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Privacy by Design and Cybersecurity for Safe, Effective and Reliable Home Health Care for Aging in Place

Helene Fournier[1], Heather Molyneaux[2], Irina Kondratova[2], Noor Ali[3]

[1] National Research Council Canada, Moncton, NB, https://orcid.org/0000-0002-8470-3226
[2] National Research Council Canada, Fredericton, NB
[3] University of New-Brunswick, Fredericton, NB

Abstract. This short paper presents findings from a research and development project on remote home health monitoring, specifically tools and technologies for Aging in Place to help seniors live independently at home for longer. A comprehensive literature review was completed to feed into an early concept design and prototype for a mobile video-conferencing application for Android, for use in remote health care services. Findings from the literature review will be presented as well as next phases of the research and development process.

Keywords: Human-Computer Interaction, Home Health Care, Aging in Place, Cybersecurity, IoT.

Introduction

The population of the developed world is aging and building digital technologies which meet the needs of an aging population is critical.This short paper presents findings from a research and development project focused on remote home health monitoring, specifically tools and technologies for 'Aging in Place', to assist seniors in living independently at home for longer. The project included a comprehensive literature review and market scan, as well as an early concept design and prototype for a mobile video-conferencing application for Android. HCI and human factors research provide a unique opportunity to bridge the gap in home health care services for seniors living at home in remote and rural locations. Specifically, in area of augmented reality applications for remote health and wellness tracking, with a focus on mobile VC applications for Android with QR code integration. There are important issues and challenges to address in these areas of research however. The literature review section will highlight some of them.

Literature Review

A search for the literature on topics of seniors aging in place and home health monitoring resulted in 357 relevant articles (keyword search included seniors, aging in place, remote check-in, AI based video systems, visual or video, home health monitoring, gerontechnology, community health). The most important themes arising from the articles search are presented as a text cloud in Figure 1.

Fig 1. Main concepts from a literature search on aging in place and home health monitoring

The literature review revealed important gaps in research on seniors, 'Aging in Place' and home health care services, including the need for more data on current practices, perceptions and attitudes around the use of health-related technologies and assistive devices in home health monitoring and remote check-ins.

Human-Computer Interaction and Human Factors

Literature in the area of Human Computer Interaction (HCI) and Human Factors highlighted important gaps in knowledge about designing useful feedback with appropriate levels of explanation for information from SMART and ASSISTIVE devices and technologies, so that feedback is useful and meaningful for a rapidly growing end-user demographic over 50+ years of age. There are also gaps and challenges around ethical issues and cybersecurity that need to be addressed. Trends around digital health services and assessment tools also bring up issues of bias in referrals to special care facilities for seniors who may do well at home.

Data protection and privacy are areas in need of further research given the massive amounts of data now available and accessible, with Big Data sets, Internet of Things (IoT), and sensor technologies. The implications of Machine Learning (ML), Artificial Intelligence (AI) and recommendation engines that offer personalized suggestions, advice and referrals also requires further investigation. Fairness and competence of AI could have serious implications for individuals and society from a health and safety standpoint.

Research and development of augmented reality applications in healthcare have the potential to transform the way home health care is delivered, while achieving important outcomes with societal impact, however, there are important issues and challenges to be addressed in terms of technology design. HCI and human factors research in areas such as augmented reality applications for remote health and wellness tracking, specifically the use of augmented reality on Smart Phones, represents an opportunity to conduct transformative research and contribute to the advancement of science and engineering.

QR codes have been referred to as a gateway to the IoT [1]. QR coding systems can potential turn any material surface into information, knowledge, data or advertising of any kind. Studies have looked at the use video chat to combat depression and social isolation among seniors [2, 3]. Potential applications of this technology in the context of home health care for 'Aging in Place' will be investigated in future studies.

HCI Interfaces and Next Generation Technologies

The literature review highlighted trends in HCI interfaces and next generation technologies, including moving away from tangible interfaces to no-touch interfaces [4] such as Microsoft's Kinect, Apple's Siri and Google's Project Glass, with the expectation that computers will adapt to us rather than the other way around [5]. Other trends include the extension of smart technologies such as the Smart Watch to textile and smart skin applications [6], the use of Internet of Things (IoT) in health care for remote monitoring, smart sensors and medical device integration [7], and context-aware sensors and assistive technologies for "Aging in Place" [8, 9,10].

Ultimately, it is projected that the human body will be the next computer interface, enabled by wearables, living services, the IoT, and Smart Technologies landscape of the future [11]. More natural ways to interact, including touch, gesture, and voice, will become an integral part of the user interface of the future. However, the literature also highlights some important limitations in multimodal interfaces, such as accuracy and privacy issues [12].

