've shared.

The next section of this paper presents the process undertaken to design and develop the methodology used to conduct Participatory Workshops and Interviews for this research.

III. Methodology

This research is a part of a larger multi-site, and multi-collaboration initiative called the Program to Accelerate Technologies for Homecare (PATH). PATH has been created through AGE-WELL, Canada's technology and aging network, which aims to provide an affordable open-access infrastructure for researchers across Canada to propose their algorithms and test their prototypes in real home environments [20].

An interdisciplinary team of engineers and social science researchers from the University of Ottawa (uOttawa) were involved in designing and implementing participatory research methods developed for older adults living in LTC settings. The participatory research design methods were inspired by a paper titled "*Judgement Call - The Game*," written in collaboration by academic and industry researchers [21]. The design methods were then implemented with older adults living in LTC. As this research is part of the PATH project, the researchers worked closely with a local long-term care facility (LTCF) to design the older adult-focused research and data collection processes. Two PATH AAL devices, the Hexoskin ProShirt™ (Fig. 1) and the AWS DeepLens™ (Fig. 2) were used to test these methods and collect ethical concerns from older adult stakeholders. The Hexoskin ProShirt™ is a wearable device that uses textile sensors to monitor cardiac, respiratory, and movement activity and can collect 36,000 data points a minute [22], while the AWS DeepLens™ is a fully programmable video camera that utilizes

Authorized licensed use limited to: University of Ottawa. Downloaded on November 03,2024 at 05:07:28 UTC from IEEE Xplore. Restrictions apply.

deep learning to make predictions through computer vision, algorithms, and AI models [23].

These devices were chosen purposely by the research team as they presented the most interesting ethical questions out of the five original PATH devices that were proposed.



Fig. 1. Hexoskin ProShirt™. (a) The style for women. (b) The style for men. Source: [22]

By conducting these new methods and obtaining the ethical concerns from potential older adult end-users, the results can corroborate the SLR findings and identify any new ethical concerns that have not been noted in the literature thus far, especially for older adults living in LTC. Additionally, the concerns collected are unique to the two devices used to test these methods. Therefore, upon completing this research, PATH researchers and affiliated members will be privy to the ethical concerns that older adult stakeholders living in LTC have with the Hexoskin ProShirt™ and the AWS DeepLens™.

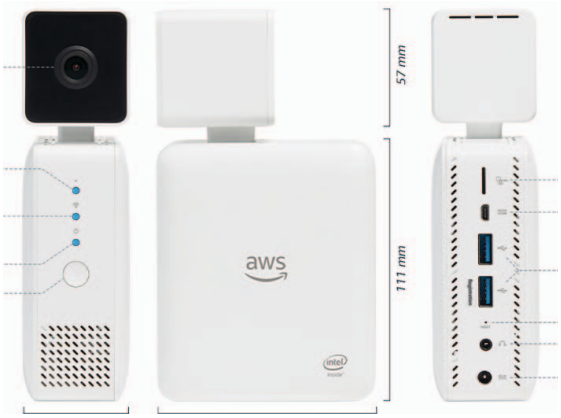


Fig. 2. Multiple views of the AWS DeepLens™ Camera. Source: [23]

The design methods presented in this paper focus on two groups of older adults who live at the LTCF: Tenants are older adults who live at the facility in private apartments or shared living spaces and are fully independent, requiring no external assistance from HCPs. Residents are older adults living in LTC, meaning they need occasional to around-the-clock support from HCPs.

There were three different stages of this research design: the initial research design, the meeting with the LTCF research coordinators, and the revision of the design. Each of these sections is presented in detail to show the progression of the methodological process from the initial to the final research study design.

A. Initial design

In an attempt to conduct research that was as interactive and as impactful for the participants as possible, the research team brainstormed the idea of collaborative workshops. In the beginning, the plan was to conduct two workshops, one for each device. Initially, each workshop would include all LTCF stakeholders, consisting of tenants, residents, caregivers (people who have loved ones in long-term care at the facility), and HCPs (people who work at the facility, including nurses, registered practical nurses, and personal support workers). In each workshop, LTCF stakeholders would be invited to participate in a two-hour-long session focused on one device, where they would discuss ethical concerns in relation to the device, as seen in Fig. 3. For the convivence of everyone involved, the workshops would take place at the LTCF so that the workshop would be accessible to all.

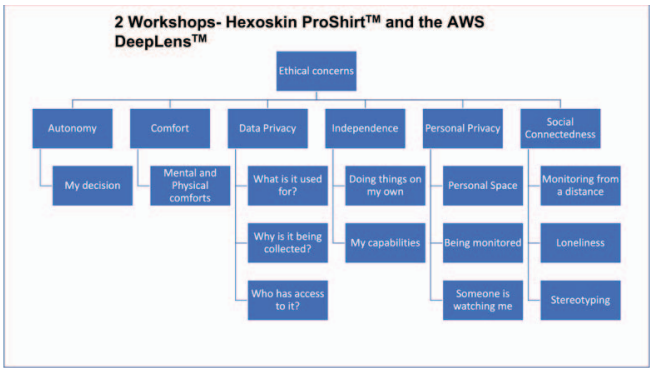


Fig. 3. Six ethical concerns identified and used for this research. Source: [16]

In the workshops, seen in Fig. 4, participants would be divided up into smaller groups, where a member from the uOttawa research team would provide a scenario for the device in question and then facilitate semi-structured conversation regarding the identified ethical concerns from the literature review and how LTCF stakeholders saw them in relation to the device. To allow for different opinions and views, each small group would be composed of various stakeholders. This would hopefully encourage conversation between different people so that stakeholders could put themselves in another person's shoes.

