

UNIVERSITY OF TRENTO

DOCTORAL THESIS

Technology Mediated Information Sharing
Within the Triad of Aged Care

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Declaration of Authorship

I, Leysan NURGALIEVA, declare that this thesis titled, "Technology Mediated Information Sharing Within the Triad of Aged Care" and the work presented in it are my own. I confirm that:

- This work was done wholly or mainly while in candidature for a research degree at this University.
- Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated.
- Where I have consulted the published work of others, this is always clearly attributed.
- Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work.
- I have acknowledged all main sources of help.
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Signed:



Date:

30/01/2019

“To my mother, Liliya Nurgalieva, and my grandmother, Saniya Krasnova.”

“To love means to embrace and at the same time to withstand many endings, and many many beginnings—all in the same relationship.”

Clarissa Pinkola Estés

Abstract

More than other age group, older adults suffer from multiple chronic conditions, receive care from multiple healthcare providers and settings, and transition across this continuum of care as they age. During the last decade, we have observed the transformation of aged care worldwide both on organizational and legal levels due to an increasing older population from one side and the use of technology in their care from another. In addition, the involvement of family members as informal caregivers introduces the concept of a *triad of aged care*: a collaboration of senior patients, their relatives and professional caregivers; and poses additional challenges such as appropriate and efficient communication from the points of views of all care stakeholders. Hence, sharing of health and wellbeing information (HWBI) in the care triad becomes particularly important, and e-Health services have shown the potential to support this, for example, by becoming a channel that could mediate sharing, while taking into account the values and concerns of all groups of users.

In this thesis, we explore existing strategies of HWBI sharing in various aged care scenarios and identify the challenges and opportunities of designing information systems that could support them. In particular, by conducting a systematic literature review and a series of user studies with all three groups of care stakeholders, we study if and how technology-based mediation of informational exchange can improve institutionalized care for older adults. We primarily focus on different dimensions of aged care scenarios, based on the involvement of triad stakeholders, the level of acceptance of technology, and the degree of control seniors have over sharing their HWBI. To gather design recommendations for such information systems, we investigate HWBI-related work practices of professional caregivers; information needs of family members, and information disclosure preferences and associated concerns of seniors, including their reasons to share or not to share. We raise a critical discussion on values addressed by e-Health interventions and illustrate the views of care stakeholders, revealing that these views can be conflicting, given their needs and priorities. For instance, tensions emerge between values that prioritize placing the responsibility on a physician for their patients versus a value system that prioritizes patient autonomy.

By discussing information and interaction design of technology-based mediation of HWBI sharing and based on the research findings of this thesis, we provide a set of design principles and requirements targeting the following areas and roles:

- e-Health and HCI researchers, providing a foundation for their future research,
- designers, who could benefit from a complete image of the abilities and needs of potential users in this sensitive and complex care context,
- healthcare and legislation policies, that could adhere to a system of values that place a premium on patient empowerment, and

- educational programs, that need to provide seniors and triad actors with the knowledge of how to share personal health information digitally.

Finally, following a user-centred design approach, we implement these design recommendations and evaluate them with caregivers to validate our findings.

Keywords: Ageing, Aged Care, Accessibility, Care Triad, HCI, eHealth, Information Sharing, Health and Wellbeing

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Abbreviations

HWBI	Health and Wellbeing Information
HCI	Human Computer Interaction
NH	Nursing Home
ICT	Information and Communications Technology
GUI	Graphical User Interface
GDPR	General Data Protection Regulation
HIPAA	Health Insurance Portability Accountability Act
FGD	Focus Group Discussion
PAEHR	Patient Accessible Electronic Health Records
IRB	Institutional Review Board
ADLs	Activities of Daily Living
RCT	Randomized Control Trial
SHO	Socio-health Operators
FTF	Face-to-face
WCAG	Web Content Accessibility Guidelines
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
HIE	Health Information Exchange

Chapter 1

Introduction

More than any other age group, older adults experience multiple chronic conditions [2] and receive care from providers in multiple care settings. As seniors age and their health and independence decrease, they tend to transition across the continuum of care [3]. In particular, one of the most common transitions is from “aging in place” (living independently in their own homes) to the long term care facilities, which is also a time of change of power, delegation of control over decision making in senior’s life, and higher care involvement of their family members. This means aged care consists of two main groups of caregivers: (*i*) professional or formal caregivers, such as nurses, doctors, and hired caregivers; and (*ii*) relatives or other informal caregivers [4].

Literature has shown that sharing health and wellbeing information (HWBI) among care network has positive impact on seniors’ care. Presenting patient’s information to the relatives increases family involvement in the care process, and improves their trust in medical staff, thus, enhancing collaborative partnerships [5], and reducing the stress and workload of professionals [6, 7]. Care staff tend to involve family members in care as additional resources [8], as relatives often advocate for seniors’ interests and have an extensive knowledge of their preferences [9].

However, it is often difficult for caregivers to find and keep the balance between providing seniors with care and respecting each other’s independence [10]. Asymmetric values create tensions between care recipients and their caregivers. For instance, patients’ motivation to share information may not always match healthcare providers’ interests to receive it [11]. To the contrary, the needs for privacy of older care recipients might not be always satisfied in the conditions of institutionalized health monitoring [12]. Patients might also choose not to share health information to “reduce burdens on family members, though these preferences may

change over time” [13, p.3]. Hence, it is particularly important to focus on both recipients’ and caregivers’ perspectives in various scenarios of care provision and levels of family involvement, when designing systems aimed at facilitating their interactions [14].

Indeed, information sharing in aged care settings is a complex and delicate practice, which should be carefully designed, and various research contributions stress the potential of technology in supporting it [15]. Beside being an instrument to improve the delivery and quality of care in healthcare facilities, ICT tools can improve its coordination, organization of care practices, and the mediation of its communication among the various involved actors [7].

However, there is still lack of research on how technology can support interactions among family caregivers and staff-family dyads [16, 17]. As a result, we know very little about the *design* of technology-mediated communication that targets different types of family caregivers [18, 19]. Furthermore, while current research often addresses the burden on formal and informal caregiving duties [20], the needs and concerns regarding health communication in the care triad, especially from the perspective of senior care recipients, are understudied. The exclusion of the central actors from the design of information systems is still common, while it is crucial to consider the preferences and expectations of patients/residential older adults, as well as their formal and informal caregivers.

1.1 Motivation and the Problem Space

This work was motivated by the potential that technology showed on improving the quality of care of seniors. Current research recognizes the role of technology in enhancing the safety and independence of frail older people, enabling access to quality care services, and extending their ability to remain in their own homes. By monitoring older patients’ vital signs, activity levels, and other indicators of their health status, technology in aged care supports the collection of longitudinal health records, which makes it possible to generate trends and alert seniors and their caregivers about critical events [3] such as falls or give early warnings of potential health problems [21, 22]. Information sharing can also improve inter-professional collaboration among staff members by boosting the knowledge transfer and evidence-based care in health care workplaces [23], which is crucial for quality of care [24].

The increasing popularity of “health datafication” [25] – the use of personal data in improving individual health outcomes – and sharing of health information transforms the traditional involvement of family members in practical care procedures into a more analytical partnership of family and staff. In particular, an exchange of HWBI in aged care often plays an important practical role in many ways, for instance, in assisting decision-making about an appropriate level of care [26] or communicating end-of-life choices [27]. On the other hand, previous research shows that extensive information disclosure and delegation of control over decisions often result in seniors’ psychological discomfort [13] and the feeling of losing control of information shared with their caregiving networks, including sharing through digital channels [28]. Hence, the dynamics in interpersonal and formal relationships between care triad stakeholders, including trust, communication culture, and alignment of views, have a dramatic effect on information exchange among them.

The health and wellbeing information exchange and opportunities for introducing digital channels supporting it also vary across aged care settings with diverse administrative, organizational, and legal dimensions.

Administrative and organizational structure of aged care facilities play a major role in information communication practices and care involvement of family members, dictating the amount and the ways HWBI is collected and disclosed to informal caregivers. While independent living within residential facilities preserves relatively high level of autonomy of older adults with minor monitoring and involvement of the staff in daily living activities of seniors, more advanced levels of residential aged care has been viewed as places of long-term treatment and therapy “dominated by the biomedical model that values efficiency, consistency, and hierarchical decision-making” [29] with full surveillance and authority of care personnel in place. Reduced independence and fragile health of seniors as precursors of entering residential care facilities also mean having an authorized representative, usually a family member “appointed as legal proxy” [30], who increasingly gain authority as older adults move across this continuum of care and access to seniors’ health related information.

Recent changes in European and the US legislation affect the boundaries of sharing this information. Sharing of medical records was impacted by the adoption of European Union General Data Protection Regulation (GDPR) 2016/679¹ [31], which raises concerns among care stakeholders and patients groups. With the enforcement of GDPR, U.S. health care organizations that

¹A regulation in EU law on data protection and privacy for all individuals within the European Union that was enforced on May 25 2018 - <https://eur-lex.europa.eu/legal-content/IT/TXT/?uri=celex%3A32016R0679>

have traditionally been used to the Health Insurance Portability Accountability Act (HIPAA) now need to think about data protection in a much more evolved way. Important considerations include data workflows, data handling, cross-border data transfer, data privacy, security monitoring, and overall policy compliance².

These regulations have radically changed how healthcare data is used, maintained, and the way health information is disclosed and shared. In particular, HIPPA provides “patients and their personal representatives” with right of access to health information, and permits sharing identifiable health information relevant to a patient’s care with involved family members or friends” [32, p.118]. Another similar recent regulation is the 2018 California Consumer Privacy Act [33], which is intended to provide California residents with the right of access and knowledge of the collection and disclosure of their personal information.

However, as beneficial and well-intended as they are, these regulations still might inhibit the sharing of health information with and involvement of the family due to their interpretation and application complexity, as it is not always clear what can and cannot be shared in health communication with family caregivers [34]. These regulations also indicate that patient information is stored and transferred using global networks, distributed databases, and the cloud. Health records might be fragmented and accessible from several locations and by multiple health care providers [35], which implies an increased risk of patient information disclosure within contexts where it cannot be controlled [36]. In addition, certain patient and caregiver groups have reduced capacity to manage digital versions of health records due to the decline of their abilities affected by ageing or the lack of technology experience. These difficulties can result in their privacy and security vulnerability and compliance with existing regulations [32]. Hence, it becomes particularly important to raise the discussion how low digital literacy and concerns about reliance and data integrity in the conditions of changing legislation and healthcare policies on HWBI sharing affect the adoption of ICT in aged care.

Considering all the aforementioned dimensions, it becomes particularly important to study the information sharing practices across the continuum of aged care: from the moment when older adults still preserve the autonomy moving towards more advanced care settings defined by higher monitoring and HWBI disclosure in place.

²Information from <https://www1.pega.com/insights/articles/gdpr-and-healthcare-understanding-health-data-and-consent>

1.2 Research Objectives

Given these challenges of sharing seniors' personal HWBI in complex and sensitive aged care settings that evolve and advance over time and with the progression of chronic conditions, the goal of this thesis is to study how information and interaction design could address the needs and values of all the actors of the aged care triad and provide insights and recommendations on how to design technological tools that could support and mediate this sharing across various aged care scenarios.

This work addresses all three groups of stakeholders involved in the caregiving for older adults: senior care recipients themselves, their family members with ranging levels of care involvement, and professional caregivers. This adds an additional layer of complexity to this work requiring such technological tools to be inclusive, taking into account ageing related ability declines of the potential users, their low or lack of ICT skills, and high vulnerability to privacy and security risks.

Considering similar socioeconomic levels throughout all studies that contribute into this work and following the natural progression of aged care and the unavoidable increase of involvement of formal and informal caregivers, this work also detects the differences in HWBI communication across the diversity of organizational, administrative, and legal dimensions of aged care.

In particular, this thesis aims to: (i) explore the *role of technology* in supporting and mediating information exchange among and within formal and informal caregivers of older adults, (ii) analyze the factors that influence this exchange including dynamics in the interpersonal and formal *relationships* between aged care stakeholders—including subordination, trust, family culture, and alignment of views, and finally (iii) study the preferences, values, and expectations of the *central actors* of aged care scenarios, senior patients or residential older adults, regarding disclosing and sharing their health and wellbeing related information.

1.2.1 Thesis Research Questions (TRQs)

To reach these objectives, we define the following main thesis research questions (TRQs):

TRQ1 What are the factors that play a major role in decisions to share or not to share HWB information in diverse aged care scenarios?

TRQ2 What are appropriate and efficient designs for technological-mediated HWB information sharing in such sensitive aged care context?

Answering to the TRQ1, we identify the types and the attributes of information to share, actors involved in this process, sharing strategies and adopted communication channels, their values, priorities, skills, and resources as the main factors that dictate whether HWBI will be shared and in what way. As for the TRQ2, we define as appropriate design the design addressing the stakeholders' needs but also considering the given constraints and limitations. As for the efficiency of the design, we identify it as the resources expended to achieve the goals [37] of sharing.

We believe that answering to these two fundamental TRQs can be beneficial to the patient and family centered aged care, for instance, by increasing family involvement, improving privacy controls, and facilitating engagement, It can be also useful to tech tech companies willing to develop more effective ICT tools. By conducting a series of users studies we attempt to gain an in-depth understanding of the values and intentions behind sharing and receiving seniors' personal HWBI, including the matching and the conflicting, and explore the potential of technology to resolve the mismatch of those values and connect care recipients and care providers together in a way preferable for both sides.

This thesis is divided in three major parts. The *first* part, "Understanding Users and Context", consists of the studies on identifying and studying various care scenarios and the HWBI sharing practices adopted in them. They include the views both of care recipients and caregivers, and allow to define the aim of this work setting the context for the later studies.

Following the findings of the previous part, namely, the tendency of older adults to share their personal HWBI and the fact that their HWBI is being shared among their caregivers, the *second* part "Design of Information Sharing in Aged Care" includes the studies that take the point of view of older care recipients on sharing. We intentionally make the choice of taking a closer look at the opinions of seniors on sharing, the primary owners of their HWBI, acknowledging the importance not to underestimate their views and consider their security and privacy concerns related to sharing on the early stages of technology development. Beside studying their views on information design of sharing, we take into account the fact that also caregivers usually belong to the older population groups, which motivated us to conduct a systematic literature review on design guidelines to support communication in the aged care context for older users.

Finally, the *third* part of this thesis, “Evaluation and Discussion”, includes the studies on the evaluation of the major research findings from the previous parts and the overall discussion of the contributions of this thesis.

1.3 Thesis Structure

As mentioned before, the work presented in this thesis is in large part based on research contributions – published, accepted, or under submission – conducted during three years of the doctoral studies. For clarity, we include the citations to these publications. All the chapters are presented in accordance with the flow of our research work described above. The chapters are connected to one another in a continuum that aims to deliver the whole picture of our work. However, due to the structure of this thesis, we acknowledged that there might be some repetitions across chapters, such as related work, description of the methodologies, and sometimes common findings.

Chapter 2. Background

In this chapter we have thought useful to collect in a single and identifiable place the related work, although each chapter has its own related work section. We summarize the previous studies in sharing HWBI within the triad of aged care, the role of technology in mediating and supporting it, and research evidence on opportunities and barriers in introducing technology in various aged care contexts. Finally, we describe the research gaps we aim to address in this thesis.

Chapter 3. Methodology

This thesis includes a number of user studies where we adopt a range of research methodologies and their combinations, as mixed research methodologies have been confirmed to be most efficient and beneficial in conducting e-Health research. In this chapter we describe them in detail and explain the choice of certain methods regarding the overall research plan.

Chapter 4. On Sharing of Patient Accessible Electronic Health Records

In this chapter we discuss sharing HWBI among general population. We analyzed the combination of a survey with 2,587 patients and 15 semi-structured in-depth interviews with cancer patients in Sweden who use the Swedish national patient portal. We explore

patients' perspective on technical, ethical, security and privacy challenges that should be considered when designing systems for sharing of medical information. We investigate strategies patients adopt in sharing their Patient Accessible Electronic Health Records (PAEHR) and discuss implications for design addressing related problems as well as security and privacy issues connected to sharing.

Part of the content of this chapter has been submitted to the Health informatics journal, and is currently under review:

Nurgalieva, L., Cajander, Å., Moll, J., Åhlfeldt, R-M., Huvila I., and Marchese, M. (2018). "I do Not Share it with Others. No, it's for ME, it's my Care": On Sharing of Patient Accessible Electronic Health Records.

My Contribution: This article is based on the data collected in the Swedish national patient survey and interviews with Swedish cancer patients. The design of the studies and the data collection were performed by the second, third, and fourth authors. I led the work on the analysis, data interpretation, the writing process, and contributed to all sections of the paper during the writing stage.

Chapter 5. Design considerations to support nursing homes' communities

Moving to the context of aged care, we set the research context for this thesis and explore current caregiving practices at Italian nursing homes with a case study. We focus on the work practices of professionals and the relational issues between professional and residents' family members. The outcomes of this work shed new light on the opportunities of using ICT solutions to improve relations, information sharing among caregivers, and provide us with important insights for future study directions.

The content of this chapter has been published as:

Di Fiore, A., Ceschel, F., Nurgalieva, L., Marchese, M., and Casati, F. (2017, June). Design considerations to support nursing homes' communities. In *Proceedings of the 8th International Conference on Communities and Technologies* (pp. 64-67). ACM. [38]

My Contribution: The study was conducted by the first and the second authors, while the design of the study involved all authors of the paper. The first and the second authors also led the analysis and the writing process. I took part in the study design, data analysis and interpretation, and contributed to all sections of the paper during the writing stage.

Chapter 6. Views of Older Adults on Information Sharing in a Care Triad

Through in-depth semi-structured interviews with 12 residents of senior care facilities, we examine the reasons why older adults choose to share or not to share their HWBI with those

involved in their care. We explore how the purpose of use, functional relevance, urgency, anticipated emotional reactions, and individual attitudes to privacy and control affect their opinions about sharing. We then investigate how those factors define what granularity of data, communication frequency and channel older adults find appropriate for sharing HWBI with various recipients. Based on our findings, we suggest design implications.

The major part of the content of this chapter has been published at the Pervasive Health 2019 – 13th EAI International Conference on Pervasive Computing Technologies for Healthcare:

Nurgalieva, L., Frik, A., Ceschel F., Egelman S., and Marchese M. (2019). Information Design in An Aged Care Context. Views of Older Adults on Information Sharing in a Care Triad. [39]

My Contribution: I conducted the interviews with the help of the second author on designing the study, recruiting participants, and distributing and conducting the surveys. The coding of transcribed interviews and thematic analysis were performed by the first three authors, which were then jointly reviewed and discussed by all. I coordinated and led the analysis and writing process, while all authors contributed to the discussions and writing stages.

Chapter 7. Older Adults' Privacy and Security Perspectives on Technology

We next focus specifically on the security and privacy concerns of senior residents of long term care facilities, that were raised in the previous Chapter. By conducting 47 semi-structured interviews with them, we identify a range of complex privacy and security attitudes and needs specific to this population, along with common threat models, misconceptions, and mitigation strategies. We describe usability issues that affect management of online data access, and we recommend privacy and security learning approaches and usable technical and policy protections that build on preferences of older adults.

A summary of this work has been published at CHI Workshop “Designing Interactions for the Ageing Populations” as: Frik A., Schaub F., Bernd J., Nurgalieva L., Lee J., Egelman S. (2018). Usable Security of Emerging Healthcare Technologies for Seniors. [40]

The major part of the content of this chapter has been accepted to be published at the Fifteenth Symposium on Usable Privacy and Security (SOUPS 2019):

Frik, A., Bernd J., Egelman S., Schaub F., Nurgalieva, L., and Lee J. (2019). Privacy and Security Threat Models and Mitigation Strategies of Older Adults.

My Contribution: The interviews this study is based on were conducted by the first and the last authors, while data analysis and its interpretation included all of the authors. My work on this paper includes coding of 23 interviews (or 1900 hours of them transcribed), data analysis, and contribution on all stages of the writing process.

Chapter 8. A systematic literature review of research-derived touchscreen design guidelines for older adults

We next present a systematic literature review that we conducted to investigate the research-derived design guidelines that set the foundation for design guideline compilations and standards. We analyze them from the perspective of experts trying to discover, classify, and evaluate the work on the area of research-based touchscreen design guidelines for older adults. The review includes 52 research articles resulting in 434 research-derived design guidelines for touchscreen applications. These guidelines are analyzed using a taxonomy that considered the ability changes addressed, and the design aspects that are target of the recommendation.

Part of the content of this chapter has been initially published as:

Nurgalieva, L., Laconich, J. J. J., Baez, M., Casati, F., and Marchese, M. (2017). Designing for older adults: review of touchscreen design guidelines. arXiv preprint arXiv:1703.06317. [41]

The major part of the content has been published by the IEEE Access journal:

Nurgalieva, L., Laconich, J. J. J., Baez, M., Casati, F., and Marchese, M. (2019). A systematic literature review of research-derived touchscreen design guidelines for older adults. IEEE Access, 7, 22035-22058. [42]

My Contribution: I coordinated and led the overall literature review and paper selection process, while the first three authors were involved equally in the analysis and writing process of both papers. The remaining authors contributed through the discussions on the data analysis process and comments based on readings of the drafts.

Chapter 9. Designing interactive systems to mediate communication between formal and informal caregivers in aged care.

By conducting three consequential sets of user studies with staff and family members of residents in four Italian NHs, we continue investigating the institutionalized care scenario in more depth and exploring the challenges and opportunities of designing information systems within it. Following the findings from the previous chapters, we place an emphasis on informational needs of family caregivers and work practices of professionals in accordance with the preferences of care recipients we learned earlier. Moreover, we incorporate and validate the findings presented across this Thesis by using them while developing interactive design alternatives of the application intended to mediate the communication between family and professional caregivers, which we evaluate with family members of institutionalized older adults.

One part of this chapter has been published as:

Nurgalieva, L., Baez, M., Fiore, F., Casati, F., and Marchese, M. (2018, September). Designing Healthcare Systems with an Emphasis on Relational Quality and Peace of Mind. In *International Conference on Social Informatics* (pp. 234-242). Springer, Cham. [43]

Another larger part of this chapter has been submitted to the Journal of the Human Factors and Ergonomics Society as:

Nurgalieva, L., Baez, M., Adamo, G., and Marchese, M., and Casati, F. (2019, April). Designing interactive systems to mediate communication between formal and informal caregivers in aged care. In *The Journal of the Human Factors and Ergonomics Society*. SAGE.

My Contribution: All the authors joined the work on the stages of study design, discussions of the data analysis and interpretation, and writing process. The interviews and workshops were conducted by me and the third authors, and I was leading the overall work on both papers.

Chapter 10. Discussion

In this chapter we discuss our main research findings and outline the major contributions.

Chapter 11. Conclusions and Future Work

We conclude the Thesis by summarizing the contributions of this work and connecting our results to the Thesis research questions. We also comment on the limitations of this research and define the directions for the future work.

Chapter 2

Background

In this section, we discuss previous research related to this thesis. We first briefly review the studies on the context of aged care, defining the actors directly involved in it, their relations and communication through the concept of “care triad”, which includes senior care recipients, professional or formal caregivers, such as nurses, doctors, and hired caregivers; and family or informal caregivers [4]. We then discuss health and wellbeing information (HWBI) sharing within the triad, which is, according to the biopsychosocial model of health status, the information comprised of physiological, psychological, and social aspects of health and illnesses [44]. We cover the studies on the benefits of HWBI sharing, as well as research on common issues and difficulties it is associated with. Finally, we review the studies on the role of ICT as a sharing channel that supports and mediates existing sharing practices and discuss the security and privacy risks related to it.

2.1 Sharing Health Information within the Aged Care Context

More than any other age group, older adults experience multiple chronic conditions that lead them to receive care from multiple care settings and professional (or formal) care providers. Formal care in this case refers to a range of home care and community support services provided to seniors by a mix of caregivers, some of which include “personal support workers, nurses, occupational therapists, physiotherapists, speech pathologists, and dietitians or provided by community support service (CSS) agencies, volunteer organizations, adult day programs, caregiver respite programs”, etc [45, p.6]. The settings such services may be delivered in include, for instance,

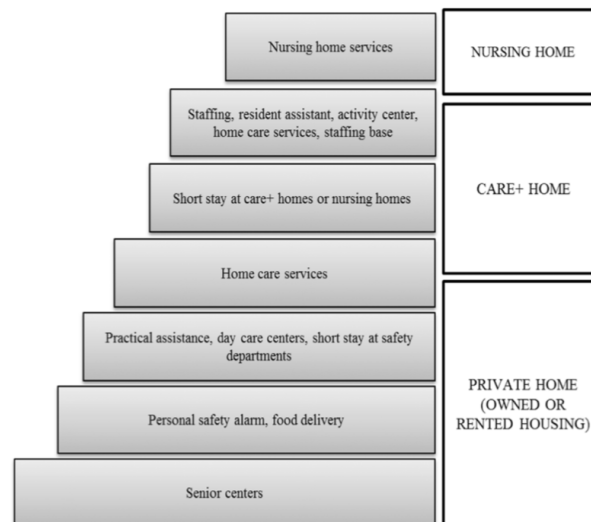


FIGURE 2.1: The care staircase of municipal aged formal care services in Norway

family residences, supportive housing (typically an apartment building with built in services), senior centres, adult day programs, or other long term care facilities.

The transitions across this continuum of care are common as seniors age and include different care levels depending on the socio-economic context and personal preferences. For instance, in Norway, the municipal aged care and social services form a care staircase (Figure 2.1), which represents the level of care and the services connected to private homes, care homes, and nursing homes [46].

In particular, the transition from aging in place, e.g. when older adults live independently in their own homes, to institutionalized care, can be a time of change of power and delegation of control over decision making due to their reduced health and independence in performing activities of daily living (ADLs). This change is usually characterized by higher involvement of seniors' family members who often act as informal caregivers [3]. Previous research [47, 48] clearly shows that institutionalization of older adults does not lower the burden of caregiving for family members. This assumption, labeled as the “myth of abandonment” [49], is proven wrong by various research contributions. While alleviating related “practical” aspects, it does not eliminate the emotional side of caring for family members [45, 48] who often adopt alternative strategies to stay engaged in care processes. One of them is “caring through data”, an analytical approach introduced by Kaziunas et al. [25], that is based on collection and exchange of seniors' HWBI and enabled by an increasing popularity of “health datafication”, collection of personal data to improve individual health outcomes. “Caring through data” transforms the traditional

involvement of family members in practical care procedures into a more systematic partnership of family and staff, facilitating a collaboration of seniors, family members, and professional caregivers (triad of aged care).

As it has been precisely noted by Thomsen et al., “healthcare is not an individual achievement, but rather a relational achievement between the patient, his/her network, and the healthcare professional” [16, p.3]. In this vein, efficient care practices enable an exchange of experiences, suggestions, emotional support and is thus something that arises out of complex interactions between care triad stakeholders. Georgiou et al. [50] studied information exchange processes and the role of technology in seven Australian long-term residential facilities. In their qualitative study, they point out three main tasks associated with information: storing and managing data, supporting decision making, and communicating it; and highlight how poor information exchange can affect the quality of care. Their findings stress the need for effective communication technology support for continuity and organization of care, especially in presenting information, emphasizing its accessibility and legibility. Continuing on the topic of strategies of health data communication, Desai et al. [51] claim that the effective usage of HWBI strongly depends on being understood by non-expert care actors. Conducting a series of focus group discussions, they explored different communication approaches and attempted to identify visual features that resonate with individuals suffering from diabetes. Their findings illustrate that efficient medical data communication practices could have a significant effect by clarifying “mental models of disease, internalizing health risks and consequences” for the members involved in the care process [51, p.2].

However, the information needs of family members and professionals do not always match the disclosure preferences of older adults, such asymmetry in sharing HWBI creates tensions between care recipients and their caregivers [11]. Hence, it is particularly important to focus on the perspectives of each group of the stakeholders involved in aged care processes when designing systems aimed at facilitating their interactions [14]. We next outline the research on benefits and barriers of sharing it for each group of care triad stakeholders: family members, professional caregivers, and care recipients.

2.1.1 The Value of Sharing for Family Caregivers

Huvila et al. highlight that “individuals caring for close relatives have the greatest interest in medical records” [52, p.3]. Indeed, family members need at least some information regarding

their loved one's disease, its progress and prognosis, treatment options, potential symptoms, and side effects [19] or simply daily routine [53, 54]. This information helps family caregivers mentally prepare for what to expect, including organizing and planning; minimizes uncertainty; provides reassurance; and promotes calmness, comprehension, and adaptation to the situation [53]. Washington et al. [19] define two broad categories of specific information needs of informal caregivers: general, which includes information relevant to large numbers of caregivers at various stages of caregiving, and specific information that is tailored to individual caregiver needs. Information seeking strategies of family members also depend on factors such as the health state of their relatives [19], perception of the staff's attitude or relationship with the staff, for instance, the lack of information may be due to feeling unwelcomed [55], person's attitudes, values, and knowledge about health and about health services; but also the beliefs and values within the socio-cultural norms [18]. Information needs also strongly depend on the caregiving experience of the family members. Comparing new and experienced caregivers, Chiu and Washington et al. [18, 19] found that new caregivers' needs change over time and influenced by such factors as "the changes the health state of their loved ones, being confused by the overwhelming information", while experienced caregivers encounter "episodic deteriorations of family member's health and needs caused by suppressed, unresolved issues" [18, p.757].

Washington et al. [19] indicate the evidence on information needs of informal caregivers of older adults (in home settings) who suffer from chronic illnesses. In their systematic review, they conclude that informal caregivers need to be provided with individualized and understandable information in a proactive way, which is particularly challenging with multiple co-morbid conditions of older adults. They also highlight that, over time, family caregivers become better informed and more experienced, resulting in a decreased number of unmet information needs [19]. Beside the fact that information needs of family caregivers vary over time, they are also multi-faceted and complex, which is described by Chiu et al. in their study [18].

These works – though focusing on informal and formal caregiving practices in various care aged settings – provide interesting dimensions to be considered in information exchange with individuals of different level of care experience and knowledge. Moreover, these dimensions are particularly important to study due to common mismatch in expectations and real life of family members of seniors, which could be due to many reasons such as the lack of experience in institutional care of family members of the residents, drastic health changes of older adults, negativated preconceptions on institutionalized care, and others.

2.1.2 The Value of Sharing for Professional Caregivers

Often, in coordinating the care, communication between professional and family caregivers and among professional caregivers is affected by various factors, such as medical and organizational issues [56]. Indeed, “even the most routine and everyday tasks can vary in the manner in which, the time at which, and the person by whom they are performed, according to the tasks to be done and the contingencies that arise” [57, p. 228]. Family members are often considered to be an additional resource to the work of care professionals [8, 20, 58]. The involvement of family (or informal) caregivers into the care practices can be increased by sharing information about older adults with them. As a side effect, such strategies also improve the trust of family members towards professionals and even reduce the stress and workload of care staff [6, 7, 54].

Data from several studies confirms the need of professional caregivers for a collaborative relationship with family members, which is rarely reflected in the clinical practice [5]. In fact, Haggerty [59] emphasized the importance of HWBI exchange within the care triad in order to achieve relational continuity and to facilitate the care process, which also creates the space for family care. The information family could contribute might be necessary not only to the care process but also to the decisions on one’s medical path. As an additional outcome, such “caring through data” could also become a mean to foster togetherness and turn family caregiving into an empathetic and inclusive process, as emphasized by Kaziunas et al. Moreover, Yamasaki et al. [60] also emphasized positive impact of it on the wellbeing and health conditions of family members by avoiding “health-related secrecy of prior generations” and sharing family health history. In the same vein, Foong et al. [61] investigated the impact of volunteer caregiver knowledge in dementia care contexts. Their results identify that such non-expert knowledge can be useful in many ways: by using lay language, sharing information specific to the care recipients, and collaboratively finding strategies for interaction.

While current research often addresses the burden of formal and informal caregiving duties [20], the needs and concerns regarding health communication in the care triad, especially from the perspective of older care recipients, are often understudied. The exclusion of the central actors from the design of information systems is still common, while it is crucial to consider sharing preferences and expectations of patients/residential older adults.

2.1.3 Seniors' Opinions on Sharing

It has conclusively been shown that person-centred care is a multidimensional concept that includes seniors' subjective experiences of illness, and the family participation. Seniors see welcoming family members into their care as one of the principal elements of person-centred care [62].

However, in conditions of intergenerational dynamics of aged care, it is not always easy for caregivers to find the balance between providing care and respecting one another's independence [10]. Berry et al. [14] emphasized how asymmetric values create tensions between care recipients and their family caregivers. For instance, Jacobs et al. illustrate that by comparing HWBI sharing preferences among cancer patients, doctors and caregivers, where they found participants to be misaligned, as patients' motivation to share their health information does not always match the interest of healthcare providers to receive it [11]. In this regard, Silliman [63] stressed the need for resolving care dilemmas in different areas of the three-way relationship as well (family, care staff, and seniors), such as behavioral problems, legal issues, and decision making about placement and treatments in long term care facilities. Indeed, these issues often lie behind the absence of a proper alignment among the care actors involved in the care pathway.

Among the reasons patients do choose to share health information is to "reduce burdens on family members, though these preferences may change over time" [13, p.3]. Older care recipients share their HWBI to let caregivers know about their daily functioning [26], for emergency reasons but also to obtain caregivers' technical help in case of digital access to their health records [64]. Several studies have investigated what kinds of health information patients are instead reluctant to share, and health information connected to high privacy concerns. This information is generally related to "mental health, sexual health and genito-urinary problems", which corresponds to sensitive or embarrassing issues that may affect "how the patient will be treated by other individuals or institutions" [65, 66]. Information sensitivity can also be determined by personal factors such as "personality traits, information sensitivity, health status, prior privacy invasions, risk beliefs, and experience" [67, p.138].

Hence, observing numerous examples of the mismatch between the views on sharing HWBI of family and seniors, it becomes particularly important to consider seniors' opinions on care involvement of family members and their communication with professional caregivers [10]. However, as we have indicated above, it is still common to address families' burden on informal

caregiving duties or work practices of professional caregivers [20] rather than looking closely at current practices, needs, and concerns regarding intergenerational communication about health. At the same time, finding new solutions for information sharing depends on the understanding of the perspective of all actors of the triad [68].

2.2 The Role of Technology as a Sharing Channel

As a conclusion from the previous sections of this Chapter, optimizing and facilitating HWBI sharing depends on the comprehension of the organization of work among the actors involved in the care triad [69], of their practices in coordinating the care pathway [70], and of their values and sharing boundaries. By understanding how information is shared among actors, new solutions can be designed to support this process [71]. And indeed, a number of studies emphasize the potential of technology in it, by recognizing the efficiency of ICT tools in facilitating the coordination within the triad of care [72].

Technology has been largely explored as an instrument to improve the delivery and quality of care in health and care facilities. Previous work has also focused on designing and evaluating ICT tools for improving the organization of care practices, and to a less extent, the mediation of its communication among various involved actors. Numerous studies present technology as a channel of coherent distribution of information among care stakeholders, thus facilitating their efficient coordination on patient care pathway [7, 73, 74]. Focusing on the implementation of health information exchange (HIE) technology, Alexander et al. [75] report on the HIE preparation in the US nursing homes. This work paints a picture of the current status of technology deployment to support information exchange, describing the presence of care support systems but with little integration with external entities. An emergent theme in their study was the extensive use of paper communication and the need for better tools to communicate with family members, email being one of the tools suggested by participants.

Other works [76–79] point to scant involvement of family caregivers in technology-mediated information flows, and highlight the need for better IT support for information exchange in residential care. Literature provides evidence that ICT tools can enhance care to only to patients but also their family caregivers by “increased and more efficient communication with health care providers” [17]. However, there has been little research on designing computational technologies for “contested sensitive situations involving a multitude of stakeholders” [16]. Those channels can

be implemented in many ways. For instance, through participatory design workshops, Bossen et al. [72] design a digital shared calendar as a tool for the alignment of tasks and appointments between family and hired caregivers of older adults who value the support of care coordination provided by technology. Other studies discuss the controversy of seniors' views on technology support of communication with their formal and informal caregivers, as helping them to stay independent and, hence, reducing the burden on caregivers but also increasing the burden by making them feel obligated [12].

Chiu et al. [18] discussed different styles of using ICT-mediated information support by family caregivers that fall into two main types: reflective learner, a person who prefers to interact with the information site, no email exchange with staff; and interactive learner, a person chooses to interact with the therapist via e-mail. Another aspect of introducing ICT based communication support is the need of information personalisation, previous research has found that caregivers emphasized the importance of tailoring information to ensure that it will be easily comprehended by individual caregivers [19]. Still, these findings point at the multitude of different types of family caregivers that should be taken into account while developing communication support ICT systems.

Introducing technology may strongly affect caregiving context and influence how various stakeholders behave, "both in relation to the technology itself and co-located people" [16]. In the conditions of information uncertainty related to the NH context, it is especially important to support family caregivers in making sense of the data and understanding the future trends [51]. In this sense, efficient medical data communication practices could have a significant effect by "clarifying mental models of disease, internalizing health risks and consequences" for the members involved in the care process [51].

These contributions support the claim that technology as a tool and a channel can provide an efficient support of information sharing within healthcare contexts [15] but also might be negatively perceived by senior care recipients, for instance, due to usability issues and accessibility barriers, as design of such tools does not always address ageing related ability declines. Literature has emphasized the importance of design guidelines as precise and reliable recommendations to refer to while developing technologies for older adults. Recent works on synthesis and evaluation of design guidelines present them based on usability problems older adults face [80], while others aim at reducing "the gap between a designer's conceptual model and a user's mental model of the design" [81] and attempt to make them more applicable for the industry [82]. However,

there is a lack of works that would address the diversity of the older population recognizing its heterogeneity, instead of defining older adults solely by age or common ability declines. There are also few systematic literature reviews of research based guidelines and no works that would systematically cover both the variety of ageing related ability declines and design categories of interacting with touchscreen devices.

This implies that IT systems should be designed in accordance with the perspectives of each group of care triad actors, both caregivers and care recipients, which can be reached by gathering their requirements and including them into the design process from the very early stages [83, 84].

2.2.1 Privacy Concerns Related to Sharing

Sharing HWBI in person as well as using ICT tools and channels can pose certain privacy limitations and security risks for the triad actors. As mentioned in preceding sections, information can be sensitive and, therefore, subjected to privacy concerns. In their qualitative study with patients and family caregivers, Lim et al. [13] examine the motivations and boundaries in communication between patients and their healthcare providers. The factors that influences patients' information disclosures were perceptions of what was pertinent to share, assumptions about the consequences of sharing, and interpersonal relationships with healthcare providers, but also privacy issues involved in this communication, as they are "often the top concern" among senior patients who turn to "health information management technologies" [13, p.3].

Shared electronic access to health information (e.g., through patient portals) raises concerns about digital divide, security risks, and technical incompatibilities [66]. The literature suggests that patients tend not to feel in control of the content of information shared with their caregiving networks through digital channels [28], which rises their privacy concerns and prevents them from using digital services that allow them to access and share their health records.

2.2.2 Legal Regulations

In addition to personal views, recent changes in European and US legislation affect the boundaries of sharing health information. In European Union, sharing of medical records was impacted

by the adoption of EU General Data Protection Regulation (GDPR) 2016/679¹ [31], which transforms sharing of health records both for care stakeholders and patients groups.

On the other hand, the Health Insurance Portability and Accountability Act (HIPAA) (1996) [85] and its Privacy and Security Rules (extension to the Act of 2003) [86] in the US has radically changed the way the actors involved in healthcare use, maintain, and disclose health information. This regulation provides “patients and their personal representatives” with right of access to health information, and permits sharing identifiable health information relevant to a patient’s care with involved family members or friends” [32, p.118]. Another similar recent regulation is the 2018 California Consumer Privacy Act [33], which is intended to provide California residents with the right of access and knowledge of the collection and disclosure of their personal information.

As beneficial and well-intended as they are, these regulations still might inhibit the sharing of health information with and involvement of the family due to their interpretation and application complexity, as it is not always clear what can and cannot be done in health communication with family caregivers [34]. In addition, reduced capacity of certain patient and caregiver groups to manage digital versions health records due to the lack of technology experience also results in their privacy and security vulnerability and compliance with existing regulations [32].

Moreover, regulations imply that patient information is stored and transferred not only using local databases and closed systems but also through global networks, distributed databases and even in the cloud. Health records might be fragmented and accessible from several locations and by multiple healthcare providers, as shared access is common in medical practise [35]. This implies an increased risk of patient information disclosure within the contexts where it cannot be controlled [36]. Such electronic exchange of patients’ information poses various security risks [87, 88].

Privacy concerns related to HWBI sharing might not be always directly perceived by the care triad actors. Vodicka et al. [89] monitored patients’ access to their medical information and their privacy concerns related to that during one year and showed that even having privacy concerns, it does not inhibit the patient to continue reading their information online, as the benefits of the access to their health records may “outweigh patients’ perceived risks to privacy”. Precisely, one third of the patients were worried about the possibility of someone else gaining online access to their health records due to its simplicity, but still continued to access the information [89].

¹A regulation in EU law on data protection and privacy for all individuals within the European Union that was enforced on May 25 2018 – <https://eur-lex.europa.eu/legal-content/IT/TXT/?uri=celex%3A32016R0679>

Considering the views of seniors on HWB information sharing and the role of ICT they see in it could help researchers intervene and support the caregivers ability to smoothly conduct the care process. Hence, it is particularly important to study the key elements at the basis of privacy concerns of institutionalized older adults, thus delivering new design insights.

Chapter 3

Methodology

To address the TRQs defined in Section 1.2, in this thesis we have used the following range of research methodologies, mainly focused on a number of user studies:

- Literature overview and synthesis;
- Systematic literature review based on the guidelines from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [90];
- Case study approach as a preliminary investigation method we applied within six Italian nursing homes;
- Extended in-depth semi-structured interviews with all three groups of actors of aged care triad: seniors, their family members, and professional caregivers;
- Focus group discussions (FGDs) with gerontologists and NH staff;
- Large scale survey and brief questionnaires conducted with various groups of patients and caregivers;
- Design evaluation workshop sessions with family caregivers using interactive tablet mock-ups.

As mixed research methodologies have been confirmed to be most efficient and beneficial in conducting e-Health research [91], the studies contributing into this thesis combined the methods listed in above paragraph. Overall, this work can be separated in three main parts and related methodologies.

3.1 Understanding Users and Context: Approaches and Methodologies

As the first step in addressing TRQ1, this work was set to study the factors that influence the decision to share or not to share HWBI in the context of aged care. By exploring varying aged care scenarios and the perspectives actors or potential technology users involved in them have on sharing HWBI, we identified the types and the attributes of information to share or not to share, sharing strategies and channels the care stakeholders adopt, their values, priorities, skills, and resources. To reach these research objectives, we adopted the following research methods:

i) A literature overview of related work on information design, sharing of HWBI in aged care triad, the role of technology in it, and common barriers and concerns users have towards sharing and using technology as a channel of sharing (Chapter 2). As an essential and preliminary part of the thesis, this chapter sets up the contexts of this work and indicates the *knowledge gaps* it intends to address;

ii) A case study where we explore the setting of nursing home care scenario and investigate the views *staff and family members* of the senior residents have on sharing HWBI, which included interviews and focus group discussions (FGDs) (Chapter 4);

iii) A combination of large scale survey and semi-structured interviews to study Patient Accessible Electronic Health Records (PAEHR) sharing strategies Swedish patients adopt while using national patient portal (Chapter 5). Unlike the previous study, this work sheds light on the views of the care recipients and their attitudes towards sharing their PAEHR with healthcare staff and family members.

Applying these methods, we identified and studied various aged care scenarios and the HWBI sharing practices adopted in them. We derived the dimensions of those scenarios from the HWBI sharing and communication point of view, such as independence of older adults, the involvement of actors or stakeholders of aged triad of care, and acceptance of technology as a sharing channel.

3.1.1 Care Scenarios

As mentioned before, the studies that contribute to this thesis were conducted in diverse care settings and scenarios, ranging from independent living to terminal care at nursing homes¹. Each

¹Refers to “skilled nursing” in the US care terminology

information with professionals and family members involved in their care. Based on our findings, we suggest design implications for future ICT systems that could support sharing in similar care scenarios. In the first study we examined how the purpose of use, functional relevance, urgency, anticipated emotional reactions, and individual attitudes to privacy and control affect seniors' opinions about sharing (Chapter 6). The second study focused specifically on the privacy and security concerns of senior care recipients and is presented in Chapter 7.

Scenario 3. Finally, the third care scenario covered in this thesis is **institutionalized care at nursing homes (NHs)**, residential aged care facilities that accommodate frail seniors who require a high level of personal assistance and care. In such contexts, older adults delegate full control over access and sharing of their health information upon placement in such facility. The involvement of the family members in care in this scenario is usually significant, as they often communicate directly with the staff members. To study sharing of HWBI in this care scenario, we conducted a series of interviews with professionals and family members of the seniors in Italian nursing homes, as presented in Chapters 5 and 9.

3.1.2 Aged Care Triad Actors

Next, we took a closer look on one of the dimensions of aged care, the stakeholders directly involved in it, comprising the triad of aged care: older adults, their family members, and staff (including health care professionals, hired caregivers, and care facility management). We studied specific aspects from the perspectives of each group, such as their values and priorities, skills, resources, and analyze the dyads of stakeholder groups. We raise those issues in more detail in Chapters 5 and 9. Finally, we take the stance of the patients and long term care facility residents in Chapters 6, and 7.

An important observation across all of the personas involved in aged care is that most of them are of relatively older age, e.g. most are over 55: seniors themselves usually belong to the “old-old” population [93], their family members mainly comprised of spouses or partners and adult children who also belong to the older demographic group, and middle to older age care staff members. This particularity poses many challenges from the design perspective: older adults might be very different in their abilities and skills forming a heterogeneous group of users, while their attitudes to technology might also vary from very positive to the full resistance to it.

3.2 Methods for the Design of Information Sharing in Aged Care

The first part of this thesis empirically demonstrates that aged care, and especially institutionalized care, is a pervasive process that involves multiple stakeholders whose motivations, opinions and interests may not always align or be clearly expressed. Willingness to assist, provide care, and offer emotional support often competes with the burden of redundant information, worry, privacy concerns, and legal boundaries related to HWBI sharing, thereby posing challenges for the design of effective communication.

Information design of sharing in healthcare contexts should address the stakeholders' needs and preferences, as the core principle of user-centered design, but also unavoidably take into account many constraints and limitations of this sensitive context. It should also be efficient with regard to the resources expended to achieve the goals [37], for instance, considering the workload of the care staff or technological possibilities of the family members.

As the second stage of this work, addressing the TRQ2 we conducted a set of user studies on design of sharing HWBI in aged care context that resulted into the set of design principles and guidelines. This stage started with two sets of interviews with institutionalized seniors in the US long term care facilities: one of them focused specifically on their views on sharing their HWBI with care personnel and family members (Section 6) and their related security and privacy concerns (Section 7). These studies informed a mockup design of an interactive application called “Traduttore” (“translator” in Italian), which became a platform that helped us to investigate our research hypotheses. “Traduttore” was intended as a technology platform to be implemented on touchscreen devices (tablets and smartphones) to support synchronous and asynchronous communications between family members and professional caregivers of institutionalized older adults. As we observed that both care recipients and family caregivers belong to the older demographic group, continuing and extending this work in the direction of front-end design, we conducted a systematic literature review of the last decade of research on touchscreen design guidelines for older adults followed by a FGD with gerontologists to evaluate the findings. This extensive work is described in detail in the Chapter 8.

3.3 Methods of Evaluating the Findings with Family Caregivers of Institutionalized Seniors

The concluding stage of this work aimed at evaluating and validating the interactive design alternatives that would present HWBI of seniors to their family members through the medium of a tablet applications.

As it has previously been shown that a qualitative approach is feasible in such type of studies [94, 95], we opted for predominantly qualitative format, such as workshops and semi-structured interviews complemented by a quantitative questionnaires, since we judged that broad and deep insights were only attainable through an open and flexible discussion. This intention resulted into three sets of consequential user studies including 26 in-depth semi-structured interviews with 17 family caregivers and 9 staff members at six Italian nursing homes and two workshops with 10 family members of daycare and nursing home residents, which helped us to refine some of the features and observe what design implications from previous studies hold for those two target population groups. The detailed description of the evaluation study is presented in Chapter 9.

3.4 Methodological Challenges

In addition, conducting research in such a sensitive healthcare context as aged care poses several methodological challenges that we identified and tried to overcome as a research group [96], though we do not discuss them in detail in this thesis. The challenges start as early as participant recruitment and resulted into the delays in conducting research and even failures to do so. This was especially relevant to the institutional care scenarios, as both seniors and their relatives are in vulnerable and emotionally difficult situation related to the terminal care conditions. Involving staff members as the medium for the recruitment became a way to address those challenges, as professionals had a better understanding of each family situation and could handle the recruitment in a more appropriate way.

Other issues included the expectations participants had towards researchers, for instance, in solving their problems that were not related to research or technology such as influencing the decisions on the placement into the long term care facilities or resolving various financial hardships. Our strategy to address that was to distance ourselves from the management of the

facilities and the technology producers communicating clearly that research is conducted purely for academic purposes.

Finally, obtaining ethical approvals was another time consuming and complicated but yet necessary and unavoidable requirement in conducting our studies. Recognizing the importance of it, we made sure that the studies within all three research collaborations that contribute to this thesis are covered by appropriate ethical approvals: University of Trento Committee on Research Involving Human Beings (Application N. 2017-003), Uppsala, Sweden (EPN 2017/045), and an approval from the institutional review board (IRB) of UC Berkeley, USA.

Part I

Part: Understanding Users and Context

The first part of this Thesis includes the studies that set the research context for this thesis and explore current sharing practices in general healthcare and specific aged care scenarios. We start by studying the perspective of general population of care recipients or patients on sharing their health records with others that we discuss in Chapter 4. To achieve this goal, we conduct combination of a survey with 2,587 patients and 15 semi-structured in-depth interviews with cancer patients in Sweden who use the Swedish national patient portal.

One of the important findings of this study is that older patients have a higher tendency to share their health related information, a finding that motivated us to take a closer look at sharing HWBI in care for older adults or “aged care”. Moving to this more specific healthcare context in Chapter 5, we observe that with degrading health of seniors, sharing of their HWBI happens mostly among their formal and informal caregivers. Hence, we conduct a case study with the focus on the work practices of care professionals, and on the relational issues between professional and family caregivers related to information practices. The outcomes of this work illustrate on the opportunities of using ICT solutions to improve relations, information sharing among caregivers, and provide us with important insights for future study directions that we address in the next parts of this thesis.

Chapter 4

On Sharing of Patient Accessible Electronic Health Records

Moving to the perspective of care recipients, we conduct combination of a survey with 2,587 patients and 15 semi-structured in-depth interviews with cancer patients in Sweden who use the Swedish national patient portal. We explore patients' perspective on technical, ethical, security and privacy challenges that should be considered when designing systems for sharing of medical information. We investigate strategies patients adopt in sharing their Patient Accessible Electronic Health Records (PAEHR) and discuss implications for design addressing related problems as well as security and privacy issues connected to sharing.

A summary of the content of this chapter has been submitted to the Health informatics journal, and is currently under review:

Nurgalieva, L., Cajander, Å., Moll, J., Åhlfeldt, R-M., Huvila I., and Marchese, M. (2018). "I do Not Share it with Others. No, it's for ME, it's my Care": On Sharing of Patient Accessible Electronic Health Records.

This study aims to explore the patients' perspective on what technical, ethical, security and privacy challenges need to be considered when designing systems for patients sharing of medical information. Patients traditionally share medical information through discussions with peers and relatives. However, other possibilities to share have also emerged through the introduction of online services such as Patient Accessible Electronic Health Records (PAEHR). The political idea behind sharing medical information in PAEHR is to empower relatives to participate in the care process. In this study we investigate and discuss strategies patients adopt in sharing their health records. Data was collected through a survey with 2,587 patients, and through 15 semi-structured in-depth interviews with cancer patients. Results show that surprisingly few patients share their information but that older patients, and patients with lower educational level more frequently share information. Moreover, a large majority of patients trust the security of the system when sharing despite containing very sensitive information. Finally, we discuss implications for design addressing identified problems when sharing PAEHR as well as security and privacy issues connected to sharing. This work provides empirical understanding of barriers and opportunities for patient-centered design (including their care partners and/or family) of patient portals that would be aligned with the values and reasoning of the end users.

4.1 Introduction

A prevailing trend in healthcare is to portray the future as increasingly digital and personalized. E-services are often put forward as instrumental to more patient-centred and transparent care processes [97, 98]. In parallel to this, efforts have been made to make healthcare information more understandable and usable for the patients. However, little research has focused on patients' sharing of healthcare information.

A premise of storing healthcare information digitally in patient portals is keeping it secure. However, not all users are willing to actively protect their records [99] and many assume patient portals are secure a priori. The situation is also complicated by the fact that health information is shared outside of the portals both offline and digitally [64]. When information is shared *in person* face-to-face (FTF), patients have a higher degree of control over dissemination and they can choose when and what to share. It is also possible to comment on the shared information and provide additional context. However, FTF sharing is possible only with the patients present and it does not allow remote access and instant revision of records when their owner is not able to do so (PAEHR) [100].

When sharing *digitally*, information can usually be consulted any time after access has been granted. Sharing the entire health record is also common in e-health systems. This enables trusted readers to see retrospective information that patients may not recall [101]. However, patients may be willing to share their current health status but may not be comfortable with giving access to *historical* information [26]. Hence, it is important to understand benefits and drawbacks related to different modes of sharing to help the development of current and future e-Health systems more responsive to patients' needs.

This study aims to explore the patients' perspective on what technical, ethical, security and privacy challenges need to be considered when designing systems for sharing medical information. Applying a mixed methods approach, the study seeks to understand the attitudes towards sharing among patients who are patient portal users based on a national survey (N=2587) and a smaller interview study (N=15), with the following research questions (RQ):

- RQ1. What values, considerations, and conditions motivate patients to share or not to share medical records?
- RQ2. What are the critical issues constraining sharing of medical information in person and digitally?

Based on the results, we discuss the different modes of sharing and provide design and policy recommendations. The empirical focus of this study is on the Swedish national PAEHR system *Journalen*. *Journalen* was first introduced in Region Uppsala in 2012 [102] and from the late 2017, patients from all 21 Swedish county councils and regions have been able to access the system. The information shown to the patients differ between county councils, but in most regions patients can see visit notes, care contact history, diagnoses, vaccinations and test results.

4.2 Background

Patient portals are e-Health systems that provide a way of accessing personal health records and communicating with health service providers [103]. Crotty et al. [26] describe such systems as a “hub for families” implemented through “proxy access”, which supports patients in sharing their health related information with relatives, and account for changing “dimensions of information sharing (what information, to whom, when, how much, and under what circumstances)”.

Shared e-access to PAEHR, as provided by most patient portals, has both positive and negative aspects. Positive aspects include enhanced partnership between formal and informal caregivers of patients and better inclusion of the latter into the care process [104]. On the negative side, it possibly introduces a digital divide, security issues, and technical incompatibilities [66]. Sharing patient information through patient portals may also bring new technical, ethical and legal challenges relevant both to families and healthcare professionals [105].

Several studies have investigated what kinds of health information patients are reluctant to share, and health information connected to high privacy concerns. This information is generally related to “mental health, sexual health and genito-urinary problems”, which corresponds to sensitive or embarrassing issues that may affect “how the patient will be treated by other individuals or institutions” [65, 66]. Information sensitivity can also be determined by personal factors such as “personality traits, information sensitivity, health status, prior privacy invasions, risk beliefs, and experience” [67].

However, the importance of being able to share PAEHR has conclusively been shown in a large number of studies. Yamasaki et al. [60] support that view by investigating the impact of sharing of family health history and avoiding “health-related secrecy of prior generations” on the well-being and health conditions of family members. In their article, Huvila et al. [52] present a study on patients reading their medical records where they identify that “individuals caring for close relatives have the greatest interest in medical records”, confirming the importance of information sharing in informal caregiving and collaborative partnership with professional caregivers [5, 38]. Hence, accessing a relative’s PAEHR can be a form of care. It may, however, not always be legitimate due to the lack of defined access roles for care partners when, for instance, they are forced to access such health systems using patients’ credentials [32].

Still, a much debated question is whether there should be a possibility to share the access to PAEHR, which has grown in importance in light of recent changes in European and global legislation in 2018. Specifically, sharing of medical records is impacted by the adoption of General Data Protection Regulation (GDPR) (EU) 2016/679: a regulation in EU law on data protection and privacy for all individuals within the European Union that was enforced on May 25 2018, raising specific concerns in stakeholders and patient groups [31]. In addition, there are similar laws such as the Swedish law SFS 2008: 255 Patient Data Act and US law “The Health Insurance Portability and Accountability Act” (USA, 1996) with its Privacy and Security Rules (extension to the Act of 2003) that “provide patients and their personal representatives’ right of access to

health information, and permit sharing identifiable health information relevant to a patient's care with involved family members or friends" [32]. However, at times legal regulations about personal health records and their availability can be very difficult to interpret. For example, a decision by the Supreme Administrative Court (June 2018) in Sweden prohibits the function where the patient can share his information with others. According to the Supreme Administrative Court, this function is in conflict with the Patient Data Act. The Court finds that the law leaves room for a caregiver to only allow patients direct access to the medical records of the patient - not someone else.

Moreover, patient information is stored, distributed, and communicated not only in specific databases but also in global networks, distributed databases and even in the cloud. This implies an increased risk of patient information spreading on a set that is incompatible with the intention to control the availability and communication of the patient information [36]. However, other studies indicate that patients believe that online storing is safe [106]. In their study, Vodicka et al. [89] followed patients' access to their medical information during one year, showing that even if there is a concern about privacy issues, it does not inhibit the patient to continue to want to have and access his/her information online. One third of the patients were worried, but still continued to find it useful to access to the information. An increased spread of patient information also means an increased security risk. What security controls are taken to minimize risks then becomes an important aspect to consider [87, 88].

In Sweden, patients can access their medical records online including, for example, test results, referrals, diagnosis, and medical notes, through *Journalen*. The implementation of the PAEHR *Journalen* varies across the country. In some counties and regions the patient can choose to view journal entries that are unsigned - notes that have not yet been approved by responsible staff members [107]. In other councils, the patient can only see the information once it has been signed and approved by health care staff. Until summer 2018, patients could share their health records in *Journalen* with any person in Sweden by adding the social security number of the person to share with, followed by choosing what parts of the medical records they would like to share. The options for sharing were, for example, medical notes, booked appointments, vaccinations, referrals, diagnosis, the log list, medications, and test results. It was also possible to decide the period to share one's PAEHR. As already described, the possibility to share was removed in summer 2018, but the data collection presented below was, however, carried out while the sharing function was still in use.

4.2.1 Method

A mixed methods approach with a combination of interviews and a survey was used in our study and it is further described in detail below.

Semi-Structured Interviews

Fifteen participants were recruited in the summer and autumn of 2013 using an information leaflet placed in the waiting area for patients at a Swedish university hospital. The interview study was ethically approved by the Regional Ethical Review Board in Uppsala, Sweden, and has resulted in one other publication [106]. Study participants had cancer in different stages and all of them had used *Journalen*. The patients were between 33 and 70 years old, and 12 were women. Three researchers conducted 45-60 min long semi-structured interviews, and the interviews were transcribed, and then analyzed by four researchers. The questions related to sharing information were extracted from the 2013 study and used in the analysis in this study.