Current developments in next generation networked environments include safeguards for data protection and privacy, and open and flexible standards that lead to a sustainable digital transformation strategy [13].

Big Data Technology Landscape

The current digital technology landscape is changing fast and the amount of data generated today is several magnitudes larger than what was generated just a few years ago [14]. The expansion and availability of data in the new digital age has triggered research and discussion around data protection, privacy and ethics (i.e., Big Data, digital data, and privacy-sensitive data) with important cautions as to potential biases in data cleaning, selection and interpretation methodologies [15]. Some argue that the invasive potential of powerful data analytics can lead to potentially dehumanizing effects of automated machine-learning and algorithms that reduce complex human behaviors into few technical, knowable, measurable parameters that can be solved through technical calculation [16]. In the new digital age, "the complexities of ethics and values, ambiguities and tensions of culture and politics, and even the context in which data is collected, are not accounted for" [16, p. 70].

The dynamic pace of technological innovation also requires safeguarding of privacy in a proactive manner. In order to achieve this goal, researchers and system designers, including HCI specialists, are encouraged to practice responsible innovation that integrates privacy-enhancing technologies directly into their products and processes, based on principles of Privacy by Design [17]. To achieve this, scientists and specialists in HCI, computer science and social science are encouraged to work together at developing bias-free data-driven systems and devices to

support end-users across the spectrum—whether to enhance learning in networked environments, using context-aware sensors in health applications, or IoT and assistive technologies for 'Aging in Place'.

Collaboration between specialists in different fields is desirable. Privacy by Design considerations include human values as well as privacy-enhancing aspects of technologies, and responsible practice for addressing factors such as accountability, research integrity, data protection, privacy, and consent [17,18].

Designing for an Aging Population

Recent HCI research addresses a major societal concern that is, the population of the developed world is aging. Currently most websites, apps, and digital devices are used by adults, younger adults and those aged 50+, thus they should not be design with a 'one size fits all' approach [19]. HCI researchers are looking into age-related factors that affect older adults' ability to use digital technology, and work on technology design guidelines that reflect older adults' varied capabilities, usage patterns, and preferences.

The 50+ age group is pretty savvy with digital technology: it is the fastest growing demographic online, and, according to Home Care Magazine, 46% of baby boomers use a cell phone, 65% are active on social media, and a whopping 75% are digital buyers [20]. Research has shown that the ability and motivation to use new technologies are strongly determined by work experience and education, and the difficulties people experience around the use of technology are related to past performance rather than age-related factors [21].

Rapid development of digital proficiency in an aging population has even led to the development of a new research discipline. Gerontechnolgy is a scientific field that merges the study of aging with the study of technology, and includes the following five aspects: enhancement, prevention, compensation, care and research [22]. With over 10,000 people turning 65 every day in America, this is a market about to explode, and building technology for an aging population is at a critical tipping point [20]. However, the HCI literature points to important unresolved issues related to usability and AI in designing for an aging population [23].

The dynamic pace of technological innovation comes with challenges of integrating "intelligent" technologies into people's daily lives. Described as "do it for me" or "do it myself" automation debate, designers and developers are faced with the challenge of determining when full automation is desirable, and when people need to exercise control over systems and devices [24]. As such, user experience (UX) design for human-AI interaction in the age of machine learning , including trust and skepticism in adopting technologies, is poorly understood or can be viewed as skewed (i.e., discriminatory algorithms) or prone to exploitation (e.g., Cambridge Analytica). The issue remains as to how humans can assess the validity of data and actions produced by powerful (but potentially invasive) Big Data and IoT systems and devices, over which humans have little or no control. The above mentioned issues are of concern across a wide demographic, including the most 'tech savvy' of end users.

Designing for Dynamic Diversity

Research and development of health-related applications, including mobile or mHealth applications, is crucial in managing the health and well-being of an aging population. There is a trend in new mHealth apps that help to manage health and well-being through smart systems, and Internet of Things (IoT) devices [23]. The success of smart systems is tightly linked to features such as ease of use and user-friendly graphical interfaces (GUI). Adaptive Interfaces represent a new way to improve the GUI usability, adapting and customizing automatically features of the UI to the user characteristics, to accommodate users with different skills and impairments [25]. There is an urgent need to address the issues of designing for dynamic diversity with an aging population in mind [26]. Interestingly, User Centered Design (UCD) principles have been described recently as inadequate for addressing the needs of an aging population, since the principles were developed for user groups with relatively homogeneous characteristics. "Older people" encompass an incredibly diverse group of users, and even small subsets of this group tend to have a greater diversity of functionality than is found in groups of younger people [27].