Ideally, the smaller groups would also encourage conversation on topics outside the six identified ethical concerns from the unpublished SLR [16]. Therefore, as new topics, ideas, themes, or concerns emerged, the uOttawa research team member would note the new matter and ask questions about it to

Authorized licensed use limited to: University of Ottawa. Downloaded on November 03,2024 at 05:07:28 UTC from IEEE Xplore. Restrictions apply.

see if it was a concern that resonated with the group or just specific stakeholders.

Finally, just before finishing the workshop, attention would be called back to the front of the room so that each small group could share their findings and present new topics raised throughout the smaller conversations. To conclude, the lead researcher would explain to the participants how all of the data collected through the workshops would be analyzed and used to influence the design tool for the device that was the workshop's focus.

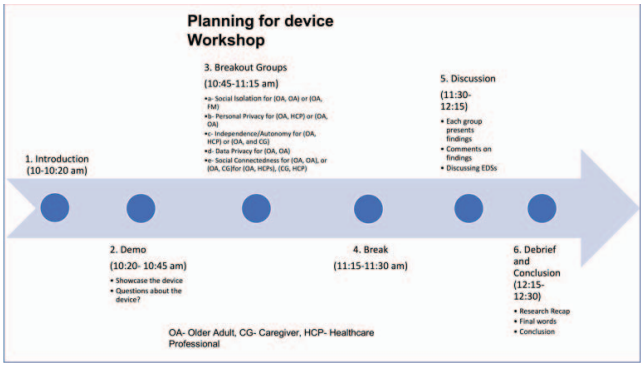


Fig. 4. Initial Workshop Planning- Example of Workshop breakdown.

Different variations of the initial study methodology were proposed to make the workshops more interactive and obtain new thoughts, opinions, or ethical concerns for the Hexoskin ProShirt™ and the AWS DeepLens™. Another study design example explored having different stakeholder groups consider how the device would impact different living space areas, such as using the AWS DeepLens™ in the living room or the Hexoskin ProShirt in the bedroom.

B. Meeting with Long-Term Care Facility Research Coordinators

Once the initial study design was drafted, a meeting was scheduled between the uOttawa researchers and the LTCF research coordinators to ensure the research plan was possible with LTCF's resources.

This meeting determined that the initial study design was not achievable due to time, mobility limitations and COVID-19 restrictions. For example, HCPs would only be available for a maximum of 30 minutes, and many tenants who would potentially participate in the research study often attended activities planned by the LTCF throughout the week. Additionally, many of the residents who would be willing to participate had mobility constraints that would make them unable to attend a workshop setting. Furthermore, COVID-19 restrictions at the time only permitted 15 people to gather indoors. Therefore, the initial study design methodology would be impossible to implement due to the above issues.

C. Revision of the design: Judgement Call- The Game

Upon hearing that the initial study methodology would not work as anticipated, a new study design was needed to conduct research with LTCF stakeholders.

In searching the literature to find examples of interactive, participatory design methodologies, a paper titled '*Judgement Call - The Game*' written in collaboration between an academic researcher and members of the Microsoft Ethics & Society group, was found [21].

Judgement Call - The Game (from here on, referred to as Judgement Call) is a methodology that was created for industry product teams so that ethical concerns could be surfaced when developing Artificial Intelligence (AI) technology so that societal harm could hopefully be identified and addressed before a product was released to a broader community [21]. To achieve this, the authors stress the theme is to "*raise a product team's awareness about the ethical considerations related to the technologies that they are designing and building*" [21, p. 2].

Therefore, the goal of Judgement Call is to create an experience in which product teams think and reflect on the ethical considerations for an AI technology that they are developing [21]. This is done by roleplaying as a stakeholder who is directly or indirectly impacted by the technology in question, reflecting on the concerns by writing out a product review and providing a rating of the technology as their stakeholder character, and conversing with other participants who are roleplaying as different stakeholders [21].

The game begins by choosing a scenario. The scenario usually focuses on the technology the product design team is developing. That way, as the product design team plays the game, they can explore the real-world implications of the technology they are building and surface a variety of ethical concerns relating to different user perspectives [21].

Please see [21] for complete details on how the game is played.

By the end of the game, multiple rounds will have occurred, allowing the product designers to have played as different stakeholders and consider various ethical principles in relation to their product and how the product may impact the stakeholder characters. As the authors note, "*Together, [the reviews] paint a more holistic picture by providing multiple perspectives on the same technology*" [21, p. 3].