National Patient Survey

The second data source used in our study is an online national patient survey available online during five months in 2016. 2,587 patients (out of the 423,141 who logged in during the period) initiated the survey which was distributed on the login page of the PAEHR. The study was ethically approved by the Regional Ethical Review Board in Uppsala, Sweden (EPN 2017/045) and was anonymous. It contained 24 five-point Likert scale questions covering several areas related to attitudes towards, experiences with, and use of *Journalen*. For this work, the questions related demographics, sharing behaviour and security (5 questions in total) have been our focus. An overview of the results from the survey has been published by Moll et al. [108].

Apart from descriptive statistics, in the present study we have used Friedman tests for detecting contrasts between the different modes of sharing (using share function, discussing with relatives and discussing with care staff) for age, education and disease groups. Wilcoxon signed rank tests, with Bonferroni corrections applied, were used for group-wise comparisons in cases where Friedman tests gave a significant result. The Jonckheere-Terpstra test has been used used to find age and education related trends in the data. Significance levels were set to 95% in all tests. The data used in the statistical tests of group-wise differences and trends are based on a numerical conversion from the Likert scale alternatives (1 = "Strongly disagree" and 5 = "Strongly agree").

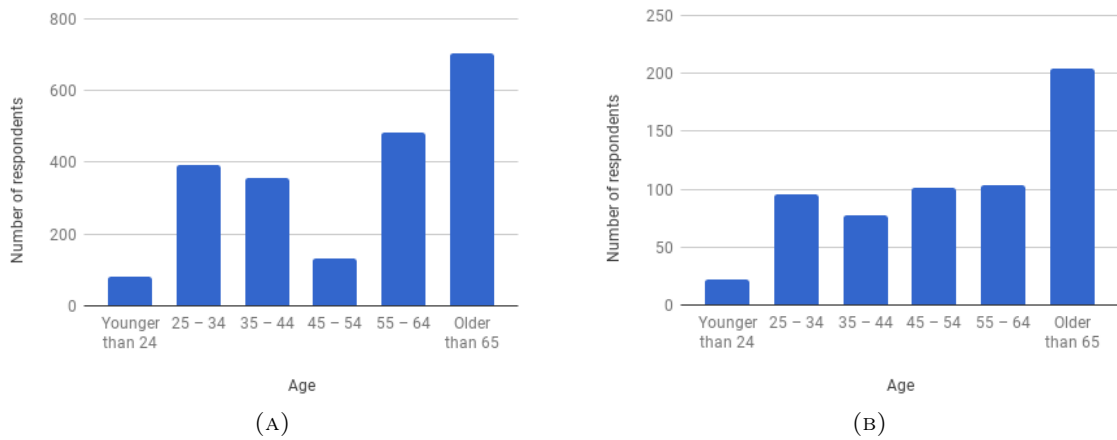


FIGURE 4.1: Age distribution of overall respondents to the survey (A), and of users who use the “Share” function (B)

4.3 Results

In this section we present the characteristics of the population who share online and offline, intercorrelations among those strategies, and indicate topics that emerge from the both studies.

Among the respondents ($n = 2587$), 63,0% identified as female (1629/2587) and 30,9% as male (798/2437). As for the education, 38,5% of all the respondents (945/2455) reached post-secondary education of 3 years or more and 19% shorter than 3 years (467/2455). Moreover, 39,8% (1030/2441) of all respondents stated that they were working in or had worked in the healthcare sector. One-third of the survey respondents (702/2148) were older than 65 years, while the least represented age groups were participants between 45 and 54 years and younger than 24 years (see Figure 4.1a).

4.3.1 Users of Online Sharing in PAEHR

In the survey, the patients were asked about the strategies they adopt in sharing their health records: discussing with relatives, discussing with staff, or using “Share” function. In total 626 respondents out of 2599 who initiated the survey indicated that they have used the PAEHR “Share” function. When asked whether patients share their records by parts or fully, 13,6% (353/2599) of the respondents reported that they share parts and 10,5% (273/2599) that they share everything.

The age distribution of those who used the “Share” function is presented in Figure 4.1b. 33,8% (204/603) of these users were older than 65 years, which is similar to the 32,7% of overall population of survey respondents. Younger adults (less than 24 years old) was the least covered age group in the survey as a whole and only 3,7% (22/626) of the respondents from that age group stated that they use the “Share” function. The Jonckheere-Terpstra test did not show any age-related trends regarding usage of the “Share” function ($JT = 1117800.5$, $p = 0.647$).

Respondents who share online associate themselves with the following disease groups: 24,6% (165/670) with *high blood pressure* and 21,2% (142/670) with *psychiatric diseases*, which also corresponds to the overall survey statistics (23,7% and 19,5%).

38,3% (240/626) of those who use the “Share” function stated that they had experience from working in healthcare, which is similar to the overall number of the respondents (39,6%). The most common education level was high school education with 3 years or more, which summed up to 28,6% (173 of 604 of answered) of all online sharers. The Jonckheere-Terpstra test showed a significant trend related to level of education ($JT=938513.0$, $p<0.001$), which shows that use of the online share function decreases as the education level increases.

Views on Online Sharing

The survey question about sharing also included a free-text field where respondents could add their comments, which was used by only 86 respondents. Many of these respondents (20/86) highlighted that they do not share their record with others. Another common response (14/86 respondents) was that there were “no information to share”. Some commented that they have never used the share function, or did not know that it exists (7/86). A few respondents also acknowledged that they have access to health records which others have shared with them.

The relatively low rate of respondents sharing online and the common free text answers were also supported by the separate set with patients who have cancer. A variety of perspectives were expressed in regard to sharing, which among other arguments included the following:

- Many cancer patients do not think that *others would check if they share*. They believe that there is no point in sharing since relatives and next of kin would not read their health related information: “No. I do not know why would they go there and check out”;
- *No need to share online with those with whom they live together*. Cancer patients expressed their preference towards sharing face-to-face with their family members at home: “I talk to those you live with and tell, but I do not share online journal”;

- *Feeling protective about their data.* Some patients would disclose and discuss medical information off-line upon request but not otherwise, not proactively: “No, I do not share it with others. No. It’s for me. It’s my care. Yes, it’s clear that if anyone would ask, I can say I have a blah blah ... but it’s nothing I’m sitting and reading and sharing. It would never come in. Have not shared (using) the service.”

Usability Factors

The survey included a question on ease of finding the “Share function” in *Journalen*. Just 9,5% of the survey respondents agreed that it is difficult to find (233/2451), which was also consistent for all types of PAEHR sharing. As for technical complexity of the system, only a small number of survey respondents (4.1% or 100/2471) agreed that they need a personal technical support to use *Journalen*.

4.3.2 Offline Sharing through Discussing

A common view expressed in both the semi-structured interviews with patients and the national survey was that PAEHR is discussed in person with relatives, but not shared online. One patient explained this in the following way: “I discuss what’s correct with my partner. I also discuss what is meant by medical terms. I did not know that you could share the journal to others, and I do not want to do it. I see no reason for someone else to read the journal, and no one has shared a journal with me.” Overall, 60,3% (1568/2599) of the survey respondents agreed that they share their health related information with relatives and/or medical staff, and this is about 2,5 times higher than the number of respondents sharing through the online share function in *Journalen* (24,1% or 626/2599). The opinion that sharing should be done in person was a recurrent theme in the interviews: “If there is anything that I want (to share)? Hm. I would like it to be that we sit down and looked at it, me and the oldest son, then look. /.../ That we sit together watching the same screen.”

48,7% (1265/2599) of all participants stated that they share their health information by discussing them with relatives, 32,5% of those (398/1225) were older than 65 years (Figure 4.2a).

The Jonckheere-Terpstra test did not show any age-related trends regarding sharing by discussing with relatives (JT = 1179011.0, $p = 0.141$). It did, however, show that this mode of sharing is used less with increasing level of education (JT = 977556.5, $p < 0.04$).

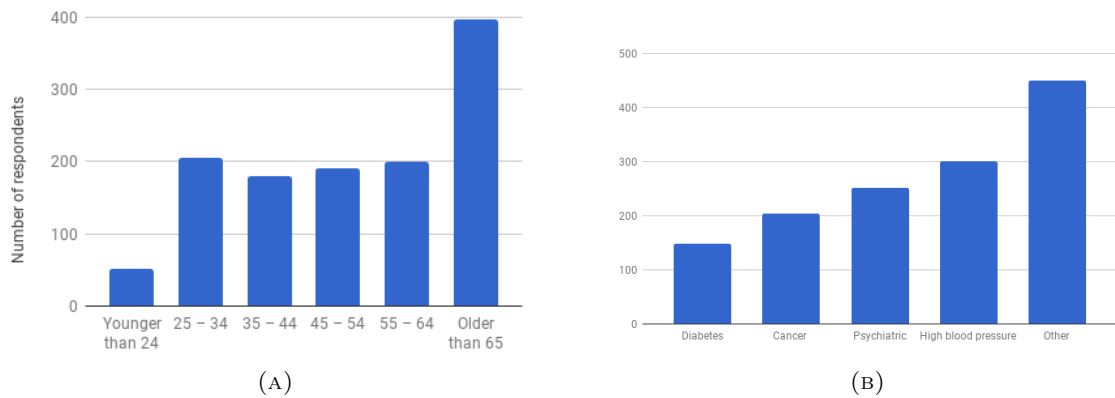


FIGURE 4.2: Age distribution and diseases of those who share by discussing with relatives

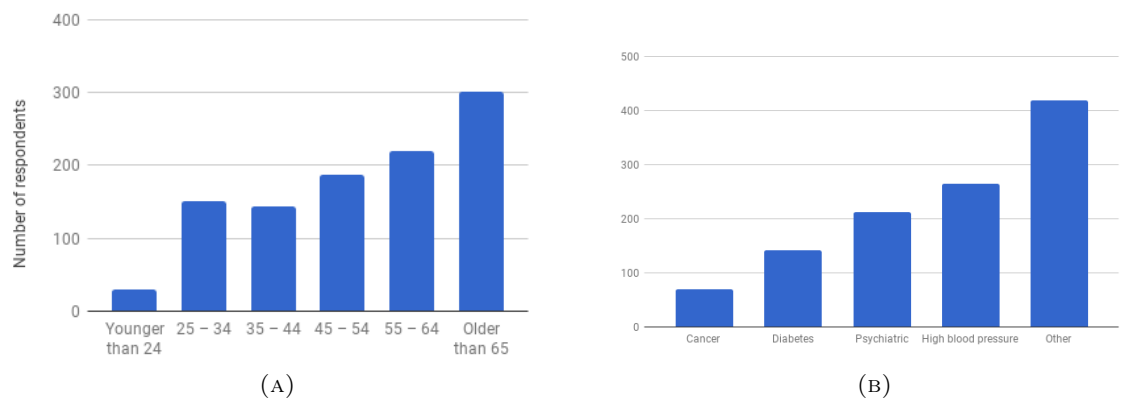


FIGURE 4.3: Age distribution and diseases of the patients sharing by discussing with staff

In Figure 4.2b, we report the main type of diseases that are shared by the patients that decide to share and discussed with relatives, which indicates that high blood pressure is the most common one (22,2% or 300/1351) as in the overall survey.

Sharing by Discussing with Medical Staff

41% of all the respondents (1066/2599) share PAEHRs by discussing them with medical staff. 29,2% of those (302/1033) are older than 65 years (see Figure 4.3a).

The Jonckheere-Terpstra test showed a significant trend regarding age ($JT=1179639.5$, $p<0.001$) – respondents discussed their health record with healthcare staff more with increasing age. The test did not, however, show any significant trend related to level of education ($JT=944426.0$, $p=0.066$).

The main type of diseases of those who share by discussing with staff members is depicted in Figure 4.3b.

4.3.3 Sharing When You Have Cancer or a Psychiatric Disease

During the analysis of the survey data, the disease groups “Cancer” and “Psychiatry” were analyzed individually since respondents belonging to these groups are likely to be chronic patients with a long-term healthcare relation. The Friedman test on the different sharing modes showed significant effects on modes of sharing for both cancer ($X^2 = 296.4$, $p < 0.001$) and psychiatry patients ($X^2 = 332.2$, $p < 0.001$). The post hoc analysis with Wilcoxon signed rank test with a Bonferroni correction applied gave a significance level set at $p < 0.017$. Table 4.1 shows descriptive statistics for the different modes of sharing for the cancer and psychiatric disease groups, respectively.

Cancer patients used the online sharing function significantly less than the offline modes sharing by discussing with relative ($Z = -12.794$, $p < 0.001$) and sharing by discussing with staff ($Z = -12.769$, $p < 0.001$), respectively. No significant differences were found between the two offline sharing modes ($Z = -0.329$, $p = 0.742$). Psychiatry patients used the online sharing function significantly less than the offline sharing modes sharing by discussing with relative ($Z = -14.181$, $p < 0.001$) and sharing by discussing with staff ($Z = -13.724$, $p < 0.001$). No significant differences were found between the two offline sharing modes ($Z = -1.286$, $p = 0.198$).

Modes of sharing	N	Mean	St. dev.
Cancer patients			
Online sharing function	330	1.53	1.08
Discussing with relatives	338	3.39	1.52
Discussing with staff	330	3.33	1.35
Psychiatry patients			
Online sharing function	498	1.58	1.09
Discussing with relative	502	3.02	1.57
Discussing with staff	497	2.93	1.48

TABLE 4.1: Descriptive statistics for the different modes of sharing for cancer and psychiatry patients, respectively. 5-point Likert-scale questions.

4.3.4 Caring by Sharing

More than half (62,3% or 376/604) of patients who share online agreed that sharing is essential to be able to actively participate in decisions about their or their relatives’ health. Also, over half (60% or 324/540) of those who access Journalen for overview of their relatives’ medical history and treatment reported that they do it to provide their relatives with better care.

Moreover, over one-third of those who share online (201/597) acknowledged that access to Journalen leads them to take better care of their relatives’ health, while for the overall population this number was 19,8% (160/809) and for those who share by discussing with family or staff it was respectively 26,2% (311/1185) and 23,6% (238/1010).

One of the ways of caring was expressed in the interview with cancer patients: “(I would share) if I felt that I did not understand much and wanted someone (to help), so I think that my grandmother would share it with me to help her but (for me) I do not know anyone who would be helpful and support (me) with my journal in any way. But it may be good for someone.”

Modes of sharing	Using share function			Discuss with relative			Discuss with staff		
	N	Mean	St. dev.	N	Mean	St. dev.	N	Mean	St. dev.
Age groups									
<24	81	1.37	0.81	81	3.35	2.60	81	2.85	1.43
25-34	388	1.59	1.11	390	3.14	1.52	388	2.78	1.45
35-44	352	1.48	0.99	355	3.00	1.56	352	2.90	1.38
45-54	427	1.57	1.05	430	2.88	1.56	424	3.03	1.43
55-64	461	1.47	1.06	467	2.82	1.59	460	3.13	1.40
>65	659	1.52	1.03	675	3.31	1.50	642	3.12	1.36
Education levels									
No formal education	64	1.98	1.35	66	3.38	1.55	63	3.37	1.45
Elementary school	148	1.76	1.27	155	3.43	1.39	145	3.15	1.33
High school, <3 years	240	1.56	1.09	240	2.94	1.46	238	3.00	1.38
High school, ≥3 years	394	1.61	1.10	397	3.14	1.56	394	2.99	1.39
University, <3 years	454	1.46	0.99	459	3.05	1.59	451	3.05	1.38
University, ≥3 years	920	1.44	0.96	929	3.00	1.58	910	2.92	1.43
Doctorate	73	1.47	1.00	74	2.95	1.54	74	3.09	1.48

TABLE 4.2: Descriptive statistics for the different modes of sharing for the different age groups and education levels, respectively.

4.3.5 Comparing Modes of Sharing

Table 4.2 shows the descriptive statistics for the different modes of sharing for the age and education categories used earlier in this section. The Friedman test showed a significant effect of sharing modes for all age groups (<24: ($X^2=75.35$, $p<0.001$), 25-34: (273.4 , $p<0.001$), 35-44: ($X^2=266.9$, $p<0.001$), 45-54: ($X^2=300.0$, $p<0.001$), 55-64: ($X^2=344.9$, $p<0.001$), >65: ($X^2=596.2$, $p<0.001$)) and all education levels (No formal education: ($X^2=43.05$, $p<0.001$), Elementary school: ($X^2=120.8$, $p<0.001$), High school <3 years: ($X^2=169.8$, $p<0.001$), High school ≥3 years: ($X^2=284.3$, $p<0.001$), University <3 years: ($X^2=370.6$, $p<0.001$), University ≥3 years: ($X^2=709.9$, $p<0.001$), Doctorate: ($X^2=57.5$, $p<0.001$)).

The post hoc analysis with Wilcoxon signed rank test with a Bonferroni correction applied gave a significance level set at $p<0.017$. All pair-wise comparisons between the online sharing function and the two offline sharing modes were significant ($p<0.001$). When it comes to the two offline sharing modes (discussing with relatives and discussion with staff) no significant differences were found for any of the education levels. When it comes to age, however, significant

differences between offline sharing modes were found for the groups <24 ($Z=-3.054$, $p<0.01$), 25-34 ($Z=-4.512$, $p<0.001$), 55-64 ($Z=-4.367$, $p<0.001$) and ≥ 65 ($Z=-3.075$, $p<0.01$).

4.3.6 Security Factors of Survey Data

Survey data analysis consistently shows that there is high level of trust in security through all types of sharing: online and offline, and it is slightly higher in sharing with staff. 88.2% (2170/2460) of overall respondents think there is high level of security, while for those who share by discussing with staff it is 91.4% (947/1036).

Just a small fraction of the respondents did not agree that only authorized medical staff is accessing their medical records in *Journalen* (7.1% or 174/2444) and even less do not feel very safe and secure when they perform actions in it (3,7% or 91/2482). In those two groups of respondents, 39,7% (69/174) and 47,3% (43/91) respectively agreed that they still share their PAEHR with relatives.

The next chapter moves on to discussing the design implications of results and recommendations for the policies that could address and possibly improve sharing PAEHR online.

4.4 Discussion

The aim of this study was to understand the patients' perspective on sharing medical information online with relatives. And what technical, ethical, security and privacy challenges need to be considered when designing information sharing through such systems or how to improve existing ones. By addressing two research questions, which focused on the characteristics of the population who share or do not share and the main barriers and difficulties in sharing, we provide empirical understanding of those barriers, related opportunities, and design implication to support designers of e-health systems that enable sharing medical information.

In the next sections we therefore move to discuss the design implications of the collected results and propose a number of recommendations for policies that could address and possibly improve sharing PAEHR online.

4.4.1 Patients Who Share and Do Not Share

Patients with lower educational level and older patients share more.

The results of this work reveal an association between sharing and education level of the respondent. The lower the patients' education level is, the more they share online and discuss with relatives. Instead, the older the patients are, the more they share, in particular, by discussing with medical staff members.

The reason for that may be that they are more willing to share in order to find support or explanations, which was also mentioned in the interviews. Another probable explanation for this is that chronic long-term conditions are more common at higher ages as well as multiple diseases [2]. As for all other age groups, older patients also preferred offline sharing before the online sharing function, which reflects their general preference towards face to face communication. Moreover, we know that patients with higher educational level are slightly healthier and thus might have less to share.

Sharing is related to diseases.

The health of patients have influence on their willingness to share their PAEHR and expectations from those they would share with. The interviews showed that cancer patients were hesitant to share online, which is also true for psychiatry patients from the survey responses. Our data analysis did not identify that chronic disease patients share more than overall participants online, however, they share slightly more offline: with family and medical staff.

Views on the types of information to share.

Another common reason for not sharing PAEHR was “no information to share” or no worthy information to share. Thus, part of the explanation behind this result may be that some respondents did not yet have any notes or diagnoses to share, thereby rendering the sharing action useless.

4.4.2 System Characteristics Related to Sharing

Sharing is connected to usefulness.

From the interviews we see that cancer patients do not share if they do not see the use of it, which is consistent with the literature, Crotty et al. [26] found that older patients who reported on sharing their PAEHR with family members also were critical about the helpfulness of the sharing

for them. They described this conditional disclosure as the following: “Elderly participants were comfortable with their children having information about their daily functioning, although only if it would be helpful”.

Being involved into relatives’ care and, providing a better care were common reasons of accessing Journalen. However, those taken care of might still want to keep the control over the information their caregivers are accessing, at times perceiving care as spying on them.

Security and usability related to sharing.

Participants trust the system and treatment of their medical information in it, they feel safe using Journalen. This behaviour concurs with the findings of [89, 106]. One can note that patients who do not trust still share their health records by discussing with relatives offline.

4.4.3 Implications for Practice or Policy

From our study, it is clear that a key policy priority should be to plan for more transparent implications of the sharing and delegating one’s health related information. More attention should be directed towards ensuring that patients are fully informed about current information sharing practices. Moreover, patients need to be informed about security issues both about storing medical records online, and about sharing their medical records with relatives.

Another relevant need is related to personalisation/customization. There is no “One-Size-Fits-All” approach in information sharing, which is also widely confirmed in related literature [26, 109]. The design and development of future systems similar to Journalen should also incorporate sophisticated and flexible access control policies that can be adapted to meet the preferences of individual patients.

4.4.4 Design Implications

The findings of this study have a number of practical design implications for patient portals, which are further presented in a form of heuristic checklist:

- Emphasize and make more visible an access to sharing PAEHR, given that the reason of not sharing for some patients is not knowing about the existence of the online sharing option;

- Support combined care when health professionals and relatives collaborate. For example, ensure the continuity of care that would focus on supporting joint efforts of professional and family caregivers to provide “a coherent, transparent and predictable care service” [110]. While at times family caregivers of patients may be managing their health records, especially in case of older adults and children, there should be defined roles for family members to access PAEHR. Well-designed user interfaces with visual presentations for older patients and their caregivers could improve the quality of life for both sides [111].
- Ensure privacy and security by design and sharing from design perspective. The lack of standard sharing mechanisms and variety of sharing strategies implemented across countries could be addressed by implementing more universal recognizable sharing features.
- Adapt online sharing for the diversity of needs and abilities of the users, for instance, for older patients whose abilities are often affected by ageing and patients with low ICT skills. Different medical literacy levels may be another barrier in adopting online sharing of PAEHR [111, 112], since health and well-being related information may be too technical to understand. Understandable and intuitive presentation of risks of treatments, medications, or changing course of therapy in care contexts could be reached by using interactive visualizations [111].
- Emphasize the rights and opinions of patients. Decisions made on behalf of them by their caregivers must take into account “the values, attitudes, and preferences of those they would seek to represent”[99].

To conclude, we note that offline sharing of personal information with trusted ones cannot be replaced. FTF communication has greater depth comparing to more frequent and superficial sharing online. As has been noted by Nguyen et al, “individuals may, in reality, reveal more personal information online but feel that they are engaging in deeper interactions FTF” [113]. However, appropriate, transparent, and safe ICT tools can be an aid in sharing and caring for each other, which could be reached by recognizing the importance of patients participation and involvement as end-users [114].

Chapter 5

Design Considerations to Support Nursing Homes' Communities

Through a case study presented in this Chapter, we set the research context for this thesis and explore current caregiving practices at six Italian nursing homes (NHs). We focus on the work practices of care professionals, and on the relational issues between professional and family caregivers. The outcomes of this work illustrate on the opportunities of using ICT solutions to improve relations, information sharing among caregivers, and provide us with important insights for future study directions.

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Caring for institutionalized older adults is known to be a complex issue both for families and professionals. In recent years, there has been an increasing interest in this topic primarily due to a growing older population and, hence, a heightened need of research contributions in this area. Previous studies on caregiving for older adults living in nursing homes recognize the necessity to support professionals' work practices to ameliorate their working conditions, and decrease the risk of burnout and job dissatisfaction. In this study, we investigated the practice of caregiving at nursing homes in the Northern Italy in the form of a case-study. We mainly focus on the work practices of care professionals, and on the relational issues between professional and family caregivers. The outcomes of this work shed new light on the opportunities of using ICT solutions to improve relations and information sharing among caregivers.

5.1 A Glance on Nursing Homes

Nursing homes (NHs) are long-terms care institutions that provide a 24-hour care to non-autonomous elderly "guests" with health conditions that vary from mild to severe impairments [115]. In Italy the residents are usually addressed as "guests", highlighting how, differently from hospitals, they are assisted rather than treated. Families normally draw on NHs to provide a complex assistance to their loved ones, and because of the accessibility of professionals caregivers.

In this Chapter we focus on the community dynamics among staff members and the guests' families of NHs. In particular, we investigate knowledge sharing among professionals and between professionals and family members. In fact, knowledge sharing is a critical concept within health-care communities [116]. A shared knowledge could facilitate the managements of emergencies, work shifts, and the interaction with the guests' families, whereas its absence may hinder work practices. Investigating organizational context, we pay special attention to the professional caregiving practices and the perception of the NH apparatus from the family point of view. Hence, in order to facilitate the care process, we address the importance of technologies to support collective knowledge among caregivers and the information and relational continuity between the families and the professionals [59].

A number of studies [47, 48, 115, 117, 118] focused on work and physiological issues of nursing homes, emphasizing the impact of work shifts on job efficiency and satisfaction of the staff, health implications for the guest's family members and the staff of the NH. In fact, besides the guests, NHs encompass two main groups of actors: care professional (formal caregivers) and the

family caregiver (informal caregivers) [119]. The former refers to the medical staff (socio-health operators, nurses, doctors) and the latter to the guests' family members. NHs are healthcare facilities that provide a certain medical attention towards older adults, as well as coordination of their family caregivers [119], which makes professional caregivers alternate medical, managerial, and social tasks. Therefore, we can identify a series of issues that provide the framework upon which we can highlight new opportunities for ICT solutions.

5.1.1 Work and Relational Issues

NHs staff faces difficulties working with guests not only from the medical and professional point of view, but also due to the emotional exhaustion of disruptive and challenging behavior of older adults suffering from severe impediments [47, 115, 118]. These hardships increase stress and, hence, higher chance of burnout, health problems, work dissatisfaction, and general decrease of the quality of care [115]. Often, in coordinating the care, communication between professional and family caregivers and among professional caregivers is affected by various factors, such as medical and organizational issues [56]. Indeed, "even the most routine and everyday tasks can vary in the manner in which, the time at which, and the person by whom they are performed, according to the tasks to be done and the contingencies that arise" [57, p. 228]. According to Hertzberg et al. [20], family caregivers are seen as a resource, but professionals perceive them also as part of their work that could be "time consuming and had low priority" [20, p. 431]. Despite being well informed about the situation of their loved ones, family caregivers still do not have professional competences and they may interfere with the staff working routine [20]. The study suggests that, occasionally, professionals do not feel recognized, by peers or managers, in their effort with the relatives.

Matziou et al. [24] claim that an effective communication among professional caregivers is crucial for quality of care. Several studies [23, 24] suggest that the absence of, or the poor communication among professional caregivers may affect their work practices. In particular, deficiency in communication not only negatively affects the quality of care, but also increases tension among professional caregivers. Other studies [58, 120] investigate the communication between professional and family caregivers and show that families need a better emotional connection and more information about their loved ones, as well as greater involvement into the care. Family caregivers often face problems that require social and physiological support [121]. Indeed, "it has been stated that communication problems are related to a lack of a shared framework and

approach to communication" [56, p. 527]. Hence, improving inter-professional collaboration may boost knowledge translation and evidence-based care in health care workplaces [23].

Institutionalization of older adults becomes a source of burden for family caregivers. Sense of guilt and lack of trust towards professional caregivers interfere on the personal life of the family caregivers and, often, this distress is reflected on how the informal caregivers relate to formal caregivers [48]. Studies [47, 48] show that placing older adults in nursing homes does not lower the weight of caregiving for family members. While alleviating related "technical" aspects, it does not eliminate the emotional side of caring for their loved ones. Hence, formal caregivers become not solely professionals working with people who have various physical and mental impediments related to ageing, but also play the role of a medium between guests and their families in a vulnerable situation [118]. This evokes ethical difficulties that create frustration in the working life of the personnels and negatively affects their quality of life [117].

Opportunities for ICT. Recent studies [122–124] provide examples on how technology can serve the community of professional caregivers, in particular, discussing how to motivate them to use it and how to address caregivers' needs. However, there is still a problem of resistance in adopting ICT tools by nursing home professionals. Literature provides three main reasons to that:

- the belief that caregiving cannot be replaced with technologies;
- the belief that technology may have ethical implications on the work of professionals (such as the loss of empathy towards the guests and their families)
- the lack of interest [124].

Nonetheless, Fatehi and Wootton state that there is a growth of ICT usage in medicine and caregiving. Recent studies [122] suggest that formal caregivers find it useful to have ICT features that would include functions "for more efficient care documentation and for a simplified access to care information and care therapy material collections" [125, p.54]. Possibilities of time and cost saving are seen as a motivation to use ICT tools by professional caregivers [122]. Therefore, addressing these issues may result in a better management of work practices to the benefit of the relational continuity [59]. To our best knowledge, these issues have not been fully addressed yet.

5.2 Case Study

We carried out our study within 6 nursing homes located in Northern Italy. The NHs were different in terms of the structure of the facilities and, subsequently, could host different numbers of guests, from 220 to 68 guests. They were similar in terms of work tasks because they were located in the same region, having the same local regulations. During our investigation we mainly focused on the communication dynamics and relational issues that occurred between staff members and family caregivers within the nursing homes. The investigation that we discuss in this Chapter took place from March 2016 to December 2016. It is part of a broader regional research project that aims to design a collaborative technology to support the relationships between professional and family caregivers in NHs.

5.2.1 Methods

During our investigation we conducted 27 semi-structured interviews [126] with the family caregivers. The interviews were based on a interview guideline we used to explore the following topics:

- why they drew on the NH;
- frequency of visits;
- their relation with the staff;
- their relation with other family caregivers;
- the management of medical information;
- ICT literacy;
- what would they change of the NH.

The guideline presented a flexible list of topics we used to let family members free to reflect on their care experience in the NH. Each interview lasted from 40 minutes to one hour and was recorded. Interviewees were randomly chosen, and included if willing to participate and able to provide the informative consent. Because of the delicacy of the context, we had the ethical approval of the University of Trento. We paid peculiar attention towards the people involved, avoiding any questions or situations that could cause distress to the participants, in

order to guaranty an efficient and respectful data collection. Moreover, three audio-recorded Focus Group Discussions (FGD) [126] with the professional caregivers of the involved NHs have been conducted. The FGDs allowed us to investigate the work dynamics within the NHs among the staff members. For each FGD we had from 7 to 9 participants, and the same moderator and assistant moderator, who respectively facilitated the focus group, and took notes. The FGDs investigated the following topics:

- the daily routine of the staff;
- the frequency of unforeseen episodes;
- what generally worries family members;
- which topics the staff believe important to communicate to the family caregivers;
- the channels of communication.

Participants where randomly selected, but to have a good coverage we tried to include all types of professional caregivers (social-health operators, nurses, doctors). Each FGD lasted about one hour and a half. The data from the interviews and focus groups has been enriched with *in situ* visits. Due to logistical limitations, we conducted one-day visit for each NH. During every NH visit, there were at least two researchers from our research group who took notes. Visits were scheduled and always accompanied by a gatekeeper; either the director or the chief nurse. Each NH provided us with their official regulations, which we cross checked with the gathered data in order to distinguish between informal practices and formal work tasks.

5.2.2 Findings

In our investigation, we paid attention to the organizational contexts of the NHs that we analyzed, focusing on the practices of professional caregivers and on how these are intertwined with the realm of the family caregivers. We observed that the NHs differ on some aspects. They allow visits within different hours, and they have different facilities, which determine the number of guests they can host and the number of professional caregivers they have. Yet, these differences do not appear to interfere on a work level; we noticed no actual implication on the situated work practices. Indeed, the work tasks appear the same in all the NHs. We identified four macro areas of analysis: *daily tasks*, *crisis tasks*, *understaffed*, *communication issues*.

Daily tasks. In general, all the NHs host older adults in different conditions, most of them were there due to physical and cognitive impairments related to dementia, femur fractures, and Alzheimer. Whereas, a minority of the guests were receiving palliative treatments because affected by rare diseases. Because of this, the daily routine of each NHs is built on a series of work tasks that follow one another in a tight schedule that can be heterogeneous and depend on the specific conditions of the guests. It includes: the delivery of the medical therapy; the delivery of the meals; recreational activities; washing and toilet procedures.

Crisis tasks. Other tasks that deeply influence the organization of work in NHs are the crisis tasks [127]. Crisis tasks occur randomly and are linked to the delicate health conditions of the guests, such as deceases, exacerbation of medical conditions, special treatments and unexpected events. Such events are usually time demanding and mess up the planned daily activities, consuming the time to dedicate to the guests and to the relationships with their family members. The staff stated that they care a lot about the relationships with the family caregivers, because are an integral and paramount part of their work. However, often those relationships are forcedly put aside.

“How can be possible to have relations during emergencies? If someone doesn't feel well everything becomes a mess!! If someone has diarrhea or pukes you have to wash him, because if you wait he will get bedsores, so you have to leave everything you were doing.” (Interview)

Understaffed. A common problem that affects the overall coordination and quality of care in NHs are understaffed professionals. They usually run from one task to another during all their shifts, bringing stress and high levels of turnover. In this scenario, only autonomous residents can keep their autonomies related to ambulation and washing activities. Whereas, those who are not autonomous have to use diapers and are moved using wheelchairs, since this is less time consuming.

On the one hand, the family caregivers understand that the staff of the NHs are overwhelmed by their workload.

“The only thing that I can say about this structure is that maybe if we had an additional care professional during the shifts it would be better for everyone. It would be better for them, but also for the guests, because they [the staff] really cannot run in every room continuously!” (Interview: wife of resident)

On the other hand, this, as a reaction, generates frustration in the family caregivers, hindering trustee relations.

“They [the staff] have to be more present. (...) I feel that some of them are lost (...) however, the director should see this things, not me.” (Interview: daughter of a resident)

“My mother walked, (...) she wanted to go to the toilet in autonomy, then they decided to use diapers and to put her in the bed and that was it for her autonomy.” (Interview: daughter of a resident)

“I know about the lay off of the staff, but I had my battles here.” (Interview: niece of a resident)

Communication issues. In the NHs we observed some similarities. They have the same structure in terms of hierarchy that is imposed by the Italian law, and upon which work practices are based. Doctors, nurses, and socio-health operators (SHO) work on different areas:

- doctors decide and manage the medical plan of each guest;
- nurses deliver medical therapy, and deal with basic medical treatments;
- SHO deal with the basic physiological needs of the guests, and they practically manage most of the activities mentioned above.

The NHs are divided in wards that generally encompass guests with similar conditions and the professionals are grouped in work units that are assigned to each floors. The units are usually formed by one nurse and several SHO. Doctors are not always present in the facility. Their physical availability is limited to their work shift, and in case of emergency the paramedics are called.

Organizational and hierarchical structure have an important impact on how communication practices are carried among professional caregivers, and between family and professional caregivers. Specifically, SHO can communicate every type of information but medical. Only nurses and doctors can communicate medical information to family caregivers. This practice is defined by law, but the limited number of doctors and nurses - widely outnumbered by SHO - often creates difficulties when family caregivers need or require certain information.

“If I report something to someone [member of the staff] I need that this information arrives to the right professional. I totally can't go around through the whole structure! (...) We need to be facilitated in doing that.” (Interview: son of a resident)

Often the work shifts may lead to information loss, which is often forgotten or not transmitted to the specific professional to whom it is intended. Both professional and family caregivers respectively stated and noted that communication has to be put in between the work tasks.

5.3 Design Considerations for NH Communities

In this Chapter, we framed the issues that characterize the care work in Nursing Homes, providing an overview of the organizational structure, working and communication practices of the caregivers. We drew an overall picture of the contexts we investigated, highlighting the communication practices within the NHs, describing the caregivers' experiences in collaborating and maintaining relations. Our data suggest that information exchange between the staff and family caregivers is necessary to build a solid relationship. Yet, the fluctuation of daily tasks - between planned routine and crisis tasks - and the lack of technologies supporting information flow affect the creation of a shared knowledge among caregivers and hinder empathetic relationships. NH professionals admitted that communication with family caregivers is time demanding and, due to NHs being usually understaffed, they are frequently overwhelmed by the tasks they carry with limited resources. Conversely, the absence of a reference point among staff members - due to frequent work shifts - often leads them to frustration.

We cannot provide a recipe to solve these frictions yet. However, we can claim that the majority of problems emerged from our study can be linked to the division of labor in NHs. Staff reductions and overwhelming workloads appear to result in fragmented care. Staff members constantly rotate, working across planned and unplanned tasks, which leads to poor communication methods that hinder the creation of community dynamics among professional caregivers, as well as between professional and family caregivers. In this scenario, the technology cannot be used as a panacea. However, it emerges the need for a technology to facilitate social interactions beyond the medical framework and fulfill work tasks, in order to allow formal and informal caregivers to establish trustworthy relationships and a shared knowledge on the guests' situation.

We thus provide some issues that we believe technology design should consider in supporting the relations between staff and relatives in NH contexts:

- professional caregivers should be supported in sharing both medical and social knowledge on all patients among colleagues;

- professional caregivers should be constantly informed respectively on the family network and the care team of the guest;
- family caregivers should have a reference point within the staff, being able to directly contact or communicate to the care professional closest to the their loved one;
- the technology should provide an always up-to-date calendar to ease appointments between family caregivers and care professional;
- the technology should provide a “space” of informal interaction among all caregivers to nourish informal interaction, and exchange of thoughts and information about the guests.

Our study is a call for action to design technologies for the realm of NHs, by providing a better micro-sociological understanding of the limits of the current care practices, knowledge distribution, and information communication. Designers should focus on supporting communities in the creation of technologies to address collective sense-making and to support relations. Whereas, the design process itself should enhance community building and support a mutual understanding among actors, revealing also the unfairness of the work dynamics that lie at the foundation of collective actions.

Part II

Part: Design of Information Sharing in Aged Care

The second part of this Thesis takes the perspective of aged care recipients exploring their views on sharing their personal health and wellbeing information with their formal and informal caregivers. Considering them as primary owners of their HWBI, we study their opinions and reasoning to share or not to share and in Chapter 6 and, more specifically, explore their security and privacy concerns related to sharing in Chapter 7. As one of the outcomes of this part, we suggest design implications for the systems that could support sharing seniors' HWBI with their caregivers from the point of view of care recipients.

Noticing the importance of accessible and inclusive design of such systems, as both care recipients and caregivers in aged care often belong to the older population group, we acknowledge the need of appropriate design recommendations when designing those systems. Given the lack of complete and comprehensive list of such recommendations, we conducted the systematic literature review on the research based design guidelines addressing ageing related ability decline that affect seniors' interaction with touchscreen technologies.

Chapter 6

Information Design in An Aged Care Context

Through in-depth semi-structured interviews with 12 residents of senior care facilities, we examine the reasons why older adults choose to share or not to share their HWBI with those involved in their care. We explore how the purpose of use, functional relevance, urgency, anticipated emotional reactions, and individual attitudes to privacy and control affect their opinions about sharing. We then investigate how those factors define what granularity of data, communication frequency and channel older adults find appropriate for sharing HWBI with various recipients. Based on our findings, we suggest design implications.

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The adoption of technological solutions for aged care is rapidly increasing in developed countries. New technologies facilitate the sharing of health information among the “care triad”: the elderly care recipient, their family, and care staff. In order to develop user-centered technologies for this population, we believe that it is necessary to first examine their views about the sharing of health and wellbeing information (HWBI). Through in-depth semi-structured interviews with 12 residents of senior care facilities, we examined the reasons why older adults choose to share or not to share their HWBI with those involved in their care. We examine how the purpose of use, functional relevance, urgency, anticipated emotional reactions, and individual attitudes to privacy and control affect their opinions about sharing. We then explore how those factors define what granularity of data, communication frequency and channel older adults find appropriate for sharing HWBI with various recipients. Based on our findings, we suggest design implications.

6.1 Introduction

Older adults require more professional (formal) and family (informal) care than any other age group. At later stages of life, they transition across a continuum of living conditions, from “aging in place” (living independently in their own homes) to institutionalized care [3]. This transition requires coordination and collaboration “among a long list of providers” [3, p.114] that comprise a “triad of care” [128] and include older care recipients, relatives, and professional medical and caregiving staff.

Professional medical and care staff often alleviate certain “technical” tasks related to caregiving (such as assistance with daily activities). However, institutionalization of older adults does not lower the burden of caregiving for family members. While alleviating related “practical” aspects, it does not eliminate the emotional involvement in care for their loved ones [45, 47, 48]. As result, families adopt alternative strategies to stay engaged in care processes. One new approach is “caring through data” [25], which is based on collection and exchange of seniors’ health and wellbeing information (HWBI). According to the biopsychosocial model of health status, HWBI is comprised of physiological, psychological, and social aspects of health and illnesses [44]. The increasing popularity of “health datafication” [25] transforms the traditional involvement of family members in practical care procedures into a more analytical partnership of family and staff. In addition, HWBI often plays an important practical role to prevent major health issues [22], improve the response to critical events [3], and assist in decision-making about an appropriate level of care [26], and end-of-life choices [27]. On the other hand,

extensive information disclosure and delegation of control over decisions often result in seniors' psychological discomfort [13], as well as privacy [28] and security concerns [35]. Current research often addresses the burden on formal and informal caregiving duties [20]. However, the needs and concerns regarding health communication in the care triad, especially from the perspective of elderly care recipients, is understudied.

In this chapter, through the analysis of in-depth semi-structured interviews, we explore the views of 12 older residential care recipients on information sharing with and among their professional and family caregivers. We also examine seniors' opinions on the role of technology in mediating this communication. We find that the dynamics in interpersonal and formal relationships between care triad stakeholders, including trust, communication culture, and alignment of views, have a dramatic effect on the decision-making related to information exchange among them. Therefore, instead of considering the recipients in isolation, in this chapter we analyze the opinions of older adults about exchange of information within the *dyads* of the care triad. We identify the dimensions of information sharing, and how counterbalancing forces affect communication decisions of older adults. Specifically, we illustrate how the interplay of purpose of use, functional relevance, urgency, anticipated emotional reactions, and individual attitudes to privacy and control defines what granularity of data, communication frequency and channel are appropriate for sharing information in certain recipient dyads. We discuss the opportunities of ICT in facilitating communication and providing aged care. We also discuss how low digital literacy, limited access to technology, concerns about reliance and data integrity hinder the adoption of ICT among seniors. We summarize how the specifics of institutionalized care facilities affect seniors' attitudes to privacy and control. Finally, we provide recommendations for future work.

6.2 Related Work

In this section, we review the related work on the sharing of health and well-being information (HWBI) in the triad of aged care: elderly care recipients, care professionals, and family members. We review the benefits and issues of HWBI sharing, the role of Information Communication Technologies (ICT) in supporting and mediating information exchange, as well as older adults' privacy concerns.

6.2.1 Sharing Health Information in Aged Care

Aged care requires a wide and complex network of care actors, which usually consists of two main groups of caregivers: (i) professional or formal caregivers, such as nurses, doctors, and hired caregivers; and (ii) relatives or other informal caregivers [4].

Sharing HWBI among them has conclusively been shown to be important in the literature. Presenting patient's information to the relatives increases family involvement in the caring process, and improves credibility towards medical staff, thus reducing their stress and workload [6, 7], and enhancing collaborative partnerships [5]. Care professionals tend to involve family members in care as additional resources [8, 129], because relatives often advocate for seniors' interests and know their preferences [9].

There is a difficult balance between providing care and respecting each other's independence [10]. Asymmetric values create tensions between care recipients and their caregivers. For instance, patients' motivation to share information may not always match health care providers' interests to receive it [11]. Hence, it is particularly important to focus on both recipients' and caregivers' perspectives, when designing systems aimed at facilitating their interactions [14]. Therefore, optimizing and facilitating HWBI sharing depends on the comprehension of the "organization of work" of the triad actors [69] and their invisible practices in coordinating care [70].

6.2.2 The Role of Technology

Various studies stress the potential of technology in supporting communication in aged care [15], as ICT channels can facilitate a coherent distribution of information among care stakeholders and improve their coordination [7]. For instance, Bossen et al. [72] demonstrate that the alignment of tasks and appointments between family and hired caregivers of older adults can be implemented by the shared use of a digital calendar.

However, technology might be perceived negatively by senior care recipients, if they do not understand how it can fit into their lives [130]. Although by reducing caregivers' care burdens, technology can make seniors more independent, ICT-enabled surveillance restrains seniors' perceptions of personal freedom [12]. Therefore, the design of these technologies must consider each group of care triad actors by gathering their requirements and including them in the design process from the very early stages [83, 84].

Our work contributes qualitative data on the views of older care recipients about how ICT solutions can support and coordinate information sharing among the actors in the care triad.

6.2.3 Privacy Concerns Related to Sharing

The literature suggests that privacy issues are often expressed as the main concern [13]. Patients tend not have privacy concerns [13] and not to feel in control of information shared with their caregiving networks through digital channels [28]. Elevated privacy concerns may prevent people from using digital services.

In addition to personal views, recent changes in European and US legislation¹ are radically changing the boundaries of health information sharing, granting patients and their personal representatives with the rights to access health information, and share it with involved family members or friends [32, p.118]. As beneficial and well-intended as they are, these regulations still might inhibit the sharing of health information with and involvement of the family due to their interpretation and application complexity, as it is not always clear what can and cannot be done in health communication with family caregivers [34]. In addition, reduced capacity of certain patient and caregiver groups to manage digital versions health records due to the lack of technology experience also results in their privacy and security vulnerability and compliance with existing regulations [32]. Moreover, regulations indicate that patient information is also stored and transferred using global networks, distributed databases, and the cloud. Health records might be fragmented and accessible from several locations and by multiple health care providers [35], which implies an increased risk of patient information disclosure within the contexts where it cannot be controlled [36]. Still, effective collaboration in aged care requires a coherent and consistent information flow among care actors [15] to facilitate the care process and relational continuity within the care triad [59]. Our study complements previous research by considering the views of institutionalized senior care recipients and examines how they communicate and share personal HWBI with their professional and family caregivers.

¹Such as the European Union General Data Protection Regulation (GDPR) [31]; the Health Insurance Portability and Accountability Act (HIPAA) [85], its extension of Privacy and Security Rules [86] ; and the 2018 California Consumer Privacy Act [33].

6.3 Methodology

We directly recruited inhabitants of long-term care facilities for older adults in the San Francisco Bay Area. We chose an urban/suburban area with relatively good technology resources and services for older adults, thus increasing the spectrum of potential participants who are aware of privacy and issues surrounding sharing information online or using ICT-based sharing platforms. The study was approved by the University of Trento Committee on Research Involving Human Beings (Application N. 2017-003) and was conducted in September 2018 at the long-term care facilities.

We administered screening surveys—over the phone, paper, or in person—and excluded individuals under 65, with serious cognitive impairments (e.g., Alzheimer’s disease, dementia), or non-English speakers. To answer our research questions, we then conducted 12 in-person semi-structured interviews², which we built on the following guidelines that focused on: (1) opinions of older adults about collection and sharing of care-related information between the care triad actors including their previous experience of sharing HWBI with healthcare professionals before the institutionalization; and (2) the role of technology in the care-related information exchange. Before each interview, participants were briefed by the researcher on the objective of the study and signed their consent to participate and be recorded during the session. Finally, after the interviews, we administered exit surveys about participants’ individual characteristics. Interviews lasted about 0.5–1 hour each, and were audio recorded and transcribed by a professional. All participants received \$15 as compensation.

For the data analysis, three coders iteratively coded two transcripts to develop individual codebooks. They then reconciled disagreements to create the final codebook. The coders used this final codebook to code all interviews. Two coders independently coded each interview, resolved coding application disagreements, and then conducted thematic analysis [131] of the data.

Study participants. Participants’ ages ranged from 71 to 103 years old ($mean = 90.5, SD = 7.9$), which is considered “middle old” to “old-old” [93]. Ten out of twelve participants were female. The majority (9/12) had “Native or bilingual” English language proficiency, described race and ethnicity as “White” (11/12), and had a Bachelor’s degree or higher (10/12). Participants self-reported their physical conditions mainly as “Good (normal physical health)” (6/12) and

²Study materials including the interview script and surveys can be found here: <https://leysann.github.io/sharinginagedcare/interviews.html>

“Acceptable (slight deficit in some primary functions, conserved autonomy)” (4/12), while just 2/12 seniors admitted major deficits in functions or limitations in regular activities (“Precarious” or “Fair”).

All of the participants lived in long term care facilities or senior housing longer than 2 years. Most of them (7/12) pursue independent living (i.e., no one assists them with their activities of daily living), while some have informal (3/12) or hired (4/12) caregivers³. Most of the respondents (9/12) were completely satisfied with the care services provided and claimed in the interviews that they either completely (6/12) or somewhat (6/12) trust the professional care providers. Respondents reported “Good” (6/12) or “Excellent” (6/12) relationships with the care providers.

Four participants (of 12) stated that they connect to the Internet every day, 3/12 never, and 5/12 connect 1-3 times a week. Six out of twelve respondents have tablets (6/12), 4/12 smartphones, and 4/12 computers/laptops; some of them own several devices, while 3 respondents have none. Participants were also asked whether they find working with computers easy, 3/12 of them agreed and 2/12 strongly on that, 2/12 disagreed and 3/12 strongly disagreed, and 2/12 were either undecided or never used a computer.

6.4 Results

We found that the views of older adults on information sharing depend on communication context, relationships among actors, and individual preferences. Moreover, the specifics of institutionalized senior care facilities affects seniors’ attitudes toward privacy and control. While ICT has potential to improve communication in a care triad, we identified a number of barriers and concerns that hinder its adoption among older adults. Our respondents had elaborate views on sharing: on their willingness to share personal information, many said “*it would depend on the circumstances*” (P3). The analysis of those “circumstances” revealed a few prominent dimensions of information-sharing preferences, which we summarize in Table 6.1 and describe in the remainder of this section. These dimensions are associated with the recipients, purpose of use, data, sharing format, and individual attitudes.

³Some of the participants had several caregiving service providers at the same time.

TABLE 6.1: Dimensions identified in the interviews and discussed in the chapter as affecting sharing

Dimensions	Sub-dimensions	Definitions
Recipients	Family members	Relationship with people with whom information is shared.
	Friends, neighbors, other residents of senior care facilities	
	Professional medical and care staff	
Purpose	Benevolent	Positive/beneficial expected purpose of use.
	Malicious	Negative/harmful expected purpose of use.
Data	Functional relevance: relevant, irrelevant	The applicability of information to fulfill the purpose or achieve an intended goal.
	Urgency: critical, non critical	The degree of importance of the information.
	Granularity: detailed, not detailed (summary) , intermediate (e.g., trends, deviations from norms)	The level of detail of the information.
Format	Frequency: regular (or periodic) , irregular (on occasion) , event-based (triggered by a specific situation)	Regularity of communication episodes.
	Channel	The medium of information sharing.
Individual attitudes	Privacy: concerned, unconcerned	Attitudes to information privacy.
	Anticipated emotional reaction	Anticipated emotional response of information recipients.
	Control: high degree, low degree, conditional delegation	The level of control over personal data and life decisions that older adults find optimal.

6.4.1 Dimensions of Sharing: Recipients

The recipients of health and well-being information (HWBI), directly involved in aged care, and comprising the triad of care, are older adults, their family members, and staff (including health care professionals, hired caregivers, and care facility management). Instead of considering the views of older adults on recipients in isolation, here we analyze the dyads, because we believe that the dynamics in the interpersonal and formal *relationships* between stakeholders—including subordination, trust, family culture, and alignment of views—have considerable effect on the decision making related to information exchange between them.

In the **Senior–Family** dyad, the intimacy of relationship, family culture, and general style of communication (even outside of HWB context) often affect the health information exchanged between the family members. Some families are very engaged, open, and transparent: “*I have two brothers and we sort of share all of our medical, and financial information. We are not a secretive family*” (P8). Other families have well defined communication “etiquette,” boundaries, and strategies about what and how to share: “*Our system is, we really wait for [our son] to text*

us [...] and if we text him, it's something major. If we ask them to come here for dinner and it doesn't fit their schedule, we wait till they invite themselves" (P1).

In the **Senior–Staff** dyad, trust plays a major role in seniors' willingness to share data. They tend to trust highly skilled medical professionals, as inferred from education level, feedback from other patients, or personal experience: *"I don't like to share personal information with people I don't know, but if it's something that she as a doctor feels that needs to be discussed, I have no problems with that. She respects my privacy. But I respect her judgment too"* (P2). Trust is also an essential factor in the decision of a doctor to engage in a direct communication with the patients, or in their remote treatment and medication management as well: *"I have a very good relationship [with the doctors], I keep good records and [...] they trust me because they know that I am giving them accurate information"* (P4); *"I communicate with my doctor by email [...]. Very unusual. Most doctors do not want that. [...] I don't think she communicates with all her patients, [but only] with those whom she considers to be responsible"* (P5).

The duration of the relationship contributes to the formation of trust: many seniors have the same doctor or caregiver for decades and form bonds of friendship with them (*"It takes time to develop those kind of relationships,"* P4). This sometimes results in an overlap of their professional and informal roles: *"I know [my doctor] like family"* (P7); *"He was a [general practitioner], but he was an old friend [...] and so we talked about our families"* (P2).

Finally, seniors' perceptions about staff's motivation and intentions affect relationships within the Senior–Staff dyad: *"I value [my doctor] so very much [...] She really is dedicated to the business of medicine and helping people. [...] And I know that there is an entirely different group of doctors who are only interested in how much money they can make. And there are others who like to write papers or become famous"* (P5).

In the **Family–Staff** dyad, some families choose a participatory approach: *"Not only does my daughter go to my appointments with me, my son-in-law, her husband goes also, frequently when he can"* (P6). Others believe the involvement of family is not necessary or even detrimental: *"Personally, I would not want to have my family involved because they have really nothing to contribute to the solution of this problem [...] In fact, family is in the way"* (P5).

Regarding the relationship of medical and care professionals and families, participants believe that *"there has to be trust, but there should be collaboration. [...] If you need medical help or supervision of some kind they should cooperate. [...] If the family is close. [...] If you have*

nothing to do with the family then you probably don't want them to know what your problems are" (P2).

Participants also commented on the exchange of information within the same recipient groups, which happens without their involvement. For instance, seniors usually do not object to the sharing of their information among staff members (**Staff–Staff**), because it improves care provision, and facilitates the coordination of multiple conditions, chronic diseases, or sophisticated medication and treatment plans. However, information exchange between doctors is not always a transparent process for the older adults: *"I am amazed when I look on the records [from my gynecologist] and I see something from my internist. [...] I definitely [think it helps them to coordinate better]. Like, if I forget, not that I take a lot of medication, but they know exactly what [medications] I take, [...] and it's like a miracle"* (P8); *"I don't know what my [new] doctor [has], she must have my files, because I guess [the recently retired doctor] gave them to her"* (P2).

Similarly, in the **Family–Family** dyad, participants are typically not bothered if family members exchange senior's HWBI directly, or assign one of the members to disseminate it to other relatives: *"I don't know what information my son gives to my daughter. That is up to him and that is fine with me. I have no secrets"* (P10).

Friends and neighbours, while not considered formal or informal caregivers, are often involved in information sharing as well: *"I talk very little, because this is actually a small close community. [...] [Other residents] are always very interested in everything, or everybody [...] That's fine. I don't mind that. I would rather have people be interested in me and checking on me than not at all"* (P6).

6.4.2 Dimensions of Sharing: Purposes

Older adults perceived access to their personal information as being either benevolent or potentially malicious. The most common **benevolent** purposes of HWBI use include health diagnostics and monitoring, emergency notifications, professional care provisions and family assistance, followed by the delegation of end-of-life decisions: *"I don't have a problem with [sharing health records]. [My adult children] have to make the final decisions when I can't make them. So that is why I make sure that they are up to date on everything"* (P6).

Another reason to disclose was to share the knowledge and best practices related to medical treatments, or personal experiences with doctors: *"If anybody else is considering this kind of*

surgery, it would be good for them to know that I had it and I would be willing to share with them any information that I had about it” (P6).

Some seniors believe that collecting HWBI for personal use “*would be a fun experiment*” (P3), and can educate or motivate self to stay healthy: “*I don’t set any records, [...] but at least 5,000 [steps] a day is my objective*” (P1). This information may be shared with others, as far as the intentions of such disclosure are not misinterpreted: “*[The doctors] will ask [about my physical activity], and I have shown them [Apple’s Health] app, ‘Oh look what I did.’ But it does seem like you are bragging on yourself*” (P1).

Even though sharing with family and staff members is generally perceived as safe and beneficial, a few respondents mentioned potentially **malicious** purposes of HWBI use, such as fraud or public release of the private data: “*I had [a caregiver] doing paperwork before I had a stroke, [for] a number of years, but then she ended up forging my signature and changing—so even though I trusted her, her husband needed the money, and so she did [the] forging*” (P7).

Some participants had only vague ideas about how information could be misused: “*To what advantage I don’t know. I mean what would be the benefit for a doctor to give false information?*” (P3).

Finally, one participant was deeply concerned about data-driven business models: “*In theory I would say to have information is always a good thing. [...] In practice [...] most of that information is used for [...] for-profit business [...] not to provide me with information*” (P5).

6.4.3 Dimensions of Sharing: Data

We observed that the willingness to share information depends less on the data type or its sensitivity *per se* than on specific *attributes* of the data. Among prominent parameters, participants mentioned functional relevance, urgency, and granularity of the content.

Functional relevance defines the applicability of given information to fulfill the purpose or achieve an intended goal. Relevance is primarily associated with practical usefulness, such as help in an emergency situation, diagnosing, or carrying out end-of-life decisions: “*I would only want to share with someone who is going to help the medical situation*” (P12); “*The only involvement [in care] that I in any way look for or advocate would be one that was effective in solving the problems, but not just for feeling good*” (P5).

In addition to practical relevance, emotional support, and expression of care were important to many respondents: “[*Sharing*] information, especially like trend data [...] is the equivalent of having somebody come and visit you every day and check you out” (P4).

The opinions of older adults and caregivers about relevance may or may not align. In some cases, information is deemed relevant by both the older adult and the caregiver: “*There is talk of wearing a monitor all the time, so they would know what is going on with my blood pressure. I would be very interested in knowing this and the doc would too*” (P1). Relevance may be associated not only with the benefits to older adults, but to others: “*I would [share] if I thought it was something that [my children] could benefit from [or] possibly inherit [...] otherwise no*” (P8); “*Something that is going to affect the length of your life, the kids should know about it*” (P1).

Some information is deemed irrelevant by both older adult and caregiver: “*That’s how I feel, and everybody in my family feels: [...] if we can’t do anything to help, let’s not get in the way just to make somebody feel better*” (P5); “*My blood pressure is taken when I go to my doctor. Sometimes it’s months. [...] He doesn’t want anybody to take it in-between and it has worked out very well that way*” (P12).