It was found that, among a sample of 65 year olds, a laborious interface was the main reason for terminating use of health-related applications within the first year [2]. It is no longer enough for UX designers to focus on improving user experiences by paying close attention to usability, utility, and interaction aesthetics. Instead, the best user experiences may come from services that automatically personalize their offerings to the user and context, and from systems that leverage more detailed understanding of people and their daily lives in order to provide new value [28].

New trends in HCI research focus on designing natural, social and safe user interfaces to reduce the digital marginalization of older adults. Despite growing technical literacy, for some marginalized adult user groups, interactions with emerging technologies (digital devices) may present insurmountable barriers that only widen the digital divide in a society that is information centric [3, 29]. Currently, two major research questions have been identified in the literature on designing user interfaces for seniors [30]. What are the challenges that older users experience with user interfaces? Which solutions have been proposed by researchers and designers to address the

identified challenges in user interfaces for seniors? Seniors have vastly different requirements than younger users, and solutions that meet their requirements require some level of participatory or human-centered design.

The literature identifies the following domains of human-computer interaction as relevant in the design of user interfaces for an aging population: 1) ambient-assisted living, 2) conceptual user interfaces, 3) mobile user interfaces, 4) user input devices, and 5) website user interfaces [30]. Unfortunately, designing useful feedback mechanisms and appropriate levels of explanation for machine learning outputs to be meaningful to end users, especially for recommender systems, has yet to be explored in gerontechnology research. As the population steadily ages, so does the need for alternative health and wellness options, including home telehealth and virtual visits as part of comprehensive health care services.

Privacy by Design and Cybersecurity

Cybersecurity is an essential part of a safe, effective and reliable health care delivery system [31]. Researchers note that security and privacy challenges can be overcome by implementing best practices to safeguard the system [32]. The context of use is important: devices operating in the home are more exposed to unauthorized access than those in more controlled environments, such as nursing homes and hospitals [33]. However, there are clear benefits to homeware and remote monitoring. For example, in Sweden both cost effectiveness of remote monitoring, as well as consideration of human dignity is taken into account - the needs of individuals are considered in order to strive for a balance between independence and social contact [34]. So even though there are additional security challenges to consider with remote monitoring, this should not act as a barrier to accessibility.

In order to protect privacy, privacy should be built into the system. The concept of Privacy by Design by Dr. Ann Cavoukian states that the principles of Fair information Practice (FIPs) need to be built into system. Compliance with regulatory frameworks alone does not assure privacy - privacy must become the default mode of operation. Privacy by design is a way in which to integrate FIPs into products and offers system designers 7 key guidelines for ensuring Privacy by Design [35]:

1. Proactive not reactive; Preventative not remedial
2. Privacy as the default
3. Privacy embedded into design
4. Functionality - Positive-sum, not zero-sum
5. End-to-end lifecycle protection
6. Visibility and transparency
7. Respect for users' privacy

Cyber threats are not all digital, they also include other real life potential breeches [30]. It is also not enough to just ensure that security is built into the system; human needs and perceptions of security and privacy also need to be taken into consideration [36].

Research demonstrates that older populations are very aware of privacy issues [36, 37]. Studies show that elderly subjects see protection of personal data as only one important dimension of privacy: they also have other privacy concerns related to bodily privacy, privacy of personal behaviours and privacy of personal communications. It is important to consider all these privacy concerns when designing health technologies for in home use [37].

Additionally, systems perceived as intrusive can impact user acceptance – a fact that many researchers overlook [36]. Applications of technological solutions still suffer from sociocultural misunderstanding of group differences, and poor acceptability of technology for patients and caregivers [36]. Researchers emphasize that elderly users should be included in the design of remote home monitoring technologies and in gathering privacy requirements for such technologies [37, 38].

Conclusion

This short paper presents findings from a research and development project on remote home health monitoring, specifically tools and technologies for Aging in Place to help seniors live independently at home for longer. A survey of the literature points to important gaps in knowledge in designing assistive technologies for an aging population, specifically how to include useful feedback with appropriate levels of explanation for information from SMART technologies. The protection of personal data is an area of concerned expressed by seniors. Privacy extends into areas of bodily privacy, privacy of personal behaviours and privacy of personal communications. It is important to consider all these privacy concerns when designing health technologies for in home us. A survey with home health care professionals is currently underway to determine the level of technology use and integration in home health care services as well as senior's level of technology adoption and acceptance managing their health and wellness. There are currently gaps in our knowledge about the level of use and acceptance of technology in home

health care delivery services. Survey data will help to inform future phases of the research on assistive technologies for Aging in Place.

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