As described above, holding workshops with multiple stakeholders would not be possible. By taking inspiration from Judgement Call, a methodology for data collection with tenants and residents living in an LTCF was developed. Although some elements of Judgement Call were retained, other elements of the methodology were modified for this research to meet stakeholders' needs.

Therefore, instead of holding workshops with all participants, two workshops (one workshop for each device) were planned with two groups of LTCF tenants. Individual interviews were scheduled with LTCF residents. As this paper is focused on the research design methods for older adults living in LTC, the research methods used for caregiver and healthcare professional stakeholders are not discussed here.

The workshops for tenants were scheduled for one hour, while the interviews with residents were scheduled for 20 minutes. The details on how the final research design was

Authorized licensed use limited to: University of Ottawa. Downloaded on November 03,2024 at 05:07:28 UTC from IEEE Xplore. Restrictions apply.

created and tested, along with some implementation outcomes, are discussed in the sections below.

IV. Final Research Study Methods

A. Participatory Design Workshops with Tenants

To recap, tenants are older adults living at the LTCF but are fully independent. This means that they live in private or shared accommodations at the facility but require little to no additional support from external parties such as HCPs. In the meeting described in Section III.B, it was suggested that any research activity with tenants should take no longer than one hour and should be planned for a time that was convenient for the tenants to attend.

These insights lead to the decision to hold two workshops: one for the Hexoskin ProShirt™ and the other for the AWS DeepLens™. To include as many interested tenants as possible and accommodate COVID-19 restrictions in place at the time, it was decided to have different tenants participate in the different workshops. Fortunately, this was feasible at the LTCF because they have two apartment buildings (A and B) for tenants. Therefore, the workshop with Building A would focus on the Hexoskin ProShirt™, while the workshop with Building B would focus on the AWS DeepLens™.

To schedule the workshops, it was important for the researchers to pick a time that would accommodate as many interested tenants as possible. Therefore, the uOttawa researchers attended a weekly scheduled coffee time that the LTCF holds for its tenants, where the researchers asked tenants their preferred time for a one-hour workshop. Due to their busy schedules during the weekdays, all tenants agreed that weekends would be best. Therefore, the workshop with Building A was scheduled to take place on a Saturday morning, and the workshop with Building B was scheduled for the same Saturday in the afternoon.

In planning the workshops with tenants, overall inspiration came from Judgement Call. However, many changes to the original methodology were made to accommodate tenant participants. For example, as this research was designed to understand the thoughts, opinions, and concerns of older adult end users living in LTC with the two AAL devices, workshop participants were not asked to identify impacted stakeholders as was done in Judgement Call. Instead, tenants would play as themselves. This way, tenants would be able to freely talk about the device in question, and how they see it impacting their lives.

Furthermore, while the ethical principle cards implemented in Judgement Call remained a feature in the workshop with tenants, they took on a different meaning in this research. Here, ethical principle cards became ethical concern cards, where the ethical concerns used in the workshops were identified in the SLR [16]. The six most discussed ethical concerns with AAL technology identified from the SLR were used to develop the ethical concerns cards used in the workshop with tenants. Examples of four of these cards are seen in Fig. 6, and the remaining two in Figs. 7 and 8. By using concerns identified in the literature, the researchers would have a starting point for the workshop to see if these ethical concerns were upheld by the tenants and if these initial concerns could spark discussion of any other ethical concerns.

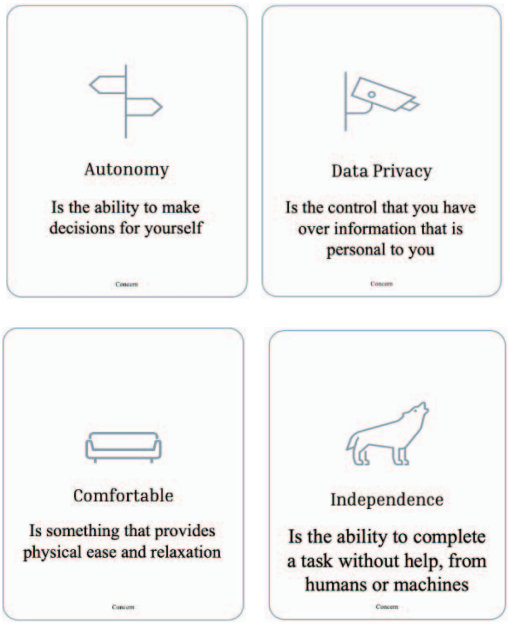


Fig. 6. Examples of the ethical concern cards used in the workshops with tenants. (a) Autonomy. (b) Data Privacy. (c) Comfort. (d) Independence.

Additionally, instead of individually writing product reviews as was done in Judgement Call, a more interactive approach was taken. With each new ethical concern card tenants were encouraged to discuss their thoughts, opinions, and fears about that concern in relation to the device.

By taking this approach, tenants would be able to share their stories and opinions, with the hope that new thoughts or concerns would emerge through the discussion. As tenants talked, they were also encouraged to write down any major ideas or concerns highlighted throughout their conversation. This was important as the notes that tenants provided were used to develop the ethical design tool, which was a key objective of this research.