Sometimes information is deemed relevant by the caregiver but not by the older adult (mentioned by 4/12 respondents): “*If you are independent, you don’t need a lot of support. [...] The support staff has their hands full. They don’t need to be bothered*” (P3). Professional care may substitute family care, alleviating the need for extensive HWBI sharing with family members: “*That is why I moved here [...] to not be a burden on my family. [...] One of the reasons for being in a place like this is your guarantee to have somebody who is looking out for you professionally. [...] That is another reason why I don’t have to share so many stuff*” (P4). The lack of interest may also be assumed by the seniors rather than explicitly expressed by the recipients: “*Son [...] is too busy to be bothered. In my opinion. He wants to know, but I don’t want him buried under information*” (P1).

Finally, in some cases (mentioned by 3/12 respondents), information is deemed relevant by the older adult but not by the caregiver. Such misalignment of views presents a particular challenge for communication design. For instance, one common situation is when older adults are ready to share more information with the family or want them to be more engaged, but the family does not respond with much interest: “*I would show [health records] to the kids if they wanted to see it [but] they never say, ‘Hey I want to see it mom’*” (P8).

This lack of interest is sometimes accompanied (or maybe even caused) by the limited understanding of medical terms or conditions. In response, some family members actively seek information and are eager to learn: “*If there is something that bothers [my daughter], she doesn’t think I explained it to her or she understands, or there is anything she has questions about, she calls the doctor*” (P9). Others do not attempt to fill this gap in their knowledge: “*[If my son doesn’t understand something about my medical health] he doesn’t call. He doesn’t know my current doctor and I’ve had her like ten years*” (P11); “*[My son] doesn’t want to know too much. [...] He thinks I am gone forever*” (P7). Even when presented with an abundance of information, many families choose not to face reality: “*[My son] knows what the normal range is [...] but [...] he does not like even thinking about me not being perfectly [healthy]. [...] He hasn’t accepted the fact that I could die tomorrow*” (P11).

Urgency is the degree of importance of the information. In our interviews, we identified 2 levels of HWBI urgency: non-critical (routine events) and critical (emergencies, major changes). Despite similarity, relevance and urgency are different concepts: relevant information may be unimportant but instrumental in achieving a goal; urgent information may be important in certain contexts but not relevant for fulfilling a particular purpose. While urgency relates to the situation and can be assessed (somewhat) objectively, relevance relates to recipient’s subjective perceptions and attitudes.

The more critical the information, the greater willingness to share it: “*It has to be tragic before I tell [my son]*” (P10); “*I don’t think it’s necessary. If I am in crisis it would be*” (P9). However, too much routine information could distract focus from something critical: “*I think routine stuff would be overkill. But I think communication would lose their effectiveness unless it was a real problem*” (P1).

Granularity is the level of detail of the information. We distinguish between detailed, intermediate (trends, deviations from norms), and not detailed (summary) information. The optimal granularity of information depends on recipients’ engagement in care, comprehension of medical information, and the importance of their involvement to fulfill the end goal. For instance, thorough conclusions of a medical examination without quantifiable test results may be considered detailed by a family member without medical background, but not by a medical professional. However, family roles and needs in the context of chronic long-term care evolve, as the family becomes increasingly educated about a condition: “*[My niece] learned over time what my particular diagnoses are, how serious they are [...] and how they affect me physically*” (P4).

Additionally, context and urgency matter: simple summaries typically suffice for daily monitoring (“*They only want the high points. How do you feel? Are you feeling any better? What are you doing about it?*” P6) but may not be enough in critical situations (“*I think trend data would be more useful. My niece is very busy. I don’t think she would even look at it on a daily basis unless [I] was critically ill,*” P4). Whether deviations from norm are worth sharing depends on what side of the urgency spectrum they are on. For instance, frequent small deviations and “*little aches and pains you don’t put on the big deal*” (P10), while large unusual deviations and consistent patterns become “newsworthy,” i.e. “deserving to be shared” [10, p.6], especially if they require the attention of medical professionals. Importantly, older adults believe that for deviations from norms to make sense, they should be customized and considered in relation to personalized trends: “*I would like to have my health measured [and to] be compared to my normal, not to the world’s normal*” (P5).

Individual abilities and preferences in information processing and visualization also play a role in defining optimal granularity and format of data representation: “*[My son] is a summary person. My daughter is a detail person*” (P11); “*It depends on whether you are a visual learner. Some people like graphics because they are more visually oriented. Some people are text oriented, so reading is better than graphics [for them]*” (P4).

6.4.4 Dimensions of Sharing: Format

The way information is shared—defined by the frequency and channels used for information delivery—affects participants’ opinions about information disclosure. We found that the main challenge for identifying the optimal frequency and channel of communication is to balance the quality of care and response in critical situations with information fatigue, intrusiveness, and usability.

Frequency of information delivery, or regularity, can be split into 3 groups: regular (or periodic), irregular (on occasion, without hard rules), and event-based (triggered by a specific situation). While more regular information exchange provides a potential for better care, 6/12 respondents mentioned that too-frequent sharing could result in information overload and overwhelming for the recipients, as “*they have their own families that they are looking after, I just wouldn’t want to add to and give them a lot of other information because after a while if you get a lot of other information it gets pushed aside*” (P6). “*A barrage of information*” (P6) is

excessive for seniors themselves too because it “*doesn’t mean anything to me*” (P10) or because they “*don’t want to become neurotic*” (P9).

Channels of information delivery indicate the medium of information sharing. Communication channels may be digital—including online (email, patient portal, video conferencing, social media), and offline (calls, text messages)—as well as paper-based (mail, print) and in-person. While traditional communication channels, such as phone calls and in-person conversations, remain prevalent among our participants, older adults appreciate that electronic health records keep their complete medical history in one place, and can be used by or exchanged between doctors: “*Every time I see a new doctor [they] go and read my record*” (P4).

However, for personal use, older adults often prefer to keep paper records: “*I haven’t had any need to [use patient portal]. Every time I leave [doctor’s] office, I have three or four sheets of paper, so I think they have given me all of the information that I need. [...] Sometimes they send me emails to confirm an appointment, but I am very good about my appointments and so it is usually not necessary*” (P6).

At the same time, 8/12 respondents appreciated the convenience of electronic channels for communicating with doctors and family: “*You have to go [to the doctor] if [...] they need to examine you, [...] but otherwise I manage my medical condition by email or telephone appointment mostly. I could have a Facetime appointment if I wanted without us having to figure out [the logistics]*” (P4). Using ICT channels is also helpful in communication with remote family members: “*I have an iPad. That’s how I hear from my son from Switzerland. [...] I have six grandchildren spread across the country. Once in a while I will Skype with [them]*” (P9).

Beside facilitating the direct interaction, ICT provides room for improvement of the quality of care: “*A friend of mine has a pacemaker and he puts his phone up to the pacemaker and that transfers to his physician. That stuff’s great*” (P8). One participant sees potential in even more progressive use of technology in health care so that “*you wear something, and it takes your vital signs, if you do anything, shiver, all of these things can be [monitored 24/7]. And whenever my readings are off [...] a signal goes up automatically and somebody [...] would call me up, call the doctor*” (P5).

Our participants appreciate the opportunity to learn through ICT about their medical conditions: “*[...] this helps with the recovery. If the patient knows what they are going to get and knows what to expect*” (P6); “*if somebody is going to say, ‘Let’s prescribe a medication for you,’ I’m*

going to say, ‘Well, what’s it for? What’s the advantage of that one over the one that I am currently taking?’ [...] We discuss things, and I do my own research too. [...] It’s a lot of work, but it’s also kept me alive, basically” (P4).

Generally, older adults try to use whatever channels are least disturbing to their caregivers, except in emergency situations, when an immediate response is required. Oftentimes the choice of communication channel not only depends on, but even signals, the urgency of the situation: “I would never call [my son] at work. I’m texting. If something bad happened to [his mother] I’d call him [...] If I called him during work, he would be worried ‘Oh my God, what has happened!’” (P1); “I communicate with my doctor by email [...] I don’t want to be interrupting her with a telephone call. You answer whenever you are [available]. [...] I only call when there is a good reason for it” (P5).

Nevertheless, while ICT adoption grows, many older adults “like personal contact. I don’t like to do this with the technical stuff” and they are “concerned about losing human communication” and feel that “there are so many new devices around. Apparently, you don’t even need to see a doctor, you can talk to your screen. I don’t like it” (P2). Hesitation to use ICT channels is also related to:

1. limited or no access to electronic means of communication, or lack of knowledge: “I haven’t figured out how to send photos [to a doctor from a phone] through that or do a report, but evidently in the system it’s possible to do that, maybe through computer. I don’t have a computer” (P4);
2. concerns about data integrity related to technology: A violation of integrity does not have to be a result of purposeful change or misuse; it can be just a mistake due to human factors: “I don’t think [electronic records are] that terribly accurate. [...] Somebody will either not hear you correctly or they change something” (P4); “When I got home, my medicine was changed [...] somebody along the line made a mistake” (P10). Changes related to advancement in medical research may also invalidate information: “Twenty years later the medical knowledge about this has changed [...] The finding that they had made [twenty years ago] about blood factor was incorrect” (P4). Furthermore, older adults find it difficult to correct mistakes in personal records: “I don’t think you can change [the electronic record]. You can just tell the next person that it is not accurate. You can’t go back and actually change things” (P4).

3. concerns about reliance and data loss: “*I’m not sure what happens to [email]. [...] I think it’s probably better to just fax it directly, [and doctors] know how to [...] put it in your medical file. [...] Otherwise you might lose something important*” (P4);
4. usability issues: “*I don’t want somebody texting me. [...] call me on the phone. I don’t want to sit and type on my little phone*” (P4); “*I don’t use email. [...] My eyesight is worse, and reading is worse. I’d prefer human contact*” (P2).

6.4.5 Dimensions of Sharing: Attitudes

Individual privacy attitudes and concerns, anticipated emotional reactions, and desired level of control over personal data affect the opinions of older adults. Moving to a care facility “*narrows down*” (P3) their world and forces to give up some privacy and control.

Privacy attitudes split our 12 respondents between 7 who are generally unconcerned and 5 who tend to be concerned about privacy. The unconcerned consider their lives “open books”: sharing HWBI with family, friends, and care professionals does not bother them, and is seen as indispensable, especially if they have good relationships and trust: “*The family should know what goes on and what went on. It’s important that you don’t keep secrets*” (P10).

Some seniors are not aware of potential risks or believe their information is not valuable (in line with the “nothing to hide” argument [132]): “*I don’t think [fitness tracker like FitBit are] intrusive. I have no idea what they do with that information. I guess that could be intrusive. [But] I wouldn’t object to wearing it. I lead such a bland life, I have no reason to object*” (P3).

While regulations aim to protect seniors’ information, some see them as burdensome: “*Under HIPPA, [staff] could only share certain types of information in certain types of situations. [...] But there are certain situations that I would want my niece to know more*” (P4).

However, 5 of 12 participants said they would not share their personal health information due to *privacy concerns*. Those concerns are sometimes triggered by the potential use of data for malicious purposes discussed in §6.4.2, or simply because some topics are considered more sensitive than others: “*I don’t share financial information. And I don’t discuss religion*” (P3).

The specifics of the institutionalized care environment also affect privacy attitudes. Respondents often see their senior living facility “*like a small village and everybody pretty much knows what goes on around here and that is why I don’t talk a lot about some things*” (P6), “*My world has*

really narrowed down over the years. [...] So, the friendships that I have are here. And we are all pretty reserved about what we talk about. [...] Your world gets smaller and there isn't a lot to confide to anybody" (P3). Seniors admit that "one gives up a certain amount of freedom when you move into any facility like this. [...] Of course, when I was living alone in a house, my next-door neighbors didn't know [everything] and couldn't care less" (P3).

Respondents typically "trust [care facility staff]. I never had any objection since I moved here" (P3), because "there have been so many lawsuits they are just scared to death on privacy" (P1) and "the people that run the [care facility] are very very aware of privacy. If you want to know something about someone, ask the someone, don't ask the nurse on the floor or whatever. [...] Gossip is gossip" (P8). Nevertheless, constant surveillance may make them feel vulnerable and uncomfortable: "It would bother me to be monitored 24/7. I'm already bothered by 24/7 surveillance anywhere" (P2).

Business practices related to personal information are trusted less: "Mr. Zuckerberg [...] is more interested in having [his business] grow fast. That's his model. So, he is far far removed from worrying about what happens to that information. He couldn't care less" (P5).

Asymmetry of power, and limited control and transparency dilute seniors' confidence in adequate privacy and security protection: "It's protected. There's supposedly no way that people who aren't allowed access [to] it can have access to it. Now whether they do or not, I don't know. If somebody is breaking, or looking at my medical records who is not authorized, I have no idea. I have no way of knowing" (P4).

Finally, legal and technical policies do not guarantee protection against privacy violations resulting from staff negligence: "[S]upposedly if you go to the doctor they look at your medical record and you hope that they close it up when you leave so that some nurse or somebody else walking in the room doesn't look at it [...] but who knows what they do in their office" (P4).

Anticipated emotional reactions are another driver of seniors' sharing habits. For example, some mentioned sharing information to mitigate family member worries: "[Children] feel better [after talking to my doctor] [...] they really want to feel comfortable and to know what's going on" (P9); "[My family] would be concerned but they would know that I am aware of [the spike in the blood pressure] myself and I am doing what is needed" (P6).

Some older adults do the opposite and limit information sharing to protect their families from worrying: "It depends on the individual that is receiving it. I guess for some patients, more might

be too much because it would make them nervous [...] And I guess it depends on [whether] it's reassuring rather than worrying" (P6); "After I find out what's wrong and everything, then I will share. There is no point in sharing with [children] now. I don't know what it is" (P8); "I don't paint too bad a picture [...] I make things as light as I can" (P12).

Embarrassment was not frequently mentioned in our interviews, perhaps due to generally trustful and close relationships within the triad of care. However, several participants were concerned about potential misinterpretation of their intentions to disclose. One participant was concerned that explicit disclosure of his relatively high physical activity will make it *"sound like he is bragging on himself"* (P1). In contrast, excessive sharing of negative information about one's health may appear to others as nagging and whining: *"Once in a while I'll say, as everybody else, 'I had a horrible night.' [But] I don't come every day and say, 'I didn't sleep well today'" (P2).*

The level of control over personal data or life decisions that respondents find optimal vary along 3 degrees: high, low, and conditional acceptance of delegation of control to others.

A high degree of delegation of control usually happens in families with close relationships: *"I have that set up through a lawyer so that [my children] can make health decisions for me and I am very comfortable with any one of them doing it" (P6); "My son takes care of everything now. We used to take care of ourselves. But when I came here, everything had to be changed. I said, '[...] Change is all up to you. Financial. Insurance. The whole spiel.' Anything that comes in the mail, I don't know what it's about. I leave it for him" (P10).*

Other seniors stated that maintaining control is crucial, and giving it up is an uncomfortable or even traumatic change, so they prefer to keep a low degree of delegation: *"I just can't stand a loss of control. I don't feel comfortable at all. I had to put my daughter on my checking account. [...] it killed me when I had to do that. [...] Nothing is private, but I want to take care of it myself. [...] It is a control issue, not a privacy issue" (P9); "I always have the last word" (P12).*

Conditional delegation of control depends on explicit consent and permission granting, transparency, relevance, and urgency: *"I would like to be aware of what is shared" (P3); "I don't mind the communication between [my family and doctors], but I'd like to have a say if [...] I can still choose. I would like to be in on the decision. And I would take my daughter's judgment, if I'm no longer capable" (P2).*

Even when older adults have control over the formal flow of information, they cannot avoid inferences or implicit data collection: “*The clinic knows we go [to the gym] regularly because the way it is positioned you come out the back door of the clinic and you are in the rehab gym, so the nurses will see us in there*” (P1); “*I am in a position where everybody can see what my health is*” (P12). Some facilities use social mechanisms and even encourage the implicit information exchange as “*an additional check of keeping track of [each other]. [...] If they don’t show up at the breakfast table, I know our eight people, we’ll call them after breakfast*” (P1). Others described monitoring systems: “*Security goes around at night and puts the tag on. If the tag still is up at 9:30am, the housekeeper, the receptionist calls and if there is no answer, then security goes in*” (P3). Typically older adults accept such implicit monitoring because “*that makes me feel safe. That’s one good reason for being here*” and prefer it over wearable devices as they “*don’t want to carry, wear anything*” (P2).

6.5 Discussion and Design Implications

Aged institutionalized care is a pervasive process that involves multiple stakeholders, whose motivations, opinions and interests may not always align or be clearly expressed. Willingness to assist, provide care, and emotionally support often competes with the burden of redundant information, worry, privacy concerns, and legal boundaries related to HWBI sharing, posing challenges for the design of effective communication. In this section we discuss the tradeoffs and suggest design implications to support communication in the aged care context.

6.5.1 Relations among Sharing Dimensions

Among the factors discussed, older adults unanimously use the purpose of use as a “sanity check” when making decisions about information sharing. Not surprisingly, they are more willing to share HWBI with trusted recipients and expect them to use personal information favorably. However, the benevolent end goal alone is not a sufficient prerequisite for information exchange, and therefore other factors are considered. In this section we illustrate how the interplay of purpose of use, functional relevance, urgency, anticipated emotional reactions, and individual attitudes all define the most appropriate data granularity, communication frequency, and channel for sharing information with a certain recipient.

Choosing recipients based on information relevance

For effective care communication, recipients need information that is useful for intended goals, e.g., making changes in a treatment plan, executing end-of-life decisions, or providing emotional support. Information relevant to one recipient may be less or more important to another group, depending on the urgency of the situation, recipients' role and involvement in care, and interpersonal relationships. The combination of urgency and relevance is often referred to as "newsworthiness," describing events that "deserve to be shared" [10, p.6]. For example, in situations where urgent medical assistance is required, health care professionals should receive all necessary information first, while the family notice can be suspended until the diagnosis is verified, to avoid unnecessary worry. If a situation requires family decisions, the priority of involving a health care proxy in decision making grows. Finally, information about how an older adult spent her day may be of high relevance to the family, but irrelevant to medical professionals. Therefore, it is important to consider the priority and level of relevance when designing the communication in a care triad.

The views of older adults, their families, and staff on the relevance of information may not always align. Designers should be mindful about framing to avoid direct confrontation or opposition of views. The communication platform may allow users to customize the priority of informing various recipients, and facilitate the collaborative and informed agreement between them, e.g., by encouraging users to make their preferences visible to each other. Moreover, the lack of recipient's response about shared data due to time issues may be misinterpreted by seniors as a signal of low relevance of this data or lack of recipient's interest, resulting in decreased self-motivation to continue close monitoring of health. Design solutions providing the necessary feedback about "quantified self" may fill this gap and encourage older adults to control their health and promote interventions aiming at improving it. The platform can also remind recipients that even if they are not able to help directly, it is reassuring to elderly people to simply know that family stays up-to-date.

Communication frequency based on urgency, relevance, and individual attitudes

Generally, event-based sharing is important for emergencies or critical deviations from norms, while irregular information exchange is optimal for communicating relevant but not urgent information. Regular information exchange may be limited to brief (not detailed) updates about

a patient's overall status or health metrics. To ensure relevance, non-critical (routine) information may be made available on an on-demand basis instead of being disseminated in a top-down manner. Recipients' requests to share data may even signal to older adults the interest to engage in the care process. However, designers should ensure that information exchange occurs with informed consent and is aligned with seniors' preferences for privacy and control. As transfer of control occurs gradually depending on elders' health and functional status [26], the delegation process should be dynamic to maximize autonomy and gradual involvement of family members.

While positive HWBI generally sends a positive signal, in some cases it may appear overly optimistic or boastful. Similarly, sharing negative information about health is important and expected to be met with compassion, but sometimes provokes annoyance and is perceived as nagging. Therefore, designers should be careful in framing positive and negative messages, and emphasize the intentions of a person disclosing information to avoid misinterpretations. Providing an opportunity for the recipients to signal interest and request information may not only satisfy their desire to express care, but also to reduce older adults' fears to appear bragging or grumpy. However, designers should be cautious to not turn the absence of recipient-driven requests into a signal of disinterest or a desire to "spy on" seniors.

Information granularity based on information relevance, and characteristics of recipient

We identified that too much information is overwhelming for both seniors and caregivers, especially when information is too specific or does not match the recipient's level of knowledge or cognitive style. Interactive screens may be helpful in minimizing information overabundance. For example, a preview screen may contain an overview of the patient's general state, including a graphic representation and short textual summary that are comprehensible for a lay person. Designers should explore and thoroughly test the use of metaphors, icons, and other graphic elements to ensure clarity and uniformity of understanding across individuals and cultures. In emergencies, this screen should also display notifications containing critical information in a remarkable way (e.g., contrasting colors). To educate older adults about their medical states, promote healthy lifestyles, and mitigate worry and concern about medical treatments, additional details and more granular information can be made available to interested recipients, for whom this information is relevant and comprehensible, by using, e.g., a "learn more" button, videos, serious games, and interactive materials.

Designers should allow users to set preferences and defaults, and switch between different formats of data visualization (e.g., images, audio, video, text, numbers) to accommodate different information processing styles. We also encourage designers to use our framework, when rationalizing about design elements, and explore how data visualization strategies relate to urgency, relevance, granularity, frequency, channels, and individual attitudes.

Deviations from norms should be personalized according to the limitations related to age, ailments, and personal and family medical history (and therefore predispositions and risks). Furthermore, our participants were interested to know not only the trends and spikes, but also the reason for a specific deviation. Communication platform designers may facilitate conversation between older adults and recipients to establish the appropriate level of granularity for exchanged information. Older adults could choose the maximum levels, and recipients could choose the modality of visualization within that range. In the beginning the explanation of medical information using accessible language can enforce the engagement of family members in care process and improve the emotional well-being of older adults. As family learns about the particular condition, the granularity and depth of information may be adjusted accordingly.

Communication channel based on urgency and established communication style.

The channel is not only a medium for communication, but also a signal about the urgency of the shared information. Phone calls often suggest that something important has happened, therefore, use of this channel for communicating non-critical events may cause unnecessary worry. Text-based channels (such as text messages and emails) do not require or guarantee immediate response, and thus are more suitable for the communication of non-critical information. Because the associated meaning and convenience vary based on individual preferences and established communication “etiquette” (defined by internal culture and rules within the communication dyad), the sender and recipient should be able to choose and agree upon what communication channel works best for both of them.

Generally, older adults are more comfortable with electronic channels for *communication* purposes (e.g., exchanging emails with doctors) than for *information storage and retrieval* (e.g., patient portals), whereas they mostly prefer paper documentation. However, they do not oppose the use of electronic means for exchange of information *between other actors* without their involvement (e.g. between doctors). The reluctance to use electronic means is often related to:

(1) suspicion about channels' reliance (i.e., fear of losing important data or introducing mistakes), (2) lack of knowledge about how to use them, (3) limited or no access to the devices or services, and (4) usability issues (e.g., those associated with physical limitations, such as small screens or low acuity due to hand tremors).

To overcome these issues, designers should provide users with support and guidance, adequate to their level of technological literacy and experience. Providing “tips” or an introductory platform “tour” to facilitate the on-boarding process and encourage new users. Designers can follow the state-of-the-art accessibility and design guidelines⁴ for older adults to improve usability of their systems and interfaces [42]. Finally, designers should embed in their platforms the functionalities that allow for printing of materials easily (e.g., using single-click highly visible buttons), which will help to address the reliability concerns, and mitigate opposition and reluctance to the use of ICT channel during the transition from paper to electronic records.

Moreover, designers should be careful in framing positive and negative messages, and emphasize the intentions of a person disclosing information to avoid misinterpretations. For example, to avoid positive HWBI appearing overly optimistic or boastful, affirmative signals about patient's good health may be presented as a recovery progress together with a note about best practices and effective therapy methods. Such framing will be positively received by family, will provide feedback on effectiveness of the treatment plan to the staff, and will set an example for peers. Similarly, sharing negative information about health is important and expected to be met with compassion, but sometimes provokes annoyance or is perceived as nagging. Therefore, providing an opportunity for the recipients to request information may not only satisfy their desire to express care, but also to reduce older adults' fears to appear bragging or grumpy. However, designers should be cautious to not turn the absence of recipient-driven requests into a signal of disinterest or a desire to “spy on” seniors.

6.5.2 Care Facilities and Information Sharing

In order to provide the best quality of care, institutions often install monitoring technologies as well as implicit mechanisms of checking on older adults, which result in constant surveillance. Such 24/7 attention of care staff removes the necessity of high engagement in care with family members, and therefore minimizes the need for HWBI sharing with them. Moreover, long-term care facilities are obliged by law to respect confidentiality, therefore they are deemed to be

⁴<http://design-review.mateine.org>.

safe and private. (Indeed, we did not observe many privacy concerns regarding information sharing within the care triad among our respondents.) In rare cases, participants saw legal privacy protection mechanisms even as a barrier to effective information flow, which questions the adequacy of the implementation of these regulations rather than the necessity to protect information privacy in general.

However, deteriorating health conditions and transfer to higher levels of care often require extensive delegation of control. Moving into care facilities requires giving up some privacy and freedom, and extensive sharing of information, including full medical records, with management and care staff, as a part of the “contract.” A few respondents admitted that their privacy can be violated (by mistake, if not purposefully), and are not fully confident to share their personal information with or among formal and informal caregivers, companies, or “non-medical people.” Finally, the small communities of senior care facilities become a world that has been “narrowed down” to a size of a “small village,” where “everyone knows everything” about each other. Older adults accept the necessity and trade-off but feel vulnerable, and express desire to maintain control as long as they can. Thus, addressing privacy concerns related to HWBI-sharing in the institutionalized care environment may reduce stress associated with diminishing autonomy and further increase the satisfaction with the quality of care.

6.5.3 Limitations and Future Work

The participants recruited for this study might not be representative of the general population of this age group (70+ years), as the majority of them were female, white, self-reported as being relatively healthy, highly educated, and experienced in using technologies. Our qualitative study provides insights and identifies the dimensions of sharing, while future (large scale) surveys may investigate the prevalence of opinions in the general older adult population.

In future research, we plan to complement our current work with the perspectives of older adults living independently (not in senior care facilities), their family members, and care staff, to compare the views of all stakeholders of the care triad. We also plan to involve all actors in collaborative participatory design and role-playing sessions, to further explore the dynamics in communication within the care triad and refine the design recommendations.

Chapter 7

Older Adults' Privacy and Security Perspectives on Technology

We next focus specifically on the security and privacy concerns of senior residents of long term care facilities, that were raised in the previous Chapter. By conducting 47 semi-structured interviews with them, we identify a range of complex privacy and security attitudes and needs specific to this population, along with common threat models, misconceptions, and mitigation strategies. We describe usability issues that affect management of online data access, and we recommend privacy and security learning approaches and usable technical and policy protections that build on preferences of older adults.

A summary of the content of this chapter has been submitted and passed the early reject stage of the Fifteenth Symposium on Usable Privacy and Security (SOUPS 2019) and is currently under review:

Frik, A., Bernd J., Egelman S., Schaub F., Nurgalieva, L., and Lee J. (2019). Privacy and Security Threat Models and Mitigation Strategies of Older Adults.

Older adults (65+) are becoming primary users of emerging smart systems, especially in health care. However, these technologies are often not designed for older users and can pose serious privacy and security concerns due to their novelty, complexity, and propensity to collect vast amounts of sensitive information. Efforts to address such concerns must build on an in-depth understanding of older adults' perceptions and preferences about data privacy and security for these technologies, and accounting for variance in physical and cognitive abilities. In semi-structured interviews with 46 older adults, we identified a range of complex privacy and security attitudes and needs specific to this population, along with common threat models, misconceptions, and mitigation strategies. This chapter adds depth to current models of how older adults' limited technical knowledge and experience and age-related ability declines amplify vulnerability to certain risks; we found that health, living situation, and finances play a significant role as well. We also found that older adults often have usability difficulties or technical uncertainties in mitigating those risks—and that managing privacy and security concerns frequently consists of limiting or avoiding technology use. We recommend educational approaches and usable technical protections that build on seniors' preferences.

7.1 Introduction

Due to increasing life expectancy, the number of people in the U.S. over 65 is expected to double by 2060 [133]. The need for professional care is rising accordingly, while the labor market for caregivers is projected to shrink [134]. These factors are stimulating investment in emerging “smart” technologies for older adults—aimed at sustaining independent living, increasing quality of life, and mitigating health issues via early detection [135]. Emerging smart technologies such as wearable medical devices, fall sensors, and therapeutic robots [136] may yield benefits, but due to their novelty, complexity, and propensity to collect vast amounts of information, they also pose security and privacy risks.

Due to limited technological literacy and experience, and to age-related declining physical and mental abilities, older adults are particularly unaware of and susceptible to those privacy and security risks [137–139]. Even (or especially) people who are unaware of privacy and security risks and consequences deserve consideration and protection from threats that expose them to financial, health, and psychological risks. While seniors themselves often express privacy and security concerns in relation to technology [140–142], their views are underrepresented in privacy and security research. At the same time, the limited literature on the topic shows that privacy

preferences of older adults are heterogeneous [143] and fine-grained [137, 144], and thus warrant further exploration.

While some studies have surveyed seniors' privacy and (to a lesser extent) security concerns, their approaches to managing privacy and security risks and protections have not been investigated comprehensively. Our research aims to better understand privacy and security attitudes and mitigating behaviors of the population aged 65+.

The goal of our research is to inform the design of effective systems that empower older adults to make informed decisions, to have better control over their personal data, and to maintain better security practices. To this end, we conducted semi-structured interviews with 46 older adults. We identify their common security and privacy concerns and threat models, behaviors and strategies to mitigate perceived risks, usability issues with current protections, learning and troubleshooting approaches, and misconceptions and blind spots regarding security and privacy.

We added depth to current models of how older adults' relatively low technical knowledge and experience and age-related declines in abilities amplify their vulnerability to certain risks, and found that health and living situations and financial considerations also play a significant role. We also found that older adults often have usability difficulties or technical uncertainties in mitigating those risks—and that managing privacy and security concerns frequently entails limiting or simply avoiding use of new technologies. Finally, building on the preferences of older adults, we offer privacy- and security-enhancing recommendations for product developers, and for educational efforts.

7.2 Related Work

Technological solutions aiming to meet older adults' needs span different domains (e.g., health, nutrition, safety, or navigation [136]) and forms (e.g., wearable, ambient, or camera-based devices [145]). Both aspects factor into what data is collected: wearable devices, for instance, enable collection of orientation, movement, and vital signs with embedded gyroscopes, accelerometers, and other sensors [146, 147]. Context-aware systems use sensors as well, often with the addition of image capture to monitor activities or to detect falls (e.g., [148]); newer solutions incorporate computer vision to recognize behavioral patterns and artificial intelligence to detect anomalies [149]. Likewise, dynamic care robots [150–152] leverage sensors and sometimes cameras for medication management or companionship. Many emerging technologies establish a

network of devices connected via Wi-Fi, Zigbee, or similar protocols [153, 154], thus, integrating wearable devices with context-aware sensors into a larger ecosystem.

The effectiveness and quality of assistance in critical situations often rely on collecting extensive data. However, extensive monitoring and surveillance trigger privacy and security concerns among users of such technologies [140–142]. Older adults' privacy concerns and risk perceptions are often different from the concerns of the better-studied younger population [143, 155]. Trust has been identified as a core factor affecting older adults' adoption of ubiquitous computing technologies [156–158]; similar results were obtained in Chung et al.'s research [157]. Lee et al. found this to be especially true with respect to video and financial data among wearable device users [159]. However, Knowles and Hanson [160] found that (dis)trust may not be especially relevant to older adults' practical decision making around technology (non)use; the language of distrust was more relevant to larger value-related issues surrounding digital technologies.

Technology adoption should not be viewed as indicating trust or acceptability [160]. One concern is invisible audiences and absence of feedback from monitoring systems when they are being used or when data is accessed [147]. Other research suggests that the recipients of personal information matter to seniors: who accesses data, how often, and at what level of detail [144, 161]. Although older adults tend to rely on family members in “dealing with technology” [144], delegation of security choices should not be considered a safe behavioral strategy [162]. Additionally, older adults may overly rely on surface cues and affordances, leading to inaccurate perceptions of security. For example, one participant in a study by Hornung et al. felt confident about sharing her bank details with Amazon because “the complete number isn't displayed, only the last two digits” [144].

On the other hand, misconceptions about data collection may raise false concerns that can be mitigated by appropriate explanations [163]. Older adults are also capable of using data controls and security strategies in certain cases, such as basic password encryption [144, 164]. Furthermore, individual differences are found to heavily affect privacy and security preferences: seniors with severe health conditions are more likely to share their information [163, 165] and generally value independence and safety more than privacy [166–168].

Seniors also represent a more heterogeneous population than younger people [169], due to differences in their health conditions, education, living conditions, and experience. Physical and cognitive impairments may further complicate usability issues. These findings suggest that older

adults' privacy and security attitudes and mental models are context-dependent and heterogeneous in nature. While others have studied seniors' privacy and security concerns regarding assistive living technologies (e.g., [170]), we chose to explore these concerns surrounding a broader set of technologies.

7.3 Methodology

To study older adults' privacy and security attitudes, we conducted 1–1.5 hour semi-structured in-person interviews, in which we discussed: (1) privacy- and security-related concerns and threats and (2) user management strategies.¹

We reached out to inhabitants of nursing homes and senior residences, members of senior centers, and cultural organizations for retired people in the San Francisco Bay Area. To engage a population with a wide range of skills, literacy levels, and physical conditions, we screened potential participants using surveys in several formats—online, phone, paper, and in person—but excluded individuals with serious cognitive impairments (e.g., Alzheimer's disease and dementia), non-English speakers, and those under 65. With IRB approval, we conducted interviews in May and June 2018 with 46 participants at locations of their choice: private residences or public senior centers, and paid \$20 as compensation.

In the interviews, we discussed: (1) general opinions on emerging technologies in relation to daily needs and difficulties; (2) mental models about data collected by these technologies and recipients of this information;—which we will not discuss in this chapter, and focus instead on—(3) privacy- and security-related concerns and threats; and (4) user control strategies. We administered exit surveys about participants' individual characteristics.

The structure of our interviews was inspired by Zeng et al. [171], who interviewed 15 smart home inhabitants about their respective privacy and security attitudes and behaviors. However, our study focused on older adults, discussed healthcare and wearable devices in addition to context-aware smart technologies, and involved both users and *non*-users of emerging technologies².

¹In addition, we explored general opinions of older adults on emerging technologies in relation to daily needs and difficulties, and their understandings of what data such devices collect and who it is shared with. We will present the latter in a separate paper. The interview guide can be accessed at <https://tinyurl.com/interview-guide-seniors>. Entry and exit survey instruments can be accessed at <https://tinyurl.com/survey-seniors>.

²Entry and exit survey instruments can be accessed at <https://tinyurl.com/survey-seniors>.

We audio recorded and the interviews and had them professionally transcribed. Three coders iteratively developed a codebook by independently coding subsets of transcripts and jointly resolving conflicting codes. Four coders then divided coding of the remaining interviews, so that two coders independently coded each interview and jointly resolved conflicts.

Limitations Our study was qualitative in nature with the goal of uncovering and understanding older adults' privacy and security perceptions and concerns with respect to emerging technologies. Due to our sample size, we refrain from making claims about the prevalence of our insights in the general older adult population. We conducted our study in an urban/suburban area with relatively good technology resources, programming, and services for older adults, and a relatively high average income due to the high cost of living. Because we primarily recruited through senior centers, programs, and assisted living facilities, which often offer computer classes, our participants may be more likely to have attended or at least heard about such classes, and therefore may have more awareness of privacy and security issues.

As a result, our participants may be more reflective about technology; therefore, the issues we identified may be even more pronounced in the broader older adult population. Similarly, technology needs and attitudes may differ in other areas, countries, and cultures; possible means to address them might differ as well.

7.4 Participant Characteristics

Our 46 participants were 65–95 years old (mean=76), 65% female, mainly white (76%), with self-reported native or bilingual English proficiency (45%) or advanced non-native proficiency (37%). The majority have an advanced (44%) or Bachelor's (33%) degree, live alone (63%) in rented or owned accommodations (87%) (the rest live in senior care facilities), and do not have a caregiver (80%); 9% have a hired caregiver, 7% a informal caregiver, and 4% have both. Respondents self-reported "excellent" (17%), "good" (50%), "fair" (24%), "poor" (7%), and "very poor" (2%) health conditions. Income level is below \$35K for 35%, \$35-75K for 35%, \$75-150K for 13%, and \$150K+ for 9% of the participants (9% did not specify).

Similar to 36% of the general adult US population [172], 39% of our participants use three types of devices—mobile or smartphone, laptop or computer, and tablet. Laptop or computer is used by the majority of participants (38/46 or 82.6%), which is slightly higher than the general US

adult population (78%) [173]. Owners of the devices tend to be the heavy users. Among owners of laptops/computers, 28/38 use it every day. Mobile or smartphones are used by 34/46 of participants, out of which 24/34 use it every day. Tablets are popular but less frequently used: among 21/46 of participants who own it, 9/21 use it every day. Just 5/46 did not use any of those devices.

To further assess participants' experience with technology, we asked in the exit survey how difficult it is for them to perform a certain task using digital devices.³ For 6 out of 9 tasks, at least about half of the participants said that it was "very" (for the majority) or "somewhat" easy to perform them (for instance, sending emails (36/45), information search (31/45), managing calendar (22/45), or downloading files (20/45); to send text messages (23/45); or to use a computer, tablet or smartphone for entertainment (27/45)). Among the rest, very few participants said that it was difficult to perform a task (except for installing a computer program, which 12 out of 46 people found hard). Instead, they said that they did not try to do it either because they did not know how to or did not have the appropriate device. For instance, many participants did not know how to make a video call (31/45), download a mobile application (24/45), install a computer program (20/45), or send a text message (18/45).

Thus, most of those who tried using these devices felt fairly confident performing basic tasks; only a few tried to perform more advanced tasks.

7.5 Findings

Through our interviews, we identified privacy and security concerns, mitigation and learning strategies for alleviation of risks, usability issues with security and privacy mitigations, and misconceptions about data practices. In general, the threat models and associated misconceptions that came up in our interviews are also common among the younger population [174, 175]; however, we found that, due to infrequent use of technology and limited technical knowledge, health and living situations, financial considerations, and age-related ability declines, older adults may be particularly vulnerable to certain risks, and face issues with mitigating them.

³One participant did not respond to the question.

7.5.1 Privacy and Security Threat Models

In this section, we describe participants' threat models, both real and perceived, and discuss how older adults may be particularly vulnerable to certain risks. We identified that participants find data flows, especially in emerging and unfamiliar technologies, not transparent. Even if they do not engage with such technologies directly, they still feel exposed to privacy and security threats posed by them (e.g., passive data collection, and bystanders' concerns). Privacy choice is particularly limited for the residents of senior care facilities.

Taxonomy of Threat Models

We characterize privacy and security threat models mentioned by our participants using two dimensions: the *consequences* of privacy and security violations, and *activities* or processes and actions that cause security and privacy risks.

We divide the consequences of privacy and security violations into three main groups: financial losses and material damages; personal health and safety risks; and intangible consequences. The latter category includes ethical, social, and psychological issues, often involving emotional distress, such as reputation damage, anxiety, or discomfort with information sharing (see examples in Table 7.1). While older adults are familiar with examples of physical attacks and reputational damage in the offline world, they noted that modern technology exacerbates them (*"When you are having a private discussion with someone, you ought to be able to feel that it's as private as those that are involved in it are willing to be, you know. You can't obviously be sure that they won't go blabbing it all to the next person they talk to, but, I wouldn't want technology doing that for me,"* P15). Participants were particularly concerned about location data and data about their in-home activities, such as sleep patterns and appliance use, which were most often seen as sources of compromising information that could facilitate physical attacks on their lives or property. Some reacted negatively to the idea of others having or using their data, even if they did not mention specific consequences (*"I will talk and I will share but there are things that you will never know about me that I don't want you to know. Because it's none of your business. Simple as that,"* P22).

TABLE 7.1: Consequences of privacy and security violations.

Consequences	Description	Supporting quotes
Financial losses and material damages	Material and financial losses including robbery or property damages.	<i>“Will they get something from my pattern? Would they track my daily activities? [...] so they can break into my house. I’m worried about that,”</i> P103.
Damages and threats to health and life.	Health damages, injuries, and threats to life.	<i>[I: How do you think this recorded conversation or medical records or location or activity level or anything can be misused?] “R: Well people can spy on it and then they want to come in and kill you. They want to know when there is no sound and you are asleep, then they come in,”</i> P37.
Intangible consequences	Emotional, social, or ethical consequences of information misuse, such as reputation damage, formation of stigma, social judgment, and anxiety.	<i>“[They could say] ‘Oh he has a smart phone and he’s [...] going to a meet up place where guys meet up.’ [...] It could be interpreted. Surmised [that] I’m [a] bi-sexual guy. [...] I don’t know exactly how they would take it. Or getting rebuffed and stigmatized,”</i> P9.

Classifying harmful activities, we follow Solove’s taxonomy [1], which divides them into 4 groups:

- information collection (using surveillance, interrogation);
- information processing—searching, storing, combining, manipulating, and using the data (including aggregation, identification, insecurity (failure to protect collected data), secondary use, or exclusion of data subject its handling);
- information dissemination (including breach of confidentiality, disclosure, exposure, increased accessibility, blackmail, appropriation, or distortion);
- invasion—direct privacy or security attack on the data subject (including intrusion, and “decisional interference”).

We include examples and supporting quotes in Table 7.2.

TABLE 7.2: Privacy and security risks and concerns based on Solove's taxonomy [1].

Group of risks	Examples	Supporting quotes
Information collection	<p>Online browsing tracking; video and audio monitoring; collection of data using wearable and context-aware sensors; surveillance including potentially dangerous personal stalking, broader government and political surveillance, as well as the usually benign—yet still often anxiety or annoyance inducing—monitoring of older adults by family members, medical care staff, or senior facility management. Passive audio and video collection by phones, , computers, fall detectors, smart TVs, voice assistants and home-control systems.</p>	<p><i>“We Jews don’t face the repression in this country today that we faced in my parent’s generation, okay? [...] [But] I am never completely far removed from thoughts of political repression. That’s why I talk about surveillance,”</i> P113; <i>“These Alexa things [...] I guess it’s always on, and always capturing [my data],”</i> P104; <i>“A person has some kind of a [...] voice assistant and that [...] record his private conversation and send it to somebody else. So I don’t think it is a safe thing to have. I would throw it out of the window,”</i> P37; <i>“I was surprised to be reading that any information about me is being collected [by Google Home]. I don’t know what is collected,”</i> P123; <i>“With the new smart televisions if you know, like with the computer too, they have the camera that they can look at you. [...] Some people cover up the camera with a piece of paper or tape. I am not quite that paranoid,”</i> P33.</p>
	<p>Violation of bystanders’ rights, especially with respect to voice-activated, video-monitoring, and other context-aware systems.</p>	<p><i>“I guess it’s like an invasion of privacy. [...] When someone puts you in a room, they should tell you that there’s a recorder there,”</i> P37.</p>

Continued on next page

Table 7.2 – continued from previous page

Group of risks	Examples	Supporting quotes
Information processing	Data aggregation, individual profiling, targeted advertising.	<i>“They know everything you are doing, they know what you are looking at, they know what you are, you know, searching for and everything else [...] One thing if you are looking at it on the computer but then if you are talking to somebody and you make a remark about somebody or something or about politicians or something, well somebody could actually gather all that data and use it and say well this person is a nasty democrat or left-wing or right-wing or whatever so that is the only thing concerning, about the smart speaker especially,”</i> P33.
	Telemarketing, spam (e)mail and calls, and other unsolicited marketing.	<i>“Oh yeah, you get a lot of weird calls when you are a senior in a rest home,”</i> P108; <i>“When you go on to these other sites looking for something then you get a barrage of emails afterwards. And I either delete them and if they keep on coming I try to find the place I can unsubscribe to them,”</i> P110.
	Fraud and scams (including fraud and scam in medical context), phishing, and identity theft by phone, email, and through social media, including dating websites.	<i>“They could probably scare me. They could say you have cancer, or you have something that we can’t cure, or you need a surgery that you don’t need. [...] Just for profit. [...] Let’s say that they are a doctor who doesn’t accept Medicare or your [insurance] plan, and they say well you have to pay for this out-of-pocket because you think you have cancer and you need a special medication or something,”</i> P46; <i>“Somebody was using [my friend’s] Kaiser⁴ number and getting services at another Kaiser location, and then she started getting these weird co-pay bills and discovered [her medical identity was stolen],”</i> P71.

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⁴Kaiser Permanente is a major U.S. health care and insurance provider.

Table 7.2 – continued from previous page

Group of risks	Examples	Supporting quotes
	Unauthorized access to personal information, e.g., by hacking, accidental access sharing, or abusing of power.	<i>“People that shouldn’t have access to your records who are in an official capacity could, you know, use information about you that they happen to see. [Say] somebody works at the DMV⁵ and they looked up address of ex-girlfriend [...] and then they’ve got out and hurt that person,”</i> P71.
	Price and service discrimination, including jeopardy to benefits older adults might otherwise receive, such as social subsidies, disability allowance, insurance coverage, and eligibility for senior housing or assisted living facilities.	<i>“[My personal information] might be used to influence my insurance company to raise my rates,”</i> P22. <i>“I am grandfathered in. [...] [The director of senior residence] would like to get us out. She’s attempted in the past. [...] We have to [...] report income every year. [...] And when she first saw mine, she was very uppity about why the hell I was there. I was honest in what I had. I have a comfortable IRA. [...] But if I paid current rent [...], I’d be homeless in 10 years. And she said, ‘Well then you would qualify for here,’”</i> P36.
	Viruses, malware, ransomware.	<i>“You just can’t tell what’s a virus and what’s authentic. It does make me, I got a virus on my computer from something and got scolded. For falling for something [...] both [by] my son and the repairman,”</i> P18.
	Data integrity concerns, mistakes and errors in personal records.	<i>“You wouldn’t want somebody putting misinformation in your record. Or [...] changing information in there,”</i> P71.
Information dissemination	Disclosure, data breach, selling of the personal information to a third-party, or accidental shared access.	<i>“Not so much the smart phone, as the computer with cookies, they know where I go. They have data about me that I really don’t like them having. This whole idea of computers knowing how the users are using the computer and gathering that data and then selling that data to others who make money from that data. I have real difficulty with that. It’s a rip-off,”</i> P60.

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⁵Department of Motor Vehicles (DMV) is a state-level government agency that administers vehicle registration and driver licensing.

Table 7.2 – continued from previous page

Group of risks	Examples	Supporting quotes
Privacy invasion	General concerns about violation of privacy as fundamental human right, interference in personal decisions.	<i>“If other people can find out things about you that you don’t tell them yourself, yes, I would consider that intrusive,”</i> P1.

Information Collection Our participants were primarily concerned with surveillance, and lack of transparency about and control over information gathering. The latter issue was acknowledged by 28 out of 46 participants, and 26 specifically mentioned concerns about the collection of data without meaningful notice and consent.

While existing literature has documented the general lack of effective consent mechanisms and transparency regarding data collection practices [176], this concern is amplified among older adults due to lower technical literacy and experience [177]. For instance, synchronization across devices was a “black box” and source of concern for some participants, even for respondents like P123, who volunteers helping others configure devices and is considered a computer expert by peers: *“The sharing just surprises me sometimes. You don’t know how stuff can go from one to the other, you are surprised it’s there. [...] I was concerned that [...] you think you know what [an Apple device] shares, but stuff can wind up on another computer so easy with an Apple,”* (P123).

One participant noted that, although data collection by corporations is not new, the Internet and related technologies make these processes easier, ubiquitous, and at the same time more opaque: *“The old way, it seemed there was an appearance of consent. [...] Now it’s just more seamless,”* (P71).

Passive audio and video collection by phones, computers, and especially by emerging technologies, like smart TVs, fall detectors, voice assistants and home-control systems, are specific examples of uncontrollable information collection mentioned by 17 participants. Participants believed that the information collected this way may be used for unsolicited marketing, causing physical harm, or violating personal privacy: *“It’s scary. Just like, it invades – if the government were to put a microphone in everybody’s house and listen to everything you say, people would object. But they are voluntarily putting these devices in their homes and it’s doing the same thing,”* (P108).

Participants often personified data collection practices (as though it is done by individuals, even if they knew it was an automated process), and (rightfully) thought that top management is accountable for that: *“The computer [...] probably tracks what you are watching, what you are going to, what you are inquiring about, and keeps a record of it internally. [I: For what reason?] Because Steve Jobs made it that way. To track data,”* (P69); *“On Facebook, I started – and then they have this Zuckerberg thing about what they were capturing,”* (P104). This can partially explain why certain people rely on the reputation and trustworthiness of the company and people running it when trying to estimate the risks (see §7.5.2).

Surveillance is another common data collection practice, acknowledged by 20 of 46 participants. While a few participants mentioned broad concerns about government and political surveillance and personal stalking, the most prominent form of surveillance discussed by older adults was “care surveillance” [178, 179]. Although monitoring of older adults by family members, medical care staff, or senior facility management is usually done for benign purposes (e.g., to monitor health status and well-being, and provide the appropriate level of care), such surveillance still induces anxiety, annoyance, and privacy concerns among our elderly participants: *“I know a lot of these devices have cameras in them and rightly so because they are designed to be helpful but you know, it’s always a concern, I think, when you are using some of the new electronic, is how private are the things that you do,”* (P22).

Surveillance is especially common in the context of assisted living. Senior care facilities try to maximize the quality of provided care, while minimizing staff. The use of surveillance in care facilities may also be driven by accountability and liability reasons, such as contractual and legal obligations to ensure the safety of care recipients, or to review staff responses to various incidents and emergencies (*“There are sensors so that if you don’t go up and go to the bathroom, someone will come down the hall and see if you are okay,”* (P69); *“If [my wife] goes out the front door, it activates a buzzer [in the building]. There are other residents there who have the same device. Not all of them, but some of them do. The ones that are considered [...] ‘exit-seeking,’ ”* P15).

Moving to a care facility is often motivated by deteriorating health conditions and the need for a higher level of care. Therefore, older adults living in care facilities are often resigned to giving up privacy in exchange for safety and care: *“You cede a lot of your personal privacy rights when you move into a place like this, in exchange for services being rendered to you. So I think that’s a different kind of a setting than somebody that is living in a private setting and would be using devices,”* (P71). This finding is consistent with the literature about tradeoffs between

privacy and quality of care [180, 181], and with studies showing positive correlations between the acceptance of privacy risks and deteriorating health conditions [182].

Additionally, older adults living in senior housing and care facilities reported that they do not always have a choice regarding monitoring technologies, and have to accept them: *“I know it’s now becoming a requirement in some places [to install] the devices for the elderly. Not just the elderly. People who fall in an emergency,”* (P26).

Surveillance is also a concern among seniors who live independently. On the one hand, in addition to attempting to ensure safety and reduce emergency response times, home care surveillance is driven by a desire to prolong independent living: *“I’ve managed not to be in the hospital since [...] 2010. Normally somebody with my issues would be in and out of the hospital, but I’ve managed that through jostling medication. Which works only because I have doctors that respond to my email right away and make a decision that I have to implement right away,”* (P71).

On the other hand, home care surveillance presumes continuous monitoring and limits independence and privacy of older adults. Hence, while inhabitants of senior care facilities have already accepted to exchange care for personal independence, for seniors who live independently and want to protect both—health and independence—it is yet a decision to make, and it is hard to balance privacy concerns with benefits of care surveillance. This tension between the jeopardy to independence and its prolonging, in line with previous research [183]. Nevertheless, seniors who currently live by themselves recognized that, with deterioration of health should they need more care in the future, they will expect to give up some privacy in exchange for independence or safety (*“If [I] cannot function at all, I need help, then I might sacrifice some of my privacy, but I just hope [...] it will not be hacked,”* P108).

Finally, while not very common among older adults, yet still important, we observed several concerns about bystanders' privacy. These concerns were especially related to emerging technologies, such as voice-activated, video-monitoring, and other context-aware systems. Despite—or even because—older adults may not be familiar with, own, be primary users of, or even deliberately avoid using smart systems, they are often exposed to monitoring or data collection by these devices, fail to recognize when these devices are in use, and feel uncomfortable about their use by others. Generally, older adults feel helpless in maintaining control over personal information collection in the age of ubiquitous computing. For example, P43 noted, *“All my charge cards, all my whatever, everybody knows exactly what I’m doing, even though I never put it on a computer. It’s on a computer from someplace else. [...] Every phone call you make is recorded somewhere.”*

Information Processing Almost half of our participants (19/46) mentioned aggregation of personal information from multiple sources into individual profiles, e.g., based on online browsing, smart TVs, and wearable fitness trackers. While some participants found customized recommendations beneficial, in general they found individual profiling to be concerning. Yet, a couple of our participants seemed to have limited understanding of how combined pieces of data facilitate rich inferences—a blind spot common among younger users too [184, 185]—or were not certain how much is currently occurring (*“If I were the evil genius, who had that record, I think I could [...] probably tell you more about yourself than you would know about yourself. Or I may be exaggerating, but not too much. [I: Do you believe anyone has the record on you?] I hope not, but, you know... I think most people would find it rather boring, but... [I: Do you think there’s some evil genius exists somewhere in the world?] N-n-no, no. This is a hypothetical,”* P51).

Using collected data to create detailed user profiles also enables secondary uses of the data [1], among which our participants were widely aware of fraud, scams, and identity theft (25/46); targeted advertising (22/48); spam and telemarketing (17/46); and price and service discrimination (7/46).

In addition to financial fraud and run-of-the-mill online scams like phishing, 3 participants mentioned potential for fraud on dating websites. This suggests that seniors’ engagement with social media and online dating websites—generally considered to be the purview of younger generations—should be included in computer training programs for older adults.

Four participants mentioned that fears about information disclosure and/or re-identification limit their willingness to engage in online political discourse (*“I am always chatting about politics and, even on the phone, sometimes I hesitate because I know they cap all that information,”* P46; *“I would do a [Facebook] like, or submit, and now I’ve decided not to do that because you just don’t know what’s being captured. But I really want to support those people. I don’t think we know enough about what’s being captured,”* P104).

Moreover, older adults are more engaged in health care activities than the general population [186], which increases their vulnerability to *medical* fraud and scams (see examples in Table 7.2). Participants generally viewed medical staff as trustworthy recipients of sensitive personal information and described using online patient portals for managing and exchanging medical information. However, a few participants were concerned that medical staff may misuse this data for their benefit (e.g., to assign unnecessary or more expensive treatments or for personal motives and retaliation). Misuse may have severe consequences: *“I got a bill from the hospital*

for \$26,000. They had padded it. [...] I can't prove that none of that stuff happened. They looked up all my old records and padded [them], and all this stuff. It just, it was criminal and I never had that experience before" (P5). Unlike with commercial data, in the few cases where participants mentioned specific cases of medical data having been shared in ways they considered to have violated their privacy, it was generally obvious to them who had shared it and under what circumstances.

Disclosure of sensitive economic and health conditions, accelerated by the proliferation of e-health, health-monitoring systems, and online banking, can endanger benefits older adults might otherwise receive, such as social security, disability allowance, insurance coverage, and eligibility for senior housing or assisted living facilities.

Insecurity resulting from inadequate protections was another source of concern. Specifically, 24 participants mentioned hacking. While viruses, malware, and ransomware comprise frequent computer security risks, only 6 mentioned them. This lack of specificity may in part be due to limited computer use or to delegating maintenance and security management to someone with more computer expertise (see §7.5.2.)

Information Dissemination Regarding information dissemination, older adults were primarily concerned with their personal information being sold for profit, or its disclosure for malicious intentions to cause reputational damage, humiliation or embarrassment. Specifically, 11 participants discussed the possibility of information being sold and subsequently used for secondary or malicious purposes. P10 noted, *"If it's confidential and private, I don't care if they have all my information. [...] As long as [...] it wouldn't be abused, or I'd get a bunch of salesmen calling me trying to sell a device or a pill or something."* Others' concerns were more general (*"I would just like to see some kind of safeguard [...] in the technology so that strangers [...] don't have access to knowing everything about you because strangers don't really need to know,"* P47).

Participants concerned about scams and fraud often recognized that the information being used by scammers (or even hackers) for illegitimate purposes came originally from disclosures someone purposely made to legitimate recipients, demonstrating again the limits of users' control (*"I no doubt shared my social security number with some other entity, benevolent [...] but that someone decided that that might be of value in the open market,"* P51).

However, participants also expressed the desire for balancing privacy and security with benefits of data portability, especially in the healthcare context, its accessibility for research purposes,

and legitimate access delegation: *"I wish [doctors] would share [my medical records with each other], but they don't. It's so compartmentalized that it's [...] really frustrating... it's a benefit and it's a curse, [...] because [...] unless you tell them [...], they don't know what is going on with the [other] doctors in your life or the other problems that you have had,"* (P46). For instance, the poorly defined legal role of informal caregivers builds up constraints and annoyance about privacy and security protections and may erode peoples' privacy values (*"The privacy to me seems like overkill. The concern about the hoops I have to jump through to be able to order the wife's prescription or to speak for her. I know that there are lawsuit reasons, why it has to be done, [...] so they have to be so so so so careful. But I don't share that concern. It probably shows that I am naïve,"* P123).

Privacy Invasion Some older adults were concerned about privacy in general, and about secondary use in particular (see above). A few participants were also concerned with interference in their decisions, such as use of social media to interfere in the U.S. elections (*"I think that they expected that Facebook information would be effective in addressing specific group of voters. When you think about it, it is not far-fetched. It is perfectly reasonable,"* P121).

Seniors' Views About Age-Based Differences

Some participants believed generational differences explain their privacy attitudes. Some respondents also think that malicious actors may make assumptions about vulnerabilities and worthiness of elderly and exploit them for attacks.

Do Seniors Believe They Are More Concerned about Privacy than Younger People?

We observed a dichotomy in seniors' views on "generational differences" in privacy attitudes. Some participants (9/46) expressed fundamental beliefs about privacy, and acknowledged that they grew up with the idea of privacy as a valuable human right, while information sharing has limits and rules defined by social norms (*"...People say, 'Well, if you've got nothing to hide, why don't you tell them?' It's none of their business! [...] It's much less so in this new age: the millennials, they don't seem to be quite so concerned about it. But when I was growing up there was some very strong limitations on what you ask people, what you told people. [...] So, it's a generational thing"* P22).

Some other participants (4/46) expressed the contrasting belief that older adults do not have as many reasons to worry about privacy as younger people do. One reason is that retired people, not involved in the job market anymore, do not have to face the risks of personal information disclosure potentially jeopardizing job security (*"If I was younger, it might hinder me from jobs or even benefits of some kind. But now I don't think it would inhibit me from benefits,"* P21). Another reason, as for example P6 expressed it, is that *"this may be a function of age because, at this stage of my life, I don't feel like I have great secrets or private information,"* which directly contrasts an opinion of P113: *"I'm old fashioned enough to know what privacy is and to value it. [...] If at my age I don't have a few things to hide from a few people, my life has been totally wasted."* This illustrates that while seniors may feel less protective of information about their current activities—in older age—they still may find information about their personal life from earlier adulthood private and sensitive.

Do Seniors Believe They Are Seen as Attractive Targets? Participants held some contradictory opinions about whether older adults are viewed as better targets for security and privacy threats. Several participants 5/46 (ID 5,7,13,21,23) believe older adults are specifically targeted because they are viewed (correctly or incorrectly) as vulnerable, easy targets, especially for social-engineering attacks, either due to low technical literacy; lack of support (*"I think [the falsified bill] is because they think old people are stupid or they're not aware and I was there alone. I couldn't prove anything,"* P5); or gullibility (*"Because it's elderly are more fallible, or they're more trusting so they take advantage,"* P7). At least one believed attackers made assumptions about their financial situation (*"Maybe he thinks I'm wealthy and [is going] after my money,"* P13).

In contrast, a few older adults believe that attackers do not see them as "major consumers" (P110) and doubt that their information is useful enough to be misused or utilized for commercial purposes (*"I think that I am not a focus of whatever these companies are looking for. They probably look at my data—if they look at it—and say, oh, don't bother with her. She's too old to participate or maybe doesn't have enough money or I don't know what they think,"* P110).

Threats Not Recognized by Older Adults

Older adults in our interviews sometimes did not purchase their own devices and instead relied on the use of public or used (received from other people or refurbished) equipment and services.

Such participants did not mention potential privacy and security threats associated with the use of public or used devices, which we discuss below.

Use of Public Devices and Services Older adults are less likely to own their own computers or smartphones than younger people [173], therefore, seniors are more likely to use public devices. In our interviews this was even the case for medical devices. Six participants mentioned that they use public computers (e.g., in libraries or at senior centers). Two participants mentioned that because they do not have blood pressure machines at home, they *“go to Walgreens and other places, where they have free checks. And I got it checked recently at a health fair,”* (P10). Privacy and security in such situations depends on what data is collected, how it is stored and used, and whether the devices and entities collecting it are subject to HIPAA [187].

Participants' use of public devices is usually motivated by either high costs associated with purchasing a device or a lack of perceived utility in owning one, e.g. due to infrequent use. The infrequent use in its turn amplifies security risks related to lack of skills and experience, e.g., in detecting malicious events or suspicious websites, links, or documents [188, 189].

Participants did not express concerns regarding public devices or public Wi-Fi networks, even though, due to use in public spaces and by many people, they are more likely to expose users to such vulnerabilities as malware infection, data leaks, privacy and security threats resulting from accidental shared access, shoulder surfing, and public network risks [190]. Instead, they appreciated that someone else was maintaining the devices: *“That’s another reason why I don’t want a home computer. I go to the library, and if [the computers their] crash, they’ll deal with it. [...] If I had one, and it crashed [...] I’d just leave it off. I don’t want to have to pay for the repairs,”* P10. However, the effectiveness of maintenance is a function of the expertise and diligence of the person in charge and available resources at the public facility—and the security efforts of administrators can still be compromised by user behavior [191].

Use of Second-Hand Devices Seven participants mentioned that they used second-hand devices given them by family, friends, or neighbors—usually smartphones, computers, tablets, and TVs, though one person mentioned a cleaning robot (*Grandpa gets the oldest phone. When they get upgraded, the phones trickle down. [...] I am thrilled with it, and it is too old for anyone else to use in that household,* P121). Refurbished computers were also mentioned.

Exploitation of used devices entails serious security and privacy risks, for both the previous owner (e.g., personal data disclosure, unauthorised access), and the new owner (e.g., malware and viruses). Moreover, due to ageing of the device models and operating systems, access to appropriate technical support and security updates declines, increasing vulnerability. However, no older adults among our participants mentioned potential risks of using second-hand devices, and only one mentioned that the previous owner reset the device, although it is not clear how effectively it was done (*"My friend did give me her old Mac. So I need to set that up. She wiped hers out. It's an older one, but she was using it for school, and she did video chats and everything on it, so it's very up-to-date. I don't need the latest,"* P36).

7.5.2 How Older Adults Manage Privacy and Security Risks

Similar to previous studies with older adults [137, 143, 144], participants hold a range of attitudes about whether privacy and security concerns can be addressed in the current environment, which affects their attempts to mitigate those concerns. Some participants were pessimistic, believing that users have lost control over their personal information: *"I wish they would take the word privacy out of the dictionary. There is no such thing anymore. [...] I think it's the genie out of the box. I don't think it can be addressed,"* (P43). One reason for such fatalism is a perceived lack of control and transparency, which eventually leads to inertia in taking active security- and privacy-enhancing steps (*"I was thinking of cancelling my Facebook account but then I read that even if you're not a member, that they can get all kinds of information, so I don't know if I want to bother with that,"* P20). Another reason is lack of confidence in having the knowledge and skills to protect information (*"I'm not sophisticated when it comes to all these electronic gadgets and so I don't know what the possibilities are for control that is unavailable to hackers and thieves,"* P20).

Some participants explicitly attributed their attitudes to age (*"Don't forget, I'm old. And some things [...] you just sort of have to let go and you don't want to use your energy at it. [...] I want my information back and they say no, sometimes you just have to go ahead [...] Not everybody can fix everything. You just have to live with the consequences. That's why you shouldn't be saying nasty things on the Internet, because it comes back to haunt you and you can't fix them,"* P107).

Other participants are more optimistic—or at least less fatalistic and discuss how privacy can or should be restored and protected (*"I value privacy. I don't necessarily want anyone who wants*

information about me to be able to get it too easily, and too cheaply. If they are going to get it, I want them to work for it, and pay for it, as a way of discouraging them," P113).

Passive and Active Mitigation Strategies

TABLE 7.3: Mitigation and coping strategies.

Mitigation strategies	Description	Supporting quotes
Passive strategies		
Limiting or avoiding technology use	Refusal to keep personally controllable data online or in digital format; to engage in activities like online banking, online shopping, or social media; or to use devices in general.	<p><i>"I guess whatever [a computer] knows about me is whatever I have put in or somebody else has. [...] That's why I continue to not use online banking or online payment services,"</i> P25; <i>"I don't want [my financial information] on the Microsoft cloud, I don't want it on the Apple Cloud. I want it on a hard drive that I know is on that computer and the portable hard drive that is hooked up. I don't use a wireless backup, a cloud back up. So I guess I am really concerned about anything that has financial information on it,"</i> P123. <i>"I am not counting on protection of my privacy. [...] I do not use Facebook, I do not use any social media at all,"</i> P121.</p>
	Even when participants are not sure about specific risks or do not believe negative consequences are likely to occur, they still sometimes prefer to take precautions.	<p><i>"I would do a 'like' [for political candidates on social media] [...] and now I've decided not to do that because you just don't know what's being captured. And not like anything bad's going to happen to me, you know what I mean? I'll [not] get stopped at the border or something. [...] I mean, that's far-fetched,"</i> P104.</p>

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Table 7.3 – continued from previous page

Mitigation strategies	Description	Supporting quotes
Using services and devices with good reputation or brand image	Reliance on manufacturers to ensure security protection; confidence that a product with reputable name is safe against security threats.	<i>“I trust Apple more than most anyone. [...] if you sign into iCloud, if you have that two-layer security turned on, whatever that is called, that’s pretty secure stuff,”</i> P123; <i>“The nice thing about using Apple, Linux is the system I use, is that there aren’t hackers like there are with Windows. Windows everything gets hacked so you have to have an anti-virus, an anti-something-else, and you have to have the firewall. My Mac has two firewalls and that is all I need,”</i> P25.
Trying to be cautious	Self-censoring of the transmitted content.	<i>“I’m aware that there is no privacy, so I would never say anything on my phone or put anything in an email that I felt was in some way exposing me to liability or whatever,”</i> P121.
	Development and application of the methods to recognize suspicious content or untrustworthy intentions, e.g., in online dating.	<i>“I try to be very careful with what I get on my email. I don’t indiscriminately open every message I get. If it’s not a name I recognize, I delete it, I don’t even open it,”</i> P110; <i>“He’s real rich, and he’s so handsome. [...] He writes down pages and pages, [...] as far as ‘You make my life complete’ and he hasn’t met me yet! [...] So after a few times, I said ‘You’re too good to be true’ and that sets off a red flag,”</i> P13.

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Table 7.3 – continued from previous page

Mitigation strategies	Description	Supporting quotes
Accepting or ignoring the risks	Unawareness of privacy/security risks, consequences, or protection means; personal information as unavoidable tradeoff in exchange for safety, or “free” Internet services; high financial cost, time and effort required, or questionable effectiveness of a remedy.	“One of the advantages of living in [an assisted living facility] is that they have your complete records, and are in touch with your doctor,” P121; “Facebook is free. In exchange [...] you give up all this information because it goes to advertisers. [...] So lots of different things that used to be [...] technically free, they never really were, they were all monetized,” P71; “I would have to find out what I could do regardless of what they are doing. I wouldn’t know. Am I going to delete something from the computer? I’m capable of doing that? [...] of doing what needs to be done,” P107.
Active strategies		
Authentication mechanisms	Passwords, screen-locking PINs, two-step verification, and biometric authentication.	“They are working on some login IDs that you know, it is almost impossible to break because it would take almost a million years to be able to calculate the different numbers to get the password to get into it so hopefully they are working on that, to get that accomplished,” P33.
Configuring settings	Declining of location sharing permissions, deleting of cookies, managing audiences.	“I only have GPS on my phone when I need it. Nobody needs to know where I am—like MoviePass. MoviePass.com apparently wants to know where you are”, P104), managing cookies (“I have set [Mozilla] Foxfire [sic.] so that when I close [it], all the cookies are deleted,” P108; “You can have a universal setting [on Facebook] and then when you post you can change that for the particular post,” P108.

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Table 7.3 – continued from previous page

Mitigation strategies	Description	Supporting quotes
Protective software and services	Anti-virus, ad-blocking and online anti-tracking programs.	<i>“Well after being hacked, I don’t know if [...] it can really be secure. I mean you purchase this anti-virus stuff that you put on there but it seems like they are not able to do the work. If someone is bent on wanting to get into your data or whatever device. That is pretty freaky,”</i> P5; <i>“I don’t think you have much choice. You can block an ad on Facebook but then you’ll just get a different one,”</i> P108.
Active management of personal information	Refusing to provide personal information; providing fake information or dummy email addresses; deleting of personal records.	<i>“I never give them my correct personal information. Just email. And a email is just set up for [contests],”</i> P104; <i>“As I learn how to use it, I will delete what I didn’t feel comfortable with. If it wasn’t applicable to me. [...] If it wasn’t useful information, I would delete it,”</i> P60.
Discontinuing the service	Unsubscribing, discontinuing, or simply abandoning a service.	<i>“If you put the freeze [on your account with a credit bureau], nobody can use your name to apply for new credit card. And then if you know something happens, just close the account, right?”</i> P103; <i>“My daughter got me a Facebook account. [...] When she set it up, we went on it together, and I haven’t been back,”</i> P15.

We categorize the end-user security and privacy management strategies participants talked about along a scale of *passive* vs. *active* approaches.

One of the most commonly mentioned (28/46) passive mitigation strategies was to limit the use of technology or to avoid it altogether—sometimes causing notable inconvenience to the non-user. Other passive strategies included using services and devices with good reputation or brand image, and trying to be cautious. While generally benign, relying on such passive strategies is a double edged sword. For example, relying on caution is subject to overconfidence bias [192], and depends on the user’s vigilance, knowledge, and skills in detecting malicious actions and

predicting the consequences of their behavior [193]. As we described earlier in §7.5.2, many participants mentioned simply accepting or ignoring known risks.

Active mitigation strategies include configuring privacy and authentication settings, using protective software and services, or deleting or refusing to provide personal information. Many participants mentioned strategies that mitigated the consequences of violations rather than the causes, such as blocking unwanted contacts or content; others mentioned discontinuing their use of devices or services after experiencing privacy or security violations. We provide more details about these strategies, with supporting quotes, in Table 7.3.

The Role of Usability and Learnability

Our participants often explicitly viewed themselves as vulnerable to privacy and security threats because they have trouble using and configuring new technologies by themselves and/or because they know less about how the technologies work.

Usability, Learnability, and Risk Participants mentioned obstacles related to usability and learnability of privacy and security functions, often resulting from or amplified by general usability issues.

Despite their prevalence, passwords suffer from well-known usability issues [194–196], such as needing to be memorized and changed (*“I have a list of [passwords], and sometimes the computer will remember them which is helpful and then sometimes not. I have it written down and sometimes they make you change the password and I forget to write it down,”* P6). Participants had a variety of strategies for dealing with this. Most such strategies are commonly viewed as poor security practice (writing down, re-using, choosing simple/guessable passwords). Many participants were aware of this, but could not effectively implement all of the sometimes conflicting security advice they had heard (*“I use the same password for everything and I have used the same password for years. Even though we have been advised not to do that. [...] It’s hard enough for me to come up with a password that I can remember and not write down—they tell you not to write it down so I don’t do that,”* P110).

Besides authentication, other participants mentioned potential privacy-relevant usability issues like accidentally activating voice control on a phone or not being able to figure out how to sync email so a message could be deleted on all devices at once. In addition to a general feeling of

lost control or absence of mechanisms to exert it, several participants doubt that offered controls would be usable (//I: “What if the system will give you control over the information so you can decide who can access it? [...]” P: “That’s just too much trouble. [...] By observing other people with computers, they are always messing up. [...] It’s not just push a button and have it do what you want,” P1).

Delegation of Privacy and Security Management A related issue is that older adults often involve others in managing their privacy and security (e.g., configuring settings), and may hand it over completely to family members, someone in their community, or technical experts (“It’s called Touch ID? [...] Yeah, I think I’ve heard of that, but my son did not set me up for that,” P103). Delegation of security maintenance is a common practice among the general user population [197, 198], but due to especially limited digital literacy and experience, it may occur more frequently among senior users [199].

Older adults’ need to turn to others for help with non-security-related technical issues (e.g., general setup and maintenance) can have security consequences. (Table 7.4 provides a general overview of older adults’ tech troubleshooting strategies and issues that arise with each.) For example, sometimes older adults share account credentials with family members, friends, and (professional or volunteer) technical assistants [200]. One such community “technical assistant” commented: “She didn’t mind if I put [her] Amazon account in [my] phone, the credit cards and stuff, but I didn’t want to get my Amazon account confused with hers, that’s for sure,” P123.

TABLE 7.4: Troubleshooting resources used by participants.

Troubleshooting resources	Comments	Quotes
Providers	Older adults in our study most frequently look for help from the service provider, the device manufacturer, or the store/vendor. In some cases, they find these sources satisfactory.	“The iPad, I went down to Apple, they’re always crowded but I went very late and um, I was there for like an hour and a half and they got it—you know, they updated it. So, I think they do a good job because as you say, if you buy equipment and you can’t get it to work, it’s very frustrating,” P44.

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Table 7.4 – continued from previous page

Troubleshooting resources	Comments	Quotes
	However, some expressed reservations about how much time it could take to get help, or irritation at having to deal with chat bots or non-native English speakers.	<i>“What happens frequently [...] you have a question, an issue, and you’re offered live chat. [...] Which really isn’t a chat, it’s sort of a messaging. I hate it. I cannot, I won’t go near it. [...] I want to deal with humans,”</i> P15.
Personal network	The first call many participants make is to children, relatives, neighbors, or others in their personal network. Some of these helpers are (or were) computer or IT professionals; in other cases, they may only just know more than the participants themselves.	<i>“I have a guru that lives in southern California. I mail him stuff, we just sent him my computer, the hard drive just died. [This guru] it’s my son! He’s my computer expert. I want a new computer. I have a new computer. He sends it up, all installed. All I have to do is plug it in,”</i> P77.
Freelance or volunteer technicians	Several participants also mentioned computer experts they frequently call on—either paid technicians, or volunteers at a senior center or library. Some volunteers are also older adults, who provide help to others in their senior programs or housing facilities.	<i>“Okay, depending on how- how bad a technical issue it was- we used to have a guy that - our place provided somebody that used to come to - to help people with technology. You know, or to teach them how to get around,”</i> P36.
Do it themselves	Participants may first try to set up the device or solve the problem themselves, either relying on their prior knowledge or searching online for how-to videos, instructions, or help forum postings.	<i>“I figure them out [the technical issues]. If I don’t figure them out, there are one or more persons that I could call,”</i> P21.

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Table 7.4 – continued from previous page

Troubleshooting resources	Comments	Quotes
	Less frequently, they may try to find answers in the instruction manual, but some find manuals confusing or opaque.	<i>“The instructions have to be a, b, c, d, and e. You can’t just do a and b and skip c and go to d and e. [...] Smartphones don’t always tell you everything that the phone can do. You have to figure it out yourself. I have trouble with that only because it’s so complex,”</i> P35.

The Consequences of Delegation for Learning Although relying on relatives and acquaintances to take care of technology setup and maintenance, including privacy and security functions, works for some participants, others discussed the difficulties such reliance can create. In particular, children or other family members might not have enough time to help, or when they do, might try to forestall further needs by discouraging older adults from fully using the technology. Limited explanations may leave older adults with an awareness of privacy and security risks but few details on how they come about (*“My son is very good protect for my computer, not everybody can get it. It’s very security for that. He just don’t want me to check this, check that, get a virus. [Interviewer: So how does he protect...?] I don’t know,”* P16). These issues emphasize the need for older adults to have independent channels for learning about and troubleshooting technology.

A few participants acknowledged explicitly that relying on others to set up and troubleshoot devices means they don’t have much understanding about how they work (*“It’s just part of my resistance to technology. [...] [The paid technician] is a smart guy and I don’t have the patience to unravel it if it is not doing what it is supposed to do,”* P8).

A few said they just aren’t interested in learning (*“I kind of just decided that I’m not interested in learning a lot of new technology,”* P77), but even those who are interested can find themselves falling back on asking others to solve problems for them (*“I belong to the computer club. [...] I’ve gone to their picnics a couple of times, but if you belonged to the club you have someone that will come and help you if you have problems with your computer. I don’t have to know that much about it if I have a problem,”* P5).

Sources of Information on Risks and Mitigation

Even participants who had not been targeted for specific privacy or security attacks seemed generally aware of potential issues and described sources where they learned about risks.

News media, for example, is a common source. Given the timing of the interviews (May–June 2018), Facebook's recent Cambridge Analytica scandal [201] came up frequently (*"Judging from the recent things that have come out with Facebook and Mark [Zuckerberg], I realize that whatever you type in, goes out"* P32). Several participants mentioned having heard about Alexa mistakenly sending a private conversation to a random contact in their address book [202], as well as other stories about identity theft, data breaches, and data brokering.

Stories are sometimes accompanied by tips on how to avoid such scams or mitigate consequences of larger incidents, especially in publications for seniors such as the *AARP Bulletin* (*"Sometimes when [the service provider says], 'You should change your password. Your identity may have been stolen,' or something like that, then I would change my password. [...] Or, you know, on TV they would make that suggestion,"* P13). Data breach notifications from companies did not feature prominently in our interviews.

When the mitigation against a particular incident is fairly simple, these channels seem effective. However, more general or complicated stories sometimes leave participants confused about the actual pathways data can take, and with a garbled or incomplete idea of how to protect themselves (*"Well I, reading in the paper that there are these search engines and when they can get into computers [...] especially through Wi-Fi so I have Wi-Fi turned off,"* P108).

Another source of information about risks and mitigations is materials, classes, or lectures targeted specifically at older adults. Computer classes we saw advertised for seniors contained some privacy and security content.

Several participants mentioned having attended or heard about talks on how to avoid scams; for those, the relevance was generally clear (*"They have seminars on [...] how to avoid being scammed. [...] [I: Do you believe that it could happen to you too?] Yeah, why not, sure, but..."* P7). But in other cases, participants did not make the connection between lecture content and consequences for their data (*"Somebody came and talked about the cloud. What is it, what does it do, you know, that kind of thing. I went and I thought I don't need all this. [...] I just look things up and send a few emails and that's about it. I don't care about anything else,"* P5).

7.5.3 Notable Misconceptions and Blind Spots

We identified common misconceptions regarding technology, data collection and sharing, and protections that could lead to formation of inaccurate privacy and security threat models, or increase older adults' vulnerability to such risks.

Uncertainty about Information Flows

Uncertainties about how and what data is collected, transferred, and used are common in the general population [203] and among our participants in particular. In addition to lack of transparency about data practices in devices' design, lower technical awareness and experience can aggravate the proliferation or extent of such misconceptions among the elderly.

As noted in §7.5.1, some participants expressed uncertainty or incorrect assumptions that technology only collects information users input themselves, and had limited awareness about the extent of passive or implicit data collection that may happen without active user participation (*"I like to think that the smartphone only has in it what I put in it. Now I could be dead wrong but I like to think that,"* P22; *"I don't see my phone capturing my data, unless—what I enter,"* P104). In contrast, some assume that virtually everything is collected, shared, and retained, which can lead to fatalism or resignation (*"Apparently they can track, from cell phones and cell phone towers they have a record, they can piece together so much about you,"* P113; *"I am hearing all these things about gathering knowledge on people. I don't know if [the wall sensor detecting falls] would be able to pick up conversations, pick up information,"* P34).

In a couple of cases, misconceptions about data collection were due to uncertainty about which devices are Internet-enabled (*"I am assuming that [a smart speaker] is not really connected to the Internet. It has to do with information you put in, so I wouldn't worry about what information they had about me. [...] [I: ... It is connected to the Internet.] [...] Okay well I am wrong then, then it will know a lot more,"* P46). However, it was rarely so clear whether our respondents thought data collection was happening on-device or being sent off-device. Although studies have shown [204] that this is an important distinction for users when asked about it explicitly, our study participants did not specify it unprompted.

Data flows in emerging technologies are especially opaque for older adults as they may be less familiar with the state-of-the-art sensors and algorithms, or advances in artificial intelligence,

compared to the younger population who may learn about it through education or work channels [205]. They may base their assumptions about how devices work—and therefore their privacy mitigations—on analogies with more familiar technology (I: “What kind of information would you expect the devices to collect about you? [...] What about the smart speaker? [...]” R: “Answering questions. I have begun to use this feature in the phone. [...] So, I guess what the smart speaker would do would be anything that the smart phone can do and then maybe more. I don’t know what that might be,” P60)—cf. [206].

Uncertainty about Data Persistence

We also identified misconceptions about the effectiveness and extent of data deletion. A couple of participants said that when they delete a file or an email, they believe there’s no longer any record of it, while in practice it is still locally stored and was simply moved to a “trash” folder. The feedback they receive from synced devices (when working correctly) reinforces this belief: when email is deleted on a computer, you can no longer see it on a mobile device, suggesting that it was deleted permanently (“It is all connected. Once I delete it [on the computer], the phone is also,” P7).

Several participants believed that data is overwritten rather than stored permanently on the device or in a digital database. Sometimes these assumptions are based on analogies with older or more familiar technologies. As one participant described, “I thought it was just... like recording over the tape [...] like where you used to tape programs from television. If you recorded over that tape, you wiped out pretty much what had been said or done,” P35. A couple of participants were also surprised about the duration of data retention (“I hadn’t even thought about [apps] collecting [personal data], or where all that stuff goes. I think it’s only me hearing it. Phew. Is a record of that around forever?” P123).

Some participants assumed that the log available for their review is a complete record of the information collected by the device (i.e. what their phone shows is all this phone collected): “There’s nothing that is recorded. [...] The only thing the phone would show is who called me,” P110.

Blind Spots in Mitigation Strategies

Beyond data deletion, misconceptions about data flows and persistence, or about security mechanisms, may lead to older adults relying on other ineffective means of protection, or using protection strategies ineffectively.

Several participants mentioned not being sure about the effectiveness of their strategies (*"I gave money to a firm that said that they would provide some protection for my bank account, brokerage account. I don't know whether really that they would be that effective. [...] Probably a waste,"* P51). In extreme cases, the "security service" turned out to be a scam or ransomware attack, for example, (*"I got a call from some outfit [store] that said that there was [...] some billing that had been done on my account from Russia. [...] And I said I didn't order that. [...] They persuaded me, which was an error on my part to buy some service from them and I bought the service and then I was told that that service offering was a scam,"* P20).

In contrast, some other participants may be overly confident about the effectiveness of the mitigation strategies they use, or due to lack of knowledge, consider less technologically advanced threat models. Such overconfidence may lead to neglecting security advice or reducing protection efforts: (*"The nice thing about using Apple, is that there aren't hackers like there are with Windows. In Windows everything gets hacked so you have to have an anti-virus, an anti-something else, and you have to have the firewall. My Mac has two firewalls and that is all I need. [...] I think they come installed,"* P25).

Even when participants were aware of threats, they often did not know how to effectively protect against them. For example, P22 said *"I try to change my passwords regularly. And a lot of my passwords are so obscure I would be surprised if anybody could figure them out, although I know that they can be figured out. The references in my passwords are to things that nobody would associate with me. [...] And the numbers are things that you would really have to dive deep to find a reference to them. So that's how I try and protect myself"*. When choosing her password, she did her best (to the extent of her abilities) trying to make it harder for a lay person, presumably knowing some basic information about her, to guess it. However, such passwords may not at all be "obscure" for a hacker using brute-force, key loggers, or a man-in-the-middle attack. Although P22 acknowledges the possibility of violation, it is hardly in her control (and definitely should not be solely her responsibility) to protect from such attacks.

Several participants also mentioned strategies that mitigate privacy and security consequences, rather than the risks themselves. However, they did not necessarily recognize that these strategies are not addressing the causes of the threat—or were not concerned that they do not. For example, a participant mentioned blocking telemarketing calls (*“I also have a call blocker on my phone. So I got rid of those unwanted calls [and] robocalls,”* P110); the participant was satisfied with the strategy, but of course a call blocker does not remove personal information from call lists. A few participants acknowledged the ineffectiveness of mitigating consequences in addressing root causes, but said they felt helpless to find a better solution (*“You lose control once some outside agency has information. I am unable to stop the flood of phone calls whose origin and purpose I cannot imagine. The only thing I can do is what one daughter-in-law suggested—don’t answer it,”* P69).

Unsubscribing, discontinuing, or simply abandoning a service can be as ineffective in addressing the root cause of the risk as mitigation of consequences. And when not done properly it may even increase exposure (e.g., abandoned accounts are often used for social engineering attacks and identity theft [207]) (*“The other [incident of identity theft] almost had to be dishonest people that can view credit bureaus. Because a couple of accounts that we had zero balance on, we had cut up the credit cards, we had not closed the accounts,”* P123).

Finally, mitigation strategies are a completely blind spot against risks participants do not even recognise, for example, when using public or hand-me-down devices (see §7.5.1).

Belief They Have Nothing to Hide

Echoing the “nothing to hide” fallacy [208], commonly recognised in the privacy literature, many participants felt that an honest person that has nothing to hide should not feel a need to protect privacy (*“I have no nefarious activities, so I have no problem,”* P121; *“I’m not that sensitive. I’m very ‘open book’ person,”* P31). Similarly, some participants do not recognize the potential risks of personal data misuse (or underestimate the probability of its occurrence) if they do not find this information sensitive or worthy (*“Who would really care how many steps a day I take? [...] I can’t see how anybody could use that information to make money. [...] Unless maybe they wanted to sell me some exercise equipment, like a treadmill. [...] I don’t see that as a realistic possibility of ever happening,”* P7).

One possible explanation why these misconceptions occur is that participants often rely on the assessment of reputation damage and overlook broader security risks that lead to material and financial consequences, or physical safety threats. Although not unique to the older population, this misconception was quite common in our interviews, so we believe it is important to consider when designing privacy and security interventions for older adults.

7.6 Discussion and Implications

Our findings demonstrate that certain privacy and security risks are amplified for older adults. Our participants were concerned and confused about data flows; yet unaware about potential threats such as use of public and secondhand devices; and provided insights on barriers to learning about, understanding, and using privacy and security protections, which are heightened by memory decline and physical limitations. In particular, we find that the sense of difficulty in using technology—whether older adults attribute it to user-unfriendliness or to their own lack of skill or knowledge—led to a lack of self-efficacy about privacy and security. Therefore, addressing those barriers is an important basis for empowering older adults to use technology more safely and comfortably. Based on our findings, we provide recommendations for providers of security awareness programs and education and for technology designers. We further discuss potential future work.

7.6.1 Suggestions for Awareness and Education Programs

We find that many older adults lack a nuanced understanding of ICTs and the data they collect, leaving them especially vulnerable to privacy and security violations. Their particular concerns, misconceptions or blind spots could be addressed through tailored training and educational efforts.

Expand educational programming. Existing programming that older adults find valuable, such as computer classes, lecture series, or computer clubs, can be expanded. We recommend developing security and privacy materials *specifically designed for this age group*, in collaboration with trainers and older adults themselves. In addition to scams, such materials should address issues of most concern to older adults, such as surveillance, and misconceptions about data collection, persistence, and sharing. Engagement in social media, including dating websites,

should not be overlooked. Risks of using public or hand-me-down devices, and how to mitigate them, should also be considered.

Targeted materials will allow those leading the classes to more easily tailor them to seniors' needs—including making the necessary connections between technical facts and practical consequences, so that seniors better understand the relevance of the technical details.

Leverage existing points of contact for outreach. Privacy and security information for older adults can be disseminated via channels they already use to get help with computer problems (Table 7.4), as well as resources they look to for general help and advice, such as publications or websites directed at seniors. Vendors and computer-repair experts could make age-appropriate privacy and security “checkups” a standard part of setup or troubleshooting conversations with seniors.

7.6.2 Suggestions for Technology Developers

Participants often avoided or discontinued the use of technology due to privacy and security concerns or violations, which also affect their intentions to purchase and use emerging technologies. Participants frequently linked their privacy and security behaviors to usability concerns (see discussion of passive and active mitigations in §7.5.2). This finding is an important illustration of the direct economic incentive for technology designers, developers, and manufacturers to address privacy and security concerns of older adults.

Improve transparency and control, address misconceptions. Security and privacy controls should be designed to account for misconceptions common among older adults (see §7.5.3), to anticipate and address respective risks. Incorporating privacy controls *where the default is the most private setting*, as older adults rarely configure them [209], is a first, basic structural change.

Standardizing and being upfront about the types, amount, and granularity of information collected and shared may enhance older adults' awareness and reduce the likelihood they will discontinue use after being surprised by a perceived privacy violation. Device descriptions and apps should make clear when information is sent over the Internet (rather than processed on-device), and where possible should incorporate data-transmission indicators [171, 210, 211].

Address usability issues and improve system design. Interfaces should be designed to optimize senior users' ability to authenticate, configure settings, and accomplish other security

tasks without errors in a reasonable time. For instance, usability issues associated with aging-related ability declines, such as reduced vision and acuity, hand tremors, memory worsening, and lower skin conductance [212], may complicate authentication management [213] and may lead older adults to choose less secure mechanisms (e.g., avoiding two-factor authentication to reduce the burden of reading text). To address the identified usability issues, designers can rely on expansive knowledge and guidelines in that area [214]. For instance, by adding security indicators of “trustworthy” applications or by providing default configurations for data backup [215]. Designers and developers should focus on facilitating information management (e.g., editing and deleting personal records). Companies should involve older adults in the development process through participatory design and usability testing.

7.6.3 Future Work

Some of the patterns we identified in our exploratory qualitative study merit further systematic exploration, to determine how general they are and what the concrete consequences are, such as older adults' uncertainties about data deletion and retention, or their use of public and secondhand devices. Consequences of those behaviors could be assessed in controlled behavioral studies. For example, it is not yet clear how the issues we identified affect older adults' privacy and security behavior compared to the general population, e.g., regarding the propensity to agree to data collection that goes against their general preferences, or whether older adults' security and privacy management strategies are more or less effective than those of the general population.

Older adults' use of emerging technologies, especially healthcare technologies, also warrants further exploration. Due to concerns that older adults might have less understanding about the security and privacy of new technologies and how to manage them—especially due to potentially amplified usability problems—we included questions about such devices and apps in our interviews. While many of our participants used such technologies, or had heard of them, their use and knowledge was sufficiently heterogeneous that clear themes did not emerge. Further research is needed to examine specific privacy and security questions about older adults' use of these technologies in greater depth and at larger scale.

Finally, the measures we recommend should be tested “in the wild” to determine their efficacy. For example, we might test whether having targeted training materials improves educational programs and can positively impact older adults' privacy and security behaviors; or whether

more transparency about data collection and sharing improves their comfort with using an app or device. Of particular importance would be age-specific usability tests of enhanced privacy and security controls, especially for new types of technologies such as healthcare and other monitoring devices.

7.7 Conclusions

As the population of older adults grows and turns their attention to technology, (including emerging, interconnected, and Internet-connected devices) systems will need to be designed to enable informed choices, better control over personal data, and improved security for this user group.

Through semi-structured interviews with 46 older adults, we identified a variety of privacy and security attitudes and concerns, threat models and mitigation strategies, common misconceptions, and usability issues of currently deployed privacy and security controls. Although in general, the threat models and associated misconceptions mentioned by older adults are also common among the younger population [174, 175], we confirmed that, due to relatively low technical knowledge and experience and age-related declines in abilities, older adults may be particularly vulnerable to certain risks and experience difficulties in mitigating them. We also shed light on the role of health and living situations and financial considerations.

Emerging technologies featuring smart sensors or machine learning algorithms were especially concerning for our participants; data flows were difficult for participants to understand, likely because of their opacity. Participants specifically mentioned concerns about passive data collection and the privacy of bystanders. In addition to these concerns, participants also mentioned concerns over the disclosure of sensitive economic and health conditions, which could be accelerated by the proliferation of e-health, health-monitoring systems. Participants mentioned that such disclosures may endanger benefits they might otherwise receive, such as social security, disability allowance, insurance coverage, and eligibility for senior housing or assisted living facilities.

Residents of senior care facilities often acknowledged their resignation to the loss of privacy in exchange for care and safety. For seniors living independently, balancing the tradeoffs between care/safety and privacy is an open dilemma, as it conflicts with their desire for independence.

Age-related ability decline amplifies usability problems found in many current privacy and security controls. For instance, due to memory decline, it is harder for seniors to remember passwords or to follow security advice than for younger people; due to vision problems, skin conductance, and acuity decline, it may be harder for seniors to interact with small-font text or touch-screens or biometric readers on smartphones.

Finally, we found that one of the most commonly mentioned approaches to mitigating privacy and security risks was to avoid or limit using the technologies. This finding suggests that businesses offering devices or services targeted to or used by older adults may accrue economic benefits and gain a competitive advantage by considering the opinions and addressing the concerns of this population.

Chapter 8

A systematic literature review of design guidelines for older adults

We next present a systematic literature review that we conducted to investigate the research-derived design guidelines that set the foundation for design guideline compilations and standards. We analyze them from the perspective of experts trying to discover, classify, and evaluate the work on the area of research-based touchscreen design guidelines for older adults. The review includes 52 research articles resulting in 434 research-derived design guidelines for touchscreen applications. These guidelines are analyzed using a taxonomy that considered the ability changes addressed, and the design aspects that are target of the recommendation.

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The distinct abilities of older adults to interact with touchscreen devices has motivated a wide range of contributions in the form of design guidelines, which aim at informing the design for the aging population. However, despite the growing effort by the research community, many challenges still remain in translating these research findings into actionable design guidelines, with reports hinting scant adoption or implementation issues, which ultimately hurt the development of more accessible interactive systems. In this systematic literature review we look at the research-derived design guidelines that set the foundation for design guideline compilations and standards, analyzing the aforementioned issues from the perspective of experts trying to discover, classify, and evaluate the work on the area of touchscreen design guidelines for older adults. The review analyses 52 research articles resulting in 434 research-derived design guidelines for touchscreen applications. These guidelines are analyzed using a taxonomy that considered the ability changes addressed, and the design aspects that are target of the recommendation. The results point to the use of different definition of older adults, which go as early as 55+, with design of displays and interaction styles to accommodate to vision and dexterity declines as the most prominent areas of research. However, proposed guidelines and recommendations were validated in only 15% of articles analyzed. The analysis also revealed that identifying guidelines and characterizing their focus in terms of ability declines and design aspects addressed is a demanding activity and prone to error, given the quality of reporting and details offered in research articles.

8.1 Introduction

Older adults are turning their attention to interconnected devices as attractive means to stay in contact with family, friends, and the world around them, bringing significant benefits, especially to those who are less able to interact physically with others [216]. In particular, they turn to mobile touchscreen technology [217] as it can be more intuitive, regardless of the user's age [218]; furthermore, such interfaces allow for essentially “complete freedom of design and interface options” [219] as they are not limited by physical buttons or similar hardware. More intuitive interactions can then better support the use of such devices and related applications for older adults and, thereof, increase their access to digital products and e-services [220].

However, interacting with touchscreen devices and applications poses many challenges for older adults, including usability and accessibility issues. More than for any other age group, for older adults these challenges result in frustration and anxiety [216, 221–224].

The specific challenges of older adults in interacting with devices has motivated a wide range of research contributions in the form of design methods and guidelines for making devices usable and accessible for this population [81, 82, 225], for instance, by providing a voice-activated dialing for people with limited hand dexterity [226], text entry for older adults with severe visual declines [227], or adapting gestures for interacting with touch based interfaces for age-related motor declines [228].

Nowadays we observe an expanding research in the field of human-computer interaction for older adults with an ever-growing list of research-derived guidelines published every year. Despite the potential of this research to inform the design of interactive systems, experiences validating and applying existing compilations of guidelines [212, 229–233] tell us that many challenges remain in using them successfully:

- Guidelines can be confusing, or become obsolete [229, 232, 234],
- Guidelines might contradict or appear to contradict each other [229, 235],
- They can be defined in concepts that are difficult to the designers [236–238], moreover, design guidelines and checklists become more complex over time [239],
- Importance of the guidelines, and which ones to enforce might not be clear [234, 240, 241],
- Older adults form a heterogeneous population group, which might not be always recognized by practitioners and reflected in the research [242].

As a result, despite the ongoing effort by the community, the potential of research-derived guidelines is still untapped, which seems especially crucial due to the large variation in the design recommendations for older adults and the related difficulty that practitioners face in identifying and applying them. This phenomena raises questions about the quality of design guidelines, and whether they are “consumable” not only by designers but also experts and makes it particularly important to organize and present them and to enhance their effective use [232]. Moreover, previous research has also confirmed that design guidelines benefit from being revised and/or expanded by the scholarly inquiry [239], and beside being “valuable and helpful”, they are still related to the “conditions of the study (population included, devices configuration, executed tasks)” [218], which should be taken into consideration upon deciding on applying them.

In this Chapter we look at the research-derived design guidelines that set the foundation for design guideline compilations and standards, analyzing the aforementioned issues from the perspective of experts trying to discover, classify, and evaluate the work on the area of research-based

touchscreen design guidelines for older adults. This is the first systematic review studying these issues at this scale and specifically addressing the following research questions (RQs):

RQ1. What are the characteristics of the older adult population and interaction design addressed by current research-derived guidelines for touchscreen? With this research question we aim at i) analyzing the different definitions used to describe the heterogeneous older adult population, ability declines and related design support, and also ii) gaining an overview of the specific populations and design aspects addressed by current state of the art.

RQ2. What is the quality of the methods and strategies used to generate and validate the design guidelines? We aim at assessing the process followed by the researchers in deriving the design guidelines (reliability), and the methods used to validate them (validity). By considering the strength of the evidence, we also highlight areas where more experimental research is needed.

RQ3. What issues emerge and what effort is required in identifying and cataloging research-derived guidelines, as to make them available to the average practitioner? This is an important question, as the quality of the reporting may affect the chances of guidelines being discovered and correctly interpreted. Thus, we also report on our experience in extracting and characterizing the focus of the guidelines.

This work attempts to improve the access to the existing research-based touchscreen guidelines by classifying them using a fine-grained capability model and appropriate design taxonomy and make current guidelines more useful for the practitioners, letting them have a better understanding of the importance of each guideline, how reliable it is, which of guidelines they need to enforce according to the target population and to the technology that will be used to run the application. Furthermore, increasing adoption of guidelines would result in more usable and accessible applications, and thus, benefits for older adults and population in general. Finally, this work aims at contributing to the research body by presenting a mapping of guidelines according to the proposed capability model, highlighting the abilities that are well covered, pointing out the gaps indicating where more research is needed, and calling attention to individual guidelines, identifying which ones of them are well supported and could be certainly enforced, and which ones are ambiguous, confusing, or contradicting.

In what follows we analyze the related work in accessibility of touchscreen interfaces for older adults, describe our systematic literature review and proposed taxonomy to categorizing final set of guidelines, and present our search interface for facilitating the access to them.

8.2 Background

Researchers have adopted different perspectives on the definition of design guidelines. Smith and Mosier [243] refer to guidelines as an encapsulation of expert judgment whose use varies depending on the user. Dix and colleagues [244] define them as the “direction for design, in both general and more concrete terms, in order to enhance the interactive properties of the system”. Stewart and Travis [245] instead refer to them as “sets of recommendations from software providers or agreed within development organizations to increase consistency of design and to promote good practice within a design process of some kind”. Informed by these definitions, in this systematic review we consider design guidelines as following: concrete recommendations that can inform interaction designers in the development of interactive software systems. We specifically focus on design guidelines derived from peer-reviewed scientific articles.

8.2.1 Prior Work on Compilation of Guidelines

Literature has emphasized the importance of design guidelines as precise and reliable recommendations to refer to while developing technologies for older adults.

Early attempts at compiling and validating them in user studies with older adults comprise the work of Apted et al. [246] where they describe the use of design guidelines for such touchscreen devices (in this case a tabletop) and that address general ageing related challenges, “losses in vision, cognition and motor skills”, in using them.

More recent works on synthesis and evaluation of design guidelines for a wider range of touchscreen devices present them based on usability problems older adults face, for instance, searching for information or issues with gestures, element complexity, or feedback [80]. Some of them aim at reducing “the gap between a designer’s conceptual model and a user’s mental model of the design” [81] and attempt to make them more applicable for the industry, for instance, providing a checklist of prescriptive design guidelines [82].

Other studies provide general summaries of literature on design guidelines [212, 247, 248] but do not provide a systematical analysis, such as deriving them from a qualitative empirical analysis of system and user interface (UI) requirements developed for older adults [249].

Summarizing, previous works focus on various aspects of older adults interacting with touchscreen technologies, either targeting usability aspects, or ageing related issues. However, there is a lack of works that would address the diversity of older population recognizing its heterogeneity, instead of defining older adults solely by age or common ability declines. There are also few systematic literature reviews of research based guidelines and no works that would systematically cover both the variety of ageing related ability declines and design categories of interacting with touchscreen devices. Hence, the main motivation for conducting a systematic literature review was to critically assess the current state of the art in the field of design recommendations for older population that experiences ageing-related ability declines. Through the analysis of current trends and gaps in designing for heterogeneous ageing population we aim to provide a snapshot of the current state in this area. In addition, we also address the need to review the methods for deriving and validating the guidelines.

8.2.2 Prior Work on Identifying Issues in Design Guidelines

Previous studies and literature overviews point out that design guidelines can be confusing, contradictory, and obsolete (due to the advances of technology), as it happened with Web Content Accessibility Guidelines (WCAG 1.0) [229]. In their website usability tests with disabled users, Romen et al. [229] empirically validated the usefulness of using WCAG as a heuristic for website accessibility and found that “the application of WCAG alone is not sufficient to guarantee website accessibility” but they rather should be applied in combination with other recommended lists of guidelines.

A number of studies conduct literature reviews to further evaluate current research based design guidelines. For instance, in such kind of study Zaphiris et al. notice that design guidelines can also be “too long, general and not too specific”, which makes them difficult to interpret and apply to a user interface by designers who might not even know “when and how they can be used” [232]. Previous studies also recognize that guidelines can be defined using concepts that are unclear to designers and do not always address their needs as recipients of this research-based guidance [236, 237]. Moreover, designers do not always realize the importance of guidelines, or if they do, they do not know which ones they should enforce [240, 241].

Some guidelines might lack a rigid clear structure and sometimes contradict each other, especially as the research in this area expands as well as “the likelihood of contradictory guidelines [...], creating significant accessibility problems for designers”, as has been noticed by Newell et al. [235]. For instance, Carmien et al. recommend the use of colours, icons, and graphics in displaying information and claiming that it should be prioritized over using text for older adults with vision declines [233], while Caprani et al. warn that displaying information by “grouping menus by colour alone can also lead to difficulties. Instead it would be preferable to use text, spacing or frames” [212].

The definition of target population addressed by the guidelines can also be misleading being described by age, while nowadays older adults form a diverse group with various levels of ICT skills and abilities. Vines et al. performed a critical analysis of 30 years of ageing research in HCI research community where they discuss the prevailing homogeneity of the older population group in HCI research. They found that the homogeneity is either expressed through comparisons between older and younger users or “the ways older participants are discussed in the method, findings, and discussion sections of publications”, for instance, as “retirees” or “grandparents” but without specifying the socioeconomic and cultural contexts of participants [242].

Studies on the evaluation of guidelines also raise questions about their quality and whether they are “consumable” not only by designers but also experts, and emphasize that it is particularly important to organize and present them in order to enhance their effective use [232]. Other studies on application of general guidelines, such as of Kim [234], report on their usability problems when “designers have trouble in accessing and retrieving relevant guidelines, thereby not being used as an integral part of the design process” and recommend to organize them in a multidimensional structure that would include both design and user factors. Inline with that, Petrovčič et al. [239] confirm that design guidelines benefit from being revised and/or expanded by the scholarly inquiry. Beside being “valuable and helpful”, they are still related to the “conditions of the study (population included, devices configuration, executed tasks)” [218], which should be also known to the experts and taken into consideration upon deciding on applying them.

A number of studies provide various taxonomies used to categorize design guidelines and it is reported that the scale of them increases over time [218]. However, there is no standard or commonly recognized taxonomy that could facilitate the access to current best research-derived

practices and simplify their application to the specific research and industrial projects targeting heterogeneous ageing population.

In their literature review, Petrovčič et al. [239] investigated the categories that were included in the mobile design guidelines and checklists, the most mentioned ones being related to selected visual and haptic issues (e.g., high contrast, font size, button type, button size, button positioning). By contrast, the least frequent were categories related to the elements of textual interface and to screen and menu aspects. Their results suggest that despite the increased complexity in terms of dimensions and categories, there have been many usability dimensions of age-friendly mobile phone UI design which could be better covered by the authors of the guidelines and, thus, warrant further development in the future. Petrovčič et al. confirm that validation in the sense of repeatability and reproducibility seems to be one of the weakest aspects of current design guidelines and checklists. In their literature review, “only half of them were validated in the original papers and even fewer used different empirical methods as a basis for establishing evidence that the guidelines had fulfilled their intended requirements”.

8.3 Conceptual Framework for Guideline Categorization

It has been recognized that software developers and designers targeting older populations do not always have access and/or understanding of research-based design guidelines for older adults [236]. Thus, a good starting point to understand the complexities of design guidelines is to analyze them from a perspective that can inform a design task: What practical considerations should I take when designing for older adults?. This requires us to consider the characteristics of the population targeted by the design guidelines, and the aspect of the interaction design that merit the recommendations.

8.3.1 User’s Capability Model

To characterize older adults, we consider the aspects that define an individual’s ability to interact with a system in a *user’s capability model*. In doing so, we aim at representing the diversity of the older adult population, and have a better understanding of the guidelines that should be enforced according to a specific target, a population with its own strengths and limitations.

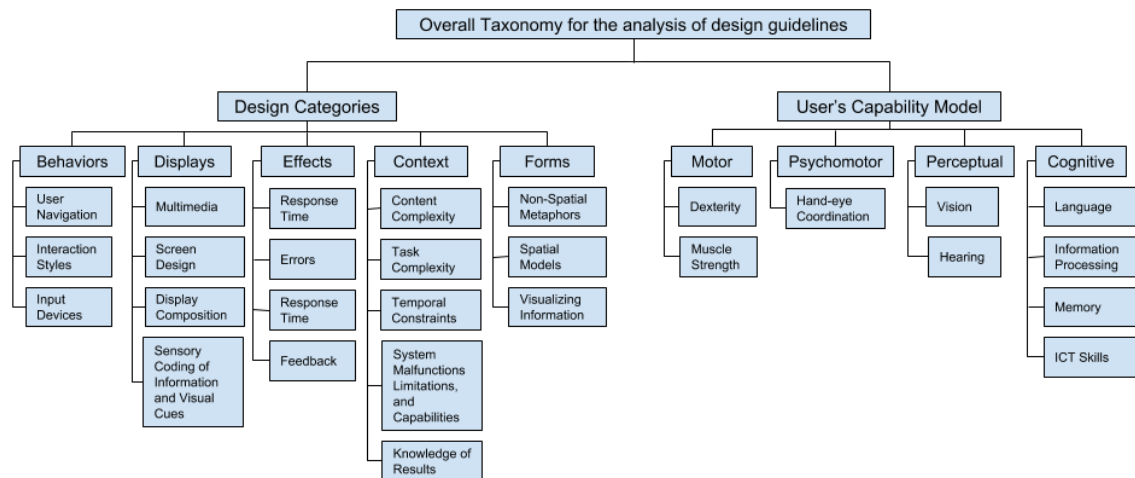


FIGURE 8.1: Taxonomy of the conceptual framework

For the user's capability model, in our opinion, the most suitable taxonomy for the purposes of this literature review should present ability categories in a function-based user modeling approach (as older adults might not have same level of abilities at given age), like the one proposed by [250] and chosen for this work. The user profile variables proposed in [250] are connected to specific user interaction abilities and constraints and further subdivided into perceptual, cognitive, and motor classes. In addition, during the process of guidelines categorization (and contacting guidelines' authors for a confirmation of our categorization, which will be discussed later), we found that the "hand-eye coordination" subcategory being in the "cognitive" ability category caused a lot of confusion, so it was moved into a separate "psychomotor" category following the taxonomy for the user's capability model defined by [212]. Considering those changes, our final user's capability model resulted into the following categories:

1. Perceptual abilities including vision and hearing as primary output modalities in manipulating touchscreen devices;
2. Cognitive abilities such as working memory, divided attention, and information processing speed, declines of which can significantly affect user's capacity to interact with technology;
3. Psychomotor abilities. Slowness and imprecision in motor control and declines in hand-eye coordination may make touchscreen input problematic for older adults and reduce their access to the technology itself;
4. Motor abilities, affected by a decrease in muscle strength and dexterity and resulting into mechanical difficulties in navigating touch based applications and devices themselves.

Thereby, we adopt user's capability model combining the models presented by Caprani et al. [212] and Peissner et al. [250] with additional dimension of ability decline severity categories.

We defined three ability decline severity categories as the following: "severe" for critical cases, such as color blindness for severe vision decline; "mild" for cases when decline could be corrected, such as minor memory problems; and "universal" specifically created for guidelines stated as fitting for both younger and older populations, e.g., providing a possibility to adjust the interaction depending on severity of specific case ("Provide a possibility to adjust the volume" [81]).

8.3.2 Design Taxonomy

In order to describe systematically the user interaction with touchscreen technologies, we were set to find and adopt the structure that would contain a wide range of related design dimensions. Our intention was to use this structure or design taxonomy to categorize design guidelines derived from the current literature review.

Various design taxonomies were considered, mainly coming from two sources, such as: industry, like design categories of guidelines proposed by Yahoo ¹, Microsoft ² or Android ³, and from academia, for example, taxonomy defined by [251], which consists of categories such as trust or motivation, or [252] that includes categories such "actions" and "objects". However, mentioned taxonomies were not adopted due to their specific focus on the interaction aspects strongly related to the devices. From another approach, traditionally, guidelines are classified in terms of abstract design principles [253], for instance, searching for information or using gestures [80]. This way of presenting them may make it challenging to select a guideline easily and apply it to the specific design issue older adults might face, which once again motivated us in finding a taxonomy that would provide concreteness and relevance towards covering specific design solutions.

Finally, the design taxonomy that we chose as the most suitable reflects the view that the user interface is composed of seven fundamental components: Actions, Behaviors, Contexts, Displays, Effects, Forms, and Goals [254], which cover both design and interaction dimensions users face while using touchscreen technologies. Actions and Goals were eliminated due to not being relevant towards user interface design guidelines; *actions* refers to traditional hardware

¹<https://developer.yahoo.com/ypatterns/>

²<https://msdn.microsoft.com/library/windows/desktop/dn742479.aspx>

³<http://developer.android.com/design/index.html>

components of processing, i.e., cpu, I/O, and peripherals; and *goals* represents the motivating forces behind HCI. The final selected components are the following:

1. *Behaviors*, which refers to the user's interaction styles with the system, its navigation, and information input. For instance, this category includes guidelines on gestures used when using touchscreen devices or possibilities of multimodal data input;
2. *Context*, refers to the settings in which the user behavior can occur and that have effect on the performance of users. Complexity of the system content and tasks related to the its navigation as well as the time needed to perform them are typical subcategories of "Context";
3. *Displays*, denotes the visualization of information for its own sake. Typical guidelines that belong to this category span topics such as multimedia used in the systems or composition of the content, and others related to the displaying information to users;
4. *Effects*, denotes feedback about the system actions as a response to the user interactions. For example, this category includes guidelines about error messages displayed to older adults;
5. *Forms*, refers to models or metaphors in which actions, effects and displays are embedded, for example, in relying on familiar notions to older adults when developing touchscreen applications.

The overall taxonomy proposed and used in this work can be seen in Figure 8.1.

8.3.3 Capability Model Evaluation by Healthcare Professionals

In order to evaluate the capability model and the distribution of the guidelines along the ability decline categories from the perspective of healthcare professionals specialized on ageing, we have conducted a focus group discussion (FGD) followed by a further expert evaluation by two with geriatric medical professionals.

A focus-group discussion (FGD) was conducted in November 2016 in English with 5 geriatric medical professionals: a physiotherapist, three geriatricians and a nurse. The FGD lasted for one hour and included the following topics: categories of the most common ageing related ability declines in their practise, the issues of older patients interacting with technology, their recommendations to touchscreen applications adapted to ageing population. The focus group

was given an introduction, explaining the general procedure and the importance of applying design guidelines in designing touchscreen applications for individuals experiencing ageing related ability declines. A description of the capability model and the overall categorization of the guidelines was also described.

Detailed summary of the qualitative results of the session was composed from the audio recordings by the corresponding researcher. Transcripts of the focus group were later analyzed, discussed and the findings cross-validated with a geriatrician and a geriatric nurse in the form of semi-structured interviews that lasted for 30 minutes and were also further analyzed and discussed by the first three authors of this study. Overall, healthcare experts provided a positive evaluation of the applied capability model in a given HCI research context. They have also commented on the specific ability decline categories that occur more often in their work practice, which we discuss in detail in the discussion section.

8.4 Methods

This study has been undertaken as a systematic literature review following the guidelines described in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [90].

8.4.1 Identification Phase

The first phase of our systematic literature review consisted of identifying the articles that should be reviewed. We limited our search to the databases that contain papers from conference proceedings and journals that we consider the most relevant to the areas of ageing and HCI (see Table 8.1 for the complete list). Additionally, we performed a wider search on the SCOPUS database, as to cover relevant work from other sources not present in the initial list.

For each database, we searched the titles and abstracts of every article for keywords related to the following topics: "older adults" (older adults, elderly, elders, ageing, aging, senior), "design guidelines" (design, guidelines, recommendations, suggestions, principles), and "touchscreen devices" (tablet, touch based, touch devices).

The search covered research articles written in English and published between January 2005 and November 2017.

TABLE 8.1: Sources of selected papers

Source	Type	Database
Universal Access in the Information Society	Journal	Springer
Gerontechnology	Journal	Gerontechnology
Computers Helping People with Special Needs	Conference	Springer
Australian Conference on Human-Computer Interaction (HCI)	Conference	The ACM Digital Library
OZCHI		
Human-Computer Interaction INTERACT	Conference	Springer
Behaviour & Information Technology	Journal	dblp
Computer Human Interaction (CHI)	Conference	dblp
Mobile HCI	Conference	dblp
International ACM Conference on Assistive Technologies (Assets)	Conference	dblp
International Conference on Advances in Computer-Human Interaction (ACHI)	Conference	dblp
International Journal of Human Computer Interaction (IJHCI)	Journal	dblp
ACM Transactions on Computer-Human Interaction (TOCHI)	Journal	dblp
BCS conference on Human Computer Interaction	Conference	The ACM Digital Library
ACM SIGCHI Symposium on Engineering Interactive Computing Systems	Symposium	The ACM Digital Library
Human-Computer Interaction	Journal	dblp
Computers in Human Behavior	Journal	dblp
Universal Access in HCI	Conference	Springer
Computers Helping People with Special Needs (ICCHP)	Conference	Springer
Assistive Technologies	Journal	The ACM Digital Library
HUMAN FACTORS	Journal	dblp
Procedia Computer Science	Journal	Elsevier
Educational Gerontology	Journal	Taylor & Francis Online
Interacting with Computers	Journal	dblp
Ergonomics in Design	SAGE	dblp
International Conference On Neural Information Processing	Conference	Springer
International Conference on Software Development and Technologies for Enhancing Accessibility and Fighting Info exclusion	Conference	dblp

8.4.2 Screening Phase

At the screening phase, we evaluated, to a deeper level, which of the identified articles could contain useful content for the systematic literature review. During this phase, three researchers independently screened the content of each article and tagged it with either *Yes*, *No*, or *Maybe*, where *No* indicated that the article did not contain any useful information, and *Yes* and *Maybe* indicated that:

- The article could contain design guidelines⁴ applicable to touch devices, or
- The article could address interaction design issues targeted to older adults⁵, or

⁴researchers considered the definition of design guidelines that is explained in Section 3

⁵in this case older adults may defined either by age, for example, 65+ or 60+, or with ability declines related to aging

- The article includes older adults as participants in their study group.

Articles tagged with *Maybe* and disagreements were resolved in face-to-face discussions between all three researchers for the final list of included papers. Papers deriving recommendations for specific applications (and not generalizable) or that gave guidelines exclusively for hardware design were discarded.

8.4.3 Eligibility Phase

At the eligibility phase, each article was evaluated in detail. For each article we extracted the proposed guidelines (if applicable) and the details of the studies that either conducted to and/or validated those guidelines. During this phase, articles were also removed from the systematic literature review if the proposed design guidelines found in them were considered as design principles, hence, too general for this work, or confusing for the experts (coders) to interpret.

In order to keep records organized during the classification and filtering process, we applied several data management tools. As a tool for an easier collaboration and collective work, online Google spreadsheets were used to store the records obtained from reviewed articles as well as to discuss the data and make annotations. More specifically, during this phase two forms were used:

- A form to store the extracted design guidelines and the name of the article from where they came from.
- A form to store information related specifically to each selected article. Coding parameters were the following: date of publication, authors, short summary, type of ability decline and its screening methods if any, type of target touchscreen device, pre-studies (that guided the creation/definition of the proposed guidelines) and post-studies (that either applied the guidelines, or validated them) including data about subjects (size, age, percentage of females), format of user study (group or individual), mode of assessment (technical or non-technical), and presentation of the final design guidelines.

Three researchers, independently, conducted a full-text analysis of each article and extracted design guidelines from each of the selected articles and the information related to them into the 2 standardized data coding forms described above. This process resulted into a set of preliminary design guidelines that support the design of solutions that target declines of abilities of older adults.

8.4.4 Included Phase

At the included phase, we performed a qualitative analysis on the extracted information to better categorize the design guidelines and to prepare the coded data for replying to the research questions that guided our systematic literature review.