To help start and facilitate the discussion, probing questions were written on the back of each ethical concern card to help tenants formulate their own thoughts, stories, or ideas. The questions on the back of each ethical concern card were unique to each device (Figs. 7 and 8).

Authorized licensed use limited to: University of Ottawa. Downloaded on November 03,2024 at 05:07:28 UTC from IEEE Xplore. Restrictions apply.

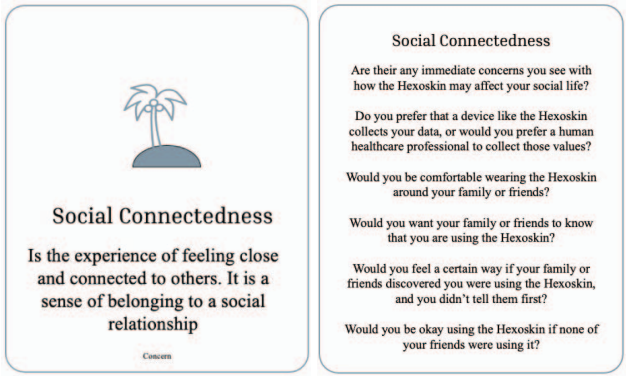


Fig. 7. Ethical concern card for Social Connectedness for the Hexoskin ProShirt™. (a) Front side. (b) Backside.

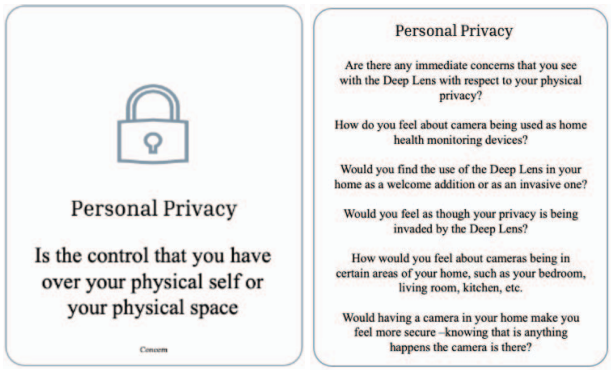


Fig. 8. Ethical concern card for Personal Privacy for the AWS DeepLens™. (a) Front side. (b) Backside.

Lastly, it was decided to keep the element of product review rating in the new study design method. To do this, once the discussion between tenants for an ethical concern came to a natural end, each tenant was asked how they would rate the device in relation to the ethical principle they were just discussing. For example, if the tenants were discussing autonomy in the workshop focused on the Hexoskin ProShirt™, each tenant was asked to rate this device in relation to how they saw it impacting their autonomy.

1) Beginning the Workshops with Tenants:

To begin each workshop, tenants were invited to have coffee and donuts as soon as they entered the workshop room. This was meant to signal to the tenants that the researchers appreciated them taking time out of their Saturday to participate in the workshop. Once all tenants arrived, introductions were made. Next, all participants and researchers were introduced and asked to share a fun fact about themselves. This small activity allowed tenants to settle in, familiarize themselves with participants they didn't know, and become more comfortable with the researchers.

2) Introducing Tenants to the Research:

After the introductions, the researchers explained the purpose of the workshop, what tenants would be asked to do in the workshop, and reminded tenants that they had consented to be audio recorded throughout the session as was described in the Informed Consent Document that all participants signed. After the instructions, tenants were shown a short video made by the researchers about the device that their workshop centerd around, i.e., the Hexoskin ProShirt™ for Building A and the AWS DeepLens™ for Building B. As the devices were not available to bring to the LTCF, this video was developed as a device showcase allowing tenants to see the device, learn about its characteristics, and observe it in operation. After the video finished, tenants were given a moment to ask any clarifying questions about the video or the device itself. If the question related to something that would be discussed during the workshop activity, the researchers encouraged the participant to hold onto their question as it would be discussed later. After all questions were addressed, the researchers provided the tenants with the instructions for the interactive activity.

3) Providing a Device Scenario to Tenants:

To begin the activity, the researchers presented the tenants with a scenario of the device that was the focus of their workshop. This was a critical element of the workshop as the devices were new to the tenants. Therefore, the scenario was meant to give tenants an idea of how the device may fit into their lives if they were asked to use it for research purposes, as with PATH, or if they adopted it into their daily routines.

4) Conducting the Interactive Activity with Tenants:

Once the scenario was finished, the interactive activity began. For the workshop with tenants from Building A, tenants were divided into two groups due to the number of participants. Having two groups, each group would discuss three ethical concerns instead of six and how they saw the ethical concern relating to the Hexoskin ProShirt™. For the Building B workshop, there was a smaller number of participants, so all tenants remained together and discussed all six ethical concern cards related to the AWS DeepLens™.

To start the interactivity activity, all ethical concern cards were placed into a box. From there, one participant was asked to draw a card for their group to discuss. For Building A, this was done twice, one for each sub-group, and for Building B, once. Upon drawing the first card, discussions between the participants could begin. Participants were encouraged to use the questions on the back of the concern card if they didn't know how to start their conversation. Each group was also given blank file cards and markers so that major concerns, ideas, thoughts, or opinions could be jotted down as they arose throughout the discussion. Additionally, the researchers were available if the tenants had any questions. For the Building A workshop, one researcher stayed with each group to help facilitate conversation and write down important points throughout the discussions. For the Building B workshop, one researcher facilitated the discussion with tenants using the questions on the back of the ethical concern card, while the other researcher used the file cards to record notes from the conversation.

Authorized licensed use limited to: University of Ottawa. Downloaded on November 03,2024 at 05:07:28 UTC from IEEE Xplore. Restrictions apply.

After the allotted time for the discussion with each ethical concern card, each tenant was asked to provide a rating for their opinion of the ethical concern in relation to the device.

Once ratings were collected, a new tenant was asked to draw a new ethical concern card from the box, and the activity continued until all cards were drawn and discussed by participants.

For the workshop with Building A, a small debrief session was held with all participants after the final round of ethical concern card discussions. This was an important element because it allowed both groups to see the ethical concerns that the other group discussed and talk about any new insights or concerns that came out of the smaller group discussions.

5) Introducing the Ethical Design Tool to Tenants:

To conclude each workshop, the researchers provided more detail about how data collected from the workshops would be used. By doing this, researchers introduced tenants to the concept of the ethical design tool that would be created by using the data collected through the interactive activity. To show tenants what they helped design through their participation, the researchers displayed all of the file cards that were generated throughout their activity grouped by ethical concern, to demonstrate that the ethical design tool would be developed using the comments shared throughout the workshop (Fig. 9).

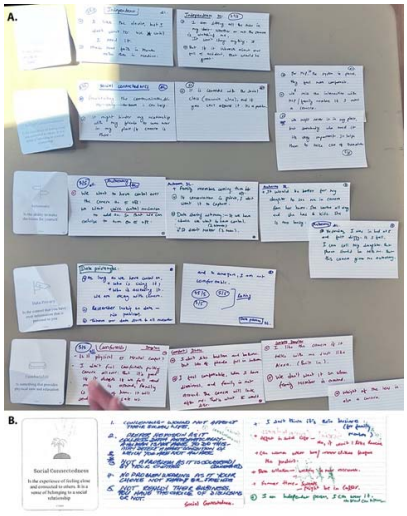


Fig. 9. Data collected from workshops. (a) Collected cue cards AWS DeepLens^{TM} workshop with tenants to demonstrate proposed ethical design tool. (b) Close-up on Social Connectedness file cards.

6) Concluding the Workshop with Tenants:

To finish the workshop, tenants were encouraged to share their thoughts on the design tool, describe anything they believed should be included in the tool, or to ask or share any remaining questions or opinions.

For this research, a total of 14 LTCF tenants participated in the workshops- (9 from Building A and 5 from Building B).

B. Participatory Design Interviews with Residents

Once again, residents live in LTC and require partial to total assistance from HCPs. During the meeting with LTCF research coordinators, it was discovered that many of the residents who would be eligible to participate in the study had mobility issues, meaning that attending an in-person workshop would possibly be inconvenient. Additionally, the LTCF research coordination staff advised that research with residents should last no longer than 20 minutes, as the residents often had guests, participated in other activities, or quickly grew tired. Due to the insights obtained by the LTCF research coordination team, it was decided that interviews would be a better method of data collection than larger workshops. This decision led to conducting 20-minute interviews, focused on one device, with residents in their rooms at the LTCF.

Using the modified version of Judgement Call described above, the interviews were designed to elicit residents' thoughts, opinions, questions, and concerns regarding the Hexoskin ProShirt^{TM} or the AWS DeepLens^{TM}.

1) Beginning the Interviews with Residents:

Interviews with residents started similarly to the workshops conducted with tenants. The researchers provided a quick introduction to the purpose of the research and reminded the resident that they would be audio recorded, as was agreed to in their informed consent document.

As was done in the workshops, the researchers played the video for the device that was the focus of the interview. Once the video was presented, the researchers provided the residents with a scenario so that they could picture the device in their lives. As with the workshops, presentation of the scenario was important to get the residents to understand how the device might fit into their lives.

2) Conducting Interviews with Residents:

Once the scenario finished, the researchers began a semi-structured interview process. The questions asked in the interview were the same questions found on the back of the ethical concern cards used for the workshop with tenants. Therefore, each of the questions asked by the researchers in the interviews with residents focused on the identified ethical concerns from the SLR and were meant to explore how the resident saw the device impacting their lives. Using a semi-structured interview methodology allowed residents to ask their own questions, raise new thoughts or ideas, and voice any additional concerns that they saw with the device that had not been touched upon.

3) Concluding the Interview with Residents:

To conclude the interview, the researchers asked the residents to provide a rating for the device being discussed. This rating was meant to consider their understanding of the device, along with the advantages and disadvantages they could see if the device was introduced into their lives. Lastly, the researchers informed the residents that the data they shared throughout the interview would go towards developing an

Authorized licensed use limited to: University of Ottawa. Downloaded on November 03,2024 at 05:07:28 UTC from IEEE Xplore. Restrictions apply.

ethical design tool that would help to identify their concerns with the device to the engineers and designers responsible for designing and developing AAL technology.