To perform the qualitative analysis we used the data collected in the 2 forms described earlier and the taxonomies for design categories and user's capability model pictured in Figure 8.1.

Following our research questions introduced in Section 1 and based on our analysis of the selected articles and the information extracted from them:

- For RQ1. What are the characteristics of the target population and touchscreen interaction addressed by current research-derived guidelines? We coded the target population either as people affected by ageing related ability declines, or as people that reached a certain age.
- For RQ2. What is the quality of the methods and strategies used to generate and validate the design guidelines? We extracted measurable information, i.e. metrics related to the studies conducted (materials and formal methods used, screening methods, and number of participants) and formality of the methodology and number of sources in case of literature reviews.
- For RQ3. What issues emerge and what effort is required in identifying and cataloging research-derived guidelines, as to make them available to the average practitioner? We tagged the guidelines with keywords that represent the challenges that a reader has to surpass to extract and understand those guidelines.

The overall process of the included phase was performed in three iterations.

In the first iteration, guidelines were classified and grouped according to the ability type that was explicitly addressed by the original paper.

In the second iteration, guidelines in each ability group were analyzed and re-evaluated based on the description text of the guidelines themselves in order to confirm if they belonged to the ability group identified in the first iteration or to another group; this was necessary as there were several articles that targeted several ability types. If a guideline was found to fit better another ability group, then it was moved to that ability group; this ability group change had

to be confirmed by a majority vote of internal expert agreement. Moreover, single guidelines targeting ability declines not affecting older adults were excluded in this iteration.

In the third iteration we added the selected design taxonomy, and each individual guideline was classified as belonging to one of the design categories and subcategories described in Figure 8.1. At the same time, guidelines themselves were evaluated based on the definition of “design guideline” as presented in Section 3. For example, the following text “Provide a way to exit on every screen” [233] matches our definition of guideline and was included, while the following text “Consider task complexity in navigation tasks” [255] did not conform with our guideline definition (was found to be more a design principle), and thus, was excluded. Finally, the severity category of each ability decline was added, classifying guidelines as either “severe”, “mild”, or “universal”. “Universal” decline referred to guidelines stated as fitting for both younger and older population. This iteration was also intended to identify and remove repeated guidelines from the list. By the end of the third iteration, the level of inter-rater agreement was 55% for classification of ability declines and 59% for design categories.

After the included phase, we took the final list of guidelines and rephrased them into a heuristic checklist for designing accessible solutions for older adults that could be generalized and applied to different touchscreen technologies, and be easily comprehended and adopted by software developers and designers.

During each iteration of the classification and filtering process, structured questions were used to perform a guideline quality control, for example, “Do you agree this guideline belongs to this ability/design category?” or “Do you agree with rephrasing the guideline text?”. Each expert had three options for the answer: “Yes” for confirming the guideline text/categorization, “No”, to indicate that the guideline needed a review, and “Not sure” to wait on the decision of the other experts.

Disagreements were addressed by asking the third expert to classify the guidelines in question, and the final decision was reached by consensus in face-to-face discussions. These discussions also provided insights into the challenges of interpreting and understanding the guidelines as currently reported. We discuss these challenges and issues in the Results section.

As described above, analysis of coders agreement outcomes was both quantitative and qualitative. Quantitatively, three answer options were considered and calculated for the two taxonomies:

design categories and user's capability model. Qualitatively, each guideline text that had to be rephrased was discussed by at least 2 researchers to avoid the loss of the original meaning.

8.4.5 Evaluation of the Quality of the Processes Related to the Extracted Guidelines

We evaluated the quality of guidelines using 2 dimensions.

The first dimension is associated to the quality of the methodologies used to define/propose design guidelines and we refer to it as the *reliability of a design guideline*. We think this assessment is important as it can be a good indicator of how likely is a guideline to support its target population. For instance, we investigated if the guidelines were provided after conducting user studies with participants from the targeted population or by a related literature synthesis, and then tried to evaluate the quality of those methods.

The second dimension is associated to the quality of the methodologies used to validate or test design guidelines and we refer to it as the *validity of a design guideline*. We consider to perform this assessment as it can be a good indicator of how likely is a guideline to improve the usability of a solution for its target population. For instance, we looked for the presence of studies and experiments conducted to test/validate design guidelines, e.g., check whether a guideline improves the usability of touchscreen user interfaces for older adults with a specific ability decline.

Our evaluation method was performed in two steps and, in what follows, we describe them in detail.

In the first step, for each article, we classified the methodology used for deriving/proposing guidelines (to compute the *reliability*) and the methodology used to validate them (to compute the *validity*) in one of the following categories:

- *User studies* that propose (or validate) guidelines based on the results of experiments where participants interacted with user interfaces and/or prototypes;
- *Literature reviews* that aggregate design guidelines from other articles;
- *Expert evaluations* that either assess specific types of accessible applications or that describe their development process.

In the second step, we evaluated the methodologies according to their category.

For *user studies*, we considered the number of participants in the study and if the participants had to have a disability; we did collect other information related to the user studies but we did not use it for our evaluation. We came with this assessment method by following the recommendations presented in [256] where authors analyzed several research methods and suggested that the quality of a user study can already be assessed with these two variables. More specifically, authors in [256] suggest that a research study with a general population of users should have a minimum of 20 to 30 participants to be considered valid. When doing a research study that focuses on a population with disabilities (recognizing the difficulty of the recruitment for these cases) authors from the same work say that it is acceptable to have just from 5 to 10 participants.

Based on these suggestions we evaluate user studies as follows:

- User studies with participants without disabilities were scored as follows: If the number of participants was fewer than 20, the score of the study was **Low**; if the number of participants was between 20 and 30, then the score was **Good**; and if the number of participants was greater than 30, then the score was **Optimal**.
- User studies with participants with disabilities were scored as follows: If the number of participants was fewer than 5, the score of the study was **Low**; if the number of participants was between 5 and 10, then the score was **Good**; and if the number of participants was greater than 10, then the score was **Optimal**.

For neither, *literature reviews* nor *expert evaluations*, we could find a strong method to evaluate their quality, unfortunately. Nevertheless, to give an assessment, we decided to look at the formality of the procedure, i.e., if the methodology followed a systematic procedure. A systematic methodology received the score **Optimal**, otherwise the methodology received the score **Low** (there was no **Good** score for these methodologies as our scoring variable was binary).

8.5 Results

In this section we present the results of our literature review in relation to our initial research questions.

8.5.1 Study Selection and Guideline Extraction

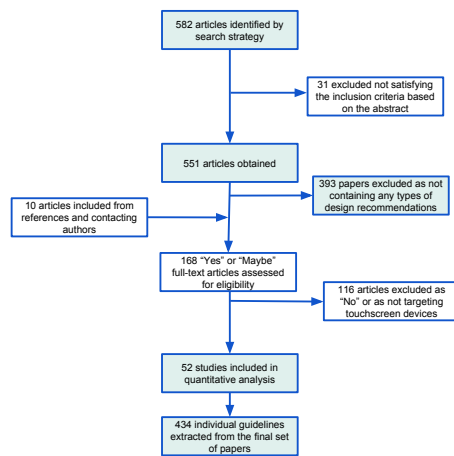


FIGURE 8.2: PRISMA flow diagram for this study

and 393 either did not contain any guidelines or contained guidelines that were application specific or did not target touchscreen devices.

At the *Eligibility phase*, we performed a full-text analysis of the 168 articles with the purpose of extracting from them their corresponding guidelines. This analysis excluded 116 more articles due to: not proposing actual guidelines, or the guidelines were too general or confusing and, hence, matching more the definition of design principles rather than guidelines. This phase resulted in 52 articles marked as containing relevant guidelines for designing touchscreen applications for older adults.

Proceeding with the *Data extraction* (“Included phase” by PRISMA), we further reviewed the final set of 52 included articles in order to extract the contained guidelines and the details of the studies that either produced the design guidelines and/or validated them. The final outcome of the literature review is **a set of 434 guidelines for designing touch-based applications for older adults**⁶ where some papers had a large number of guidelines (up to 143) and others only a few or even just one of them.

The actual process we have followed in our study for filtering relevant papers can be seen in the PRISMA diagram in Figure 8.2.

⁶Guidelines available at the <http://design-review.mateine.org>

The primary search, or *Identification phase*, selected 582 works from a set of a little more than 10K articles.

During the *Screening phase*, we evaluated the 582 articles and identified 158 articles that seemed to contain guidelines, or content that could be interpreted or translated into guidelines; later 10 more articles were included based on the communication with authors and follow-up studies. From the excluded articles: 31 were editorial articles or duplicate works,

8.5.2 Characterizing the Target Population and Interaction Design Aspects

We thus address the first part of our first research question: *What are the characteristics of the target population and touchscreen interaction addressed by current research-derived guidelines?*

Target population

By analyzing the articles directly related to older adults, we discovered that the target population is identified using one of the following characteristics:

- **Chronological age** (52%): the target population belongs to an age range or is above a certain age. For this we took either the explicit definitions in the papers, or the age of participants in the reported studies.
- **Functional** (44%): the target population is affected by one or more ageing related ability declines.
- **Hybrid** (4%): the target population is defined by both of the previously defined characteristics, i.e., it belongs to an age group and is affected by one or more ability declines.

Figure 8.3 shows all the articles that define older adults chronologically, in ascending order.

Defining older adults by age or *chronologically*, researchers traditionally refer to official definitions such as by the World Health Organization (65 years and older) [257] or the United Nations [258] (60 years and older). In this review, we found that the *chronological* definition starts as early as age 55 [80], while just three articles [233, 259, 260] specifically defined their target population as individuals aged over 65 years and five [219, 261–264] – as 60+ by the United Nations.

Just one among all selected works explicitly focused on the oldest old (80+) age group [259], while other articles included the 80+ population in their studies but did not distinctly focus their research on them. We also found one particular article that addresses older workers, people in the transition age from work life to retirement [249], which in this case was considered to be the age range 55–75.

The next definition category in the table collects the articles that define older adults using *functional* characteristics, focusing on ability declines related to ageing. In this group we identified articles that tackle specific diseases related to ageing like Alzheimer’s [237] and Parkinson’s disease [265]; furthermore, there are articles that target a specific health issues that affect

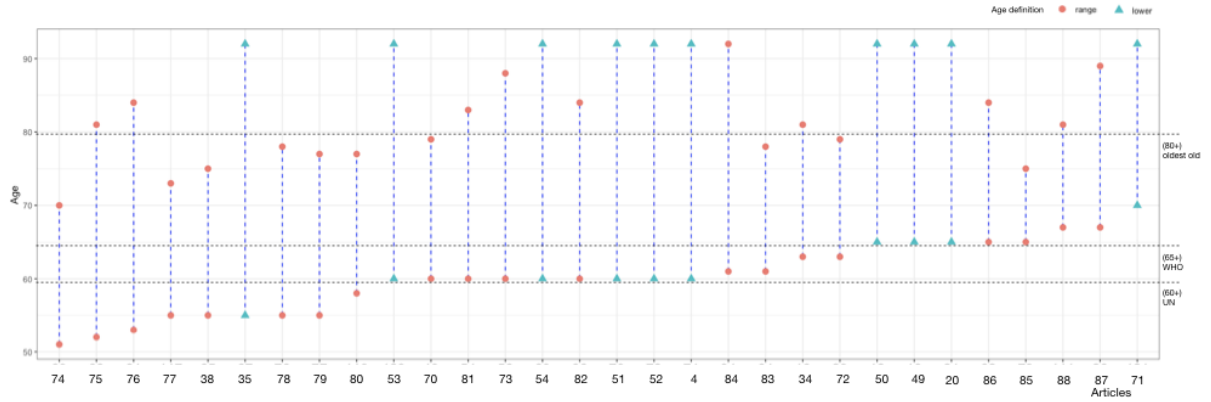


FIGURE 8.3: Chronological age distribution in included papers. Arrows represent unbounded age and lines represent age ranges.

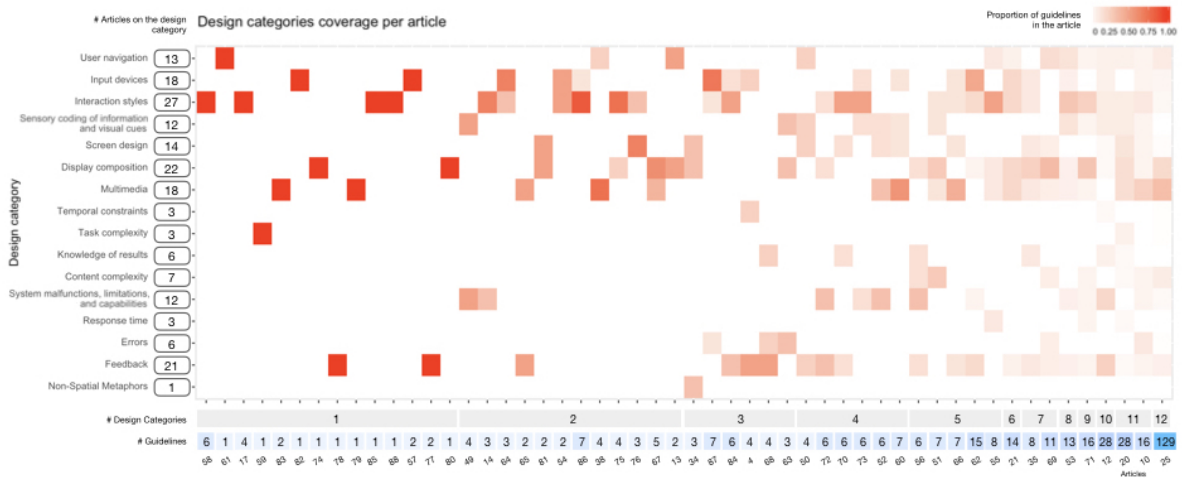


FIGURE 8.4: Distribution of design guidelines based on design categories and article

older adults but can also affect people of all ages, for instance, aphasia [266]. Our reviews also identified articles that address more general health problems caused by ageing, e.g., motor impairments [226, 227, 230, 267, 268], cognitive declines [269–271], and vision loss [260, 272]. Ten of the reviewed articles cover various ability declines within one study or set of guidelines [81, 82, 212, 273–279].

Finally, two articles apply a *hybrid* approach using both age and functional characteristics. For instance, Kobayashi et al. [280] recruit participants in their 60s and 70s with vision and hearing problems, and Wacharamanotham et al. [264] target older adults affected by hand tremor.

Ability declines targeted

In this subsection we go deeper into characterizing the specific abilities that are supported by the individual design guidelines. Their classification based on the capability model can be seen

in Table 8.2.

TABLE 8.2: Distribution of design guidelines based on the user’s capability model

Ability	Sub category	Example	# and % of Guidelines
Cognitive	ICT skills	“Outline the main features of the system” [281].	52 or 12%
	Info Processing	“Display main information on the center of the screen” [237].	68 or 15.7%
	Memory	“Always provide a ‘home’ button, and let users know ‘where’ they are” [233].	31 or 7.2%
	Language	“Ensure that feedback messages is not in commando-style” [237].	38 or 8.8%
Perceptual	Vision	“Use capital letters for highlight important text.” [233].	126 or 29.1%
	Hearing	“Provide a possibility to adjust the volume” [81].	16 or 3.7%
Psychomotor	Hand-eye coordination	“Increment the size of the zone round an hyperlink” [237].	58 or 13.4%
Motor	Dexterity	“Implement the ability for the interface to allow whole-handed and multifinger input. This is particularly important for individuals with hand tremors or arthritis” [282].	41 or 9.5%
	Muscle strength	“Address physical factors, such as the weight of the device and dexterity issues of this population, and account for limitations in the mobility of the appliance, e.g. users may not be able to use the appliance while walking” [259].	3 or 0.7%
	Speech	“Use acoustic models dedicated to seniors for the speech recognizer” [237].	1 or 0.3%

From Table 8.2 we can clearly see the asymmetry in the coverage of ability declines by extracted guidelines. The ability declines that are well covered correspond to **cognitive** (189 out of 434 or 43.6%) and **perceptual** (142 out of 434 or 32.8%), while **psychomotor** (58 out of 434 or 13.4%) and **motor** (45 out of 434 or 10.4%) are considerably less covered by design guidelines.

Drilling down into the subcategories of each ability, we can see that for:

- **Cognitive**, the guideline coverage is relatively equally distributed among all subcategories including declines in language and information processing, reduced memory, and low ICT skills. Still, predominating ability declines are reduced information processing (68 out of 189 or 35.9%) and low or lack of ICT skills (58 out of 189 or 27.5%).
- **Perceptual**, the guideline coverage is dominated by those that support people with vision problems, e.g., blindness, color-blindness, low vision, etc. (126 out of 142 or 88.7%).
- **Psychomotor**, all the guidelines in this category (there are no subcategories) aim at helping people with hand-eye coordination problems.

- **Motor** ability decline category, which included dexterity problems and muscle strength, the guideline coverage is dominated by the ones that help people with reduced dexterity, i.e. problems in moving either their fingers and hands or arms (41 out of 45 or 91.1%).

Design categories targeted

To characterize guidelines by their relation to the design aspects of interactive systems, we classified the final set of guidelines in different design categories defined in the adopted taxonomy shown in Figure 8.1.

From the Table 8.3, the design categories that are more affected by guidelines are **Displays** (182 out of 434 or 41.9%) and **Behaviors** (140 out of 434 or 32.2%), which had to do with how information and content are shown and how to interact with the system.

Following, we have **Contexts** (58 out of 434 or 13.3%), which is related to how the system shows, or reacts to, the current status of a task; **Effects** (53 out of 434 or 12.2%) that is related to the different types of feedback that a system or task should give; and finally, **Forms** (just 1 out of 434 or 00.002%) that has to do with associating tasks with known metaphors to make the tasks easier to learn and understand.

If we drill down into the subcategories of each design category, we can further say that for:

- **Behaviors**: half of the guidelines are related to the different interaction styles that users could have with the system (71 out of 140 or 50.7%), while the rest of the guidelines are divided among how users navigate through a task or system (30 out of 140 or 21.4%) and how they can input information into the system (39 out of 140 or 27.8%). Typical examples of guidelines in those categories are “provide a way to exit on every screen”[233] (user navigation) and “allow recognition of multiple voice commands at a time”[272] (input devices).
- **Displays**, most of the guidelines are related to managing the multimedia content (81 out of 182 or 44.5%), for example, “avoid justified aligned text”[237]; and display composition, i.e. arranging the information on the screen (64 out of 182 or 35.1%): “use different colors to categorize information visually”[237].
- **Contexts**, the majority of guidelines have to do with managing the different accessibility options and peripherals as well as the errors associated to them, i.e. “System Malfunctions, Limitations, and Capabilities” (24 out of 58 or 41.3%), for example, “display a help panel

TABLE 8.3: Distribution of design guidelines based on design categories

Category	Sub category	Example	# and % of Guidelines
Behaviours	User navigation	“Show the actual location all the time” [237]	30 or 6.9%
	Interaction styles	“Avoid instant features that change with each new interaction such as filters and auto-completion” [281]	71 or 16.4%
	Input devices	“Allow wait time setting on entering each character” [272]	39 or 9%
Displays	Display composition	“Use capital letters for highlight important text” [233]	64 or 14.8%
	Multimedia	“Support different types of contrast” [262]	81 or 18.7%
	Screen design	“Provide shallow menus. Spread functionality across menu bar and pages” [233]	19 or 4.4%
	Sensory coding of information and visual cues	“Make names of items on the screen heard as they are touched” [81]	18 or 4.2%
Contexts	Content complexity	“Use active voice rather than passive voice” [237]	20 or 4.7%
	Knowledge of results	“Let the users know that they have successfully completed an action in the app” [278]	7 or 1.7%
	System malfunctions, limitations and capabilities	“Make the touch screen startable in any position on the screen” [81]	24 or 5.6%
	Task complexity	“Allow tasks to be accomplished serially, don’t force them to be done at the same time requiring cognitive switching” [233]	4 or 1%
	Temporal constraints	“Make it possible to hold they key up to 2 s before the action will repeat” [81]	3 or 0.7%
Effects	Errors	“Ensure that error messages feedback provide mechanisms for resolving the error” [237]	7 or 1.7%
	Feedback	“Make buttons highlighted when pressed to support correct selection” [81]	43 or 10%
	Response time	“Avoid time dependent controls” [265]	3 or 0.7%
Forms	Non-Spatial metaphors	“Rely on familiar aspects of manipulating physical photographs. This reduces the amount to learn and remembering is easier since the user already knows how to move and share physical photographs” [246]	1 or 0.3%

and tips about the features in the first user access”[281]. The second largest subcategory here is the complexity of the information communicated to the users (20 out of 58 or 34.4%) and example of the related guideline is “avoid abbreviations and symbols”[237].

- **Effects**, most of the guidelines refer to the different ways of giving interaction-based feedback to the users (43 out of 53 or 81.1%): “provide a confirmation of every completed function”[81].

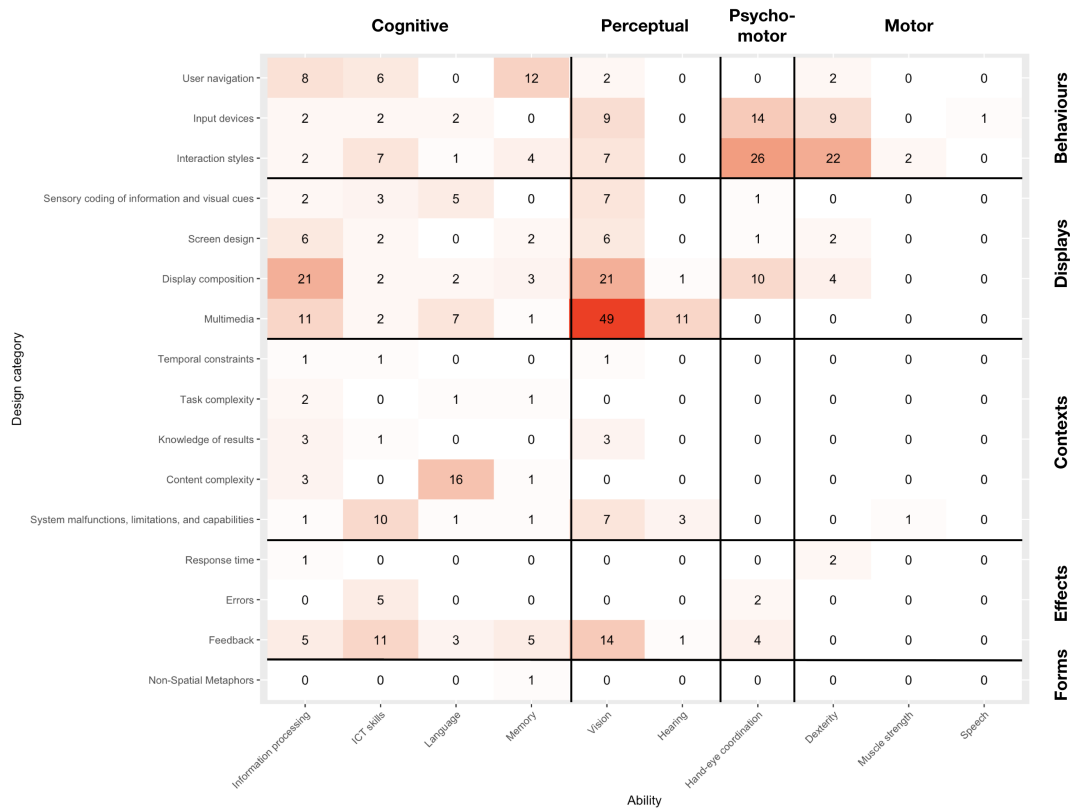


FIGURE 8.5: The distribution of guidelines by the design and ability categories

- **Forms**, included just one guideline for the subcategory *Non-Spatial Metaphors* and is the following: “Rely on familiar aspects of manipulating physical photographs. This reduces the amount to learn and remembering is easier since the user already knows how to move and share physical photographs” [246].

The heatmap in Figure 8.4 indicates how most articles propose guidelines in the areas of Interaction styles, Display composition, and Feedback. We can also see that half of the articles (26 out of 52) address one to two design categories simultaneously.

Cross-dimensional analysis

Analyzing the distribution of guidelines in both design and ability categories (Figure 8.5), we can see some archetypes emerging in the following areas:

- **Design of multimedia content to address vision declines** (Vision - Multimedia), with 49 guidelines that are related to how to show content so it can be comfortably and properly seen in spite of vision declines. A typical example of such intersection is to “implement 60% opacity for all highlighting to render a good contrast between the black text and background colour” [275];

- **Interaction styles to address coordination and dexterity declines** (Hand-eye coordination, dexterity - Interaction styles), with 26 and 22 guidelines that are related to how to make touchscreen interactions, such as gestures, accessible to older adults with hand-eye coordination and motor function declines. For instance, to help users to target the right spot, one should “make selections using gliding gestures for direct manipulation” [81];
- **Organizing the display composition to address information processing and vision declines** (Information processing, vision - Display composition), with 21 and 21 guidelines that are related to how to arrange content so that it reduces the cognitive load on the users, and avoid creating unnecessary distractions for those with vision declines. For example, Ghorbel et al. recommend to “present only one message in a single interface” and “avoid using tones of similar lightness near to each other” [237];
- **Adapting content complexity to declines in language processing** (Language - Content complexity), with 16 guidelines that are related to the way information is presented and organized on a screen and how the language used on the screen matches the user’s ability to comprehend it. Guidelines like “Guide the user by means of messages in clear, objective and educational language” [281] and “Express only one idea per paragraph” [237] are examples of such intersection;
- **Design of feedback to accommodate to declines in vision, and lower ICT skills** (Vision, ICT skills - Feedback), with 14 and 11 guidelines that are related to the user’s ability to perceive what is displayed on the screen and skills and experiences in using current ICT user interfaces, which are supported by the feedback about the operations of the application in response to user behaviors. For instance, it could be implemented by providing users with “positive feedback icon” as “a motivator [...] and an important indicator that they are making progress” [219] or by the use of the “audio confirmation to help elderly with reduced vision” [263].
- **Designing user navigation to address memory and information processing declines** (Memory, Information processing - User navigation), with 12 and 8 guidelines that give us an insight of how reduced ability to remember the UI procedures and to orientate oneself, as well as the ability to process related to that information in an appropriate time could be addressed by an improved navigation systems. In this vein, Nunes et al. recommend to “provide clear information of current location at all times” [265], while Al-Razgan

et al. state that “the most important features should be available directly via a labeled button and not via menu navigation” [263];

- **Handling errors to accommodate lower ICT skills and coordination declines** (ICT skills, hand-eye coordination - Errors), with 5 and 2 guidelines that are related to the importance of efficient error processing in interaction with the UI and supporting users who are less experienced in using the touchscreen technologies or have hand-eye coordination difficulties, which could result into errors. This could be implemented, for instance, by ensuring “that error messages feedback provide mechanisms for resolving the error” [237] or by setting large space between commonly used buttons. “To minimize hazards and unintended actions, “Yes” and “No” touch buttons [should be] located at the farther left and right sides of the touchscreen, and other touch buttons [should be] placed on the main control panel” [82].

All the other areas present less than 20 guidelines, with several having none at all (see the related heatmap in Figure 8.5).

8.5.3 Reliability and Validity of Current Guidelines

In this subsection we address our second research question: *What is the quality of the methods and strategies used to generate and validate the design guidelines?* As detailed in Section 8.4.5, to estimate the **reliability**, we evaluate the studies used to derive/propose design guidelines and for the **validity** we evaluate the studies used to validate design guidelines they proposed.

Reliability of design guidelines

After analyzing the studies from each of the included articles by using the methodology presented in Section 8.4.5, we computed the following reliability scores:

- **Optimal:** we found that 31% of the included studies are ranked in this level, from which 3 are literature reviews, 1 is an expert evaluation, and 12 are user studies (7 of them recruited participants with disabilities).
- **Good:** we found that 23% of the included studies are ranked in this level. All of them are user studies from which 3 required participants with disabilities.

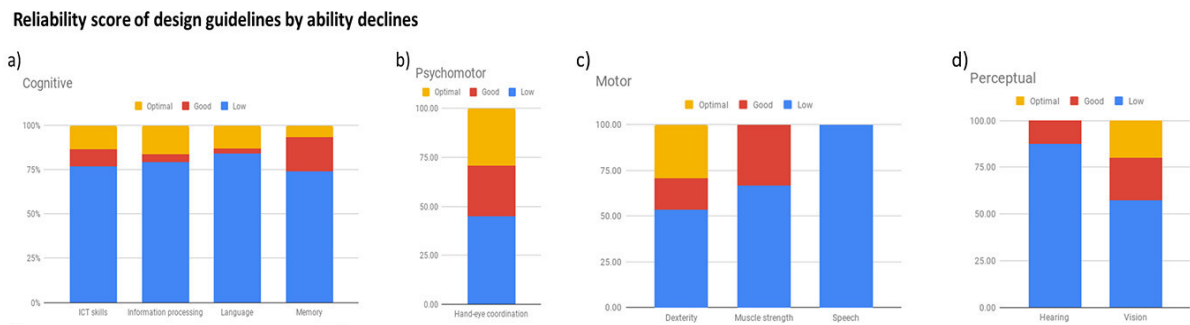


FIGURE 8.6: Reliability score distribution according to our capability model.

- **Low:** we found that 46% of the included studies are ranked in this level, from which 10 are literature reviews, 4 are expert evaluations, and 10 are user studies (none of them require participants with disabilities).

Table 8.4 summarizes the references for each category of studies. Our analysis shows that about half of the included articles produced good or optimal quality guidelines.

TABLE 8.4: Categories of studies producing design guidelines

Type of study	Subcategory	References
Literature reviews	Non-systematic reviews	[80, 82, 212, 233, 237, 246, 263, 267, 274, 279]
	Systematic literature reviews	[261, 270, 272]
User studies	Ability-based user studies	[81, 226, 227, 230, 260, 264, 265, 268, 269, 271]
	User studies with older adults (age based)	[219, 249, 259, 262, 275, 280–298]
Expert evaluations	Expert agreement	[266, 273, 277, 278]
	System description	[276]

The reliability score of each article is passed down automatically to the guidelines extracted from that article. Figure 8.7 shows the distribution of our reliability score for all the extracted guidelines.

Figure 8.6 shows the distribution of the reliability score according to our capability model. We can see that only in the psychomotor (b) category more than half of the guidelines received a good reliability score or better, for all other categories, more than half of the guidelines received a low reliability score.

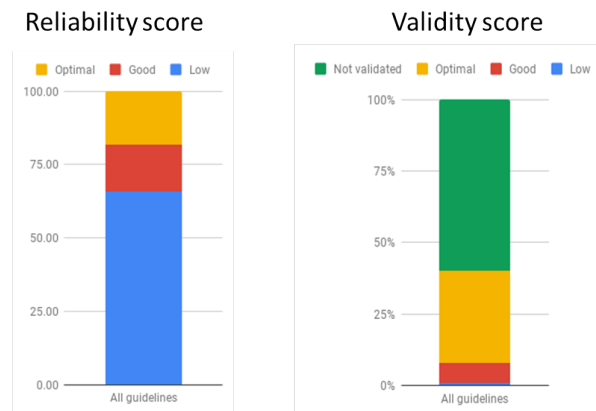


FIGURE 8.7: Reliability and Validity scores of all extracted guidelines.

Validity of design guidelines

Unfortunately, only 11.5% (6 out of 52) of the included articles provided validation studies of their proposed guidelines, while the rest 88.5% did not validate their findings.

From the group of articles with no guideline validation, two studies attempted some testing: Rodrigues et al.[293] performed a computer simulation to evaluate the guidelines, but did not involve end users; Ruzic et al.[82] used their proposed guidelines in a software development process but without further testing the software with the target population.

The studies that actually validated their proposed guidelines [81, 226, 237, 246, 279, 287] usually did it by applying them in the development of an application and later testing with the target population.

After analyzing the 6 studies that performed guideline validation, we computed the following validity scores:

- **Optimal:** we identified 2 articles that fall in this level [237, 279], both of them target users with disabilities.
- **Good:** we identified 2 articles that fall in this level [81, 226], both of them target users with disabilities.
- **Low:** we identified 2 articles that fall in this level [246, 287], both of them target older users with no disabilities.

The validity score of each article is passed down automatically to the guidelines extracted from that article. Figure 8.7 shows the distribution of our validity score for all the extracted guidelines.

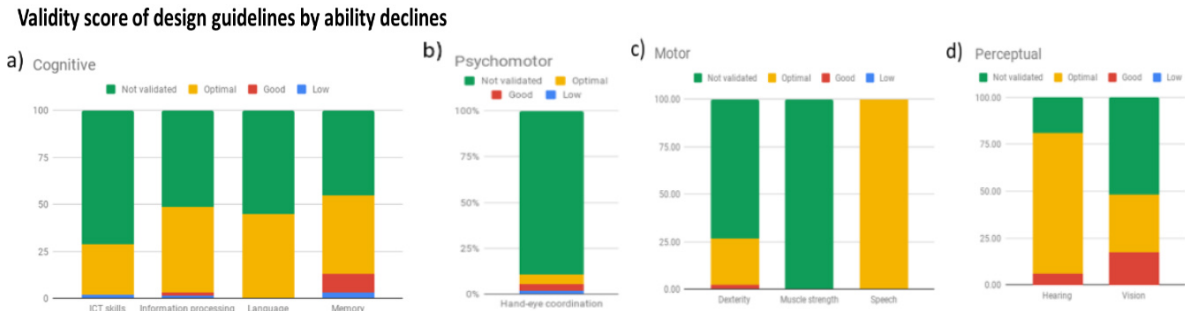


FIGURE 8.8: Validity score distribution according to our capability model.

Figure 8.8 shows the distribution of the validity score according to our capability model. In this case the distribution the psychomotor category is the one that has the least validated guidelines together with motor (consider that speech is just 1 guideline). Then we have cognitive with almost half of the guidelines validated and most of them received an optimal validity score. Finally we have the perceptual category where more than half of the guidelines are validated and the majority of them received an optimal validity score.

8.5.4 Identification and Cataloging of Design Guidelines

In this subsection we address our third, and last, research question: *What issues emerge and what effort is required in identifying and cataloging research-derived guidelines, as to make them available to the average practitioner?*

Identifying guidelines

Thus, to address this question and give an indication of the effort required in the process of *identifying and extracting* design guidelines, we describe the guidelines in terms of how they were reported, and how salient they were, in:

- Almost 67% of the included articles **present guidelines in a clear and structured format**, presenting them explicitly in checklists, making them easy to identify, or at least narrowing the search to a section of the article;
- Other 33% **present guidelines in an unstructured format**, writing them in the form of discussions, using unclear formulation (sometimes simply incomprehensible), and consequently, making it difficult to assess whether certain findings could be indeed defined as design guidelines.

Identifying and extracting design guidelines when they were not structured was, generally, a complicated task.

This task was performed independently by three researchers, to reduce bias in what is still a subjective process, which was followed by face-to-face discussions in order to resolve disagreements consisted in approximately 17.4% for all the analyzed articles. Disagreement was calculated based on whether an article contained design guidelines, which was straight forward if they were presented in a structured way, otherwise the first three authors had to interpret the contribution to evaluate if it represented a guideline.

Cataloging guidelines

Cataloging guidelines can inform practitioners of the focus and target of design guidelines, but doing so requires experts to characterize them based on a reference taxonomy. To provide insights on the required effort and potential issues in cataloging guidelines, we report on the classification process involving our design taxonomy.

The guideline classification process was more challenging, as it required interpreting the limited guideline text and associating it to one of the categories from the chosen taxonomies. In this case we had a 55% interrater agreement on ability categories, and 59% on design categories.

To further avoid ambiguity, the original authors of the articles were contacted for feedback on the identified guidelines, to confirm (or correct) our guideline classification and rephrasing. This resulted in 65% answer rate. Original authors either confirmed or commented on the classification and guideline phrasing, few of them asked for more detailed information about our work. There were also cases of authors that requested to re-word their initial findings and make some corrections, which we did.

8.5.5 Focus Group and Expert Evaluation

We conducted a focus group discussion with healthcare professionals specialized on aging (geriatric care) in order to assess our capability model, and get their value judgment on the changing abilities that require more attention.

Experts started with an overview of their practice and the challenges they most commonly face. With respect to physical ability declines, experts commented that older adults they treat are

generally affected by physical musculoskeletal declines (usually due to arthritis), visual and hearing declines, hand tremors, and mobility difficulties (walking, stairs climbing, maneuvering the obstacles). Their patients are usually 80+ (old-old), homebound, and do not actively participate in community/social life. As for the most common cognitive declines, healthcare professionals mentioned memory problems, executive function difficulties (planning, organizing), and low ICT skills. Experts also indicated that in absence of major critical health event, e.g., a heart attack or a stroke, physical declines appear first (and patients might stay cognitively active until the very old age), however, if there is a cognitive decline, physical declines unavoidably affect older adults as a consequence.

From their condition as experts, and based on their experience, the participants commented that the capability model covered the most important changing abilities. However, they added the following points to consider:

- Aging related ability declines are symptoms of common diseases that appear in older age;
- They emphasized the importance of using screening tools when addressing ability declines and recruiting older population groups, especially the oldest old (80+);
- As diabetes is a common disease in older age, reduced touch sensitivity is a common decline among older adults.

An important takeaway is that declines are not always independent, but are oftentimes manifestations of conditions that affect more than one ability. This indicates that to make guidelines really actionable, design guideline compilations and repositories should provide “profiles” of typical conditions that would facilitate the mapping to changing abilities and guidelines. Our capability model provides the building blocks to build such a profile-based discovery.

Finally, the experts were asked to rank the ability declines from our capability model based on their clinical geriatric experience, which resulted in the following list of the most relevant declines for each ability category. The most relevant **cognitive** declines are:

1. Reduced memory;
2. Problematic information processing;
3. Low or absent ICT skills;
4. Language processing problems.

The most relevant **perceptual** declines are:

1. Various vision declines;
2. Hearing declines.

The most relevant **motor** declines are:

1. Reduced muscle strength;
2. Dexterity problems;
3. Speech declines.

We pick up on this ranking later to discuss different aspects of our findings.

8.6 Discussion

In this section we discuss the implications of our results, the topics that emerged, and what we learned during this systematic literature review.

The last decade of research on touchscreen design guidelines form an extensive body of valuable recommendations that target a wide range of services and technologies being adapted to ageing related declines. The works included in this review address important and critical questions of making touchscreen devices usable by older adults through various design recommendations. However, the compilation process uncovered some shortcomings in terms of coverage, formulation, poor structuring, and reliability of findings. We discuss those issues below.

8.6.1 Characteristics of the Older Adult Population and Interaction Design (RQ1)

Different chronological definitions, targeting general rather than specific populations, and an emerging functional focus

Two approaches to defining the target population were identified in this review: chronological and functional definitions.

We observed articles that adhered to official chronological definitions, setting the starting age as early as 55. Interestingly, the target was dominated by the younger end, with only 8 out of 30⁷

⁷The number of articles that reported on conducted user studies involving older population

starting at 65+. There was also a majority of articles addressing population ranges spanning more than 20 years, which points to rather wider ranges of the target population.

The issue with these rather general definitions is that older adults conform to a heterogeneous group [218, 242, 299, 300], where differences in functional abilities can greatly vary from the young to the oldest old, as declines tend to accelerate with age [301, 302]. For the same reason, focusing on younger populations has the effect of leaving out individuals that are more likely to benefit from the implementation of proper guidelines, and therefore of ICT.

Older adults within the same age cohort can also be expected to be different, as declines can be moderated by many factors such as level of physical activity, social connections, education, presence of disabilities, among others [301–304]. Thus, taking a chronological view only is a limited way of describing the older adult population.

Nearly half of the articles we reviewed, however, adopted a functional approach, addressing specific ability changes – or adapting interactions to the special abilities of the population – instead of generalizing groups by age. In taking this perspective, the resulting guidelines have the potential of talking more precisely to individuals, and supporting design approaches centered in user abilities (e.g., Wobbrock et al. [305]).

The takeaway message here is that defining more precisely the target population is paramount to having guidelines that can effectively guide practitioners in the design process, avoiding some of the stereotyping discussed in the literature [306]. Guidelines cannot be expected to be “universal” and generalize to the entire older adult population but rather cater to different, possibly smaller, groups of individuals.

This should be clear to software designers and developers who do not always have a realistic picture of their target population when they refer to older adults [306], usually treating them as a homogeneous group that is affected by a set of physical and cognitive declines [299].

Design guidelines archetypes covering the most important ability and interaction design dimensions

Guideline categorization process revealed that each design parameter is not exclusive to just one ability, and neither is one ability determined by a single design dimension. Confirming and extending this observation, guideline distribution clearly shows that design of multimedia content and display composition (layouts) are crucial elements in addressing perceptual (vision and

hearing) declines, as well as reduced cognitive (information processing) abilities. Another topic that emerged in guideline distribution analysis is the importance of efficient interaction styles and input techniques to address dexterity and ageing related hand-eye coordination changes. As for the cognitive declines in general and low ICT skills in particular, beside efficient interaction support, implementing appropriate user navigation, error and feedback handling were the most prominent.

Previous research has also raised the importance of proper design of displays in touchscreen devices for older adults. In their literature review, Petrovčič et al. [239] investigated the categories that were included in the mobile design guidelines and checklists, they found that the most frequently mentioned categories were related to selected *visual and haptic issues* (e.g., high contrast, font size, button type, button size, button positioning), which aligns with our observations and emphasizes the importance of appropriate visualization of information as well as providing adapted interaction opportunities for users with ageing related ability declines, such as reduced vision.

Research on interaction styles emerged as another hot topic in this review. Although the *direct* input enabled by touchscreen devices are known to be more accessible than the *indirect* input provided by the traditional mouse and keyboard interactions [307], some type of gestures can still be more problematic than others for older adults. Indeed, Motti and colleagues [248] tell us in their literature review of interaction techniques that effectiveness of touchscreen interactions depend on the skills and background of the user but also on the configurations of the devices and specific technique used. Our review shows that efforts are well focused in this area, especially when it comes to addressing coordination and dexterity declines.

The organization of both display composition and user navigation, given the changes information processing abilities, are prominent archetypes in our analysis that have also been identified as important by previous research. Wildenbos et al. [308] investigated the usability issues encountered by older adults using mHealth apps, and identified that the most severe issues were related to unnatural navigation through the App, which was affected by slower cognitive performance but also technology anxiety, longer learning time and speed of performance. The same work also refer the importance of designing feedback to accommodate to lower ICT skills, an archetype identified in this review. According to Wildenbos and colleagues, the usability issues related to ‘forgiveness and feedback’ are affected by technology anxiety and low computer literacy, which translates into “Errors” and “Feedback” in our design taxonomy (see Figure 8.1).

In their more recent work [309], the same authors also connect usability issues related to ‘Errors’ and ‘Efficiency’ to vision declines.

Looking at the coverage of perceptual ability declines, is worth noticing that in this review there are only a handful of works that address specifically *hearing problems*, which are usually discussed in works related to general accessibility but there is no research specific for them. This could be explained by the focus on visual feedback and multi-modal interactions. Auditive interactions are used normally for notifications, and these can be replaced with other types of feedback, haptic or visual. Most of the proposals that address hearing declines are related to adding captions to videos and providing text alternatives to audio information. Other ability declines that have a very low coverage are *speech and muscle strength* (related to the motor category). The lack of guidelines for declines in speech has a similar explanation than for hearing; the lack of guidelines for declines in muscle strength could be explained by the lack of interactions that require grip (or a similar) type of interactions. Thus, in the context of touchscreen interfaces (including mobile phones and tablets), most of the research is focused on gesture-based interactions, with conversation-based or natural interactions not very present in this medium.

8.6.2 Quality of the Methods and Strategies Used to Generate and Validate the Design Guidelines (RQ2)

As detailed in section 8.5, we evaluated the quality of the procedures used to generate or validate design guidelines in the included articles. These consisted of experiments and user studies with older adults [81], as well as analysis of findings with comparison to existing body of literature. We start discussing first the findings related to the methods used for generating and validating guidelines, and then we discuss the quality of the particular guidelines, with a particular focus on the guidelines that address the most relevant ability declines that affect older adults (according to the experts from our focus group).

For the evaluation of user studies, we used the approach proposed in [256] and defined an objective and unbiased methodology. Unfortunately, for literature reviews and expert recommendations we could not find any methodological approach on how to evaluate these type of studies. Thus, we evaluated them assessing whether they followed the method of systematic literature review or not.

Good research on creation, more needed in validation

Taking in consideration all the methods that we found for proposing design guidelines (user studies, literature reviews, and expert evaluations) we have that the quality was “good” or better (in the scale low, good, optimal) in a little more than half of the selected works (54%).

The average number of older adults recruited in studies to later derive guidelines consisted of 23 participants, if we consider the overall number of participants (including younger age groups), the average number of participants raises to 31. A little more than half of the user studies (19 out of 34) used some type of screening method to identify the presence of ability declines in older adults: In 5 of them participants were recruited directly from facilities for specific ability declines; in 4 of them participants self-reported their ability declines, e.g., lack of ICT skills; and in 10 of them participants were screened using validated methods like the Snellen eye chart (for measuring visual acuity), the Mini-Mental State Examination (for measuring cognitive impairment), and spiral drawing (for measuring hand tremor).

On the contrary, validation of proposed guidelines has been stated only in about 11.5% of works, which represents a rather disappointing trend. This finding raises awareness of the need of further experimental investigations in order to determine the trustworthiness and efficiency of existing guidelines and providing an operational framework for new reliable design recommendations generation.

We could say that the “low” quality of methods for user studies can be explained, or justified, by the recruitment difficulties of studies explicitly with older adults as has been mentioned earlier [239, 310].

Good quality of validated guidelines but still more validation needed

From the point of view of individual guidelines, we can see in Figure 8.7 that around 70% of guidelines have low reliability. This indicates that the studies with a good reliability or better (around 50% of them), unfortunately, did not propose many guidelines. If we do the same analysis for validity, we see that around 60% of guidelines are not validated. However, almost all of the validated guidelines have a good or better validity score. Furthermore, despite that only 11% of the included articles validated their proposed guidelines, they amount to almost 40% of all the validated guidelines, which means that each article validated a large number of guidelines.

Taking in consideration the most relevant ability declines (according to the experts from our focus group) we can see (Figure 8.6) that for: **cognitive** declines, around 75% of guidelines have a low reliability, this applies to all sub-categories; **perceptual** declines, around 60% of guidelines for vision (the most relevant ability decline for this category) have low reliability; **motor** declines, around 70% of guidelines for muscle strength (the most relevant ability decline of this category) have low reliability; and **psychomotor** declines, around 45% of guidelines have low reliability. This is the only category (with hand-eye coordination as the only sub-category) where more than half of the guidelines have a good or better reliability. This is an indicator that there is a lot of room to improve the methods used to propose guidelines, especially the ones that address the most relevant declines.

A similar analysis for validity shows us a slightly different picture as not all guidelines have been validated, so for: **cognitive** declines, we have that around 50% of guidelines for the most relevant declines (memory and information processing) are validated and most of them have good or better validity. The other categories, ICT skills and Language, have around 30% and 50% of validated guidelines respectively, with most of them having good or better validity, **perceptual** declines, around 50% of guidelines for vision (the most relevant ability decline for this category) are validated and most of them have good or better validity. Most of guidelines for the hearing sub-category are validated but we need to consider that there are in total 16 of them (most of them with optimal validity), **motor** declines, none of the guidelines for muscle strength (the most relevant ability decline of this category) are validated. The dexterity sub-category has only a little more than 25% of validated guidelines and the speech category misguides as it has only 1 guideline, which is validated, and **psychomotor** declines, we have less than 10% of guidelines with validation. This is an indicator that more work is needed to validate proposed design guidelines, especially for the categories with less validation.

A last remark, we consider studies to validate guidelines slightly more important than studies to propose them, as the validation helps to confirm the utility of the proposed guidelines.

8.6.3 Identification of Research-derived Guidelines and Their Availability to Practitioners (RQ3)

The process of identifying and cataloging research-derived guidelines included evaluation of the guideline visibility and usability, the effort required in extracting them and characterizing their

focus. Based on the inferred guidelines quality discussed earlier, we next discuss the potential of guidelines to be discovered and correctly interpreted by practitioners.

Reporting can make identification of guidelines demanding, and lead to missed opportunities

One of the outcomes of our evaluation is that the guideline extraction process was straightforward just for half of them: the half where guidelines were clearly stated in the article. For the rest of the papers, guideline identification and extraction required much more effort and time, as guidelines were presented as experiment outcomes, future recommendations, and observations. As a consequence this process can be lengthy (as experimented by the authors), potentially prone to error, and may lead experts to overlook relevant guidelines – as reported in the results section, guidelines overlooked by a first expert were identified by the second one.

Previous research acknowledge that the identification of guidelines or the effort necessary to recognize and extract them from each selected paper highly depends on the way they are presented, as well as the skills of experts in identifying them [238]. Making findings and contributions difficult to identify and consume indicate a missed opportunity, as this prevents the uptake of recommendations by the larger community. The use of standard reporting formats for reporting, and the development of knowledge bases could help address this issue and benefit the whole community.

Challenging identification of the guideline precise focus

One of the findings that emerged during the guideline classification process was the complexity of the process. Due to the limited guideline text and context, the level of detail provided in the articles, and the way they were reported, made the task of interpreting them and identifying their precise focus time consuming and challenging. It required multiple iterations of discussions among the authors and even contacting the authors of original articles. Another important issue that became evident from our review and analysis is the lack of a common validated categorization framework that could be universally adopted to classify existing research-based design guidelines.

Traditionally, the clarity of the guideline application purpose (usability) was investigated by either identifying the usability problems they target or by comparing guidelines with each other to detect the ones more useful [234]. In both cases, a general requirement of the guidelines

is to be usable for designers to build efficient interfaces according to them, and for that it is particularly important that the design guidelines are easily accessible, clearly indicate their focus and addressed usability problems.

These findings complement those mentioned earlier and emphasize not only the need of having easier and clearer access to the best design practices for developing touchscreen applications for older adults, but also the need of a more structured approach in their categorization and validation.

As an attempt to target that issue, the final list of included papers and respective guidelines was depicted in a repository (<http://design-review.mateine.org>) as a collection of guidelines derived from our review. We believe that similar approaches to categorize new guidelines and make them available will benefit future contributions in this area. We also see its potential in allowing researchers and developers to apply and consult the guidelines while developing touchscreen application or conducting studies for and with older adults.

One more thing that could help guidelines be more usable is the indication of the technology for which they can be applied. We found that 37.3% of all articles state that their guidelines target medium “touchscreen devices” without specifying the exact type of them. From these, we have that 33.5% of them define these “touchscreen devices” as “mobile touchscreen devices” or sometimes as “smartphones”. The rest of articles either specify a type of touch-based device, like tablet (11.8%) or tabletop (5.9%), or state that touchscreen devices were also included in their study together with other input devices [249, 261, 283]. The reason for this lack of specificity of devices could be due to the generality of some interactions, like visual interactions, that are touchless and thus, can be applied to several types of devices, or could be defined as device agnostic interactions.

8.7 Conclusions

We performed a systematic literature review with identification of research trends on the topic of touchscreen design guidelines for older adults and gaps to be covered. Guidelines derived from the literature formed a list, which could be applied while developing inclusive touchscreen applications. In this process, we addressed three relevant research questions.

First, target population aimed to be supported by application of design guidelines was defined using different chronological definitions. We observed that they targeted general rather than specific populations and contained an emerging functional focus. As for the design dimension, we identified guideline archetypes covering the most important ability and interaction design dimensions, such as design of multimedia content to address vision declines or adapting content complexity to declines in language processing.

Second, we evaluated the process of guideline extraction to investigate their accessibility and clarity, which proved to be a challenging task. We introduced the capability model and the design taxonomy that we used to categorize the final list of research based design guidelines derived from the literature review. With this contribution, we present the areas related to the touchscreen interaction of older adults that are covered more than others, bring attention to their uneven distribution, and indicate the potential gaps that could benefit from future research.

Third, we analyzed the methodology associated papers adopted in producing and validating design guidelines. By this, we aimed at making the guidelines more useful for designers and developers, supporting them in their understanding of the relevance of each guideline and its validity. Our findings point out to the need in more validation of existing guidelines and increasing the quality of producing the new ones.

The question that remains is: “Is there a need for more research in areas that are lacking design guidelines?” or, maybe, by the nature of the type of touchscreen interactions there is no actual need for them. This question becomes even more important, as designers have to prioritize and choose wisely considering the possible compromises and trade-offs [311], but unfortunately, there is little guidance on how to choose and apply available guidelines [270].

As a byproduct of our review we also provide a collection of research guidelines for touchscreen application targeted at older adults, and a reference taxonomy that could help in analyzing and characterizing guidelines.

The collection of guidelines could indicate which of them are validated and how they are distributed in covering abilities of heterogeneous group of aging populations. This could help developers and designers understand better abilities of older adults and consider varying severity and combinations of their declines. It could also be used to display the abilities that are not covered by design recommendations and indicate the areas that need further research but also encourage researchers to reproduce and validate existing findings.

As an attempt to address that need, the final list of included papers and respective guidelines are depicted in a repository (<http://design-review.mateine.org>) as a collection of guidelines derived from our review. We believe, it would allow researchers and developers to apply and consult the guidelines while developing touchscreen application or conducting studies for and with older adults, and has a potential to become a repository to submit new guidelines and make them available for future contributions in this area.

8.8 Future work

Regardless all the design recommendations addressing touchscreen devices that were extracted from the research performed in the last decade under the scope of applications for older adults, there are still gaps in this field. In particular, hearing and muscle strength loss was addressed by very few number of guidelines, which could serve this research as a base for future studies. Results from this literature review highlighted main trends of popular ageing related ability declines supported by guidelines, the most covered of them being lack of ICT skills, difficulties in information processing, visual decline, and hand-eye coordination problems in interaction with touchscreen.

There are few data available on the oldest old of age above 80 years and older workers, which could also be a possible direction of future research, especially considering that nowadays increasing number of older adults live to old age and preserving ability to work.

As has been identified, there is also no solid agreement on a functional definition of an older adult as a user of interactive touchscreen system, thereby, different profiles of older adults could be distinguished according to ability declines and their combinations in order to have a clearer definition.

At the same time, as has been found, majority of provided guidelines do not have a strong validation, which could be also an important and interesting topic for future studies.

8.9 Limitations

Classification limited to available information. The classification of guidelines was performed based on the information provided in the research articles, and discussions between the researchers. Given the limitations in the reporting styles, the classification might not correspond to the actual focus intended by the authors. We addressed this limitation by collecting feedback from the authors, but the information was not available in all cases.

Guideline assessment limited to the methods used in the research articles. The assessment heuristic employed in this Chapter was based on previous literature, limited to the methods used to produce or validate the guidelines. This gives us an indication of the process used in the research articles, but it does not guarantee that the resulting guidelines are indeed of good quality.

Part III

Part: Evaluation and Discussion

The last part of the thesis concludes this work by presenting the final set of user studies in institutionalized care scenario that refine the design implications from previous studies and evaluate whether they hold for the care stakeholders acting as the primary recipients of HWBI of seniors, namely, their family caregivers. The detailed description of the evaluation study is presented in Chapter 9.

Finally, this part also includes the discussion of the research findings of the overall PhD work in Chapter 10, drawing the conclusions and discussing the limitations and the directions of future work in Chapter 11.

Chapter 9

Designing Interactive Systems to Mediate Communication Between Formal and Informal Caregivers in Aged Care

By conducting three consequential sets of user studies with staff and family members of NH residents, we investigate the institutionalized care scenario and exploring the challenges and opportunities of designing information systems in it. We place an emphasis on informational needs of family caregivers and work practices of professionals, report on the current information practices, factors that influence them, and explore design alternatives that could target identified challenges.

One part of the content of this chapter has been published as:

Nurgalieva, L., Baez, M., Fiore, F., Casati, F., and Marchese, M. (2018, September). Designing Health-care Systems with an Emphasis on Relational Quality and Peace of Mind. In *International Conference on Social Informatics* (pp. 234-242). Springer, Cham. [43]

Another larger part of the content of this chapter has been submitted to the Journal of the Human Factors and Ergonomics Society as:

Nurgalieva, L., Baez, M., Adamo, G., Casati, F., and Marchese, M. (2019, April). Designing interactive systems to mediate communication between formal and informal caregivers in aged care. In *The Journal of the Human Factors and Ergonomics Society*. SAGE.

In this Chapter, we explore the challenges and opportunities of designing information systems in healthcare with an emphasis on informational needs of family caregivers and work practices of professionals. We focus particularly on the context of Nursing Homes (NH), where family members and care professionals are often faced with challenging situations that can affect their ability to interact, communicate, and collaborate effectively, and thus, leading to the episodes of conflicts or mismatch of expectations. We report on three sets of user studies with staff members and residents' family members in four nursing homes, studying current information practices and their impact on the individuals and workload. We then build on successful practices, and validate our attempts to incorporate them in current healthcare systems in the form of interactive tablet mockups.

9.1 Introduction

Shifting from *in-home* to *nursing home (NH)* care is a stressful transition for both older adults and their family members, with challenges ranging from the adaptation to a new environment and lifestyle to feelings of guilt and even failure by family members and lack of trust in how the NH staff will care for the loved ones [312–316]. In such situations, the NH staff plays not only the role of caregiver for the new resident, but has to carefully manage the interaction with the family members as well and to some extent even coordinate care, as family members often act as informal caregivers [48, 317].

Several studies [49, 318] investigated the communication between professional and family caregivers showing that *families need more information* about their loved ones and a greater involvement into the care process [53, 319]. Thus, the staff-family interaction and the kind of information that is (or is not) exchanged is important for the wellbeing of the family members and the role of information becomes critical both for the mind state of the family members and the family-staff interaction patterns. The way professionals communicate residents' health related information to their family may also significantly affect the work routine of the staff, increasing or reducing their (often very high) workload [320].

Mediating and semi-automating aspects of the staff-family interaction via technology has a lot of potential in terms of improving the quality, quantity, timeliness, and consistency of the information exchanged, of increasing transparency and therefore providing increased sense of trust and control, and of reducing the staff workload in this specific aspect of their daily routine.

On the other hand, the personal interaction is often essential, and technology may actually make things worse, for example, by generating unnecessary worry and doubts in family members when information is given without the proper context or explanation at the level appropriate for the specific recipient (which in turn results in the need for more interaction to clarify doubts) is communication, and in general what information about a resident is relayed to family members and how may affect the caregiving context and influence how various stakeholders behave, “both in relation to the technology itself and co-located people” [16].

Not surprisingly, discovering the most effective ways of mediating such relations and communications using ICT is recognized as a prominent research direction [51]. A simple signifier that something could be better is that only about 50% of all information recalled from consultations is in fact remembered correctly [16]. Significant part of out-of-home caregivers already use health IT in their caregiving activities [321], and there is a big interest among “technology nonusers” in using it in their caregiving responsibilities [321], which does not always result in the adoption. This mismatch may be explained by barriers such as “perceived cost, potential resistance by the care recipient, and a lack of user-centered focus in the design and implementation of current long distance caregivers (LDCs) systems” [321, p.1961].

However, only few studies have explored how technology can support family caregivers and staff-family interactions [16, 17]. As a result, we know very little about the *design* of technologically mediated communication that targets the different types of family caregivers [18, 19], both from information architectures and interactive or visual points of view.

One of the goals of information visualization is to support information exchange through the use of external visual aids, which becomes particularly useful in the contexts of sensitive and complex information exchange such as aged care context. Technological interactive tools can act as visual cognitive aids to enhance understanding and communication of complex health cases and large or frequent amounts of health related data. Although technology and visualizations are already used in such care contexts, the opinions of actors involved in aged care on their design and the effect of such tools on users’ care related behaviour and emotional state need to be investigated.

In the following we investigate the information seeking behavior, information expectations of family members, and factors that define them. We also explore communication practices of professionals and the rationale behind them, with the goal of identify if and how technology can provide a contribution. An area of specific interest, as pointed to us by NH management, was

the opportunity to selectively communicate information taken from the NH information system (storing all sort of information, also related to health and wellbeing of guests at a high level of detail) to the family members, possibly endowed with explanations to make information easy to understand by non professional. Specifically, we aimed at answering the following research questions:

- RQ1: What are the communication practices and information sharing expectations of formal and informal caregivers of older adults in NH context and how do they match or mismatch?
- RQ2: What are the main design considerations in technology-supported information sharing between NH staff and family members? This research question is focused on identifying challenges and design aspects that should shape the design space of HWBI sharing with a focus on relational quality and peace of mind of the stakeholders.
- RQ3: What are main design challenges, recommendations that could address them, and potential reactions of family members on receiving information in certain way?

Answering these questions is tricky: as we discovered, while at a high level caregivers are in favor of information exchange and greater transparency, when we drill down to details and discuss specific examples, we uncover various forms of resistance and challenges to be addressed for a system to be successful and accepted by all parties and to fit into the daily processes of a very complex and stressful work environment such as that of a NH. For this reason we proceed by designing a set of studies, first to understand the space of problem and opportunities and then to focus on specific cases and specific designs. We run the studies in several NHs throughout Italy, to also capture the different NH policies and attitudes related to staff-family interactions.

As we will see, the results show us that there is a space for the introduction of technology but it is rather narrow: most of the initial beliefs, not only by non-professional like us but by NH management as well and even by family members, turned out to be wrong, although there are specific situations where technology can help.

We report on three sets of user studies with staff members and residents' family members in four nursing homes, studying current information practices and their impact on the individuals and workload. As the interaction takes place in a very stressful and challenging context, the staff rarely see the idea of semi-automated information exchange as positive, and even family members for specific items have expressed the wish *not* to be informed. However, there are areas

where technology has a lot of potential and that we had completely neglected at first, such as the opportunities for information exchange in the opposite direction, with the family members informing the staff on how their loved one wishes to be cared for.

9.2 Background

Technology has been largely explored as an instrument to improve the delivery and quality of care in health and care facilities in aged care. Previous work has focused on designing and evaluating ICT tools for improving the coordination, organization of care practices, and to a less extent, the mediation of its communication among various involved actors.

9.2.1 ICT Mediation of Communication in Aged Care

One of the recent studies on health information exchange (HIE) technology is the study of Alexander et al. [75] where they report on the HIE preparation in 16 U.S. nursing homes (NHs). Their findings paint a picture of the current status of technology deployment to support information exchange, describing the presence of some care support systems but with little integration with external entities. In the conditions of the lack of human and technological resources that is a recognized problem in aged care context, they underline the importance of supporting information flow between healthcare providers. Douglas et al. [78] also discuss the barriers to exchange information using aged care service systems emphasizing that their uptake strongly depends on understanding the workflows and processes, as they have a strong impact on information and communication technology design.

Beside the necessary high rates of information exchange among care staff, the communication of professionals with family members of the NH residents is an important part of care process. Extensive body of literature shows that it contributes into the workload of the staff, which might not always be recognized, and affects the quality of care and satisfaction with provided care services both for older care recipients and their family members [70]. Overall, technological solutions are proven to support this communication and make it more efficient.

Patient portals are a right step in breaking information silos to involve patients but also their family members. Being seen as a “hub for families” implemented through “proxy access” [26], an e-access to health and wellbeing information (HWBI) provided by most of them may enhance

partnership between formal and informal caregivers of patients and better inclusion of into care process [66]. Caregivers believe that systems such as patient portals could reduce caregiving stress by providing better access to the health data of their loved ones [26].

In the same vein, previous work have explored televisits and distant caregiving [321], technology to improve the relationship between family caregivers and NH residents [322, 323], and technology-supported education of family caregivers to enhance communication with NH staff [324]. In their systematic literature review, Chi et al. [17] also investigate telehealth interventions from the angle of their usefulness to patients' family caregivers. Review outcomes provide strong evidence that using telehealth tools among informal caregivers result in less anxiety and improved coping. Moreover, while being proxy for the patient, the availability of tools providing access to information is particularly important. Findings also suggest that ICT mediated support can provide efficient care and save travel costs for caregivers of long-term care patients. Similar interventions with carers of older adults have also shown benefits, for example, in spousal carers [325, 326] – the carers in this scenario being older adults themselves.

Georgiou et al. [50] also studied information exchange processes and the role of technology in seven Australian long-term residential facilities. Their qualitative study points to three main tasks associated with information: storing and managing data, supporting decision making and communicating data; highlighting how poor information exchange can affect the quality of care. The results stress the need for effective communication technology support for continuity and organization of care, especially regarding accessibility and legibility of information. Illustrating that, Thomsen et al. explore technological support of the consultations between healthcare personnel, cancer patients and their relatives as they happen during treatment of cancer in a hospital department of oncology [16]. Their findings indicate that using ICT tools among medical staff does not mean being experienced in applying them in communication with patients and their family members

These works and others (e.g., [76–79]) provide valuable insights into how technology can support family caregivers but also point to scant involvement of family caregivers technology-mediated information flows, and highlight the need for better ICT-based support for information exchange in residential care.

9.2.2 Presentation of Health and Wellbeing Information

Not only efficient information design in communicating HWBI between formal and informal caregivers of older adults in aged care is important, but also presentation of this information to enhance its understanding in family members. It is relatively unexplored how to convert HWBI into knowledge and how to visualize the relevant information for the non-professional caregivers of older adults [327].

A vast literature has devoted to exploring visualization for self-reflection and behavior change [328–330], health risk prediction [331], and making medical data more intuitive [51, 332], among others. The most prominent and recent example is the work by Desai et al. [51], who conducted a series of studies to systematically explore different communication approaches and attempted to identify visual features that resonate with individuals suffering from diabetes. Emphasizing that the effective usage of HWBI strongly depends on being understood by non-expert users, they identified that efficient medical data communication practices could have a significant effect by “clarifying mental models of disease, internalizing health risks and consequences” for the members involved in the care process [51].

These findings are also inline with the systematic review of Washington et al. [19]. They identify that in such dynamic and complex healthcare environment as aged care, technology could target different levels of care experience and knowledge of older informal caregivers, helping medical professionals build a more customized interaction practices. By presenting current evidence on information needs of informal caregivers of older adults who suffer from chronic illnesses, authors conclude that informal caregivers need to be provided with individualized and understandable information in a proactive way, which is particularly challenging with multiple comorbid conditions of older adults.

Within the ambient assisted living (AAL) context, the work of Davis et al. [333] illustrates how ambient intelligence can be used to provide peace of mind and display a qualitative sense of a senior’s daily activities to caregivers concerned to foster the sense of connectedness. In their studies, they design a “bidirectional peripheral activity awareness system” and conduct a field trial of an experience prototype of it with elderly-caregiver pairs, identifying that “the awareness of activity levels gave a sense of increased closeness for both target groups” [333, p.7]. Another contribution of their work is a set of design implications that could support social connectedness between the elderly and their caregivers in AAL environments, which emphasize the importance

of understand the users in context to provide them with the solutions tailored to their needs. In their another work, Davis et al. [334] investigated intelligent lighting system in AAL context to communicate activity levels of older adults to their family caregivers. Study participants preferred 3 different colors as simpler visualization to combinations of hue and brightness that was more informative.

Forkan et al. [335] investigated a monitoring system that shared events related to a patient with family, friends and doctors on Facebook. Forkan et al. develop and evaluate a context-aware system for monitoring of older cardiac patients living alone and sharing context data generated by wearable sensors with their contacts through social networks. Similarly, Huang et al. [336] - how introducing an additional ICT based communication channel between older adults and their children could enhance.. Taiwanese context, having vital signs over social networks. "There was high satisfaction in encouraging communication between older adults and their adult children by using CDF. Sharing photos and videos on CDF enriched the content of conversations."

Information needs of family caregivers are multi-faceted, complex, and vary over time, depending on various factors, primarily such as gaining more care experience and health changes of their loved ones [18]. These works indicate an important dimension to be considered in information exchange with individuals of different level of care experience and knowledge.

Zhang et al. demonstrate the use of visual information displays within a healthcare informatics application, they identified that most existing electronic medical record (EMR) systems make it difficult to get a quick assessment of patient status [337]. Belden et al. identified a number of reasons why the adoption of EMRs has lagged behind expectations, and established the following usability design principles: (a) minimize caregiver cognitive load, (b) design for UI simplicity, naturalness and consistency, (c) make colour meaningful, and (d) preserve context [338]. For instance, they emphasize the importance of color in conveying meaning to the user, such as all aspects of information presentation, navigation, or differentiation of screen areas. In their study with formal caregivers of long term care residents, Stevens et al. designed a tablet based visual analytics tool that collects, structures, and visualizes healthcare data where they used "green/yellow/red voting system, with green indicating improvement, yellow stability, and red decline" to allow caregivers to consistently assess resident's status [339, p.280]. Applying colours they address usability issues identified by previous research such as reducing cognitive load associated with text, while adding redundant coding they make the visualization readable by people with vision declines, for instance, colour blindness.

Providing overview and “detail-on-demand” [340] is equally important—salient information should become available on a whim when requested but just as quickly disappear when no longer relevant [337]. A frequent paradigm is to organize the patient records along the time axis [337]

These works contribute to the efforts in making making HWB information more intuitive and understandable, especially to non-experts. However, the information sharing and presentation requirements when it comes to sensitive scenarios, with a strong relational component, and targeted at family members and not patients, is still a largely unexplored topic.

9.3 Methods

For our research, we first organized a set of informal visits and observation in 12 NHs throughout Italy, to become familiar with the environment, to understand the problem space to help us shape the subsequent studies and to understand the practicalities involved in organizing the studies. The reason for the high number of NHs involved is that we also wanted to get a sense of how varied the NH practices and the characteristics of residents are across different NHs and to ensure that we know how many and which NH to target in our studies to capture this breadth.

After this preliminary phase, three sets of user studies were conducted in four different nursing homes (NHs) in two regions in Italy. Each institution selected a variable number of family caregivers and staff members who signed an Informed Consent. The studies were approved by the University of Trento Committee on Research Involving Human Beings (Application N. 2017-003).

During every NH visit, there were at least two researchers from our research group who took notes. Visits were scheduled and always accompanied by a gatekeeper; either the director or the chief nurse. All studies were carried out at the NHs in places deemed private and comfortable by the researchers and NH contacts. We paid peculiar attention towards the people involved, avoiding any questions or situations that could cause distress to the participants, in order to guaranty an efficient and respectful data collection. Prior to the start of each interview, participants were briefed by the researchers on the objective of the study and signed an informed consent, which included a written and verbal consent to record the session.

9.3.1 Study 1. Communication Practices and Relational Attitudes

The first study focused on the RQ1 and aimed at exploring emerging communication practices in NH settings from the perspectives of NH staff and family members of the residents.

Participants

Participants were recruited with the help of the nursing home contacts, so as to get a representative sample of family caregivers and NH staff (e.g., different roles). We conducted a total 26 semi-structured interviews with family caregivers (17, 65.5 mean age and 59% of females) and NH staff (9, 48.9 mean age and 55.6% of females) who volunteered to participate. Each interview was conducted by a native Italian speaking researcher with background in sociology (with experience in running studies with vulnerable populations) with the assistance of an HCI researcher. Prior to the start of each interview, participants were briefed by the researchers on the objective of the study and signed an informed consent, which included a written and verbal consent to record the session.

The interviews with family caregivers focused on i) information seeking strategies, ii) expectations and attitudes towards the NH staff in relation to the sharing of information, and iii) reactions to different type of HWB information. The interviews with the NH staff followed similar themes, with an emphasis on i) information communication practices, and ii) factors that shape their practices and communication strategies. Each interview lasted from 20 to 30 minutes and was carried out in full anonymity without the involvement of third parties.

9.3.2 Study 2. Design Considerations for HWB Information Sharing

In this study we build on the findings from the previous interviews and explore the specific dimensions of information exchange by navigating NH staff through low-fidelity prototypes in order to identify challenges and design aspects that should shape the design space of health and wellbeing information sharing (Research Question 2) focusing on relational quality and peace of mind of the stakeholders.

This second study used a combination of semi-structured interviews and surveys with nine NH staff members. Due to inability to follow the original interview script of the Study 2 with four family members, as it has not been possible to include family members for logistical reasons or

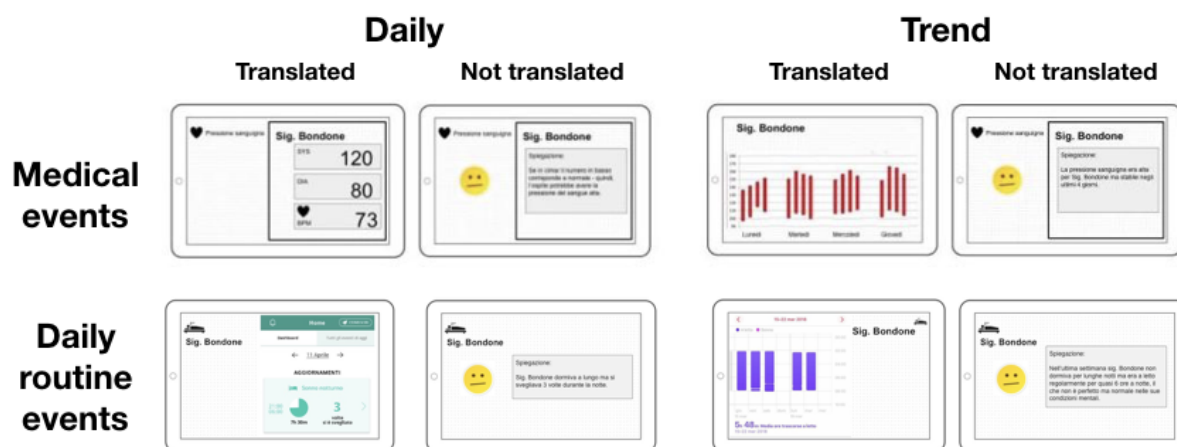


FIGURE 9.1: Information design alternatives (type, granularity, and presentation)

for lack of volunteers, these interviews followed the structure of the previous study and reported in the analysis of the Study 1.

Participants were firstly asked about their background information, professional responsibilities, and their personal work practices of communicating information about the residents to their relatives.

Following results from Study 1 on common information communication practices from the staff in connection to the characteristics and preferences of the family members, NH professionals were asked about relevance, importance, and views on preferred ways of communicating examples of NH routine events. Events included medical (sodium and glucose levels and blood pressure), daily routine events (meals, sleep, and social events), and change of therapy.

Staff members were presented with the idea of ICT mediated dissemination of those events to families of the residents. Questions and surveys were specifically focused around the implications of different *design alternatives* characterized by type of event (medical, non medical), granularity (single events and trends) and presentation (raw events, and enriched), as illustrated in Figure 9.1. For that, the intervention was designed in a form of 2x2 factorial study: raw events, e.g. specific instant medical values or daily information, and trend over several days were combined with direct representation and version translated by NH professionals.

Regarding each screen, staff members were asked to express their informed opinion regarding expected reactions of the family members upon receiving information in a given way, and their expected level of stress, as well as the readiness of staff to share in that way (design alternative). NH staff members are the main actors who would have to take care of the workload created

by ICT based dissemination of information given the interest in such services from the side of the family members. Thus, their opinion, combined with their experience communicating information to family members was considered primary in getting early feedback in the design.

Participants

Overall, nine semi-structured interviews were conducted with NH staff members (50.6 mean age and 66.7% of females) who volunteered to participate. Each interview lasted from 20 to 40 minutes based on the workload of the staff. We particularly tried to assure staff members in the anonymity of their responses and non-disclosure to the administration of the facilities or any other third parties.

9.3.3 Study 3. Visualization and Evaluation

The aim of the third concluding study was to evaluate interactive prototypes with one of the target groups of end users, namely family members of institutionalized seniors, using an empirical evaluation method in a form of two workshops. We opted for this for of predominantly qualitative user study, complemented by minor quantitative questionnaires, since we judged that broad and deep insights were only attainable through observation in combination with an open and flexible discussion format, as it has previously been shown in previous research [94, 95].

Two workshops took place at local aged care facility in Trento, Italy, which includes day-care and nursing home services, from where participants were recruited with the help of the facility staff. Each of two workshops lasted about sixty minutes. The workshops were conducted using an Asus MEMO Pad with a 10.1" screen running interactive mockups (Figure 9.2) and the testing material was only available in landscape. Prior to the start the workshop session, participants were briefed by the researchers on the objective of the study and signed an informed consent, which included a written and verbal consent to record the session.

The workshops were aimed at: i) evaluating the sufficient amount and preferred modalities of the alternative HWBI presentations, and the users' reasoning defining them, and ii) exploring the potential emotional reactions and actions of the participants on receiving information in a given way.

In the beginning of each workshop, we facilitated an initial group discussion of communication practices in place. Then, workshop participants were split into two smaller clusters of 2 or 3 people to explore and evaluate “Traduttore” mockups (Figure 9.2) in a co-discovery manner, to then reconvene back into a group for discussion of the participants’ experiences and final recap. Each cluster was facilitated by one researcher who showed the interactive mockups on the tablet.

Following the Study 2, the mockups presented 2 examples of weekly trends of medical and daily routine events at the NH (blood sugar level and sleep) in 3 modalities: chart with metaphor, chart with metaphor and a short explanation from the staff, longer explanation narrative from the staff.

Figure 9.2 depicts the mockups used during the workshops in each cluster of participants and includes 3 alternatives for sleep and the values of blood sugar of older adults over the week time period: 1) a chart with numeric values and metaphor translating the values over the last week, 2) a chart with a metaphor and short textual explanation from the staff, 3) a long narrative explanation from the staff without numeric values.

Participants

In addition to the two HCI researchers who facilitated the session, overall 12 of family members (MEDIAN = 58, SD = 8.7, 70% female) of the seniors in two types of institutionalized care settings (adult daycare center and nursing home or skilled nursing) participated in the workshops. Participants were recruited with the help of the care facility contacts, as to get a representative sample of family caregivers (e.g., different level of involvement in care).

90% of all participants are primary family contacts for the care facility and visit every day. 4/10 of them reported “Middle school diploma” as their highest degree, for other 4/10 it was “Courses after high school degree or higher study”, and for 2/10 the highest degree is “Diploma (high school) of upper secondary school or diploma of professional qualification”. All of them agreed or strongly agreed that they trust the care facility staff and are satisfied with the services provided to their loved ones.

80% of participants own computer, also 80% of them own a cellphone/smartphone, while 6/10 own both of these devices at the same time. Just 3/10 reported on owning a tablet.

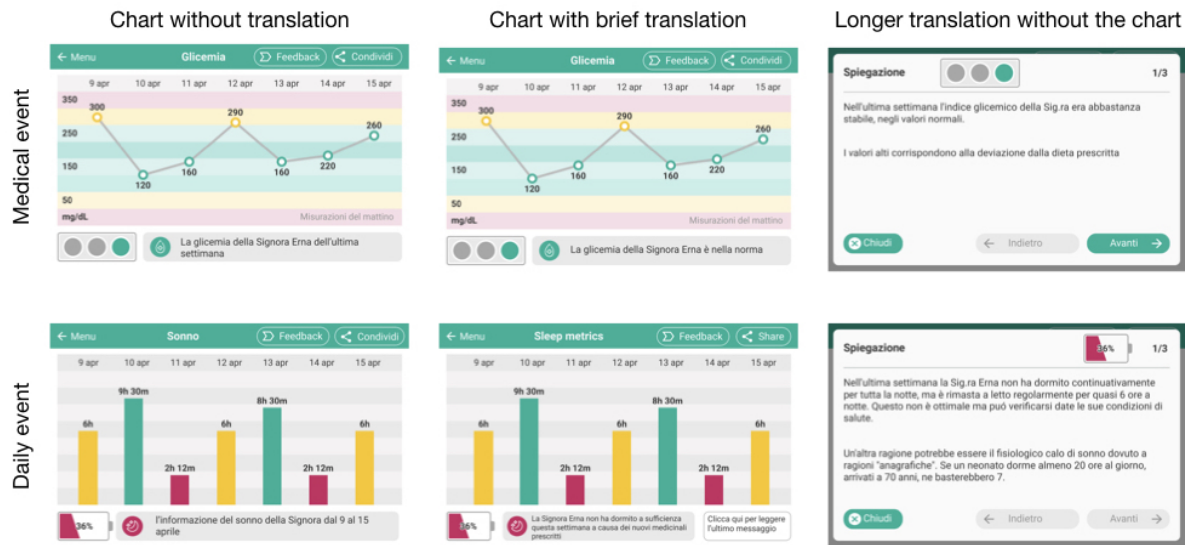


FIGURE 9.2: Interactive mockups

9.4 Study 1. Communication Practices and Relational Attitudes

The first set of user studies was mainly set to explore communication practices and mutual attitudes of formal and informal caregivers regarding information sharing in nursing homes. The qualitative analysis revealed specific communication practices and attitudes depending, primarily, on the type of HWB information, the role of the NH staff member, and the characteristics of the family member involved.

The qualitative analysis revealed specific communication practices and attitudes depending, primarily, on the type of HWB information, the role of the NH staff member, and the characteristics of the family members involved.

9.4.1 Communication Practices of NH Staff

Critical events such as falls and going to the hospital are communicated proactively by the NH. For example, in the unfortunate case of a fall, the event is always communicated immediately by phone. Alarms in relation to the specific health parameters, for example, blood pressure outside normal ranges, are usually not communicated. Instead, the doctor makes the necessary therapy changes and reaches family members if approval is necessary. Information is usually provided by doctors face-to-face via fixed appointment (unless there is an emergency), and with very little (to not at all in some cases) communication with family members over the phone. NH staff

members call based on their competence area and cannot communicate the information they do not have access to.

Other types of information, such as test results and daily events are communicated upon request and mostly during the visits. Requests are mostly based on the condition of the resident. For example, for some family members the fact that a relative has eaten is very important, so stomach aches makes them very worried. Overall, they communicate “trends” but not specific events, e.g., not if a person has skipped a meal but if the person is eating less in general. This is because in some cases they should first do a medical evaluation to understand the reasons, but also because NH staff finds that there is no sense in communicating events that might not be relevant anymore by the time they are received.

In general, for non-critical events, the professional judgment plays a main role in deciding what information to share: *“It depends from case to case. In the sense that if the parameters are outside of norm, I need to see. If things are very bad and worrying, I call the family members. Otherwise, no, we communicate it at the next appointment when we meet”* (P1, doctor).

It was consistently recognized that communicating with family members required a particular set of skills, and that staff who communicates with family members should have skills to do so: *“It is important to know how to communicate, those who can do it well should do it, otherwise, not communicate. There are ways of communicating the information, special words that should be used, it really matters how the information is delivered”* (P2, nurse). *“I would prefer just some of the nurses to communicate information to the FM, the ones who know how to do it”* (P1, doctor).

9.4.2 Information Seeking by Family Caregivers

We observed three distinct types of family caregivers among the participants based on their organization and involvement, which affects information exchange: individuals (5), care teams (6) and proxies (2). *Individuals*, makes reference to family members who play the role of primary contact and who reported little to no involvement from other family members. *Care teams* are a set of family members that share the responsibility and involvement. These teams were composed by children of the resident, siblings of the resident, or a child of the resident with his/her core family (partner and grandchildren). *Proxies* are persons hired by the family to visit and spend time with the resident on their behalf and rely information on their status.

All participants reported on-site interaction during visits as the main mode of information exchange. This is not surprising as the majority of family members visits twice a week or more. Interactions via phone were also mentioned as a mode of communication, which aligns with the information exchange practices reported by the NH staff. However, for the participants these communication were mostly initiated by NH staff, and in two cases participants even reported never having called or received a call (participants visiting on a daily basis and with the loved one in no critical condition). No other modes of information exchange with the NH were reported. The importance of human contact in communicating was explicitly raised by three participants from the relational perspective (*"They are people who take care of my mother, it would be nice to see them, to talk to them. And the same for them, I believe that they would like to see the family members,"* F1, daughter), while those with the loved one in a critical condition stressed the importance of the appointments with the doctor.

Most of the time the communication between nursing homes and family members of the residents happens during the visits, for the urgent cases NH staff calls to the family, usually the primary contact. For non-urgent but particular cases, family members come to the doctor's appointment.

When it comes to communicating among family caregivers, phone calls was reported as the dominating mode of communication. In care teams this is used to coordinate and update each other on information collected by the one visiting (*"we are always on the phone with each other [among sisters],"* F3, daughter). Individual carers report little communication with the direct family members not involved – though it was mentioned in one case occasional updates to the larger family. Proxies mentioned updating family members via phone and email.

As for the information source, all participants reported interacting with the NH staff for information exchange. This includes interaction with the doctors and the responsible nurses. Interestingly, four participants indicated the resident as their main source of information: *"My mother is the first one to tells me news. For example, that she did not sleep well last night. I ask staff only if there are problems"* (F10, son). *"My mother knows better, so she calls and tells us herself [about her condition]. If there is something, it is her who informs us. Because she knows better about her "values". She asks herself [to the staff] what are her values, what medicine they give her"* (F1, daughter).

The Web also emerged in three cases as an additional source to investigate about health-related information, e.g., *"If tomorrow I am told that he has herpes, of course I will search about it [on the Web]. Also if I don't know something now [about current illness]"* (F13, sister).

In terms of the general interest and need for information exchange, we observed different approaches determined particularly by the critical or non-critical condition of the resident and the level of trust on the NH. Family caregivers of residents in a non-critical condition showed either a more passive approach to information exchange, expecting the NH staff to inform them of relevant updates (e.g., *“I do not ask but if there is something [wrong], I guess they will tell me,”* F11, daughter) or contacting them when they observe an issue (e.g., *“yesterday I came here and I saw that [my mother] did not have socks on... then, I asked [the staff] to put some socks on her because she is a lady who is always feeling cold,”* F0, daughter). Two participants with relatives in a more critical conditions showed more interest in having access to all available information, but also reported negative experiences and differences with the NH staff (as we will expand on the next subsection).

When asked about the type of information they usually request, general information about the situation of their relative was the dominant theme (*“What is good, what is bad. Information about the day,”* F10, son). One participant even pulled out his mobile phone to show us the Fitbit¹ app as an example of the level of detail it collects about sleep, and mentioned that he did not need all that information, just to know if his father slept well in general (F12, son). Two participants (F5, proxy; F11, daughter) explicitly mention social and relational information as the most important one (*“[I want to know] about the mental state, if she interacts with others, if she communicates... I had my mother sick at home too and the most important for me was her mental decay. I would like to know if she interacts with others,”* F5, proxy).

Some participants mentioned their interest in medical information but were not precise about the specific parameters, and so their interest was leaning more towards what the NH could volunteer and deemed relevant. Indeed, one participant mentioned explicitly that she was not aware of the type of medical tests they were running. This aligns with the interviews with the NH staff, where they reported that family members rarely asked about specific health parameters, and that most were not aware of the specific tests.

9.4.3 Mutual Views in Relation to Information Exchange

Most family caregivers reported being satisfied with the communication with the NH. One of the main contributing factor in these cases was the stable or non-critical condition of the resident (*“At this point therapy is quite consolidated”,* F12; *“My mother takes just one medicine, there*

¹Fitbit is a commercial fitness tracker: <https://www.fitbit.com/>

is nothing much to discuss", F11). In two particular cases however, participants expressed dissatisfaction with the NH staff, which raised a series of communication exchange problems.

A participant who, along with other family members (care team), is involved in the caring process of his loved one (resident with diabetes and heart problems) highlighted episodes of confrontation where they considered the NH did not take the appropriate actions in a case of emergency. This participant indicated that they would like to see all the test results with the exact numbers:

"I would like to see the exact numbers. Because now, for example, my mother has diabetes. [Early this year] we had a meeting with a diabetologist in [a nearby city] to see the state of the diabetes. Back then, she was under control. Now, for about a month, we give a her a medicine [for her diabetes], the minimal dose. First, it went up and then down. And now, [NH staff] controls [the progress of diabetes] just once a day. It's not enough. We asked the coordinator, how [my mother] is doing, and [the coordinator] told fine. What does it mean 'fine'? At home we measured 3 times a day and now here nothing."

The above quote encapsulates a couple of themes. First, the feeling that family was taking a better care of the resident at home, which was raised at other points during the interview (e.g., *"At home we had a diary where we put all the measurements with meals: breakfast, lunch, dinner, then at 10 p.m. and at midnight, to be sure. 5 controls at home"*). Second, an apparent lack of trust in the NH practices, shaped by the participant previous experiences. Third, the involvement of third parties (experts) to verify the care practices. Fourth, issues related to expectations and understanding of the information provided by the NH staff, a point that later followed up with a specific example (*"For example, yesterday she did a test of 'sodium', and it was outside of the normal range. [The NH staff] gave her a medicine for that. They didn't explain, they said 'no sodium, we start the therapy for sodium'. It would be useful to know the explanation."*)

Another participant (individual carer, brother not very involved), expressed dissatisfaction with the doctor in particular, but for different reasons: *"I am not very satisfied with the doctor because [with him] I cannot express myself. He doesn't update me [on my mother health condition] if I don't ask, even if there are things to be communicated. I would prefer to have more appointments, [but] he never calls. In 4 years I've had 3 calls. For the medical tests, they also don't tell about it, I don't even know they do them."*

This participant showed a different expectation in terms of how information should be communicated by the NH staff, wishing for a more proactive communication. The quote also highlights some more introvert personal traits that might get in the way of a more fluent communication, as the participant also raised several times during the interview (*"I don't like to ask. When I visit, they usually tell me. I don't like to keep asking."*, *"I don't like to ask and disturb much."*). As a way to manage the situation and uncertainty, the participant wish was to be inform if only to be told that things were fine (*"If they'd [keep me informed], it's always good. It's also good to know that everything is going well"*).

On that last point, all participants were aware that calls from the NH are to communicate critical events, so there is a sort of negative connotation around these calls as the "bearer of bad news". One participant exemplified this in a personal experience: (*"I heard someone calling, I run to the phone, it was the number from [the NH]. The nurse tells me not to be afraid, 'it's just your mother who wanted to talk'. Before they never called, [to me] it was an emergency"*).

The **interviews with the NH staff** gave a us rich perspective into different dimensions they use to categorize and describe family members. We were able to identify a number of "personas" that are relevant to information exchange:

- Personas based on reactions to receiving updates: qualified in terms of level of worry, anxiety and irrational requests;
- Personas based on care involvement or available time to spend with their relative at the NH;
- Personas based on views about the NH as a facility and services it has to provide them with;
- Personas based on care related knowledge and experience;
- Personas based on trust on practices adopted by the NH professionals;
- Personas based on feeling of guilt towards moving their relative to the NH, which is also influenced by cultural context and society stigma;
- Personas based on expectations towards amount of work and quality of it that staff members should perform;
- Personas based on amount of questions family members ask the staff;

- Personas based on health condition of the resident.

Personal relations are very important, based on how well staff knows a FM, they communicate the events accordingly. It matters what are the personal relations, how comfortable they feel to communicate certain events directly or in a less detailed fashion. It is important to know, however, that the knowledge of these “personas” is implicit knowledge and different communication strategies scattered through the NH staff.

9.5 Study 2. Design Considerations for HWB Information Sharing

After introducing the concept of the technology-mediated information exchange with family members (through low-fidelity prototypes), participants were unanimous in the view that it could improve the communication with family members. However, most of them expressed concern of increase in the workload with introducing such tools if information would have to be logged manually: *“Well, it could be nice and probably reassuring for the family members. I am asking you if a nurse who takes care of 102 residents during the night also has time to do this. I have doubts”* (P1, doctor).

9.5.1 Presentation of HWB Information.

Following the 2x2 factorial design of the Study 2 described in the Section 9.3, screens contained raw events (instant measurements or daily information) and trends of events over certain period that were presented in direct and translated fashion. Discussing *raw* singular events, daily or medical, NH staff emphasized the importance to add a reference value or range for raw values for the medical parameters, given that family members may not know how to interpret them. However, they also noted that each case is unique and it is usually difficult to explain the meaning of the values generically: the interpretation of the vital signals depends on the specific health situation.

When shown the concept of event enrichment and explanation, which included smileys (Figure 9.1) as a way to facilitate the interpretation of the event (negative, neutral, or positive), most of the professionals stated that showing such summaries was a good idea. However, one participant expressed the opinion that a smiley can also miscommunicate information. At times,

family members may know better the mood or state of their relative and indicating it with the smiley may mismatch their perception of the situation.

"If the program will let me [add]... also just a smiley, sad or red, green, anyway these are the signals that make relatives understand that there is more explanation, that it says that everything is going well" (P4, nurse coordinator). *"The family members know the resident, they can see things we do not see, if they see the red smiley and instead they know that it is not critical... [may be stressful]"* (P6, nurse coordinator).

In case of events indicating an issue, for example, waking up at night or skipping the meal, NH staff stated that the visualization for the family should also contain the explanation, not leaving the relatives to wonder and ask staff additional questions increasing the workload of the latter.

Events communicated directly without translation by the professionals and presented only graphically could be perceived as "cold and distant." This theme came up, for example, in discussions with a professional who is most in touch with family members: *"This one [raw event without translation] is more technical, colder, more detached. Instead this one [raw event with translation], even more visually, it makes you immediately understand the situation"* (P8, social worker).

Reports over a period of time (trends) were evaluated as helpful for family members, for example, for seeing deviations and verifying past activities or therapy. Moreover, trends were seen as helpful for the staff members as well. Reports of the last several months were compared to the Individualized Care Project, an evaluation of the resident's health by the whole NH care team organized periodically, and seen as a way to monitor overall wellbeing or therapy. *"[On the trend of having meals] I think that having a graph like this would nice to have for us too. To understand better"* (P6, nurse coordinator).

Regarding the time periods for such reports, most of the staff members (5 out of 9) expressed the preference towards the weekly reports: *"[The best is] a weekly report, I would put a week, a sort of diary... I would make it for all the parameters"* (P6, nurse coordinator).

NH staff believe that retrospective information is less stressful for family members. However, they also pointed out that in cases where family members were not informed about some negative events or certain dynamics in their loved one's health, discovering it later in trends may raise additional questions.

“They would also ask [the NH] if they were not informed in advance. In the sense that, if things are not going well and they did not know, seeing the trend like this, they would ask “How come?” They would call immediately if they were not informed. If instead they already know the dynamics, they understand, expect it. They may not even call, they are informed” (P6, nurse coordinator).

Staff members expressed worries that sending singular events would overload family members with excessive information, and thought that trends would help manage this situation: *“Rather than bombarding a [family member] with SMS everyday to say “today he went to the bathroom, today she walked, today he ate a beef steak”... [trend] is less invasive”* (P7, physiotherapist).

9.5.2 Expected Preference and Reactions

Together with the qualitative evaluation of the design alternatives, participants were asked to evaluate each of the randomly selected screens in relation to two main factors: preference based on efficiency and simplification of communicating events, and expected reactions and stress level of family members upon receiving information in a given way.

Efficiency

While talking to the staff members about their views that sending translated events to family members could make the staff-family communication more efficient, in 75% of responses participants agreed or strongly agreed that it could, while only 12.5% did not. As for direct communication of not translated events, 58.4% of responses were positive about increasing the efficiency of such communication and 37.5% were negative.

Simplicity

Simplicity of communication with family members was another aspect investigated in the survey. 66.7% of all comments on the design alternatives were positive that translated events could indeed simplify information the interaction. Just 8.4% disagreed. As for the design alternatives of not translated events, in more than half of their responses, staff members stated that they would share the events in this way to simplify the communication, while in 37.5% of comments they did not think so.

Anticipated reactions by family members

As the response to receiving medical events, staff members would expect relatives to call the nursing home for the clarifications (occurred in 44% of responses), while the most expected reaction on daily routine updates would be asking during the visit, which was mentioned in the 38.5% of the responses.

As for the anticipated level of relatives' stress, medical events were seen as more stressful than daily events. In 29.2% of responses, staff would expect extreme stress in family members after receiving medical updates, while for the daily information it is just 4.2% and the most common—no stress at all (45.9%). Translation of events was considered as bringing less stress comparing to the direct communication. Expectations of light stress or no stress at all occurred in 79.2% of comments on translated events, while for the alternative it was 45.9%.

9.6 Study 3. Information Presentation and Delivery

Following the findings from the previous two studies (Sections 9.4 and 9.5), this third study was set to investigate the preferred level of detail and presentation metaphors for the HWB information communicated to family members, and how these preferences are modified by the type of information and its positive or negative connotation.

As described in Section 9.3, the sequence of interactive mockups varied for each subgroup of workshop participants. The mockups contained different amount and combination of textual (long and short narratives) and visual (metaphors, charts, colours) aids that aimed at making HWB information more understandable for the family members of older care recipients. However, the discussions always started from an example of NH daily events and followed by a medical event.

9.6.1 Daily Events

The mockup alternatives with textual narratives of daily activities (sleep or meals) (Figure 9.3) included specific information of the resident's weekly trend (Part 1) and general description of values that hold for general older population, for instance, the fact that seniors sleep less with age (Part 2). Part 2 was incorporated with the idea of providing general context to understanding the

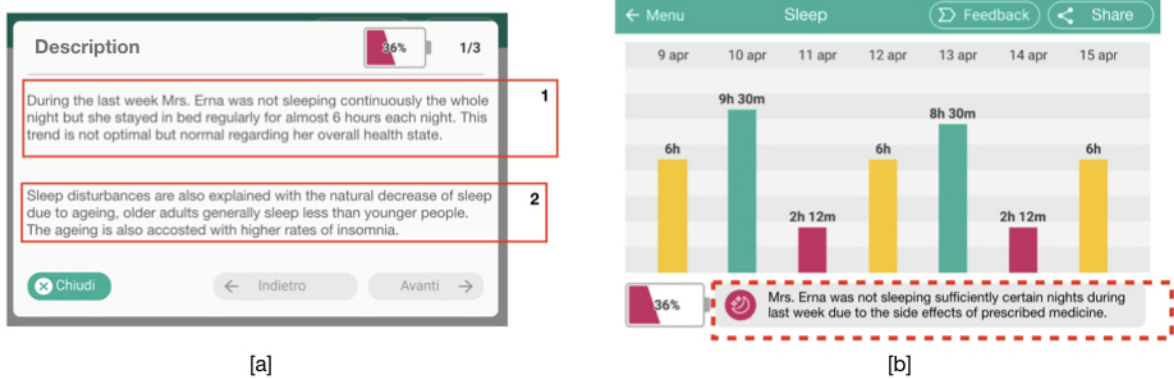


FIGURE 9.3: Weekly sleep trend examples: long narrative (a), visual overview /chart (b)

information, but in this modality (text narrative) it created confusion among participants, who expected messages to be more personalized (“*I don’t understand this “due to ageing” [referring to the Part 2]*”).

Participants did not expect to be worried or to require further follow-up information upon receiving **positive trends** of their loved ones daily information overviews (Part 1) e.g., calling to get more information: “*If they tell me she has slept and she is calm, I wouldn’t call anyone, everything is fine. If that’s what they tell me, things written here [emphasizing that the message is positive], no worries.*” The visualization in the form of long narratives was seen as enough information in this case. Participants also expressed that an application communicating these events might be less relevant to those with loved ones’ overall health not critical: “*I think that if the [older adult] is doing well, [the application] is not needed, one can just visit. However, if there is a problem, one could use the application.*”. To family members who visit frequently, communication in virtual channels revolve around negative events, an aspect also observed in our previous study.

Imagining the future, in cases when there is a **negative trend** over some time, for instance, a sleep disturbance over a month period, participants would like to know if the NH staff has done something about it (performed an intervention) and if their loved one could be helped in general: “*If just once—no, if she doesn’t sleep for a month, well, then yes, I ask if [staff] did something about it.*” “*If she is helped to understand why she doesn’t sleep, why she doesn’t sleep during the night.*” This was an aspect not covered in the mockups but that points to how important pieces of information depend on the type of trend.

When shown the chart visualization, participants switched to a more analytical state trying to

interpret the data. They were able to understand the chart, reading aloud the sleeping hours per day (“*Well, it says she slept 9 hours, 6 hours*”) but were not able to easily derive the trend, even with the help of the metaphor of the battery charge. However, seeing the chart with numbers could give some family members higher confidence that the information is trustworthy, more than the textual narrative explanation: “*The chart like this [is good] for me. It is more fundamental than ‘the Mrs. slept...’ [referring to the narrative]. Because maybe... [implying that it might not be the case]. Like that [in the chart], I understand immediately*”. This preference appears to be related more to a desire of having level of scrutiny than in comprehension, an aspect already observed in our previous study where the need for detailed information was in some cases rooted in negative experiences or lack of trust in NH staff.

Comparing to the screen alternatives that contained a visual overview (chart), detailed textual narratives from the staff were considered by participants as being “warmer” or more human-like communication, showing more effort from the staff to make family understand the information: “*I think that the [detailed narrative], I think it is much better because they did an analysis... they had to reflect about her health. Instead, another one [chart with short message] is without any reflection, let’s say very “cold.”* In this case, adding a short message to accompany and explain the chart (a message on Figure 9.3) was seen as beneficial.

9.6.2 Medical Events

The second category of events presented to the participants was medical information that is being collected and shared within care facilities and with family members, for instance, blood pressure or blood sugar level.

Similarly to daily routine information, generic information in the long narrative was also seen as redundant and lacking the value for the medical events: “is it same for everyone and generated by a computer?” Moreover, one of the participants commented that such general information may also compromise their trust and demotivate them to read such descriptions in future: “*I am only interested if the blood pressure of my relative was at least evaluated. Just that. This information is not useful [the part 2]. I would not even read the rest. I would not trust the information you would give me anymore.*”

Most of the comments were not in favor of long messages, for example, expressing the concern that they might trigger “Dr. Google” behaviour [341]: “*more information you give, more effort*

you have to provide, more... of those who continue searching on computer for various sicknesses and then has all the symptoms." Participants also recognize that long messages might overload them with information: "*[you can show this information] even without [the long message] to read because when you are at home, your head is already full"*, and expressed their preference to request additional information in cases when they need it.

Chart visualization of medical information, however, was perceived as more understandable by the participants "*I see that [chart] is something that you understand immediately," "I am for the chart. The chart is more straightforward."* This representation of the information put participants again in an analytical state and there were discussions among the participants – who showed knowledge of how to interpret the glucose levels and the implications. Interestingly, the information in the chart was easier to interpret than the daily information, possibly due to the familiarity with the type of data and well established critical values (also displayed in the chart).

It became evident during the analysis of medical events that information presented should carry not only the "numbers" but also contextual information, in a way that it is precise and accurate. The lack of event-specific context (e.g., whether the measure was taken before or after a meal) raised questions that made it difficult for the participants to decide on whether the information was of concern or not: "*I mean, here she has 120 of sugar level that means it is high but perhaps it is after a meal. [...] in the morning, is it before or after the breakfast? Because it is one problem if that's before breakfast, and another if it's after."* Adding a short message from the staff to the chart gave a reassurance that the values were previously assessed by the medical professional whom family members trust, hence, giving more clarity: "*Practically, I can say that [chart with a short message] was already seen and evaluated by a doctor, so it was after the meal because it is inside the normal values"*.

This becomes particularly valuable in cases when certain medical test values might be unfamiliar for the relatives with low level of medical literacy, as the chart values might not be enough info to interpret and make sense of the information about an event: "Well, if one doesn't know the values [of medical tests]. Well, what would it say [to this person]?" Providing contextual information and aids to interpret correctly the data was thus more appreciated and needed in visual representations than in narratives (e.g., the same information we tried to convey in Part 2).

Overall, participants expressed strong preference towards seeing the chart values for medical events, which is supported both by many qualitative comments (“*No, anyways, now, after seeing the chart, I am for the chart. To see the values*”). Quantitatively, this alternative was considered slightly less efficient than the narrative for both events.

As we observed during the workshops, naturally, participants explained their preferences and provided comments by comparing the screen alternatives “*No, anyways, now, after seeing that chart, I am for the chart. To see the values [about the narrative after seeing chart].*” However, the views of the family caregivers still converged for each type of events, e.g. daily routine and medical events, regardless the flow.

Additional comments

Overall, participants strongly emphasized the importance of personalizing the HWB information they would like to receive, as the same event could be very important for one family caregiver and irrelevant for another: “*[I would like to know] that my aunt managed to leave the bed for an hour. For another person it could be [important to see] other daily events*”, which may also depend on the specific health state of the senior (“*For my aunt, to walk in the room after the lunch and to walk around alone is important*”). In particular, the importance to see certain medical information is dynamic and depends strongly on its relevance. Moreover, family members expressed their preferences to opt out from receiving certain events if they are not critical for their loved one’s health or do not change over time. For example, they might rarely check the blood pressure that fluctuates around the same values: “*if it is always the same, [I would check it] maybe not all days, but maybe once a week*”.

The interest of participants to receive certain types of information also depends on the facility service their loved one is provided with (nursing home or daycare), which can also change over time with transition of aged care.

As can be seen in Section 9.3, most of the participants belong to the older population group, and indeed, they emphasized the importance of accessible design of the mockups. Moreover, one of the participants was colour blind, which yet another time indicated the importance of accessibility of such applications: “*I am a bit colourblind, it is a limitation. Put like that, I see it a bit more intense, but if not, for me they are all the same.*”

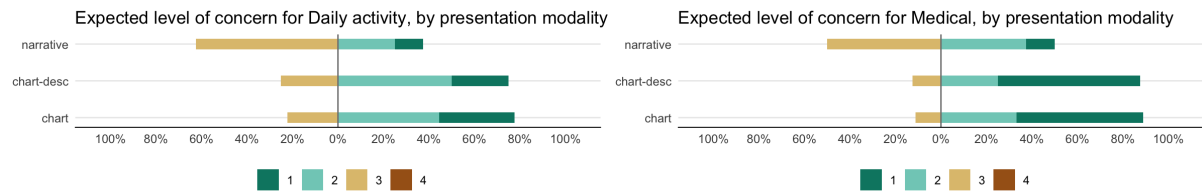


FIGURE 9.4: Expected level of concern upon receiving HWB in a certain modality

As NH residents stay in the care facility, family members always rely on staff’s judgment and generally wish to be notified in case when something is wrong: *“as we are not obliged to see them every day, as they are under a continuous control here. Because they are always under control, so this [application] is a little... yes, I could ask how she is doing but, to my mind, they will tell me if there is something wrong,”* while feeling of obligation to dive into practical care processes again is undesirable for them.

In this vein, participants suggested introducing an alert system of notification, expressing the reoccurring topic of their trust towards NH staff in pointing out the problematic events: *“Maybe if there is something that is wrong, they could put an alert—“look”. And they tell you to check if something is wrong.”* They also suggested that the nursing home staff could ask them if they prefer to be more or less informed through the application: *“would you like to be informed, do you need to be informed daily about the health of your parent?”, one could say “yes”, one could say “no” and makes this choice, to be informed or not.”*

9.6.3 Reactions and Actions of Information Recipients

Both survey and qualitative discussion on mockups included the questions on potential reactions family members could have upon receiving updates on their loved one’s state in a given way. In case of singular high levels, there will be questions and answers to them could anticipated: *“How come [the sugar level is so high]? How come, was it before eating, what did she eat?”, “if she would have 200 of blood pressure here, which is outside [the norm], perhaps I would ask “but did you follow this up?” To know what they did, whether they resolved the problem.”* Quantitative survey data also confirms that anticipated emotional responses would strongly depend on the type of event and the modality of its presentation. As depicted in Figure 9.4, receiving the updates, both daily routine and medical, in the form of a narrative would make family members “moderately worry” (level 3), while the would be least worried upon receiving medical updates supported by a chart representation (level 1 - “not worried at all”).

The reactions of family members might also be based on specific situation. For instance, in case of the values inside the norm the participants “*wouldn't do anything. But if it is not normal, there are some questions.*” Participants emphasized that the connotation of an event would play a major role in their actions upon receiving it: “*it depends how is the information, if the health is not good, well, I would call, but if it is normal, I wouldn't call.*” Survey data supports these views (Figure 9.5), participants indicated that receiving updates of a resident’s sleep over a week, an example of daily routine information, would cause calls to the care facility if presented in a form of narrative, while supporting it with the chart could make the actions of family less invasive, i.e. they would ask for the clarifications during the next visit. As for the medical events, for example, a blood glucose level, seeing chart could prevent family members from asking additional questions, while the narrative would result into additional calls to the NH.

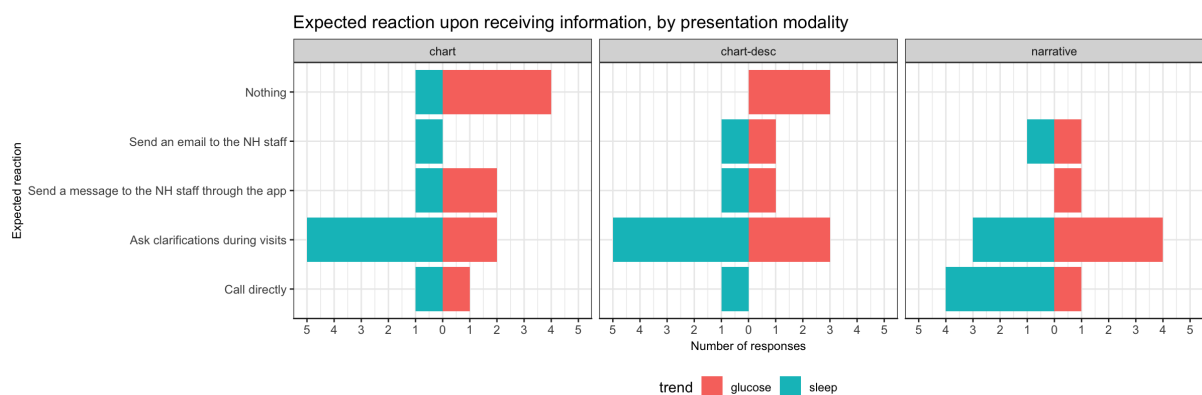


FIGURE 9.5: Anticipated reactions of family caregivers upon receiving HWB in a certain modality

Raw data (specific values) with negative values could be perceived as an expectation to action, while family members do not have any “medical power”: “*Why is not something I decide, seeing the high or low blood pressure, what would we do? Because that’s them who [take actions], as I said before to the doctor.*”

Overall, the participants were very positive that introducing additional ICT channel could support their interaction with the care facilities. However, their views on the efficiency of such communication also varied depending on the modality of the event visualization. As can be seen in Figure 9.6, narrative format was seen as least helpful in this sense (2—“disagree”, 1—“strongly disagree”), while adding a chart was seen quite positively (5—“strongly agree”, 4—“agree”) with few participants who stayed “undecided” (level 3).

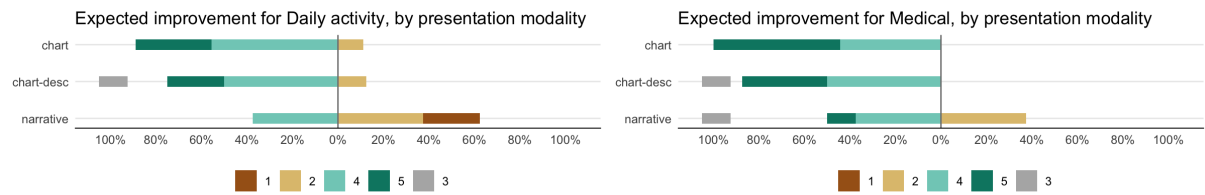


FIGURE 9.6: Expected improvement of communication upon receiving HWB in a certain modality

Participants also recognize that introducing an additional communication channel and communicating to them larger amount of information through it could add more workload to the staff and asked questions the way information would be gathered and communicated (“*but do [staff members] put this here? Would they manage to have such results?*”, “*yes, but is this [information] inserted by a doctor or is it some statistics from the chart?*”).

9.7 Discussion

The aim of this work was to examine communication strategies, mutual attitudes of family and professional caregivers regarding information sharing in nursing homes (NHs), and the strategies of presenting health and wellbeing information. Starting from the high level overview of the information exchange practices the caregivers adopt and information architecture principles, we moved to the evaluation of the design alternatives that could mediate sharing of HWB information in Nh care context.

All three studies included in this paper build on the each other’s results consequentially and provide cumulative findings that inform the design of an ICT systems, which could be accepted by both staff and family members and integrated into the daily practices of each caregiver groups. Overall, we identify several main challenges that emerged across all three studies and discuss each of them in detail translating the results of this work into design considerations to be taken into account when addressing them.

9.7.1 Information Access and Delivery

Family members involved in care of institutionalized older adults form a heterogeneous group in relation to their information needs and care involvement. For instance, among other variables, they differ depending on the specifics of care facility services their older relatives receive, their

loved one's health state, and personal care experience or ICT skills. In this work, we identified both a large number of "personas" of individual family caregivers and family care organization styles, such as individuals, care teams, and proxies, that affect their communication practices with care facility staff. Together with variety of family situations, relationships among family caregivers and between them and NH residents, our findings reveal a major challenge that comes with the introduction of ICT channels in aged care.

Account for individual characteristics and information preferences.

Personalization is known to increase satisfaction but these needs are not always evident to the family members. Moreover, the NH staff has the capacity and knowledge to help to make "hidden" needs of family members evident and to map the way they classify family members today (from a communication perspective) into the technology to tailor information communication.

Tackle positive and negative updates appropriately.

In case of positive trends or non-critical state of a NH resident's health, family members might not expect further follow-up information. Here the visualization in the form of a narrative could be sufficient to satisfy their information needs. However, such textual aids are efficient only being personalized, as communicating generic information might not only be inefficient but even compromise the trust family members have towards the care facility. It is also important to consider the relevance of reporting positive results or the fact that there are no major issues, just to make people aware of what is going on.

As for negative health trends, the timing for each type of events is also important. For instance, a month could be an acceptable time period before starting to receive specific updates on the sleep disturbance of a NH resident, while for medical events immediate communication in case of abnormal values is extremely important. Possible updates could include the information on the actions or medical interventions that were undertaken to mitigate acute symptoms, the updates on the future prevention plans, or the reasons why this event has occurred. Prompt communication in this case becomes particularly important to family members who visit frequently, as their communication in virtual channels revolve around negative events.

Consider the proper granularity for events,

from single events to "trends". Single events can be useful in reporting critical events, but others could be more informative when looking at trends (e.g., alarms or improvements). More

specifically, trends of medical and daily routine updates should be communicated differently. While daily events could mimic the personal communication of family members with the NH staff and be shorter and less formalized, medical updates are preferred to have visualizations of specific values and their explanations to avoid confusion. Both family members and professional caregivers of NH residents stated that medical events could be the most stressful and causing the most problems, which emphasizes the importance of making them as clear as possible and providing further details when needed. Raw events could increase the efficiency but in specific cases—medical events.

Figure 9.7 summarizes the insights of the participants and the flow of information based on their preferences for category of events and their positive or negative connotation.

9.7.2 Information flows and comprehension

As mentioned before, family members might not always have a full understanding and knowledge of their loved one's condition or a possibility to visit frequently, which introduces another challenge of ICT mediated information communication by the care facilities. As emerged from our studies, updates out of context might cause additional confusion, worry, and follow-up questions by family caregivers, as they might fail to interpret communicated information. Moreover, medical events might not be the primary interest in some situations and providing wellbeing or social information of NH resident could be seen as more desirable and valuable communication in this case. In this vein, providing contextual and event-specific information aids could be an efficient strategy to target this design challenge, in particular, the following design recommendations might apply.

Implement strategies to make sure information is clear and understandable,

e.g., by giving as much context as possible, considering the patient “normal”, and “translating” technical vocabulary to what non-experts can understand. Misinterpreting information can lead to situation of stress and uncertainty, which in turn can harm the relation with the NH. Simplicity over richness of information, detail on demand. Delivering raw information to family members could increase the efficiency of family—staff communication but only in particular cases, when updates on the specific medical events are requested.

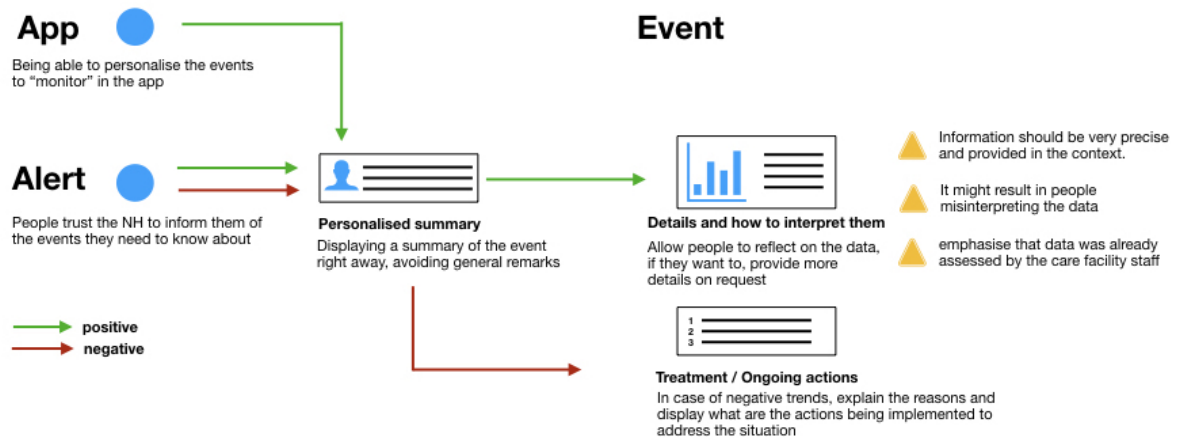


FIGURE 9.7: HWB information lifespan

Provide scaffolded and contextual information presentation,

from summaries of what is the general condition of the resident, to summary of health parameters, to specific details, giving family members the possibility of understanding the situation at a glance and navigate information at their desired level of detail. In addition, provide information that is relevant to the time and context, which implies thinking in terms of what information can be delivered through synchronous and asynchronous channels.

Consider tools for contextual education,

so that users can learn about the meaning and implications of the information they receive, especially when they are first confronted with the type of information presented.

Provide wellbeing and relational information,

while interest in medical information was varied, we noticed an overwhelming interest in the basic questions we also ask each other every day, such as how we slept and ate or if we took part to activities. Family members want to have the same information, which is only partially collected by the NH today but that technology now can help us get semi-automatically.

9.7.3 Communication Modalities and Channels

The preference and appropriateness of different channels of information delivery might be dynamic for family members.

Consider the modalities of information sharing,

in terms of proper granularity, contextual information, and explanations. Information on trends is considered useful by both staff and family as it avoids information overload. Contextual information such as condition of the resident and historical data can give useful information to interpret the data. Explanations or “translations” provide useful narrative to properly interpreting information, and give an additional human touch.