For this research, a total of 6 LTCF residents were interviewed.

V. Results and Discussion

It was found that the ethical concerns identified in the SLR (Fig. 6-8) and used in the workshops and interviews resonated with the older adults (tenants and residents) for the two devices. In addition, the methodology allowed tenants and residents to suggest and expand on additional ethical concerns that they saw with the devices used for this research. Furthermore, both tenants and residents expressed their interest and anticipation in the ethical design tool, with hopes that it can facilitate the design and development of AAL technology using the devices explored in this research.

As this paper is meant to focus on the design methods developed and used to conduct this research, full results of this research along with the ethical design tool developed from this research will be discussed in subsequent papers. Therefore, the remainder of this section presents some of the lessons learned when designing and testing participatory research methods with an LTC population.

A. The importance of interaction with local partners while designing the research

Our findings showed that interaction with the research coordinators and stakeholders before and after designing the research methods was very important. They can provide critical information about the venue, timings, and length of the workshops/ interviews.

For this research, we had a series of online meetings with the research coordinators at the LTCF so that we could gain a better understanding of the facility and the dynamics of the people living there. Once pandemic restrictions were eased in Ontario, we were able to visit the LTCF and meet with the research coordinators and the tenant building manager which allowed us to plan more practical research methods, such as conducting workshops with tenants and short interviews with residents. This finding is consistent with the results from previous researchers [24], [25].

B. Using interactive methods to engage the research participants

We received many comments about how enjoyable the sessions were throughout and after both workshops with the LTCF tenants. Tenants were thrilled that they had the opportunity to share their thoughts, discuss their opinions with other participants, and learn about new AAL devices that they may potentially use in the future.

Multiple tenants also commented that they were happy they had the chance to 'use their brains.' They were challenged to think about the ethical concerns that were presented to them in relation to how the device might impact their lives and to think of any other concerns they could see with the device.

C. Use of big fonts and shorter informed consent forms

This research showed the importance of using larger font sizes when providing written documents to an older adult population, as they have difficulty reading smaller font sizes. Even though we considered this issue beforehand by using a larger font size for the informed consent document, some of the research participants still had difficulties.

Similarly, many participants also complained about the length of the informed consent form and often asked why the form could not be shorter with fewer details. However, the informed consent forms were approved by the University of Ottawa Research Ethics Board, which requires participants to have all of the information about the research before agreeing to participate.

This is an ongoing debate as ethics boards want all of the details, and research participants want a shorter form. However, a more concise form should be considered as a way to improve practicality and convenience, and it would also save time and money. These findings are consistent with previous findings from [26]. Recently, researchers are also using the interactive narrative approach to get consent among children [27], which might be an area to consider while doing research with an older adult population.

D. Important to consider the participants first

It is crucial to consider the participants first when planning workshops and interviews. In discussions with the LTCF research coordinators, we discovered that many of the tenants who would be willing to participate in this type of research are very active in the LTCF community, meaning that they have very busy schedules. Therefore, it was essential to meet with tenants to discuss times they thought were best to hold the workshops.

This turned out to be very important as initially the workshops were planned for a weekday. However, upon speaking to tenants during their coffee times, many suggested the weekends would be better for their schedules. Therefore, planning the workshops on the weekend meant tenants had more free time and were happy to stay past the original one-hour time limit of the workshops.

E. Allocate additional time when planning workshops and interviews

As per the advice from the LTCF research coordinators, we planned for one-hour workshops and 20 minutes interviews with tenants and residents, respectively. However, both workshops and many of the interviews went longer than planned as tenants and residents wanted to talk more about their lives, previous professions, and thoughts on the devices. In addition, participants enjoyed the open discussion format of the workshops and interviews and took the time just to talk.

Therefore, our experience shows it is important to find times that work with participants' schedules and to allocate extra or buffer time for sessions in case the workshop or interview runs longer than expected.

Authorized licensed use limited to: University of Ottawa. Downloaded on November 03,2024 at 05:07:28 UTC from IEEE Xplore. Restrictions apply.

F. Other points to consider when speaking with older adults

Older adults are a wealth of knowledge and experience. Many of our participants asked many questions about our research and expressed many concerns about the devices which we were able to collect through our research methods. However, some of the questions or concerns that were asked were not things we had answers for, as we did not design or develop the two devices. Therefore, it is important to be prepared to receive questions that you don't have the answers to. However, being polite, providing additional information, and promising that you will try and find the answer to follow up with the participant makes the situation flow easily and comfortably for everyone.

G. Being flexible to the many changes brought about by COVID unpredictabilities

The entirety of this research took place during the COVID-19 pandemic. Therefore, many changes occurred throughout the design of the research methods to accommodate changing federal and provincial government restrictions and the LTCF's mandates. These changes included managing group sizes, arriving early to sessions at the facility for mandatory testing, and being flexible with the plans if new restrictions arose.