9.7.4 Relational Aspects of Information Exchange

Coming with the idea of sending HWB updates on their loved ones to the family members from the care facility, after conducting the studies, we observed that the possibility to provide feedback and have a bidirectional communication that mimics the human interaction is important both for family members of NH residents but also to the staff. Hence, the following design solutions could be beneficial in introducing ICT mediation of such communication.

Give a human touch to virtual information exchanges,

e.g., by showing a human face in the interactions instead of hiding behind institutional accounts, facilitating mutual awareness through profiles. Emphasize the ICT channel as an additional channel supporting and enhancing personal communication but not replacing it.

Allow for family to staff communication,

to let staff know the care preferences and habits of the resident that the family member wants to be respected if possible.

Provide tools to allow for coordination and information exchange

in family care teams, as well as tools to relay information to the larger family within the limits of GDPR and related regulations.

Overall, this work strengthens the idea that it is critical to consider both preferences of family members of nursing home residents and work practices of the staff in designing information services such as e-health systems. However, the studies have also reshaped the initial belief of nearly all actors involved (including us), from a focus on communication of medical information from staff to family to focus on i) bidirectional interaction, ii) appropriate delivery of

various types of events (daily or medical) with their positive or negative connotation, iii) social and wellbeing events, and iv) paying attention to personas and personalized explanations and contextualizations.

9.8 Limitations

The study has several limitations and the most frustrating one for us was the difficulty in approaching family members that are remote or visit rarely. This is due to a variety of factors including the fact that we were asked to go through NH to contact relatives. However this means that the results are only applicable to “frequent visitors”.

Another important limitation of the study is exclusion of the care recipients, NH residents. Obviously also their needs and requirements should be also taken into account, which we addressed in other publications [39, 40]. However, NH care in Italy has its specificity, as the residents mainly belong to the “oldest old” population group with high degree of impairments.

Chapter 10

Discussion

The exciting possibilities of “health datafication” and the use of technology in aged care have begun to shift the organization of it: enabling seniors to share their personal health and wellbeing (HWB) information inside the triad of aged care: with their care providers and family members; and allow the latter to interact among each other to provide a better care. Technology has a lot of potential to support and mediate this information exchange but it also introduces additional challenges for research.

In this thesis, our aim was to enhance the understanding of *i*) the outcomes and the factors that influence sharing HWBI within the triad of care across various aged care scenarios, and *ii*) the role of ICT tools in supporting and mediating sharing from the points of view of all care triad stakeholder. Furthermore, within those two main research objectives, we investigated human values and value tensions that may be implicated through engagement with or the use of such technological tools. At the end of the first Chapter (Section 1.3) we listed the studies that were conducted over the years and helped us build, incrementally, this research work.

Overall, our work is split in three phases or stages. The Part I included the studies that set the research context and explore current sharing practices in general healthcare and various care scenarios, where we investigated the perspective of care recipients and caregivers on sharing health records. The outcomes of this first stage outlined on the opportunities of using ICT solutions to improve relations, information sharing among caregivers, and provided with important insights for research directions that we addressed further. In the Part II we took a closer look at the perspectives of aged care recipients exploring their views on sharing their personal health

and wellbeing information with their formal and informal caregivers, and paid attention to their security and privacy concerns related to sharing.

The first two stages of this work also resulted into a set of design implications (principles and guidelines) aimed to support ICT tools mediating HWB information sharing, which took into account the specifics of care contexts and the characteristics of actors involved in them. The concluding Part III of this thesis consisted of the final set of user studies in institutionalized care scenario that helped us to refine those design implications and evaluate whether they hold for the care stakeholders acting as the primary recipients of HWBI of seniors, namely, their family caregivers.

In this Chapter we discuss our main contributions from each part of this work and describe how they address the thesis research questions (TRQs).

10.1 Sharing HWB Information Across Care Scenarios

The findings of this thesis empirically demonstrate that aged care, and especially institutionalized care, is a pervasive process that involves multiple stakeholders whose motivations, opinions and interests may not always align or be clearly expressed. For caregivers, willingness to assist, provide care, and offer emotional support often competes with the burden of redundant information, worry, privacy concerns, and legal boundaries related to HWB information sharing, thereby posing challenges for the design of effective communication. For seniors, at times, it is also difficult to find balance between sharing information with their loved ones, not making them worried or overwhelmed by this information, while at the same time preserve independence and control over their data.

Even though human contact is essential part of such a sensitive context as aged and terminal care, in various degrees ICT tools are present in each of care scenarios, and all care stakeholders acknowledge the role of technology in making care related communication more efficient. Hence, sharing of HWB data could be supported or mediated but never replaced by the technological solutions.

Still, the way information is currently shared affects actors' opinions about ICT channels for information disclosure as well. As an attempt to model and organize the factors or circumstances that influence sharing in aged care (TRQ1) in Chapter 6 (Table 6.1) we defined five sharing dimensions, such as the recipients HWB information is shared with, sharing purposes, data and format of sharing, and attitudes of the stakeholders towards sharing.

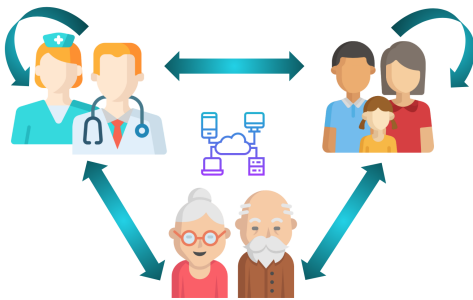


FIGURE 10.1: Sharing HWB information within the dyads of the triad of aged care

We studied different strategies and power distributions of HWB information communication within the triad of care: from patients being in control of sharing their personal health records to family and professional caregivers of frail older adults exchanging HWB information between and among each other. Sharing in those evolving care contexts depend on many factors that are also specific to provided care scenarios, in particular, in this work we considered three of them: 1) independent pa-

tients who receive care from healthcare providers with minor involvement of family members;

2) older adults living in long term aged care facilities; 3) institutionalized care for older adults (nursing home care).

The recipients of health and well-being information, directly involved in all care scenarios, and comprising the triad of care, are patients or care recipients, their family members, and staff (including healthcare professionals, hired caregivers, and care facility management). Instead of considering the views of care recipients on sharing in isolation only, we also chose to analyze the dyads (Figure 10.1), because we observed that the dynamics in the interpersonal and formal relationships between stakeholders—including subordination, trust, family culture, and alignment of views—have considerable effect on the decision making related to information exchange between them across all care scenarios. We next discuss each of the triad stakeholder groups, the factors that affect their HWB information communication and the role of ICT tools the see in supporting it (TRQ2).

10.2 Sharing by Older Care Recipients: Multiple Factors to Consider

Sharing for older adults who reside at **long term aged care facilities** greatly depends on their level of autonomy. For instance, those at independent assisted living have a higher autonomy and preserve a certain level of control over their care and personal information. They are the primary active owners of their health related information and they decide who else could have the access to it. Still, anticipating or even experiencing major health declines, gradually or not, they have to give up this control to their professional caregivers and family members involved in their care, which is unavoidably associated with various concerns.

In this sense, the decisions on sharing HWB information highly depend on health-related conditions, perceived usefulness of disclosure, and seniors' judgment on information "worthiness" to share. In particular, the state of health has influence on seniors' willingness to share as well as their expectations from those they would share with. For instance, the lack of the feedback from information recipients might trigger older adults' fears of disinterest and the lack of involvement in their care and prevent them from further sharing. Technology could address those factors and facilitate the conversation between older adults and recipients: by supporting them in obtaining a common ground on the amount of shared information and the frequency of updates,

by providing the option for responses and customized modalities of feedback to be provided by the recipients, hence, encouraging the sharing.

The *purpose* of sharing in aged care was seen as generally benevolent, such as health diagnostics, emergency notifications, or family assistance. However, seniors also recognize the cases when they would hesitate to share. Among others, the most common cases include perceived risks of public release of their personal information or lack of knowledge of sharing consequences.

The attitudes of independently living seniors towards *control, privacy, and emotional reactions* of information play an important role. Our work confirms previous research showing that privacy of personal information is a key aspect in sharing it digitally, while perceived privacy risks often result in the limiting or even avoiding the use of technology for older adults. Sharing and delegating one's health records should be designed in a transparent fashion, ensuring that patients are fully informed about current information sharing practices, including storing medical records online. Moreover, as there is no universal approach in HWB information sharing, the design of future systems that enable it should incorporate flexible access control policies that should be adapted to meet the preferences and abilities both of care recipients and their family caregivers who should have defined roles to access seniors' personal health records.

Upon their placement into **nursing home (NH) or skilled nursing care**, residential aged care facilities that accommodate frail seniors who require a high level of personal assistance and care, older adults delegate full control over access and sharing of their health information. The involvement of the family members in care in this scenario is usually significant, as they often communicate directly with the staff members. Decisions made on behalf of seniors by their caregivers in this case must take into account “the values, attitudes, and preferences of those they would seek to represent” [99].

In the **Senior–Staff** information sharing, the most common purposes include health diagnostics and monitoring, emergency notifications, professional care provisions and family assistance, followed by the delegation of end-of-life decisions. Seniors see the benefits of disclosing their personal HWB information, for instance, to receive best practices related to medical treatments, improve general care provision, and facilitates the coordination of multiple conditions, chronic diseases, or sophisticated medication plans, which make them consent to the exchange of information within the group of professional caregivers without their involvement. Transitioning from the independent assisted living to the nursing home and terminal care, older adults delegate

more and more of this information to the care team, and trust plays a major role in seniors' willingness to share data.

Seniors tend to trust highly skilled medical professionals, as inferred from education level, feedback from other patients, or personal experience. Trust is also an essential factor in the decision of a doctor to engage in a direct communication with the patients, or in their remote treatment and medication management as well. The duration of the relationship contributes to the formation of trust: many seniors have the same doctor or caregiver for decades and form bonds of friendship with them. Finally, seniors' perceptions about staff's motivation and intentions affect relationships within the Senior–Staff dyad.

Digital channels could support this communication by ensuring the benevolence of the usage of seniors' data, emphasizing the benefits of sharing, and make information exchange between care professionals transparent for the older adults.

Senior—Family dyad. Family caregivers is the most common information recipient groups across all of the studies, both for seniors and their professional caregivers at more advanced stages of care. The relationships and information exchange “rules” in families affect the attitudes towards HWB information sharing by the seniors, varying from very limited disclosure of just critical events to full disclosure of information and involvement in care of multiple family members. Moreover, as we saw before, the views of older adults, their families, and staff on the relevance of information may not always align usually resulting into conditional disclosure in this dyad. It is defined by various factors, which digital channels could accommodate for. Similarly, regarding the **Family—Family** dyad, seniors typically accept that family members exchange their HWB information directly, or assign one of the members to disseminate it to other relatives. However, the relationships inside the family play a major role.

10.3 Sharing by Professional Caregivers: Balance of Workload, Quality of Care and Services

In institutionalized care settings, sharing strategies of professional greatly depend on the structure in terms of hierarchy that is imposed by the organization of care facilities, and upon which work practices are based. For instance, doctors, nurses, and socio-health operators (SHO) work on different areas: doctors decide and manage the medical plan of each resident and can communicate medical information to family caregivers, while SHO deal with the basic physiological

needs and can communicate every type of information but medical. This practice often creates difficulties when family caregivers need or require certain information, as is limited number of doctors and nurses are usually widely outnumbered by SHO.

Care staff recognizes that communication with family members of seniors is important to ensure the quality of care. While the dynamics in the interpersonal and formal *relationships* between caregivers—including subordination, trust, and alignment of views—have considerable effect on the decision making related to information exchange between them, this relational work care staff performs introduces the notion of additional “invisible work” related to it. As digital channels (email, patient portal, video conferencing, social media) enter care communication space more and more, they require certain level of promptness and personalization, which increases the risk of increasing the workload of the professionals even more and, as a consequence, may pose resistance in using digital communication channels.

In this transition, it becomes particularly important to support professional caregivers in sharing both medical and social knowledge on all patients among colleagues, while the lack of standard sharing mechanisms and variety of sharing strategies implemented across different care facilities even inside one country could be addressed by implementing more universal recognizable sharing features.

10.4 Family Caregivers: Information Needs and Care Involvement

Family members involved in care of institutionalized older adults form a heterogeneous group in relation to their information needs and care involvement. They also differ depending on the specifics of care facility services their older relatives receive, their loved one’s health state, and personal care experience or ICT skills. Extensive body of literature shows that presenting senior’s information to the relatives increases family involvement in the caring process, and improves credibility towards medical staff, thus reducing their stress and workload [6, 7], and enhancing collaborative partnerships [5].

In this thesis, we identified both a large number of “personas” of individual family caregivers and family care organization styles, such as individuals, care teams, and proxies, that affect their communication practices with care facility staff. Together with variety of family situations,

relationships among family caregivers and between them and NH residents, our findings reveal a major challenge that comes with the introduction of ICT channels in aged care, the importance of *personalization* in delivering HWB information.

Personalization is known to increase satisfaction but these needs are not always evident to the family members. Moreover, the NH staff has the capacity and knowledge to help to make "hidden" needs of family members evident and to map the way they classify family members today (from a communication perspective) into the technology to tailor information communication. For instance, family members might not always have a full understanding and knowledge of their loved one's condition or a possibility to visit frequently. Misinterpreting information can lead to situation of stress and uncertainty, which in turn can harm the relation with the NH.

Hence, in introducing digital communication channels, it is important to account that the updates out of context might cause additional confusion, worry, and follow-up questions by family caregivers, as they might fail to interpret communicated information. Moreover, medical events might not be the primary interest in some situations and providing wellbeing or social information of NH resident could be seen as more desirable and valuable communication in this case. In this vein, providing contextual and event-specific information aids could be an efficient strategy to target this design challenge. Simplicity over richness of information and "detail on demand" could be efficient strategies in tailoring HWB updates to the family information needs.

Coming with the idea of sending HWB updates on their loved ones to the family members from the care facility, we observed that the possibility to provide feedback and have a bidirectional communication that mimics the human interaction is important both for family members of seniors but also to the staff. Showing a "human face" in the interactions instead of hiding behind institutional accounts, facilitating mutual awareness through profiles is important in aged care context. ICT channel should be introduced as an additional channel enhancing personal communication, which could support family-staff bidirectional communication and care-related family coordination as well.

Chapter 11

Conclusions and Future Work

In this closing chapter we present the conclusions of this thesis and indicate the limitations of this thesis as well as future research directions. We outline applicable design recommendations supported by examples of their graphical representations in Appendix A.

11.1 Conclusions and Lessons Learned

Having the perspectives of all three main care triad stakeholders, we observed that sharing of HWB information does not always necessarily involve remote or digital interactions, which made us shift from the view of technology as only unidirectional channel of sharing (from care recipients of staff to family), to a medium supporting existing sharing strategies where it is needed and appropriate. We learned that HWB information sharing in this case should be bidirectional with the consent of seniors as the primary requirement, whenever it is possible. Moreover, the organization of family involvement in care may take diverse forms including primary contacts as well as family care teams. This means that technological tools in aged care context should be designed to allow for coordination and information exchange in diverse family structures within the limits of GDPR and related regulations.

We thus derive three main findings: i) the role of technology should not be limited to enabling sharing of HWB information, but rather aim to improve care coordination and match the values of the stakeholders; ii) the workload, the motivation and opportunities to share HWB information from the professional caregivers point of view are crucial in the institutionalized care scenarios;

and iii) older adults should be at the centre, highlighting the importance of their opinions, as sharing of their personal information is at stake.

Discussing sharing practices of NH residents' HWB information with professionals and family members in the nursing home (NH) context throughout the studies included in this thesis, we identified various communication issues. Such issues include the importance of professional roles in sharing certain types of HWBI, the specifics of aged care scenarios with their hierarchies and work practices, and the role and the level of care involvement of seniors' family members. We learned that positive outcomes of using technology in sharing are possible by enabling *collaboration* among family members and professional caregivers. We also observed that sharing related views of family members and professionals may vary and even be in conflict. These findings emphasize how important it is to account for the needs and opinions of each group of care stakeholders but also in connection to each other, to be able to identify the mismatch between them, and investigate other specific care scenarios and dimensions.

Our findings reveal that the types of information to share and its urgency affect the decision of professionals on whether to share and the detail of the information, while the diversity in organization and "personas" of seniors' family members greatly affect the HWB information exchange and should be taken into account when designing information sharing in institutionalized care contexts. The importance of combined care through collaboration of healthcare professionals and family members cannot be overestimated. This collaboration should be supported by ensuring the continuity of care with the focus on joint efforts of professional and family caregivers to provide a coherent, transparent and predictable care service.

11.2 Thesis Limitations

We do not claim that the outcomes of the studies contributing in this thesis are the only possible comprehensive overview of sharing information in care context for older adults. Studying the effect of sharing strategies on human subject and using IT-mediated solutions often impose limitations and challenges.

One of the main limitation of this research work was to eliminate the effect of organizational stimulation. Participants recruited for the studies could be influenced by the involvement of managements and staff of care facilities and socially enforced to complete the study sessions.

Although the participation was always emphasized to be on voluntarily basis, still the facilitators and organizers could be potential stimuli for the participation and adherence to the intervention.

Another limitation is that the results of this work have to be interpreted in context. The studies were conducted in nursing homes and other care facilities in Italy and USA and involving Swedish patients, where care and technology related challenges and preferences of the participants might differ. Even among Italian nursing homes included in the studies participants mentioned the importance of the context, since nursing homes might have different regulations, provide different services, count with more or less resources and personnel.

With respect to sharing, it would have been helpful to conduct studies using real health information and trying to share real health cases. This would allow to analyze not only the intention to share, but other aspects such as the interest from the network of family members in seniors' real health data and the reaction of older adults to this interest, as well as the effect the type of data can have on the engagement of family in care. However, respecting privacy and conditions of ethical approvals, this research dimension was not explored also due to the time constrains we had to ensure proper consent and compliance of studies with GDPR.

Another limitation of the work reported in this thesis is the locations of conducted studies, which were usually an urban/suburban areas of relatively wealthy regions with rather good access to technological resources, ICT educational programs, and services for older adults, as well as high pervasiveness of devices in use. We acknowledge that the background, needs, and opportunities of older population, their family members, and care professionals elsewhere might be different, and possible means to address them would differ as well. However, technology knowledge and awareness of privacy and security risks of the participants in our studies allowed fruitful discussions, which resulted into insights and research outcomes we report in this thesis.

11.3 Future Work

One of the outcomes of this thesis, design guidelines for interactive sharing tools in aged care, has allowed for future studies on the suitability of the tool but also has produced new interesting research questions.

In our studies, participants felt quite confident that they understood most of the content in their own or their loved ones' health records, follow-up studies could specifically look into whether

this perception is correct and how to support those who have difficulties in understanding the content. It would be interesting to study how seniors and their family members may have learned to use the technology over time, for example, whether they learn and make sense of the ‘medical language’. Furthermore, as some study participants expressed that they or other aged care triad actors become worried through accessing HWBI, further studies could investigate what actually causes worry or distress. For example, whether this is caused by the technology or by the current situation (e.g., not knowing what is going on), and how actors manage these situations.

Addressing one of the limitations of this thesis, future studies could complement our current work with the perspectives of older adults, their family members, and care staff living and working in different socioeconomic and cultural contexts, to see how different their views and needs are from our study participants.

We believe that the most important outcome would come from the longitudinal evaluation of the effect of technology as a channel on care related information exchange, which we see as the best evaluation and validation for our contributions, since it has not been done. Such channels could support various forms of HWBI sharing among different stakeholders (among the senior’s extended family, with grandchildren through health information shared online, with other institutionalized seniors). It would be interesting to measure the effect that the sharing strategies and channels have. Especially, whether the facilitated sharing can lead to an improved care for older adults and reduce care burden for family members and professional caregivers. As we have mentioned in Introduction, we hope future researchers will find this research useful, our findings will bring the light to aspects not previously taken into account, and this work would improve the field of e-Health interventions in aged care.

Appendix A

Appendix A. Design Recommendation for HWB Information Sharing Systems

A.1 Personalization of Information Delivery

All three groups of stakeholders of care triad relied on the notion of “personas” of HWB information recipients, for instance, based on their involvement in senior’s care, reactions to receiving updates, care related knowledge and experience, or strategies and abilities family members have to process and understand shared information. Moreover, not only individual characteristics of the recipients played an important role but also their organization, for instance, family organization in care that takes diverse forms including primary contacts, proxies or family care teams. This implies that technological tools in aged care context should be tailored and personalized in their information delivery, exchange, and presentation, and allow for coordination in diverse family structures within the limits of GDPR and related regulations.

A.1.1 Ensure Accessibility of ICT Tools

Sharing digitally should be adapted to the diversity of needs and abilities of potential users. All of the studies that contribute into this thesis included older participants, both care recipients and caregivers, which is one of the specifics of aged care context. HWB information communication tools in this case should accommodate the recipients whose abilities decline due to ageing or users with low ICT skills, which is was also typical in our target user groups. In Chapter 8 we

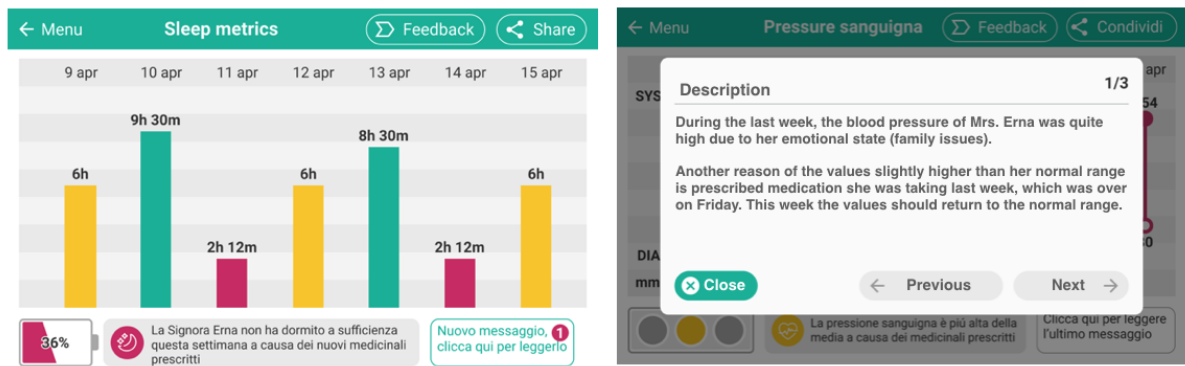


FIGURE A.1: Interactive HWB information presentation design that incorporates accessibility guidelines.

present a systematic literature review where we investigate these design challenges in detail and propose a set of specific ready-to-apply guidelines¹ designers can follow to ensure the accessibility of interactive ICT tools and to improve usability of their interactive systems and interfaces in general [42]. Illustrating the application and validation of those findings, a subset of these guidelines was applied to the mockups used in the evaluation study presented in Chapter 9, which helped us to enhance participants' navigation and comprehension of HWB information. In particular, Figure A.1 depicts the examples that incorporate the most common design guidelines, for instance, “group menus using text, spacing or frames, as grouping by colour alone can lead to difficulties” [212], “avoid dark color background” [237], and “make a screen and menus easy to explore without excessive searching” [81].

However, guidelines cannot be expected to be “universal” and generalize to the entire older adult population but rather cater to different, possibly smaller, groups of individuals. In this vein, our work indicates that older adults within the same age cohort can be different, as declines can be moderated by many factors such as level of physical activity, social connections, education, presence of disabilities, among others [301–304]. Thus, taking a chronological view only is a limited way of describing the older adult population. We strongly recommend to define target population more precisely and try to avoid age-related stereotyping [306].

Moreover, each design parameter is not exclusive to just one ability, and neither is one ability determined by a single design dimension. For instance, design of multimedia content that could support HWB information comprehension by non-expert caregivers and display composition (layouts) are crucial elements in addressing perceptual (vision and hearing) declines, as well as reduced cognitive (information processing) abilities.

¹<http://design-review.mateine.org>.

A.1.2 Support Different Levels of Medical Literacy and ICT Skills

Different medical literacy levels may be another barrier for sharing through digital channels, since HWB information may be too technical to understand for non-expert caregivers, which could result into increased confusion and worry in them and additional workload of the professional caregivers. Using interactive visualizations could provide understandable and intuitive presentation of risks of treatments, medications, or changing course of therapy in care contexts. Efficient interaction support and additional information on demand, implementing appropriate user navigation, error and feedback handling could be another strategy to support users with cognitive declines in general and low ICT skills in particular.

Our work indicates the importance of accommodating to lower ICT skills not only in informal caregivers but also in professionals. In particular, their technology anxiety and low computer literacy could translate into such usability issues as errors, which is particularly important to address in healthcare context. One of the ways of supporting these users could be designing feedback and indicating clearly system capabilities and limitations.

A.1.3 Account for the Mismatch of Information Sharing Preferences and Value Tensions

While the vast majority of care recipients appreciate timely access to their health information either personally or provided to their healthcare providers or informal caregivers, the evaluation of older adults, their families, and staff of the relevance of information, its “worthiness” and urgency to share may not always align. For instance, seniors sometimes actively keep a log of medical measurements (e.g., daily blood pressure readings) and try to share it with their doctors, but doctors, usually supervising multiple patients, may have no time to review those logs. The lack of recipient’s response about shared data due to time issues may be misinterpreted by seniors as a signal of low relevance of this data or lack of recipient’s interest, resulting in decreased self-motivation to continue close monitoring of health.

Designers should be mindful about framing to avoid direct confrontation or opposition of views. The communication platform may allow users to customize the priority of informing various recipients, and facilitate the transparency of collaborative and informed agreement between them, e.g., by encouraging users to make their preferences visible to each other. Design solutions providing the necessary feedback about “quantified self” may encourage older adults to control

their health and promote interventions aiming at improving it. The platform can also remind recipients that even if they are not able to help directly, regardless of low practical applicability, it is reassuring to elderly people to simply know that family stays up-to-date.

A.1.4 Support Different Communication Modalities and Channels

The attributes and appropriate modalities of HWBI are important for sharing in aged care, more specifically, in terms of proper granularity, contextual information, and explanations. For instance, trends of HWBI were considered useful by staff and family members, but also by the seniors, as they allow to avoid recipients' information overload. Contextual information such as senior's health conditions and historical data can help understand the shared information, while explanations provide useful narrative to properly interpret it, and give an additional human touch. Providing relevant information to the time and context is also crucial, as it implies thinking in terms of what information can be delivered through synchronous and asynchronous channels.

The channel is not only a medium for communication, but also a signal about the urgency of the shared information. For instance, phone calls often suggest that something important has happened, therefore, use of this channel for communicating non-critical events may cause unnecessary worry. Text-based channels (such as text messages and emails) do not require or guarantee immediate response, and thus are more suitable for the communication of non-critical information. Because the associated meaning and convenience vary based on individual preferences and established communication "etiquette" (defined by internal culture and rules within the communication dyad), the sender and recipient should be able to choose and agree upon what communication channel works best for both of them.

Finally, designers should embed in their platforms the functionalities that allow for printing of materials easily (e.g., using single-click highly-visible buttons), which will help to address reliability concerns, and mitigate opposition and reluctance to the use of ICT channel during the transition from paper to electronic records.

A.2 Event-based Information Communication

Generally, event-based sharing is important for emergencies or critical deviations from norms, while irregular information exchange is optimal for communicating relevant but not urgent information. Regular information exchange may be limited to brief (not detailed) updates about a patient's overall status or health metrics. To ensure relevance, non-critical (routine) information may be made available on an on-demand basis instead of being disseminated in a top-down manner. Recipients' requests to share data may even signal to older adults the interest to engage in the care process. However, designers should ensure that information exchange occurs with informed consent and is aligned with seniors' preferences for privacy and control. As transfer of control occurs gradually depending on elders' health and functional status [26], the delegation process should be dynamic to maximize autonomy and gradual involvement of family members.

In case of positive trends or non-critical state of a senior's health, family members might not expect further follow-up information. In this case the visualization in the form of a narrative could be sufficient to satisfy their information needs. However, such textual aids are efficient only being personalized, as communicating generic information might not only be inefficient but even compromise the trust family members have towards the care facility. It is important to consider the relevance of reporting positive results or the fact that there are no major issues, just to make caregivers aware of what is going on.

As for negative health trends, the timing for each type of events is important. For instance, a month could be an acceptable time period before starting to receive specific updates on the sleep disturbance of a NH resident, while for medical events immediate communication in case of abnormal values is extremely important. Possible updates could include the information on the actions or medical interventions that were undertaken to mitigate acute symptoms, the updates on the future prevention plans, or the reasons why the event has occurred. Prompt communication in this case becomes particularly important to family members who visit frequently, as their communication in virtual channels revolve around negative events. Figure A.2 depicts possible design solution to explain critical values interactively ("on tap"), which was seen to be particularly useful for medical trend communication.

Designers should be careful in framing positive and negative messages, and emphasize the intentions of a person disclosing information to avoid misinterpretations. For example, to avoid

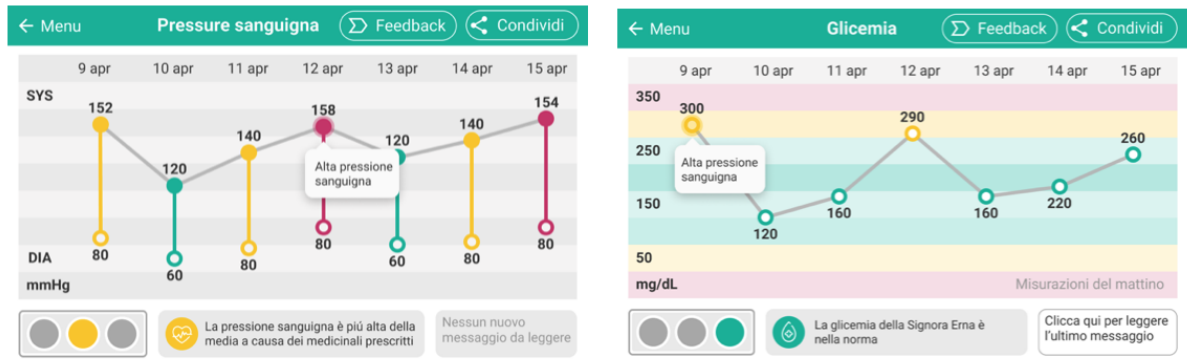


FIGURE A.2: Interactive explanations of critical values

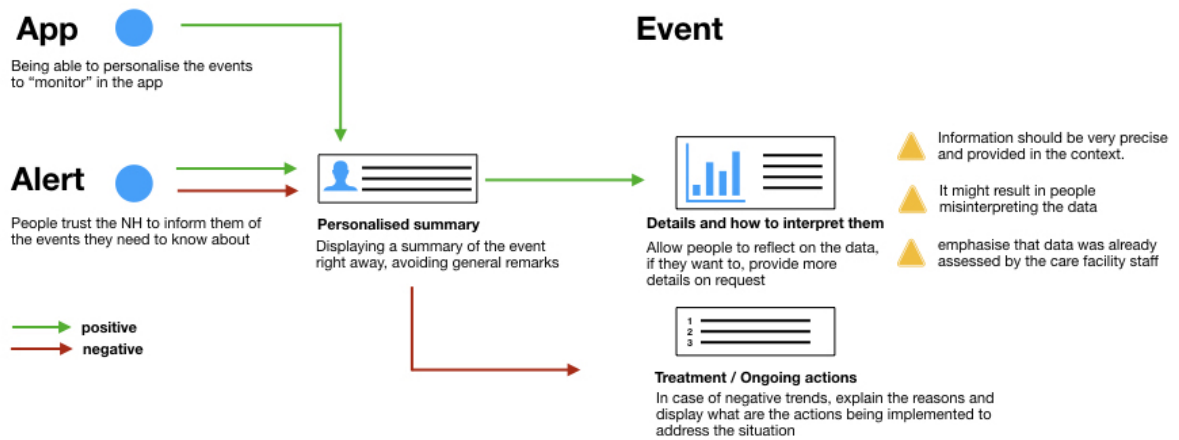


FIGURE A.3: Possible lifespan of HWB information communication to non-expert/family caregivers of older adults

positive HWB information appearing overly optimistic or boastful, affirmative signals about patient’s good health may be presented as a recovery progress together with a note about best practices and effective therapy methods. Such framing will be positively received by family, will provide feedback on effectiveness of the treatment plan to the staff, and will set an example for peers. While sharing negative updates about health, recipients should have an opportunity to request information may not only satisfy their desire to express care but also to reduce older adults’ fears to appear bragging or grumpy. However, designers should be cautious to not turn the absence of recipient-driven requests into a signal of disinterest or a desire to “spy on” seniors.

In Figure A.3 we graphically summarize design recommendations for positive and negative updates that could help to choose proper granularity and modality of the HWB updates for family caregivers and inform ICT-based communication solutions.

A.3 ICT Supported Coordination

Coming with the idea of sending HWB updates on their loved ones to the family members from the care facility, after conducting the studies, we observed that “human-like and warm” interaction and the possibility to provide feedback that mimic the human interaction is important both for family members of NH residents but also to the staff. Hence, the following design solutions could be beneficial in introducing ICT mediation of such communication.

A.3.1 Account for Relational Aspects of Information Sharing

A human touch to virtual information exchanges is extremely important in such sensitive care context as aged care, e.g., by showing a human face in the interactions instead of hiding behind institutional accounts, facilitating mutual awareness through profiles. Emphasize the ICT channel as an additional channel supporting and enhancing personal communication but not replacing it.

A.3.2 Provide Care Coordination Tools

Information exchange in family care teams usually happens by dissemination of the updates by a primary caregiver or directly by staff members if there are several family members equally involved in care process. Technological tools should accommodate for coordination and information exchange within diverse family structures, including sharing of HWBI in care teams as well as updating the larger family within the limits of GDPR and related regulations. As family members might access and manage the health records of seniors to provide care, their roles should be defined and adjusted dynamically in case of authorization changes.

A.3.3 Provide Tools for Bidirectional Communication

Allow for family to staff communication, to let staff know the care preferences and habits of the resident that the family member wants to be respected if possible. The design of these prototypes also includes the tools for bidirectional communication of care staff with family members implemented through multimodal “Feedback” options presented in [A.4](#), which include calling to the nursing home or writing a message. In cases when seniors permit is obtained and

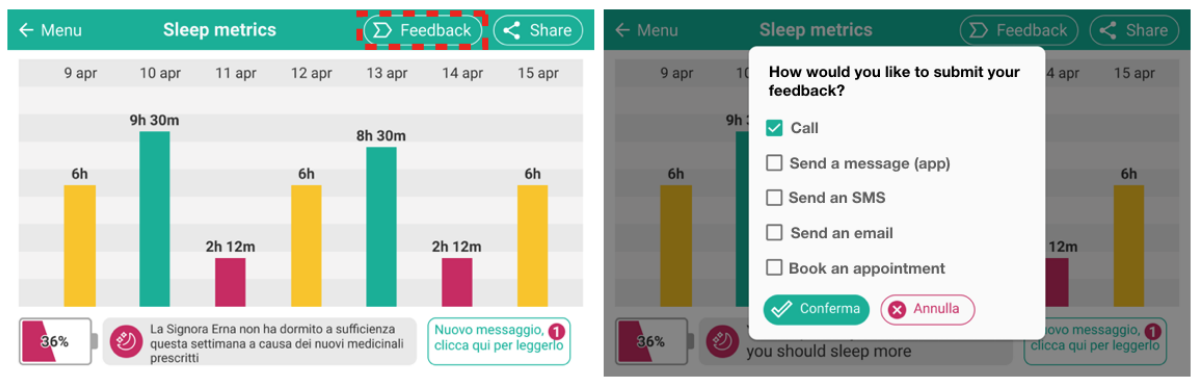


FIGURE A.4: Bidirectional communication options, choice of channels to deliver feedback to the care facility

active, sharing HWBI is also possible with the other authorized family members through the “Share” feature.

A.4 Security and Privacy of Information Exchange

In order to provide the best quality of care, institutions often install monitoring technologies, as well as implicit and informal in-person mechanisms of checking on older adults, which result in constant surveillance. Such 24/7 attention from care staff often removes the necessity for “practical” engagement in care with family members, and in cases of frequent visitors minimizes the need for HWB information sharing with them. Moreover, long-term care facilities are obliged by law to respect confidentiality, therefore they are deemed to be safe and private. In rare cases, participants saw legal privacy protection mechanisms as a barrier to effective information flow, which raises questions about the unintended consequences of some of these regulations and their implementation.

However, deteriorating health conditions and transfer to higher levels of care often require extensive delegation of control: sharing of full medical records, with management and care staff, and therefore, giving up some privacy and freedom for care recipients. In these cases, privacy of seniors can still be violated (by mistake, if not purposefully) and addressing privacy concerns related to HWB information sharing in the institutionalized care environment may reduce stress associated with diminishing autonomy and further increase the satisfaction with the quality of care.

Privacy and security by design should be the major principal in designing systems that support sharing in aged care. Universal and recognizable sharing features could address the lack of standard sharing mechanisms and a wide range of sharing strategies implemented across care facilities. Another way to facilitate the security and privacy of senior care recipients sharing their HWB information is to ensure the transparency and simplify the controls for digital sharing.

Bibliography

- [1] Daniel J Solove. A taxonomy of privacy. *University of Pennsylvania Law Review*, 154:477, 2005.
- [2] Jennifer L Wolff, Barbara Starfield, and Gerard Anderson. Prevalence, expenditures, and complications of multiple chronic conditions in the elderly. *Archives of internal medicine*, 162(20):2269–2276, 2002.
- [3] Brooke Manderson, Josephine McMurray, Emily Piraino, and Paul Stolee. Navigation roles support chronically ill older adults through healthcare transitions: a systematic review of the literature. *Health & social care in the community*, 20(2):113–127, 2012.
- [4] Dana Beth Weinberg, R William Lusenhop, Jody Hoffer Gittel, and Cori M Kautz. Coordination between formal providers and informal caregivers. *Health care management review*, 32(2):140–149, 2007.
- [5] Emily Haesler, Michael Bauer, and Rhonda Nay. Constructive staff-family relationships in the care of older adults in the institutional setting: A systematic review. *JBIR Database of Systematic Reviews and Implementation Reports*, 2(10):1–76, 2004.
- [6] Yunan Chen, Victor Ngo, and Sun Young Park. Caring for caregivers: designing for integrality. In *Proceedings of the 2013 conference on Computer supported cooperative work*, pages 91–102. ACM, 2013.
- [7] Andrew D Miller, Sonali R Mishra, Logan Kendall, Shefali Haldar, Ari H Pollack, and Wanda Pratt. Partners in care: design considerations for caregivers and patients during a hospital stay. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*, pages 756–769. ACM, 2016.
- [8] SA Zwijsen, A Kabboord, JA Eefsting, CMPM Hertogh, AM Pot, DL Gerritsen, and M Smalbrugge. Nurses in distress? an explorative study into the relation between distress

- and individual neuropsychiatric symptoms of people with dementia in nursing homes. *International journal of geriatric psychiatry*, 29(4):384–391, 2014.
- [9] Karen B Hirschman, Jennifer M Kapo, and Jason HT Karlawish. Identifying the factors that facilitate or hinder advance planning by persons with dementia. *Alzheimer disease and associated disorders*, 22(3):293, 2008.
- [10] Jomara Binda, Chien Wen Yuan, Natalie Cope, Hye Hyun Park, Eun Kyoung Choe, and John M Carroll. Supporting effective sharing of health information among intergenerational family members. In *Proceedings of the 12th EAI International Conference on Pervasive Computing Technologies for Healthcare*, pages 148–157. ACM, 2018.
- [11] Maia L Jacobs, James Clawson, and Elizabeth D Mynatt. Comparing health information sharing preferences of cancer patients, doctors, and navigators. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing*, pages 808–818. ACM, 2015.
- [12] Sebastiaan TM Peek, Sil Aarts, and Eveline JM Wouters. Can smart home technology deliver on the promise of independent living? a critical reflection based on the perspectives of older adults. *Handbook of smart homes, health care and well-being*, pages 203–214, 2017.
- [13] Catherine Lim, Andrew BL Berry, Tad Hirsch, Andrea L Hartzler, Edward H Wagner, Evette Ludman, and James D Ralston. It just seems outside my health: How patients with chronic conditions perceive communication boundaries with providers. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems*, pages 1172–1184. ACM, 2016.
- [14] Andrew BL Berry, Catherine Lim, Andrea L Hartzler, Tad Hirsch, Edward H Wagner, Evette Ludman, and James D Ralston. How values shape collaboration between patients with multiple chronic conditions and spousal caregivers. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, pages 5257–5270. ACM, 2017.
- [15] Geraldine Fitzpatrick and Gunnar Ellingsen. A review of 25 years of cscw research in healthcare: contributions, challenges and future agendas. *Computer Supported Cooperative Work (CSCW)*, 22(4-6):609–665, 2013.

- [16] Josephine Raun Thomsen, Peter Gall Krogh, Jacob Albæk Schnedler, and Hanne Linnet. Interactive interior and proxemics thresholds: Empowering participants in sensitive conversations. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, page 68. ACM, 2018.
- [17] Nai-Ching Chi and George Demiris. A systematic review of telehealth tools and interventions to support family caregivers. *Journal of telemedicine and telecare*, 21(1):37–44, 2015.
- [18] Teresa ML Chiu and Gunther Eysenbach. Theorizing the health service usage behavior of family caregivers: a qualitative study of an internet-based intervention. *International Journal of Medical Informatics*, 80(11):754–764, 2011.
- [19] Karla T Washington, Susan E Meadows, Susan G Elliott, and Richelle J Koopman. Information needs of informal caregivers of older adults with chronic health conditions. *Patient Education and Counseling*, 83(1):37–44, 2011.
- [20] Annika Hertzberg, Sirkka-Liisa Ekman, and Karin Axelsson. ‘relatives are a resource, but...’: registered nurses’ views and experiences of relatives of residents in nursing homes. *Journal of clinical nursing*, 12(3):431–441, 2003.
- [21] Jeffrey Soar and Youngjoon Seo. Health and aged care enabled by information technology. *Annals of the New York Academy of Sciences*, 1114(1):154–161, 2007.
- [22] Jake Epp. Achieving health for all: A framework for health promotion. *Health Promotion International*, 1(4):419–428, 1986.
- [23] Merrick Zwarenstein, Joanne Goldman, and Scott Reeves. Interprofessional collaboration: effects of practice-based interventions on professional practice and healthcare outcomes. *Cochrane Database Syst Rev*, 3(3), 2009.
- [24] Vasiliki Matziou, Efrosyni Vlahioti, Pantelis Perdikaris, Theodora Matziou, Efstathia Megapanou, and Konstantinos Petsios. Physician and nursing perceptions concerning interprofessional communication and collaboration. *Journal of interprofessional care*, 28(6):526–533, 2014.
- [25] Elizabeth Kaziunas, Mark S Ackerman, Silvia Lindtner, and Joyce M Lee. Caring through data: Attending to the social and emotional experiences of health datafication. In *CSCW*, pages 2260–2272, 2017.

- [26] Bradley H Crotty, Jan Walker, Meghan Dierks, Lewis Lipsitz, Jacqueline O'Brien, Shira Fischer, Warner V Slack, and Charles Safran. Information sharing preferences of older patients and their families. *JAMA internal medicine*, 175(9):1492–1497, 2015.
- [27] Karen E Steinhauser, Nicholas A Christakis, Elizabeth C Clipp, Maya McNeilly, Lauren McIntyre, and James A Tulsky. Factors considered important at the end of life by patients, family, physicians, and other care providers. *Jama*, 284(19):2476–2482, 2000.
- [28] Jane Sarasohn-Kahn. The wisdom of patients: Health care meets online social media, 2008.
- [29] Sonya Brownie and Susan Nancarrow. Effects of person-centered care on residents and staff in aged-care facilities: a systematic review. *Clinical interventions in Aging*, 8:1, 2013.
- [30] Sabina Gainotti, Susanna Fusari Imperatori, Stefania Spila-Alegiani, Laura Maggiore, Francesca Galeotti, Nicola Vanacore, Carlo Petrini, Roberto Raschetti, Claudio Mariani, and Francesca Clerici. How are the interests of incapacitated research participants protected through legislation? an italian study on legal agency for dementia patients. *PloS one*, 5(6):e111150, 2010.
- [31] General Data Protection Regulation. Regulation (eu) 2016/679 of the european parliament and of the council of 27 april 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing directive 95/46. *Official Journal of the European Union (OJ)*, 59:1–88, 2016.
- [32] Jennifer L Wolff, Jonathan D Darer, and Kevin L Larsen. Family caregivers and consumer health information technology. *Journal of general internal medicine*, 31(1):117–121, 2016.
- [33] California State Legislature. Assembly bill no. 375. ab-375 privacy: personal information: businesses, 2018. URL https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=201720180AB375.
- [34] Carol Levine. Hipaa and talking with family caregivers: what does the law really say? *AJN The American Journal of Nursing*, 106(8):51–53, 2006.
- [35] José Luis Fernández-Alemán, Inmaculada Carrión Señor, Pedro Ángel Oliver Lozoya, and Ambrosio Toval. Security and privacy in electronic health records: A systematic literature review. *Journal of biomedical informatics*, 46(3):541–562, 2013.

- [36] David Wiljer, Sara Urowitz, Emma Apatu, Claudette DeLenardo, Gunther Eysenbach, Tamara Harth, Howard Pai, Kevin J Leonard, Canadian Committee for Patient Accessible Health Records (CCPAEHR, et al. Patient accessible electronic health records: exploring recommendations for successful implementation strategies. *Journal of Medical Internet Research*, 10(4), 2008.
- [37] W Iso. 9241-11. ergonomic requirements for office work with visual display terminals (vdts). *The international organization for standardization*, 45(9), 1998.
- [38] Angela Di Fiore, Francesco Ceschel, Leysan Nurgalieva, Maurizio Marchese, and Fabio Casati. Design considerations to support nursing homes' communities. In *Proceedings of the 8th International Conference on Communities and Technologies*, pages 64–67. ACM, 2017.
- [39] Ceschel F. Egelman S. Nurgalieva L., Friik A. and Marchese M. Information design in an aged care context. views of older adults on information sharing in a care triad. In *Proceedings of the 13th EAI International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth'19)*. EAI., 2019.
- [40] Bernd J. Nurgalieva L. Lee J. Egelman S. Friik A., Schaub F. Usable security of emerging healthcare technologies for seniors. In *CHI Workshop "Designing Interactions for the Ageing Populations"*, 2018.
- [41] Leysan Nurgalieva, Juan Jose Jara Laconich, Marcos Baez, Fabio Casati, and Maurizio Marchese. Designing for older adults: review of touchscreen design guidelines. *arXiv preprint arXiv:1703.06317*, 2017.
- [42] Leysan Nurgalieva, Juan José Jara Laconich, Marcos Baez, Fabio Casati, and Maurizio Marchese. A systematic literature review of research-derived touchscreen design guidelines for older adults. *IEEE Access*, 7:22035–22058, 2019.
- [43] Leysan Nurgalieva, Marcos Baez, Francesca Fiore, Fabio Casati, and Maurizio Marchese. Designing healthcare systems with an emphasis on relational quality and peace of mind. In *International Conference on Social Informatics*, pages 234–242. Springer, 2018.
- [44] George L Engel. How much longer must medicine's science be bound by a seventeenth century world view? *Psychotherapy and Psychosomatics*, 57(1-2):3–16, 1992.

- [45] A Paul Williams, Allie Peckham, Kerry Kuluski, Robin Montgomery, Frances Morton, and Jillian Watkins. *Formal and informal care for older persons: Assessing the balance in Ontario*. Canadian Research Network for Care in the Community, 2010.
- [46] Anita Woll and Tone Bratteteig. A trajectory for technology-supported elderly care work. *Computer Supported Cooperative Work (CSCW)*, pages 1–42, 2018.
- [47] Britt Almqvist, Margareta Grafström, Kathleen Krichbaum, and Bengt Winblad. The interplay of institution and family caregiving: Relations between patient hassles, nursing home hassles and caregivers' burnout. *International journal of geriatric psychiatry*, 15(10): 931–939, 2000.
- [48] Stephanie McFall and Baila H Miller. Caregiver burden and nursing home admission of frail elderly persons. *Journal of Gerontology*, 47(2):S73–S79, 1992.
- [49] Marie T Duncan and David L Morgan. Sharing the caring: Family caregivers' views of their relationships with nursing home staff. *The Gerontologist*, 34(2):235–244, 1994.
- [50] Andrew Georgiou, Anne Marks, Jeffrey Braithwaite, and Johanna Irene Westbrook. Gaps, disconnections, and discontinuities—the role of information exchange in the delivery of quality long-term care. *The Gerontologist*, 53(5):770–779, 2012.
- [51] Pooja M Desai, Matthew E Levine, David J Albers, and Lena Mamykina. Pictures worth a thousand words: Reflections on visualizing personal blood glucose forecasts for individuals with type 2 diabetes. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, page 538. ACM, 2018.
- [52] Isto Huvila, Mats Daniels, Åsa Cajander, and Rose-Mharie Åhlfeldt. Patients reading their medical records: differences in experiences and attitudes between regular and inexperienced readers. *Information Research: An International Electronic Journal*, 21(1):n1, 2016.
- [53] Kelli I Stajduhar, Laura Funk, and Linda Outcalt. Family caregiver learning - how family caregivers learn to provide care at the end of life: A qualitative secondary analysis of four datasets. *Palliative medicine*, 27(7):657–664, 2013.
- [54] Assumpta A. Ryan and Hugh F Scullion. Family and staff perceptions of the role of families in nursing homes. *Journal of advanced nursing*, 32(3):626–634, 2000.
- [55] Ulla H Graneheim, Anneli Johansson, and Britt-Marie Lindgren. Family caregivers' experiences of relinquishing the care of a person with dementia to a nursing home: Insights

- from a meta-ethnographic study. *Scandinavian journal of caring sciences*, 28(2):215–224, 2014.
- [56] Vasiliki Matziou, Efrosyni Vlahioti, Pantelis Perdikaris, Theodora Matziou, Efstathia Megapanou, and Konstantinos Petsios. Physician and nursing perceptions concerning interprofessional communication and collaboration. *Journal of interprofessional care*, 28(6):526–533, 2014.
- [57] Juliet Corbin and Anselm Strauss. Managing chronic illness at home: three lines of work. *Qualitative sociology*, 8(3):224–247, 1985.
- [58] Meridean L Maas, David Reed, Myonghwa Park, Janet P Specht, Debra Schutte, Lisa S Kelley, Elizabeth A Swanson, Toni Trip-Reimer, and Kathleen C Buckwalte. Outcomes of family involvement in care intervention for caregivers of individuals with dementia. *Nursing research*, 53(2):76–86, 2004.
- [59] Jeannie L Haggerty, Robert J Reid, George K Freeman, Barbara H Starfield, Carol E Adair, and Rachael McKendry. Continuity of care: a multidisciplinary review. *BMJ: British Medical Journal*, 327(7425):1219, 2003.
- [60] Jill Yamasaki and Shelly R Hovick. “that was grown folks’ business”: Narrative reflection and response in older adults’ family health history communication. *Health communication*, 30(3):221–230, 2015.
- [61] Pin Sym Foong, Shengdong Zhao, Felicia Tan, and Joseph Jay Williams. Harvesting caregiving knowledge: Design considerations for integrating volunteer input in dementia care. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, page 79. ACM, 2018.
- [62] David Edvardsson, Deirdre Fetherstonhaugh, and Rhonda Nay. Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff. *Journal of clinical nursing*, 19(17-18):2611–2618, 2010.
- [63] Rebecca A Silliman. Caring for the frail older patient. *Journal of General Internal Medicine*, 4(3):237–241, 1989.
- [64] Jennifer L Wolff, Andrea Berger, Deserae Clarke, Jamie A Green, Rebecca Stametz, Christina Yule, and Jonathan D Darer. Patients, care partners, and shared access to the

- patient portal: online practices at an integrated health system. *Journal of the American Medical Informatics Association*, 23(6):1150–1158, 2016.
- [65] John Powell, Richard Fitton, and Caroline Fitton. Sharing electronic health records: the patient view. *Journal of Innovation in Health Informatics*, 14(1):55–57, 2006.
- [66] Claudia Pagliari, Don Detmer, and Peter Singleton. Potential of electronic personal health records. *BMJ: British Medical Journal*, 335(7615):330, 2007.
- [67] Gaurav Bansal, David Gefen, et al. The impact of personal dispositions on information sensitivity, privacy concern and trust in disclosing health information online. *Decision support systems*, 49(2):138–150, 2010.
- [68] Francisco Nunes, Nervo Verdezoto, Geraldine Fitzpatrick, Morten Kyng, Erik Grönvall, and Cristiano Storni. Self-care technologies in hci: Trends, tensions, and opportunities. *ACM Transactions on Computer-Human Interaction (TOCHI)*, 22(6):33, 2015.
- [69] Anselm Strauss, SY Fagerhaugh, Barbara Suczek, and CC Wiener. *Social Organization of Medical Work*. Transaction Publisher, 1985.
- [70] Susan Leigh Star and Anselm Strauss. Layers of silence, arenas of voice: The ecology of visible and invisible work. *Computer supported cooperative work (CSCW)*, 8(1):9–30, 1999.
- [71] Khuloud Abou Amsha and Myriam Lewkowicz. Shifting patterns in home care work: supporting collaboration among self-employed care actors. In *COOP 2016: Proceedings of the 12th International Conference on the Design of Cooperative Systems, 23-27 May 2016, Trento, Italy*, pages 139–154. Springer, 2016.
- [72] Claus Bossen, Lars Rune Christensen, Erik Grönvall, and Lasse Steenbock Vestergaard. Carecoor: Augmenting the coordination of cooperative home care work. *International journal of medical informatics*, 82(5):e189–e199, 2013.
- [73] Elissa G Miller. Pediatric palliative care: current evidence and evidence gaps. *The Journal of pediatrics*, 166(6):1536–1540, 2015.
- [74] Khuloud Abou Amsha and Myriam Lewkowicz. Care: An application to support the collective management of patients at home. In *Computational Science and Computational Intelligence (CSCI), 2015 International Conference on*, pages 743–748. IEEE, 2015.

- [75] GL Alexander, M Rantz, C Galambos, A Vogelsmeier, M Flesner, L Popejoy, J Mueller, S Shumate, and M Elvin. Preparing nursing homes for the future of health information exchange. *Applied clinical informatics*, 6(02):248–266, 2015.
- [76] Sarah Gaskin, Andrew Georgiou, Donna Barton, and Johanna Westbrook. Examining the role of information exchange in residential aged care work practices—a survey of residential aged care facilities. *BMC geriatrics*, 12(1):40, 2012.
- [77] JO MORIARTY, VALERIE LIPMAN, CAROLINE NORRIE, REKHA ELASWARAPU, and JILL MANTHORPE. Handovers in care homes for older people—their type, timing and usefulness. findings from a scoping review. *Ageing & Society*, pages 1–21, 2017.
- [78] Heather E Douglas, Andrew Georgiou, Amina Tariq, Mirela Prgomet, Andrew Warland, Pauline Armour, and Johanna I Westbrook. Implementing information and communication technology to support community aged care service integration: Lessons from an Australian aged care provider. *International journal of integrated care*, 17(1), 2017.
- [79] Angela di Fiore, Francesco Ceschel, Francesca Fiore, Marcos Baez, Fabio Casati, and Giampaolo Armellin. Understanding how software can support the needs of family caregivers for patients with severe conditions. *arXiv preprint arXiv:1701.07607*, 2017.
- [80] Victoria Lynne Claypoole, Bradford L Schroeder, and Ada D Mishler. Keeping in touch: Tactile interface design for older users. *ergonomics in design*, 24(1):18–24, 2016.
- [81] Na Mi, Lora A Cavuoto, Kenneth Benson, Tonya Smith-Jackson, and Maury A Nussbaum. A heuristic checklist for an accessible smartphone interface design. *Universal access in the information society*, 13(4):351–365, 2014.
- [82] Ljilja Ruzic, Seunghyun Tina Lee, Yilin Elaine Liu, and Jon A Sanford. Development of universal design mobile interface guidelines (udmig) for aging population. In *International Conference on Universal Access in Human-Computer Interaction*, pages 98–108. Springer, 2016.
- [83] Helena Karasti. Infrastructuring in participatory design. In *Proceedings of the 13th Participatory Design Conference: Research Papers-Volume 1*, pages 141–150. ACM, 2014.
- [84] Jesper Simonsen and Morten Hertzum. Real-use evaluation of effects: emergency departments aiming for ‘warm hands’. In *Proceedings of the 12th Participatory Design Conference:*

- Exploratory Papers, Workshop Descriptions, Industry Cases-Volume 2*, pages 69–72. ACM, 2012.
- [85] Centers for Medicare & Medicaid Services et al. The health insurance portability and accountability act of 1996 (hipaa). *Online at <http://www.cms.hhs.gov/hipaa>*, 1996.
- [86] US Department of Health, Human Services, et al. Protecting personal health information in research: Understanding the hipaa privacy rule. *Retrieved April, 26:2006*, 2005.
- [87] Fatos Xhafa, Jingwei Li, Gansen Zhao, Jin Li, Xiaofeng Chen, and Duncan S Wong. Designing cloud-based electronic health record system with attribute-based encryption. *Multimedia Tools and Applications*, 74(10):3441–3458, 2015.
- [88] Rose-Mharie Åhlfeldt and Isto Huvala. Patient safety and patient privacy when patient reading their medical records. In *International Conference on Well-Being in the Information Society*, pages 230–239. Springer, 2014.
- [89] Elisabeth Vodicka, Roanne Mejilla, Suzanne G Leveille, James D Ralston, Jonathan D Darer, Tom Delbanco, Jan Walker, and Joann G Elmore. Online access to doctors’ notes: patient concerns about privacy. *Journal of medical Internet research*, 15(9), 2013.
- [90] David Moher, Alessandro Liberati, Jennifer Tetzlaff, and Douglas G Altman. Reprint—preferred reporting items for systematic reviews and meta-analyses: the prisma statement. *Physical therapy*, 89(9):873–880, 2009.
- [91] John W Creswell, Ann Carroll Klassen, Vicki L Plano Clark, and Katherine Clegg Smith. Best practices for mixed methods research in the health sciences. *Bethesda (Maryland): National Institutes of Health*, 2013:541–545, 2011.
- [92] Retirement villages and nursing homes compared. URL <http://www.retirementliving.org.au/wp-content/uploads/2013/12/Retirement-Villages-and-Nursing-Homes-Comparison.pdf>.
- [93] Daniel E Forman, Aaron D Berman, Carolyn H McCabe, Donald S Baim, and Jeanne Y Wei. Ptca in the elderly: the “young-old” versus the “old-old”. *Journal of the American Geriatrics Society*, 40(1):19–22, 1992.
- [94] Robert K Yin. Case study research: Design and methods (applied social research methods). *London and Singapore: Sage*, 2009.