VI. Conclusion

This paper provides an overview of the research methods that were developed and implemented with 20 LTCF stakeholders to understand their ethical concerns with two AAL devices (the Hexoskin ProShirt™ and AWS DeepLens™).

The study design methods developed for this research were inspired by Judgement Call - a methodology used to aid product designers in uncovering ethical considerations when developing AI technology. Since being introduced, Judgement Call methodology has found great success at Microsoft and its affiliated partners but has only been used among product designers. Therefore, this research is one of the first few attempts at applying features of Judgement Call in a new context. Overall, the design methods were found to be successful for this research however, some limitations are noted.

First, as discussed in the forthcoming SLR by Robinson *et al.*, many frameworks developed to address stakeholders' ethical concerns with AAL devices and technology are proposed in a publication and are often never implemented by other researchers. By being a part of the PATH initiative, different sites will be encouraged to implement these design methods in their own LTC facilities for additional PATH devices to validate if the proposed research methods are successful with different participants.

Secondly, due to the pandemic, recruitment of participants was very difficult, which resulted in an unbalanced number of tenants and residents. Ideally, the number of tenants for each building would have been the same, as would the number of residents who were interviewed. However, due to the overwhelming interest received from tenants in Building A, all tenants who wanted to participate in the workshop were invited.

By adapting the design methodology proposed in Judgement Call, interactive workshops and interviews were designed and conducted with LTCF tenants and residents. The results obtained confirm some of the findings from a previous SLR and shed light on new ethical concerns unique to people living in LTC and unique to the two devices used for this research, such as the design of the device and safety of the device.

The data collected from the workshops and interviews will be used to create an ethical design tool that is meant to inform stakeholders of the ethical considerations that should be taken into account when designing, developing, and using AAL devices and technology.

This paper presents research design methods that can be used to conduct participatory design research with older adults living in LTC, as well as the insights that were gained throughout the process.

Most importantly, with this type of research, it is essential to consider the participants involved, as their participation is key to successful data collection.

Acknowledgment

Thank you to all of the people who have made this paper possible. It is with your encouragement, guidance, and belief, that this paper was written. We thank and appreciate the LTCF tenants and residents that participated in the workshops and interviews. Thank you to the LTCF staff members who walked us through all of the details about the facility and guided us through the design planning and changing restrictions. Lastly, thanks to all PATH and CRAiEDL team members for their ideas, input, and support throughout this research.

References

[1] E. and S. D. Canada, "Government of Canada — Action for Seniors report," Oct. 03, 2016. https://www.canada.ca/en/employment-social-development/programs/seniors-action-report.html (accessed May 24, 2021).

[2] P. Novitzky *et al.*, "A Review of Contemporary Work on the Ethics of Ambient Assisted Living Technologies for People with Dementia," *Sci Eng Ethics*, vol. 21, no. 3, pp. 707–765, Jun. 2015, doi: 10.1007/s11948-014-9552-x.

[3] United Nations and P. D. Department of Economic and Social Affairs, "World Population Ageing- 2019," United Nations, 2019.

[4] M. Coeckelbergh, "Health Care, Capabilities, and AI Assistive Technologies," *Ethic Theory Moral Prac*, vol. 13, no. 2, pp. 181–190, Apr. 2010, doi: 10.1007/s10677-009-9186-2.

[5] C. Di Napoli, P. Ribino, and L. Serino, "Customisable assistive plans as dynamic composition of services with normed-QoS," *Journal of Ambient Intelligence and Humanized Computing*, 2021, doi: 10.1007/s12652-020-02713-5.

Authorized licensed use limited to: University of Ottawa. Downloaded on November 03,2024 at 05:07:28 UTC from IEEE Xplore. Restrictions apply.

[6] M. Ienca, T. Wangmo, F. Jotterand, R. W. Kressig, and B. Elger, "Ethical Design of Intelligent Assistive Technologies for Dementia: A Descriptive Review," *Sci Eng Ethics*, vol. 24, no. 4, pp. 1035–1055, Aug. 2018, doi: 10/gd5b7w.

[7] Biermann, Hannah, Himmel, Simon, Offermann-van Heek, Julia, and Ziefle, Martina, "User-Specific Concepts of Aging–A Qualitative Approach on AAL-Acceptance Regarding Ultrasonic Whistles," in *Human Aspects of It for the Aged Population: Applications in Health, Assistance, and Entertainment, Pt Ii*, vol. 10927, Cham: Springer International Publishing Ag, 2018, pp. 231–249. doi: 10.1007/978-3-319-92037-5_17.

[8] F. Panico, G. Cordasco, C. Vogel, L. Trojano, and A. Esposito, "Ethical issues in assistive ambient living technologies for ageing well," *Multimed. Tools Appl.*, vol. 79, no. 47–48, pp. 36077–36089, Dec. 2020, doi: 10/ghtdzc.

[9] S. C. Government of Canada, "Life expectancy, 1920–1922 to 2009–2011," Feb. 15, 2016. https://www150.statcan.gc.ca/n1/pub/11-630-x/11-630-x2016002-eng.htm (accessed Feb. 22, 2022).

[10] S. U. M. Tobi, M. S. Fathi, and D. Amaratunga, "Ageing in place, an overview for the elderly in Malaysia," Kedah, Malaysia, 2017, p. 020101. doi: 10.1063/1.5005434.

[11] B. C. Stahl and M. Coeckelbergh, "Ethics of healthcare robotics: Towards responsible research and innovation," *Robotics and Autonomous Systems*, vol. 86, pp. 152–161, Dec. 2016, doi: 10/ghjv48.

[12] T. Wangmo, M. Lipps, R. W. Kressig, and M. Ienca, "Ethical concerns with the use of intelligent assistive technology: findings from a qualitative study with professional stakeholders," *BMC Med Ethics*, vol. 20, no. 1, p. 98, Dec. 2019, doi: 10.1186/s12910-019-0437-z.

[13] R. Sparrow and L. Sparrow, "In the hands of machines? The future of aged care," *Minds & Machines*, vol. 16, no. 2, pp. 141–161, Oct. 2006, doi: 10/d2hhpr.

[14] A. J. Astell, C. McGrath, and E. Dove, "'That's for old so and so's!': does identity influence older adults' technology adoption decisions?," *Ageing Soc.*, vol. 40, no. 7, pp. 1550–1576, Jul. 2020, doi: 10/ghtdx6.

[15] E.-M. Schomakers and M. Ziefle, "Privacy Concerns and the Acceptance of Technologies for Aging in Place," in *Human Aspects of IT for the Aged Population. Design for the Elderly and Technology Acceptance*, Cham, 2019, pp. 313–331. doi: 10/gh2h4g.

[16] K.-M. Robinson, P. Novitzky, and J. Millar, "Review of Ethical and Responsible Assistive Technology Design and Development," *unpublished*.

[17] M. K. Curumsing, N. Fernando, M. Abdelrazek, R. Vasa, K. Mouzakis, and J. Grundy, "Emotion-oriented requirements engineering: A case study in developing a smart home system for the elderly," *J. Syst. Softw.*, vol. 147, pp. 215–229, Jan. 2019, doi: 10/ghh2v8.

[18] G. Mincolelli, S. Imbesi, M. Marchi, and G. A. Giacobone, "New Domestic Healthcare. Co-designing Assistive Technologies for Autonomous Ageing at Home.," *Des. J.*, vol. 22, pp. 503–516, 2019, doi: 10/ghtdvp.

[19] J. Joe, A. Hall, N.-C. Chi, H. Thompson, and G. Demiris, "IT-based wellness tools for older adults: Design concepts and feedback," *Informatics for Health and Social Care*, vol. 43, no. 2, pp. 142–158, 2018, doi: 10.1080/17538157.2017.1290637.

[20] "Program To Accelerate Technologies for Homecare." https://pathplatform.ca/ (accessed May 24, 2022).

[21] S. Ballard, K. M. Chappell, and K. Kennedy, "Judgment Call the Game: Using Value Sensitive Design and Design Fiction to Surface Ethical Concerns Related to Technology," in *Proceedings of the 2019 on Designing Interactive Systems Conference*, San Diego CA USA, Jun. 2019, pp. 421–433. doi: 10.1145/3322276.3323697.

[22] Hexoskin, "Hexoskin Smart Shirts - Cardiac, Respiratory, Sleep & Activity Metrics," *Hexoskin*. https://www.hexoskin.com/ (accessed May 24, 2022).

[23] "AWS DeepLens – Deep learning enabled video camera for developers - AWS," *Amazon Web Services, Inc.* https://aws.amazon.com/deeplens/ (accessed May 24, 2022).

[24] A. Boaz, S. Hanney, R. Borst, A. O'Shea, and M. Kok, "How to engage stakeholders in research: design principles to support improvement," *Health Research Policy and Systems*, vol. 16, no. 1, p. 60, Jul. 2018, doi: 10.1186/s12961-018-0337-6.

[25] T. Beeson, M. Jester, M. Proser, and P. Shin, "Engaging Community Health Centers (CHCs) in Research Partnerships: The Role of Prior Research Experience on Perceived Needs and Challenges," *Clinical and Translational Science*, vol. 7, no. 2, pp. 115–120, 2014, doi: 10.1111/cts.12150.

[26] A. Xu, M. T. Baysari, S. L. Stocker, L. J. Leow, R. O. Day, and J. E. Carland, "Researchers' views on, and experiences with, the requirement to obtain informed consent in research involving human participants: a qualitative study," *BMC Med Ethics*, vol. 21, no. 1, Art. no. 1, Dec. 2020, doi: 10.1186/s12910-020-00538-7.

[27] F. Mayne, C. Howitt, and L. Rennie, "Meaningful informed consent with young children: looking forward through an interactive narrative approach," *Early Child Development and Care*, vol. 186, no. 5, pp. 673–687, May 2016, doi: 10.1080/03004430.2015.1051975.

Authorized licensed use limited to: University of Ottawa. Downloaded on November 03,2024 at 05:07:28 UTC from IEEE Xplore. Restrictions apply.