- [95] Sheelagh Carpendale. Evaluating information visualizations. In *Information visualization*, pages 19–45. Springer, 2008.
- [96] Marcos Baez and Fabio Casati. Agile development for vulnerable populations: lessons learned and recommendations. *arXiv preprint arXiv:1802.04100*, 2018.
- [97] WS Tuil, AJ Ten Hoopen, Didi DM Braat, PF de Vries Robbé, and JAM Kremer. Patient-centred care: using online personal medical records in ivf practice. *Human Reproduction*, 21(11):2955–2959, 2006.
- [98] MD Ross, IA Twombly, C Buyns, R Cheng, and S Sengers. Crossing the quality chasm: a new health system for the twenty-first century. *Albuquerque (NM): Institute of Medicine*, 2001.
- [99] Deborah Beranek Lafky and Thomas A Horan. Personal health records: Consumer attitudes toward privacy and security of their personal health information. *Health Informatics Journal*, 17(1):63–71, 2011.
- [100] Lina Tieu, Urmimala Sarkar, Dean Schillinger, James D Ralston, Neda Ratanawongsa, Rena Pasick, and Courtney R Lyles. Barriers and facilitators to online portal use among patients and caregivers in a safety net health care system: a qualitative study. *Journal of medical Internet research*, 17(12), 2015.
- [101] Kristiina Häyrynen, Kaija Saranto, and Pirkko Nykänen. Definition, structure, content, use and impacts of electronic health records: a review of the research literature. *International journal of medical informatics*, 77(5):291–304, 2008.
- [102] L Lyttkens. Support users to access information and services-final pilot evaluation uppsala county council, 2014. URL <http://www.webcitation.org/6fUJue03s>.
- [103] Taya Irizarry, Annette DeVito Dabbs, and Christine R Curran. Patient portals and patient engagement: a state of the science review. *Journal of medical Internet research*, 17(6), 2015.
- [104] Urmimala Sarkar and David W Bates. Care partners and online patient portals. *Jama*, 311(4):357–358, 2014.
- [105] Bradley H Crotty. Considerations and challenges in information and communication technology. In *Ethical Considerations and Challenges in Geriatrics*, pages 147–156. Springer, 2017.

- [106] Hanife Rexhepi, Rose-Mharie Åhlfeldt, Åsa Cajander, and Isto Huvila. Cancer patients' attitudes and experiences of online access to their electronic medical records: A qualitative study. *Health informatics journal*, 24(2):115–124, 2018.
- [107] Maria Hägglund and Isabella Scandurra. Patients' online access to electronic health records—current status and experiences from the implementation in sweden. *Studies in health technology and informatics*, 245:723–727, 2017.
- [108] Jonas Moll, Hanife Rexhepi, Åsa Cajander, Christiane Grünloh, Maria Hägglund, Isto Huvila, Gunilla Myreteg, Isabella Scandurra, and Rose-Mharie Åhlfeldt. Patients' experiences of accessing their online electronic health records: National patient survey in sweden. *Journal of Medical Internet Research*, 2018. doi: 10.2196/jmir.9492.
- [109] Richard Whiddett, Inga Hunter, Judith Engelbrecht, and Jocelyn Handy. Patients' attitudes towards sharing their health information. *International journal of medical informatics*, 75(7):530–541, 2006.
- [110] Angela di Fiore, Francesco Ceschel, Francesca Fiore, Marcos Baez, Fabio Casati, and Giampaolo Armellin. Understanding how software can support the needs of family caregivers for patients with severe conditions. In *Proceedings of the 39th International Conference on Software Engineering: Software Engineering in Society Track*, pages 33–36. IEEE Press, 2017.
- [111] Ben Shneiderman, Catherine Plaisant, and Bradford W Hesse. Improving healthcare with interactive visualization. *Computer*, 46(5):58–66, 2013.
- [112] Warren J Winkelman, Kevin J Leonard, and Peter G Rossos. Patient-perceived usefulness of online electronic medical records: employing grounded theory in the development of information and communication technologies for use by patients living with chronic illness. *Journal of the American Medical Informatics Association*, 12(3):306–314, 2005.
- [113] Melanie Nguyen, Yu Sun Bin, and Andrew Campbell. Comparing online and offline self-disclosure: A systematic review. *Cyberpsychology, Behavior, and Social Networking*, 15(2):103–111, 2012.
- [114] Cynthia LeRouge, Jiao Ma, Sweta Sneha, and Kristin Tolle. User profiles and personas in the design and development of consumer health technologies. *International journal of medical informatics*, 82(11):e251–e268, 2013.

- [115] TJGM Hazelhof, L Schoonhoven, BGI van Gaal, RTCM Koopmans, and DL Gerritsen. Nursing staff stress from challenging behaviour of residents with dementia: a concept analysis. *International nursing review*, 63(3):507–516, 2016.
- [116] Nicholas G Castle and John Engberg. Staff turnover and quality of care in nursing homes. *Medical care*, 43(6):616–626, 2005.
- [117] Nicole DePasquale, Kelly D Davis, Steven H Zarit, Phyllis Moen, Leslie B Hammer, and David M Almeida. Combining formal and informal caregiving roles: The psychosocial implications of double-and triple-duty care. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, page gbu139, 2014.
- [118] SA Zwijsen, A Kabboord, JA Eefsting, CMPM Hertogh, AM Pot, DL Gerritsen, and M Smalbrugge. Nurses in distress? an explorative study into the relation between distress and individual neuropsychiatric symptoms of people with dementia in nursing homes. *International journal of geriatric psychiatry*, 29(4):384–391, 2014.
- [119] Dana Beth Weinberg, R William Lusenhop, Jody Hoffer Gittell, and Cori M Kautz. Coordination between formal providers and informal caregivers. *Health care management review*, 32(2):140–149, 2007.
- [120] Marie T Duncan and David L Morgan. Sharing the caring: Family caregivers’ views of their relationships with nursing home staff. *The Gerontologist*, 34(2):235–244, 1994.
- [121] Ivan Breskovic, Aparecido Fabiano Pinatti De Carvalho, Susanne Schinking, and Hilda Tellioglu. Social awareness support for meeting informal carers’ needs: early development in topic. *ECSCW 2013*, pages 3–8, 2013.
- [122] MR Hastall, ND Eiermann, and U Ritterfeld. Formal and informal carers’ views on ict in dementia care: Insights from two qualitative studies. *Gerontechnology*, 13(1):51–56, 2014.
- [123] Jun-Ho Huh, Namjug Kim, and Kyungryong Seo. Design and implementation of mobile medication-hour notification system with push service function. *Int. J. Appl. Eng. Res*, 11(2):1225–1231, 2016.
- [124] Stefan Sävenstedt, Per-Olof Sandman, and Karin Zingmark. The duality in using information and communication technology in elder care. *Journal of advanced nursing*, 56(1): 17–25, 2006.

- [125] Farhad Fatehi and Richard Wootton. Telemedicine, telehealth or e-health? a bibliometric analysis of the trends in the use of these terms. *Journal of telemedicine and telecare*, 18(8):460–464, 2012.
- [126] David Silverman. *Qualitative research*. Sage, 2016.
- [127] Barney G Glaser and Anselm Leonard Strauss. *Chronic illness and the quality of life*. Sociology Press, 1975.
- [128] Marie R Haug. Elderly patients, caregivers, and physicians: theory and research on health care triads. *Journal of Health and Social Behavior*, pages 1–12, 1994.
- [129] Angela Di Fiore, Francesco Ceschel, Leysan Nurgalieva, Maurizio Marchese, and Fabio Casati. Design considerations to support nursing homes’ communities: Short. In *Proceedings of the 8th International Conference on Communities and Technologies*, pages 64–67. ACM, 2017.
- [130] Pascale Lehoux. Patients’ perspectives on high-tech home care: a qualitative inquiry into the user-friendliness of four technologies. *BMC Health Services Research*, 4(1):28, 2004.
- [131] Virginia Braun and Victoria Clarke. Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2):77–101, 2006.
- [132] Daniel J Solove. I’ve got nothing to hide and other misunderstandings of privacy. *San Diego L. Rev.*, 44:745, 2007.
- [133] Blaine Reeder, Ellen Meyer, Amanda Lazar, Shomir Chaudhuri, Hilaire Thompson, and George Demiris. Framing the evidence for health smart homes and home-based consumer health technologies as a public health intervention for independent aging: A systematic review. *International journal of medical informatics*, 82:565–579, April 2013.
- [134] Meredith B. Lilly, Audrey Laporte, and Peter C. Coyte. Labor market work and home care’s unpaid caregivers: A systematic review of labor force participation rates, predictors of labor market withdrawal, and hours of work. *The Milbank Quarterly*, 85(4):641–690, December 2007.
- [135] StartUp Health. Digital health insights for the 50+ market: Prepared for the aarp. Technical report, 2014. URL <https://www.aarp.org/content/dam/aarp/home-and-family/personal-technology/2014-05/2013-Digital-Health-Insights-Annual-Report-50-plus-Market-AARP.pdf>.

- [136] Iman Azimi, Amir M. Rahmani, Pasi Liljeberg, and Hannu Tenhunen. Internet of things for remote elderly monitoring: a study from user-centered perspective. *Journal of Ambient Intelligence and Humanized Computing*, 8:273–289, June 2016.
- [137] Jean Camp and Kay Connelly. Beyond consent: privacy in ubiquitous computing (ubicom). *Digital privacy: Theory, technologies, and practices*, pages 327–343, 2008.
- [138] Sherry L Willis, K Warner Schaie, and Mike Martin. *Cognitive plasticity*, pages 295–322. Springer Publishing Co, 2009.
- [139] Keith B Anderson. *Consumer fraud in the United States: An FTC survey*. Federal Trade Commission, 2004.
- [140] Vaibhav Garg, L. Jean Camp, Lesa Lorenzen-Huber, Kalpana Shankar, and Kay Connelly. Privacy concerns in assisted living technologies. *annals of telecommunications - annales des télécommunications*, 69(1):75–88, Feb 2014. ISSN 1958-9395. doi: 10.1007/s12243-013-0397-0. URL <https://doi.org/10.1007/s12243-013-0397-0>.
- [141] Lisa Thomas, Linda Little, Pam Briggs, Lynn McInnes, Emma Jones, and James Nicholson. Location tracking: views from the older adult population. *Age and ageing*, 42(6):758–763, 2013.
- [142] Andrew McNeill, Pam Briggs, Jake Pywell, and Lynne Coventry. Functional privacy concerns of older adults about pervasive health-monitoring systems. In *Proceedings of the 10th International Conference on Pervasive Technologies Related to Assistive Environments*, PETRA '17, pages 96–102, New York, NY, USA, 2017. ACM. ISBN 978-1-4503-5227-7. doi: 10.1145/3056540.3056559. URL <http://doi.acm.org/10.1145/3056540.3056559>.
- [143] V. Garg, L. Lorenzen-Huber, L. J. Camp, and K. Connelly. Risk communication design for older adults. *Gerontechnology*, 11(2):166–173, 2012.
- [144] Dominik Hornung, Claudia Müller, Irina Shklovski, Timo Jakobi, and Volker Wulf. Navigating relationships and boundaries: Concerns around ict-uptake for elderly people. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, CHI '17, pages 7057–7069, New York, NY, USA, 2017. ACM. ISBN 978-1-4503-4655-9. doi: 10.1145/3025453.3025859. URL <http://doi.acm.org/10.1145/3025453.3025859>.

- [145] Xinguo Yu. Approaches and principles of fall detection for elderly and patient. In *Health-Com 2008 - 10th International Conference on e-health Networking, Applications and Services*, pages 42–47, July 2008. doi: 10.1109/HEALTH.2008.4600107.
- [146] Simon Kozina, Mitja Lustrek, and Matjaz Gams. Dynamic signal segmentation for activity recognition. In *Proceedings of International Joint Conference on Artificial Intelligence*, 2011.
- [147] John Vines, Stephen Lindsay, Gary W. Pritchard, Mabel Lie, David Greathead, Patrick Olivier, and Katie Brittain. Making family care work: Dependence, privacy and remote home monitoring telecare systems. In *Proceedings of the 2013 ACM International Joint Conference on Pervasive and Ubiquitous Computing, UbiComp '13*, pages 607–616, New York, NY, USA, 2013. ACM. ISBN 978-1-4503-1770-2. doi: 10.1145/2493432.2493469. URL <http://doi.acm.org/10.1145/2493432.2493469>.
- [148] S. Fang, Y. Liang, and K. Chiu. Developing a mobile phone-based fall detection system on android platform. In *2012 Computing, Communications and Applications Conference*, pages 143–146, Jan 2012. doi: 10.1109/ComComAp.2012.6154019.
- [149] Cherry Home. <https://cherryhome.ai>, 2018. Retrieved on 14 September 2018.
- [150] Ageless Innovation LLC. Joy for all companion pets. <https://joyforall.com>, 2018. Accessed on 14 September 2018.
- [151] PARO Robots U.S. Inc. <http://www.parorobots.com>, 2014. Accessed on 14 September 2018.
- [152] Jibo Inc. <https://www.jibo.com>, 2018. Accessed 14 September 2018.
- [153] Qualcomm Technologies Inc. Home connectivity and integration. <https://www.qualcomm.com/solutions/health-care/home-connectivity-and-integration>, 2018. Accessed 14 September 2018.
- [154] Theora Care. <https://theoracare.com>, 2018. Accessed 14 September 2018.
- [155] Vaibhav Garg, L. Jean Camp, Katherine Connelly, and Lesa Lorenzen-Huber. Risk communication design: Video vs. text. In Simone Fischer-Hübner and Matthew Wright, editors, *Privacy Enhancing Technologies*, pages 279–298, Berlin, Heidelberg, 2012. Springer Berlin Heidelberg. ISBN 978-3-642-31680-7.

- [156] Anita Melander-Wikman, Ylva Fältholm, and Gunvor Gard. Safety vs. privacy: Elderly persons' experiences of a mobile safety alarm. 16:337–46, 08 2008.
- [157] Jane Chung, George Demiris, and Hilaire Thompson. Ethical considerations regarding the use of smart home technologies for older adults: An integrative review. 34:155–181, 01 2016.
- [158] Lynne Coventry and Pam Briggs. Mobile technology for older adults: Protector, motivator or threat? In Jia Zhou and Gavriel Salvendy, editors, *Human Aspects of IT for the Aged Population. Design for Aging*, pages 424–434, Cham, 2016. Springer International Publishing. ISBN 978-3-319-39943-0.
- [159] Linda Lee, JoongHwa Lee, Serge Egelman, and David Wagner. Information disclosure concerns in the age of wearable computing. In *Proceedings of the NDSS Workshop on Usable Security (USEC '16)*, volume 1, Jan 2016. doi: 10.14722/usec.2016.23006.
- [160] Bran Knowles and Vicki L. Hanson. Older adults' deployment of 'distrust'. *ACM Trans. Comput.-Hum. Interact.*, 25(4):21:1–21:25, August 2018. ISSN 1073-0516. doi: 10.1145/3196490. URL <http://doi.acm.org/10.1145/3196490>.
- [161] Irwin Altman. *The Environment and Social Behaviour: Privacy, Personal Space, Territory, and Crowding*. Brooks/Cole Publishing Company, 1975.
- [162] Alain Forget, Sarah Pearman, Jeremy Thomas, Alessandro Acquisti, Nicolas Christin, Lorrie Faith Cranor, Serge Egelman, Marian Harbach, and Rahul Telang. Do or do not, there is no try: User engagement may not improve security outcomes. In *Twelfth Symposium on Usable Privacy and Security (SOUPS 2016)*, pages 97–111, Denver, CO, 2016. USENIX Association. ISBN 978-1-931971-31-7. URL <https://www.usenix.org/conference/soups2016/technical-sessions/presentation/forget>.
- [163] World Health Organization. World health statistics. Technical report, Geneva, Switzerland, 2014. URL http://apps.who.int/iris/bitstream/10665/112739/1/WHO_HIS_HSI_14.1_eng.pdf. Retrieved on 4 September 2017.
- [164] Kelly E. Caine, Celine Y. Zimmerman, Zachary Schall-Zimmerman, William R. Hazlewood, L. Jean Camp, Katherine H. Connelly, Lesa L. Huber, and Kalpana Shankar. Digiswitch: A device to allow older adults to monitor and direct the collection and transmission of health information collected at home. *Journal of Medical Systems*, 35:1181–1195, 2011. doi: 10.1007/s10916-011-9722-1.

- [165] Scott Beach, Richard Schulz, Julie Downs, Judith Matthews, Bruce Barron, and Katherine Seelman. Disability, age, and informational privacy attitudes in quality of life technology applications: Results from a national web survey. *ACM Trans. Access. Comput.*, 2(1): 5:1–5:21, May 2009. ISSN 1936-7228. doi: 10.1145/1525840.1525846. URL <http://doi.acm.org/10.1145/1525840.1525846>.
- [166] George Demiris, Debra Oliver, Geraldine Dickey, Marjorie Skubic, and Marilyn Rantz. Findings from a participatory evaluation of a smart home application for older adults. 16: 111–8, 02 2008.
- [167] Sabato Mellone, Carlo Tacconi, Lars Schwickert, Jochen Klenk, Clemens Becker, and Lorenzo Chiari. Smartphone-based solutions for fall detection and prevention: The farseeing approach. 45:722–727, 12 2012.
- [168] Mirko Di Rosa, Vera Stara, Lorena Rossi, Fanny Breuil, Elisenda Reixach, Joan Garcia Paredes, and Stefan Burkard. *A Wireless Sensor Insole to Collect and Analyse Gait Data in Real Environment: The WIISEL Project*, pages 71–80. Springer International Publishing, Cham, 2015. ISBN 978-3-319-18374-9. doi: 10.1007/978-3-319-18374-9_7. URL https://doi.org/10.1007/978-3-319-18374-9_7.
- [169] Peter Gregor, Alan F. Newell, and Mary Zajicek. Designing for dynamic diversity: Interfaces for older people. In *Proceedings of the Fifth International ACM Conference on Assistive Technologies, Assets '02*, pages 151–156, New York, NY, USA, 2002. ACM. ISBN 1-58113-464-9. doi: 10.1145/638249.638277. URL <http://doi.acm.org/10.1145/638249.638277>.
- [170] Lesa Lorenzen Huber, Kalpana Shankar, Kelly Caine, Kay Connelly, L. Jean Camp, Beth Ann Walker, and Lisa Borrero. How in-home technologies mediate caregiving relationships in later life. *International Journal of Human–Computer Interaction*, 29(7): 441–455, 2013. doi: 10.1080/10447318.2012.715990. URL <https://doi.org/10.1080/10447318.2012.715990>.
- [171] Eric Zeng, Shrirang Mare, and Franziska Roesner. End user security and privacy concerns with smart homes. In *Thirteenth Symposium on Usable Privacy and Security (SOUPS 2017)*, pages 65–80, Santa Clara, CA, 2017. USENIX Association. ISBN 978-1-931971-39-3. URL <https://www.usenix.org/conference/soups2017/technical-sessions/presentation/zeng>.

- [172] Monica Anderson. Smartphone, computer or tablet? 36% of americans own all three. *Pew Research Center*, 2015.
- [173] Monica Anderson and Andrew Perrin. Technology use among seniors. *Washington, DC: Pew Research Center for Internet & Technology*, 2017.
- [174] Galen A Grimes, Michelle G Hough, Elizabeth Mazur, and Margaret L Signorella. Older adults' knowledge of internet hazards. *Educational Gerontology*, 36(3):173–192, 2010.
- [175] Wiktoria Wilkowska and Martina Ziefle. Perception of privacy and security for acceptance of e-health technologies: Exploratory analysis for diverse user groups. In *2011 5th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth) and Workshops*, pages 593–600. IEEE, 2011.
- [176] Ashwini Rao, Florian Schaub, and Norman Sadeh. What do they know about me? contents and concerns of online behavioral profiles. *arXiv preprint arXiv:1506.01675*, 2015.
- [177] Jiang Tao and Hu Shuijing. The elderly and the big data how older adults deal with digital privacy. In *2016 International Conference on Intelligent Transportation, Big Data & Smart City*, pages 285–288. IEEE, 2016.
- [178] Anna Essén. The two facets of electronic care surveillance: An exploration of the views of older people who live with monitoring devices. *Social science & medicine*, 67(1):128–136, 2008.
- [179] Hoda Moghimi, Jonathan L Schaffer, and Nilmini Wickramasinghe. Intelligent home risk-based monitoring solutions enable post acute care surveillance. In *Contemporary Consumer Health Informatics*, pages 399–412. Springer, 2016.
- [180] Robert M Califf and Lawrence H Muhlbaier. Health Insurance Portability and Accountability Act (HIPAA) must there be a trade-off between privacy and quality of health care, or can we advance both? *Circulation*, 108(8):915–918, 2003.
- [181] Rachelle Kaye, Ehud Kokia, Varda Shalev, Dalia Idar, and David Chinitz. Barriers and success factors in health information technology: A practitioner's perspective. *Journal of Management & Marketing in Healthcare*, 3(2):163–175, 2010.
- [182] Joseph F Coughlin, Lisa A D'Ambrosio, Bryan Reimer, and Michelle R Pratt. Older adult perceptions of smart home technologies: implications for research, policy & market

- innovations in healthcare. In *2007 29th Annual International Conference of the IEEE Engineering in Medicine and Biology Society*, pages 1810–1815. IEEE, 2007.
- [183] Daphne Townsend, Frank Knoefel, and Rafik Goubran. Privacy versus autonomy: a trade-off model for smart home monitoring technologies. In *2011 Annual International Conference of the IEEE Engineering in Medicine and Biology Society*, pages 4749–4752. IEEE, 2011.
- [184] Alessandro Acquisti and Ralph Gross. Predicting social security numbers from public data. *Proceedings of the National academy of sciences*, 106(27):10975–10980, 2009.
- [185] Aleecia McDonald and Lorrie Faith Cranor. Beliefs and behaviors: Internet users’ understanding of behavioral advertising. Working paper. Accessed 3 May 2017: <http://ssrn.com/abstract=1989092>., 2010.
- [186] Birgit Gielen, Anne Remacle, and Raf Mertens. Patterns of health care use and expenditure during the last 6 months of life in belgium: differences between age categories in cancer and non-cancer patients. *Health policy*, 97(1):53–61, 2010.
- [187] David D Luxton, Robert A Kayl, and Matthew C Mishkind. mhealth data security: The need for hipaa-compliant standardization. *Telemedicine and e-Health*, 18(4):284–288, 2012.
- [188] Gizem Ögütçü, Özlem Müge Testik, and Oumout Chouseinoglou. Analysis of personal information security behavior and awareness. *Computers & Security*, 56:83–93, 2016.
- [189] Daniela Oliveira, Harold Rocha, Huizi Yang, Donovan Ellis, Sandeep Dommaraju, Melis Muradoglu, Devon Weir, Adam Soliman, Tian Lin, and Natalie Ebner. Dissecting spear phishing emails for older vs young adults: On the interplay of weapons of influence and life domains in predicting susceptibility to phishing. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, pages 6412–6424, 2017.
- [190] Colleen Swanson, Ruth Urner, and Edward Lank. Naïve security in a wi-fi world. In *IFIP International Conference on Trust Management*, pages 32–47. Springer, 2010.
- [191] Mahak Arora, Kamal Kumar Sharma, and Sharad Chauhan. Cyber crime combating using keylog detector tool. 2016.
- [192] Alessandro Acquisti, Idris Adjerid, Rebecca Balebako, Laura Brandimarte, Lorrie Faith Cranor, Saranga Komanduri, Pedro Giovanni Leon, Norman Sadeh, Florian Schaub,

- Manya Sleeper, et al. Nudges for privacy and security: Understanding and assisting users' choices online. *ACM Computing Surveys (CSUR)*, 50(3):44, 2017.
- [193] Eric L Carlson. Phishing for elderly victims: as the elderly migrate to the internet fraudulent schemes targeting them follow. *Elder LJ*, 14:423, 2006.
- [194] Elizabeth Stobert and Robert Biddle. The password life cycle: User behaviour in managing passwords. In *10th Symposium On Usable Privacy and Security (SOUPS 2014)*, pages 243–255, Menlo Park, CA, 2014. USENIX Association. ISBN 978-1-931971-13-3. URL <https://www.usenix.org/conference/soups2014/proceedings/presentation/stobert>.
- [195] Rick Wash, Emilee Rader, Ruthie Berman, and Zac Wellmer. Understanding password choices: How frequently entered passwords are re-used across websites. In *Twelfth Symposium on Usable Privacy and Security (SOUPS 2016)*, pages 175–188, Denver, CO, 2016. USENIX. ISBN 978-1-931971-31-7. URL <https://www.usenix.org/conference/soups2016/technical-sessions/presentation/wash>.
- [196] William Melicher, Darya Kurilova, Sean M. Segreti, Pranshu Kalvani, Richard Shay, Blase Ur, Lujo Bauer, Nicolas Christin, Lorrie Faith Cranor, and Michelle L. Mazurek. Usability and security of text passwords on mobile devices. In *Proceedings of the 2016 Conference on Human Factors in Computing Systems (CHI)*, pages 527–539, 2016. ISBN 978-1-4503-3362-7. doi: 10.1145/2858036.2858384. URL <http://doi.acm.org/10.1145/2858036.2858384>.
- [197] Paul Dourish, E Grinter, Jessica Delgado De La Flor, and Melissa Joseph. Security in the wild: user strategies for managing security as an everyday, practical problem. *Personal and Ubiquitous Computing*, 8(6):391–401, 2004.
- [198] Alain Forget, Sarah Pearman, Jeremy Thomas, Alessandro Acquisti, Nicolas Christin, Lorrie Faith Cranor, Serge Egelman, Marian Harbach, and Rahul Telang. Do or do not, there is no try: User engagement may not improve security outcomes. In *12th Symposium on Usable Privacy and Security (SOUPS 2016)*, pages 97–111, Denver, CO, 2016. USENIX. ISBN 978-1-931971-31-7. URL <https://www.usenix.org/conference/soups2016/technical-sessions/presentation/forget>.
- [199] Vanessa Boothroyd. *Older Adults' Perceptions of Online Risk*. PhD thesis, Carleton University, 2014.

- [200] Monica Whitty, James Doodson, Sadie Creese, and Duncan Hodges. Individual differences in cyber security behaviors: an examination of who is sharing passwords. *Cyberpsychology, Behavior, and Social Networking*, 18(1):3–7, 2015.
- [201] Carole Cadwallar and Emma Graham-Harrison. Revealed: 50 million Facebook profiles harvested for Cambridge Analytica in major data breach. *The Guardian*, March 2018. URL <https://www.theguardian.com/news/2018/mar/17/cambridge-analytica-facebook-influence-us-election>. Accessed 19 September 2018.
- [202] Gary Horcher. Woman says her Amazon device recorded private conversation, sent it out to random contact. *KIRO News*, May 2018. URL <https://www.kiro7.com/news/local/woman-says-her-amazon-device-recorded-private-conversation-sent-it-out-to-random-com-755507974>. Accessed 19 September 2018.
- [203] Corey M Angst and Ritu Agarwal. Adoption of electronic health records in the presence of privacy concerns: The elaboration likelihood model and individual persuasion. *MIS quarterly*, 33(2):339–370, 2009.
- [204] Iulia Ion, Niharika Sachdeva, Ponnurangam Kumaraguru, and Srdjan Čapkun. Home is safer than the cloud!: privacy concerns for consumer cloud storage. In *Proceedings of the Seventh Symposium on Usable Privacy and Security*, page 13. ACM, 2011.
- [205] Kalpana Shankar, L Jean Camp, Kay Connelly, and Lesa Huber. Aging, privacy, and home-based computing: Developing a design framework. *IEEE Pervasive Computing*, 11(4):46–54, 2012.
- [206] Alessandro Montanari, Afra Mashhadi, Akhil Mathur, and Fahim Kawsar. Understanding the privacy design space for personal connected objects. In *Proceedings of the 30th International BCS Human Computer Interaction Conference: Fusion! (HCI '16)*, pages 18:1–18:13, Swindon, UK, 2016. BCS Learning & Development Ltd. doi: 10.14236/ewic/HCI2016.18. URL <https://doi.org/10.14236/ewic/HCI2016.18>.
- [207] Sreenivas Sremath Tirumala, Hira Sathu, and Vijay Naidu. Analysis and prevention of account hijacking based incidents in cloud environment. In *2015 international Conference on Information Technology (ICIT)*, pages 124–129. IEEE, 2015.
- [208] Daniel J Solove. I've got nothing to hide and other misunderstandings of privacy. *San Diego Law Review*, 44:745, 2007.

- [209] Ralph Gross and Alessandro Acquisti. Information revelation and privacy in online social networks. In *Proceedings of the 2005 ACM workshop on Privacy in the electronic society*, pages 71–80. ACM, 2005.
- [210] Omead Kohanteb, Owen Tong, Heidi Yang, Thidanun Saensuksopa, and Saba Kazi. signifiers.io guidelines for designing connected devices, 2015. URL <http://signifiers.io/signifiers/guidelines.html>. Web page. Accessed: 26 February 2018.
- [211] Stacey Gray. Always on: Privacy implications of microphone-enabled devices. Technical report, Future of Privacy Forum, April 2016. URL https://www.ftc.gov/system/files/documents/public_comments/2016/08/00003-128652.pdf.
- [212] Niamh Caprani, Noel E O’Connor, and Cathal Gurrin. Touch screens for the older user. In *Assistive technologies*. InTech, 2012.
- [213] Kristin Fuglerud and Oystein Dale. Secure and inclusive authentication with a talking mobile one-time-password client. *IEEE Security & Privacy*, 9(2):27–34, 2011.
- [214] Sara J Czaja, Wendy A Rogers, Arthur D Fisk, Neil Charness, and Joseph Sharit. *Designing for older adults: Principles and creative human factors approaches*. CRC press, 2009.
- [215] Erika Chin, Adrienne Porter Felt, Vyas Sekar, and David Wagner. Measuring user confidence in smartphone security and privacy. In *Proceedings of the Eighth Symposium on Usable Privacy and Security*, page 1. ACM, 2012.
- [216] Yvonne Barnard, Mike D Bradley, Frances Hodgson, and Ashley D Lloyd. Learning to use new technologies by older adults: Perceived difficulties, experimentation behaviour and usability. *Computers in Human Behavior*, 29(4):1715–1724, 2013.
- [217] Samantha J Parker, Sonal Jessel, Joshua E Richardson, and M Cary Reid. Older adults are mobile too! identifying the barriers and facilitators to older adults’ use of mhealth for pain management. *BMC geriatrics*, 13(1):43, 2013.
- [218] Philippe Gorce, Vigouroux Nadine, and Lilian Motti. Interaction techniques for older adults using touchscreen devices: a literature review from 2000 to 2013. *Journal d’Interaction Personne-Système*, 3, 2017.

- [219] Nikki L Hill, Jacqueline Mogle, Elise Colancecco, Robert Dick, John Hannan, and Feng Vankee Lin. Feasibility study of an attention training application for older adults. *International journal of older people nursing*, 10(3):241–249, 2015.
- [220] Alexis Kuerbis, Adina Mulliken, Frederick Muench, Alison A Moore, and Daniel Gardner. Older adults and mobile technology: Factors that enhance and inhibit utilization in the context of behavioral health. *Mental Health and Addiction Research*, 2017. doi: 10.15761/MHAR.1000136.
- [221] Brian D Carpenter and Sarah Buday. Computer use among older adults in a naturally occurring retirement community. *Computers in Human Behavior*, 23(6):3012–3024, 2007.
- [222] Brian O’Mullane, Brennon Bortz, and R Benjamin Knapp. Design challenges for internet interfaces for older people and widget-based, touch screen solution architecture. *Gerontechnology*, 9(2):239, 2010.
- [223] José Coelho and Carlos Duarte. Socially networked or isolated? differentiating older adults and the role of tablets and television. In *Human-Computer Interaction*, pages 129–146. Springer, 2015.
- [224] Kerryellen G Vroman, Sajay Arthanat, and Catherine Lysack. Who over 65 is online? older adults’ dispositions toward information communication technology. *Computers in Human Behavior*, 43:156–166, 2015.
- [225] Ljilja Ruzic Kascak, Elaine Yilin Liu, Jon A Sanford, et al. Universal design (ud) guidelines for interactive mobile voting interfaces for older adults. In *International Conference on Universal Access in Human-Computer Interaction*, pages 215–225. Springer, 2015.
- [226] Eric Corbett and Astrid Weber. What can i say?: addressing user experience challenges of a mobile voice user interface for accessibility. In *Proceedings of the 18th International Conference on Human-Computer Interaction with Mobile Devices and Services*, pages 72–82. ACM, 2016.
- [227] Shari Trewin, Cal Swart, and Donna Pettick. Physical accessibility of touchscreen smartphones. In *Proceedings of the 15th International ACM SIGACCESS Conference on Computers and Accessibility*, page 19. ACM, 2013.

- [228] Kavous Salehzadeh Niksirat, Chaklam Silpasuwanchai, Zhenxin Wang, Jing Fan, and Xiangshi Ren. Age-related differences in gross motor skills. In *Proceedings of the International Symposium on Interactive Technology and Ageing Populations*, pages 109–118. ACM, 2016.
- [229] Dagfinn Rømen and Dag Svanæs. Validating wcag versions 1.0 and 2.0 through usability testing with disabled users. *Universal Access in the Information Society*, 11(4):375–385, 2012.
- [230] Hugo Nicolau, Tiago Guerreiro, Joaquim Jorge, and Daniel Gonçalves. Mobile touchscreen user interfaces: bridging the gap between motor-impaired and able-bodied users. *Universal access in the information society*, 13(3):303–313, 2014.
- [231] Julio Abascal, Myriam Arrue, Inmaculada Fajardo, Nestor Garay, and Jorge Tomás. The use of guidelines to automatically verify web accessibility. *Universal Access in the Information Society*, 3(1):71–79, 2004.
- [232] Panayiotis Zaphiris, Mariya Ghiawadwala, and Shabana Mughal. Age-centered research-based web design guidelines. In *CHI’05 extended abstracts on Human factors in computing systems*, pages 1897–1900. ACM, 2005.
- [233] Stefan Carmien and Ainara Garzo Manzanares. Elders using smartphones – a set of research based heuristic guidelines for designers. In *International Conference on Universal Access in Human-Computer Interaction*, pages 26–37. Springer, 2014.
- [234] Huhn Kim. Effective organization of design guidelines reflecting designer’s design strategies. *International Journal of Industrial Ergonomics*, 40(6):669–688, 2010.
- [235] Alan F Newell and Peter Gregor. Design for older and disabled people—where do we go from here? *Universal Access in the Information Society*, 2(1):3–7, 2002.
- [236] Chris M Law, Ji Soo Yi, Young Sang Choi, and Julie A Jacko. Are disability-access guidelines designed for designers?: do they need to be? In *Proceedings of the 18th Australia conference on Computer-Human Interaction: Design: Activities, Artefacts and Environments*, pages 357–360. ACM, 2006.
- [237] F. Ghorbel, E. Metais, N. Ellouze, F. Hamdi, and F. Gargouri. Towards Accessibility Guidelines of Interaction and User Interface Design for Alzheimer’s Disease Patients. In *ACHI 2017*, page 6, Nice, France, March 2017.

- [238] Morten Hertzum. Images of usability. *Intl. Journal of Human-Computer Interaction*, 26(6):567–600, 2010.
- [239] Andraž Petrovčič, Sakari Taipale, Ajda Rogelj, and Vesna Dolničar. Design of mobile phones for older adults: An empirical analysis of design guidelines and checklists for feature phones and smartphones. *International Journal of Human-Computer Interaction*, 34(3):251–264, 2018.
- [240] Alan F Newell. Older people as a focus for inclusive design. *Gerontechnology*, 4(4):190–199, 2006.
- [241] Christophe Ponsard, Pascal Beaujeant, and Jean Vanderdonckt. Augmenting accessibility guidelines with user ability rationales. In *IFIP Conference on Human-Computer Interaction*, pages 579–586. Springer, 2013.
- [242] John Vines, Gary Pritchard, Peter Wright, Patrick Olivier, and Katie Brittain. An age-old problem: Examining the discourses of ageing in hci and strategies for future research. *ACM Transactions on Computer-Human Interaction (TOCHI)*, 22(1):2, 2015.
- [243] Sidney L Smith and Jane N Mosier. *Guidelines for designing user interface software*. Mitre Corporation Bedford, MA, 1986.
- [244] Alan J Dix, Janet E Finlay, and Gregory D Abowd. Beale rusel. *Human- Computer Interaction*, 2004.
- [245] Tom Stewart and David Travis. Guidelines, standards, and style guides. In *The human-computer interaction handbook*, pages 991–1005. L. Erlbaum Associates Inc., 2002.
- [246] Trent Apted, Judy Kay, and Aaron Quigley. Tabletop sharing of digital photographs for the elderly. In *Proceedings of the SIGCHI conference on Human Factors in computing systems*, pages 781–790. ACM, 2006.
- [247] Jeff Johnson and Kate Finn. *Designing User Interfaces for an Aging Population: Towards Universal Design*. Morgan Kaufmann, 2017.
- [248] Lilian Genaro Motti, Nadine Vigouroux, and Philippe Gorce. Interaction techniques for older adults using touchscreen devices: a literature review. In *Proceedings of the 25th Conference on l’Interaction Homme-Machine*, page 125. ACM, 2013.

- [249] Friederike Boll and Philipp Brune. User interfaces with a touch of grey?—towards a specific ui design for people in the transition age. *Procedia Computer Science*, 63:511–516, 2015.
- [250] Matthias Peissner, Dagmar Häbe, Doris Janssen, and Thomas Sellner. Myui: generating accessible user interfaces from multimodal design patterns. In *Proceedings of the 4th ACM SIGCHI symposium on Engineering interactive computing systems*, pages 81–90. ACM, 2012.
- [251] Alistair Sutcliffe. Collaborative requirements engineering: bridging the gulfs between worlds. In *Intentional Perspectives on Information Systems Engineering*, pages 355–376. Springer, 2010.
- [252] Siegfried Treu. Computer applications and tasks. In *User Interface Design*, pages 61–83. Springer, 1994.
- [253] Anette Hochberg, Jan-Henrik Hafke, and Joachim Raab. *Open I Close: Windows, Doors, Gates, Loggias, Filters*, volume 1. Birkhäuser Verlag AG, 2010.
- [254] Mark H Chignell. A taxonomy of user interface terminology. *ACM SIGCHI Bulletin*, 21(4):27, 1990.
- [255] Qingchuan Li and Yan Luximon. A comparative study between younger and older users on mobile interface navigation. In *Proceedings of the ACHI 2017: The Tenth International Conference on Advances in Computer-Human Interactions*, 2017.
- [256] Jonathan Lazar, Jinjuan Heidi Feng, and Harry Hochheiser. *Research methods in human-computer interaction*. Morgan Kaufmann, 2017.
- [257] World Health Organization et al. The global strategy and action plan on ageing and health. 2016, 2016.
- [258] Nations Unies. *World population prospects: the 2017 revision: key findings and advance tables*. UN, 2017.
- [259] Barbara Barbosa Neves, Rachel L Franz, Cosmin Munteanu, Ronald Baecker, and Mags Ngo. My hand doesn't listen to me!: Adoption and evaluation of a communication technology for the 'oldest old'. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, pages 1593–1602. ACM, 2015.

- [260] Hyung Nam Kim, Tonya L Smith-Jackson, and Brian M Kleiner. Accessible haptic user interface design approach for users with visual impairments. *Universal access in the information society*, 13(4):415–437, 2014.
- [261] José Coelho and Carlos Duarte. A literature survey on older adults’ use of social network services and social applications. *Computers in Human Behavior*, 58:187–205, 2016.
- [262] Renata Pontin M Fortes, Guilherme Almeida Martins, and Paula Costa Castro. A review of senescent’s motivation in the use of tactile devices. *Procedia Computer Science*, 67:376–387, 2015.
- [263] Muna S Al-Razgan, Hend S Al-Khalifa, Mona D Al-Shahrani, and Hessah H AlAjmi. Touch-based mobile phone interface guidelines and design recommendations for elderly people: a survey of the literature. In *International Conference on Neural Information Processing*, pages 568–574. Springer, 2012.
- [264] Chat Wacharamanotham, Jan Hurtmanns, Alexander Mertens, Martin Kronenbuerger, Christopher Schlick, and Jan Borchers. Evaluating swabbing: a touchscreen input method for elderly users with tremor. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, pages 623–626. ACM, 2011.
- [265] Francisco Nunes, Paula Alexandra Silva, João Cevada, Ana Correia Barros, and Luís Teixeira. User interface design guidelines for smartphone applications for people with parkinson’s disease. *Universal Access in the Information Society*, 15(4):659–679, 2016.
- [266] Diana Molero Martin, Robert Laird, Faustina Hwang, and Christos Salis. Computerized short-term memory treatment for older adults with aphasia: feedback from clinicians. In *Proceedings of the 15th International ACM SIGACCESS Conference on Computers and Accessibility*, page 44. ACM, 2013.
- [267] Ondrej Polacek, Adam J Sporka, and Pavel Slavik. Text input for motor-impaired people. *Universal Access in the Information Society*, 16(1):51–72, 2017.
- [268] Tiago Guerreiro, Hugo Nicolau, Joaquim Jorge, and Daniel Gonçalves. Towards accessible touch interfaces. In *Proceedings of the 12th international ACM SIGACCESS conference on Computers and accessibility*, pages 19–26. ACM, 2010.
- [269] Matt Huenerfauth, Lijun Feng, and Noémie Elhadad. Comparing evaluation techniques for text readability software for adults with intellectual disabilities. In *Proceedings of the*

- 11th international ACM SIGACCESS conference on Computers and accessibility*, pages 3–10. ACM, 2009.
- [270] Johan Borg, Ann Lantz, and Jan Gulliksen. Accessibility to electronic communication for people with cognitive disabilities: a systematic search and review of empirical evidence. *Universal Access in the Information Society*, 14(4):547–562, 2015.
- [271] Javier Sevilla, Gerardo Herrera, Bibiana Martínez, and Francisco Alcantud. Web accessibility for individuals with cognitive deficits: A comparative study between an existing commercial web and its cognitively accessible equivalent. *ACM Transactions on Computer-Human Interaction (TOCHI)*, 14(3):12, 2007.
- [272] Rafael Jeferson Pezzuto Damaceno, Juliana Cristina Braga, and Jesús Pascual Mena-Chalco. Mobile device accessibility for the visually impaired: problems mapping and recommendations. *Universal Access in the Information Society*, pages 1–15, 2018.
- [273] Rocío Calvo, Ana Iglesias, and Leonardo Castaño. Evaluation of accessibility barriers and learning features in m-learning chat applications for users with disabilities. *Universal Access in the Information Society*, 16(3):593–607, 2017.
- [274] Stefan Bachl, Martin Tomitsch, Christoph Wimmer, and Thomas Grechenig. Challenges for designing the user experience of multi-touch interfaces. In *Proc. workshop on engineering patterns for multi-touch interfaces*, 2010.
- [275] Andreas Komninos, Emma Nicol, and Mark D Dunlop. Designed with older adults to support better error correction in smartphone text entry: The maxiekeyboard. In *Proceedings of the 17th International Conference on Human-Computer Interaction with Mobile Devices and Services Adjunct*, pages 797–802. ACM, 2015.
- [276] Raúl Miñón, Fabio Paternò, Myriam Arrue, and Julio Abascal. Integrating adaptation rules for people with special needs in model-based ui development process. *Universal Access in the Information Society*, 15(1):153–168, 2016.
- [277] Rocio Calvo, Faezeh Seyedarabi, and Andreas Savva. Beyond web content accessibility guidelines: Expert accessibility reviews. In *Proceedings of the 7th International Conference on Software Development and Technologies for Enhancing Accessibility and Fighting Info-exclusion*, pages 77–84. ACM, 2016.

- [278] Christina N. Harrington Ljilja Ruzic and Jon A. Sanford. Design and evaluation of mobile interfaces for an aging population. In *Proceedings of the ACHI 2017: The Tenth International Conference on Advances in Computer-Human Interactions*, 2017.
- [279] Luuk Muskens, Rico van Lent, Alexander Vijfvinkel, Paul van Cann, and Suleman Shahid. Never too old to use a tablet: designing tablet applications for the cognitively and physically impaired elderly. In *International Conference on Computers for Handicapped Persons*, pages 391–398. Springer, 2014.
- [280] Masatomo Kobayashi, Atsushi Hiyama, Takahiro Miura, Chieko Asakawa, Michitaka Hirose, and Tohru Ifukube. Elderly user evaluation of mobile touchscreen interactions. *Human-computer interaction-INTERACT 2011*, pages 83–99, 2011.
- [281] Rafael Xavier E de Almeida, Simone Bacellar Leal Ferreira, and Horacio Pastor Soares. Recommendations for the development of web interfaces on tablets/ipads with emphasis on elderly users. *Procedia Computer Science*, 67:140–149, 2015.
- [282] Anne Marie Piper, Ross Campbell, and James D Hollan. Exploring the accessibility and appeal of surface computing for older adult health care support. In *Proceedings of the sigchi conference on human factors in computing systems*, pages 907–916. ACM, 2010.
- [283] Wendy A Rogers, Arthur D Fisk, Anne Collins McLaughlin, and Richard Pak. Touch a screen or turn a knob: Choosing the best device for the job. *Human Factors*, 47(2):271–288, 2005.
- [284] Qin Gao and Qiqi Sun. Examining the usability of touch screen gestures for older and younger adults. *Human factors*, 57(5):835–863, 2015.
- [285] Zhao Xia Jin, Tom Plocher, and Liana Kiff. Touch screen user interfaces for older adults: button size and spacing. In *International Conference on Universal Access in Human-Computer Interaction*, pages 933–941. Springer, 2007.
- [286] Wang-Chin Tsai and Chang-Franw Lee. A study on the icon feedback types of small touch screen for the elderly. *Universal Access in Human-Computer Interaction. Intelligent and Ubiquitous Interaction Environments*, pages 422–431, 2009.
- [287] Anja B Naumann, Ina Wechsung, and Jörn Hurtienne. Multimodal interaction: A suitable strategy for including older users? *Interacting with Computers*, 22(6):465–474, 2010.

- [288] Lin Wang, Hitomi Sato, Pei-Luen Patrick Rau, Kaori Fujimura, Qin Gao, and Yoko Asano. Chinese text spacing on mobile phones for senior citizens. *Educational Gerontology*, 35(1): 77–90, 2008.
- [289] Sebastian Vetter, Jennifer Bützler, Nicole Jochems, and Christopher M Schlick. Fitts’ law in bivariate pointing on large touch screens: Age-differentiated analysis of motion angle effects on movement times and error rates. In *International Conference on Universal Access in Human-Computer Interaction*, pages 620–628. Springer, 2011.
- [290] Gudur Raghavendra Reddy, Alethea Blackler, Doug Mahar, and Vesna Popovic. The effects of cognitive ageing on use of complex interfaces. In *Proceedings of the 22nd Conference of the Computer-Human Interaction Special Interest Group of Australia on Computer-Human Interaction*, pages 180–183. ACM, 2010.
- [291] Amanda L Smith and Barbara S Chaparro. Smartphone text input method performance, usability, and preference with younger and older adults. *Human factors*, 57(6):1015–1028, 2015.
- [292] Iain Darroch, Joy Goodman, Stephen Brewster, and Phil Gray. The effect of age and font size on reading text on handheld computers. *Human-Computer Interaction-INTERACT 2005*, pages 253–266, 2005.
- [293] Élvio Rodrigues, Micael Carreira, and Daniel Gonçalves. Enhancing typing performance of older adults on tablets. *Universal Access in the Information Society*, 15(3):393–418, 2016.
- [294] Susumu Harada, Daisuke Sato, Hironobu Takagi, and Chieko Asakawa. Characteristics of elderly user behavior on mobile multi-touch devices. In *IFIP Conference on Human-Computer Interaction*, pages 323–341. Springer, 2013.
- [295] Atsuo Murata and Hirokazu Iwase. Usability of touch-panel interfaces for older adults. *Human factors*, 47(4):767–776, 2005.
- [296] Hsien-Tsung Chang, Tsai-Hsuan Tsai, Ya-Ching Chang, and Yi-Min Chang. Touch panel usability of elderly and children. *Computers in Human Behavior*, 37:258–269, 2014.
- [297] Hugo Nicolau and Joaquim Jorge. Elderly text-entry performance on touchscreens. In *Proceedings of the 14th international ACM SIGACCESS conference on Computers and accessibility*, pages 127–134. ACM, 2012.

- [298] Karyn Moffatt Afroza Sultana. Target selection difficulties of older adults with small touch screen devices. In *CHI'17 Workshop on Designing Mobile Interactions for the Ageing Populations*. ACM, 2017.
- [299] Diana Kuh. A life course approach to healthy aging, frailty, and capability. *The Journals of Gerontology: Series A*, 62(7):717–721, 2007.
- [300] Sara J Czaja and Chin Chin Lee. The impact of aging on access to technology. *Universal Access in the Information Society*, 5(4):341, 2007.
- [301] Timothy A Salthouse. When does age-related cognitive decline begin? *Neurobiology of aging*, 30(4):507–514, 2009.
- [302] Aron S Buchman, Patricia A Boyle, Robert S Wilson, Debra A Fleischman, Sue Leurgans, and David A Bennett. Association between late-life social activity and motor decline in older adults. *Archives of internal medicine*, 169(12):1139–1146, 2009.
- [303] Francesco Landi, Angela M Abbatecola, Mauro Provinciali, Andrea Corsonello, Silvia Busetacchini, Luca Manigrasso, Antonio Cherubini, Roberto Bernabei, and Fabrizia Lattanzio. Moving against frailty: does physical activity matter? *Biogerontology*, 11(5):537–545, 2010.
- [304] Kristine Yaffe, Alexandra J Fiocco, Karla Lindquist, Eric Vittinghoff, Eleanor M Simonick, Anne B Newman, S Satterfield, C Rosano, SM Rubin, HN Ayonayon, et al. Predictors of maintaining cognitive function in older adults the health abc study. *Neurology*, 72(23):2029–2035, 2009.
- [305] Jacob O Wobbrock, Shaun K Kane, Krzysztof Z Gajos, Susumu Harada, and Jon Froehlich. Ability-based design: Concept, principles and examples. *ACM Transactions on Accessible Computing (TACCESS)*, 3(3):9, 2011.
- [306] D Hawthorn. Interface design and engagement with older people. *Behaviour & Information Technology*, 26(4):333–341, 2007.
- [307] Eileen Wood, Teena Willoughby, Alice Rushing, Lisa Bechtel, and Jessica Gilbert. Use of computer input devices by older adults. *Journal of Applied Gerontology*, 24(5):419–438, 2005.
- [308] GA Wildenbos, Linda WP Peute, and Monique WM Jaspers. A framework for evaluating mhealth tools for older patients on usability. In *MIE*, pages 783–787, 2015.

- [309] Gabyanne Wildenbos, Linda Peute, and Monique Jaspers. Aging barriers influencing mobile health usability for older adults: A literature based framework (mold-us). *International journal of medical informatics*, 2018.
- [310] Lona Mody, Douglas K Miller, Joanne M McGloin, Marcie Freeman, Edward R Marcantonio, Jay Magaziner, and Stephanie Studenski. Recruitment and retention of older adults in aging research. *Journal of the American Geriatrics Society*, 56(12):2340–2348, 2008.
- [311] S. Sarcar Z. Wang A. Oulasvirta X. Ren C. Silpasuwanchai, J. Jokinen. Exploring the design space of text-entry interfaces for aging users. In *CHI'17 Workshop on Designing Mobile Interactions for the Ageing Populations*. ACM, 2017.
- [312] Marianne Eika, Geir Arild Espnes, Olle Söderhamn, and Sigrun Hvalvik. Experiences faced by next of kin during their older family members' transition into long-term care in a norwegian nursing home. *Journal of Clinical Nursing*, 23(15-16):2186–2195, 2014.
- [313] Britt Almqvist, Margareta Grafström, Kathleen Krichbaum, and Bengt Winblad. The interplay of institution and family caregiving: Relations between patient hassles, nursing home hassles and caregivers' burnout. *International journal of geriatric psychiatry*, 15(10):931–939, 2000.
- [314] Annika Hertzberg and Sirkka-Liisa Ekman. 'we, not them and us?'views on the relationships and interactions between staff and relatives of older people permanently living in nursing homes. *Journal of advanced nursing*, 31(3):614–622, 2000.
- [315] Stephanie McFall and Baila H Miller. Caregiver burden and nursing home admission of frail elderly persons. *Journal of Gerontology*, 47(2):73–79, 1992.
- [316] Linda Vinton, Nicholas Mazza, and Yu-Soon Kim. Intervening in family-staff conflicts in nursing homes. *Clinical Gerontologist*, 19(3):45–68, 1998.
- [317] Madeleine Blusi, Kenneth Asplund, and Mats Jong. Older family carers in rural areas: experiences from using caregiver support services based on information and communication technology (ict). *European Journal of Ageing*, 10(3):191–199, 2013.
- [318] Meridean L Maas, David Reed, Myonghwa Park, Janet P Specht, Debra Schutte, Lisa S Kelley, Elizabeth A Swanson, Toni Trip-Reimer, and Kathleen C Buckwalte. Outcomes of family involvement in care intervention for caregivers of individuals with dementia. *Nursing research*, 53(2):76–86, 2004.

- [319] Kristin L Carman, Pam Dardess, Maureen Maurer, Shoshanna Sofaer, Karen Adams, Christine Bechtel, and Jennifer Sweeney. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Affairs*, 32(2):223–231, 2013.
- [320] Merrick Zwarenstein, Joanne Goldman, and Scott Reeves. Interprofessional collaboration: Effects of practice-based interventions on professional practice and healthcare outcomes. *The Cochrane Library*, 2009.
- [321] Steven S Williamson, Paul N Gorman, and Holly B Jimison. A mobile/web app for long distance caregivers of older adults: functional requirements and design implications from a user centered design process. In *AMIA Annual Symposium Proceedings*, volume 2014, page 1960. American Medical Informatics Association, 2014.
- [322] Valentina Caforio, Marcos Baez, and Fabio Casati. Viability of magazines for stimulating social interactions in nursing homes. In *IFIP Conference on Human-Computer Interaction*, pages 72–81. Springer, 2017.
- [323] Francisco Ibarra, Marcos Baez, Francesca Fiore, and Fabio Casati. Stimulating conversations in residential care through technology-mediated reminiscence. In *IFIP Conference on Human-Computer Interaction*, pages 62–71. Springer, 2017.
- [324] Jules Rosen, Vikas Mittal, Benoit H Mulsant, Howard Degenholtz, Nicholas Castle, and Debra Fox. Educating the families of nursing home residents: a pilot study using a computer-based system. *Journal of the American Medical Directors Association*, 4(3): 128–134, 2003.
- [325] Steffen Torp, Elizabeth Hanson, Solveig Hauge, Ingun Ulstein, and Lennart Magnusson. A pilot study of how information and communication technology may contribute to health promotion among elderly spousal carers in norway. *Health & social care in the community*, 16(1):75–85, 2008.
- [326] Madeleine Blusi, Mats Jong, and Rolf Dalin. Older people using e-health services—exploring frequency of use and associations with perceived benefits for spouse caregivers. In *Informatics*, volume 3, page 15. Multidisciplinary Digital Publishing Institute, 2016.

- [327] Noreen Beunk. Visualize my data!: translating smart home sensor data into relevant feedback for elderly, informal caregivers and formal caregivers. Master's thesis, University of Twente, 2015.
- [328] James J Lin, Lena Mamykina, Silvia Lindtner, Gregory Delajoux, and Henry B Strub. Fish'n'steps: Encouraging physical activity with an interactive computer game. In *International conference on ubiquitous computing*, pages 261–278. Springer, 2006.
- [329] Sunny Consolvo, David W McDonald, Tammy Toscos, Mike Y Chen, Jon Froehlich, Beverly Harrison, Predrag Klasnja, Anthony LaMarca, Louis LeGrand, Ryan Libby, et al. Activity sensing in the wild: a field trial of ubifit garden. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, pages 1797–1806. ACM, 2008.
- [330] Iman Khaghani Far, Michela Ferron, Francisco Ibarra, Marcos Baez, Stefano Tranquillini, Fabio Casati, and Nicola Doppio. The interplay of physical and social wellbeing in older adults: investigating the relationship between physical training and social interactions with virtual social environments. *PeerJ Computer Science*, 1:e30, 2015.
- [331] Richard Osuala and Ognjen Arandjelović. Visualization of patient specific disease risk prediction. In *Biomedical & Health Informatics (BHI), 2017 IEEE EMBS International Conference on*, pages 241–244. IEEE, 2017.
- [332] Michael de Ridder, Liviu Constantinescu, Lei Bi, Youn Hyun Jung, Ashnil Kumar, Jinman Kim, David Dagan Feng, and Michael Fulham. A web-based medical multimedia visualisation interface for personal health records. In *Computer-Based Medical Systems (CBMS), 2013 IEEE 26th International Symposium on*, pages 191–196. IEEE, 2013.
- [333] Kadian Davis, Evans Owusu, Jun Hu, Lucio Marcenaro, Carlo Regazzoni, and Loe Feijs. Promoting social connectedness through human activity-based ambient displays. In *Proceedings of the international symposium on interactive technology and ageing populations*, pages 64–76. ACM, 2016.
- [334] Kadian Davis, Evans Owusu, Lucio Marcenaro, Loe Feijs, Carlo Regazzoni, and Jun Hu. Evaluating human activity-based ambient lighting displays for effective peripheral communication. In *Proceedings of the 11th eai international conference on body area networks*, pages 148–154. ICST (Institute for Computer Sciences, Social-Informatics and . . . , 2016.

- [335] Abdur Rahim Mohamad Forkan and Weichich Hu. A context-aware, predictive and protective approach for wellness monitoring of cardiac patients. In *2016 Computing in Cardiology Conference (CinC)*, pages 369–372. IEEE, 2016.
- [336] Yu-Chen Huang and Yeh-Liang Hsu. Social networking-based personal home telehealth system: A pilot study. *Journal of Clinical Gerontology and Geriatrics*, 5(4):132–139, 2014.
- [337] Zhiyuan Zhang, Bing Wang, Faisal Ahmed, IV Ramakrishnan, Rong Zhao, Asa Viccellio, and Klaus Mueller. The five ws for information visualization with application to healthcare informatics. *IEEE transactions on visualization and computer graphics*, 19(11):1895–1910, 2013.
- [338] Jeffery L Belden, Rebecca Grayson, and Janey Barnes. Defining and testing emr usability: Principles and proposed methods of emr usability evaluation and rating. Technical report, Healthcare Information and Management Systems Society (HIMSS), 2009.
- [339] Anne Stevens, Hudson Pridham, Steve Szigeti, Sara Diamond, and Bhuvanewari Arunchalan. The care and condition monitor: Designing a tablet based tool for visualizing informal qualitative healthcare data. In *2014 IEEE Conference on Visual Analytics Science and Technology (VAST)*, pages 279–280. IEEE, 2014.
- [340] Krist Wongsuphasawat and David Gotz. Exploring flow, factors, and outcomes of temporal event sequences with the outflow visualization. *IEEE Transactions on Visualization and Computer Graphics*, 18(12):2659–2668, 2012.
- [341] Kenneth Lee, Kreshnik Hoti, Jeffery David Hughes, and Lynne Emmerton. Dr google and the consumer: a qualitative study exploring the navigational needs and online health information-seeking behaviors of consumers with chronic health conditions. *Journal of medical Internet research*, 16(12):e262, 2014.