Exploring participatory design methods for seniors with memory loss through the co-design of tangible communication tools

by

Sarah Crosskey

Submitted to OCAD University
in partial fulfillment of the requirements for the degree of

Master of Design
in
Inclusive Design

Toronto, Ontario, Canada, April 2014

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Abstract

As the number of seniors with memory loss continues to rise, the importance of designing tools that facilitate connection with loved ones to reduce feelings of isolation is becoming increasingly apparent. Feelings of isolation have been linked to poor health outcomes and consequently place larger demands on health care systems, health care professionals, family members, and friends. Seniors with memory loss (SWML) have a higher risk of becoming social isolated, and isolation can accelerate the rate of memory loss. This research addresses social isolation among this population by exploring ways to engage them in co-designing solutions. Traditional research methods and communication technologies may not be appropriate or may need to be modified in order to engage SWML. Through a combination of participatory design, co-design, and generative tools, this research explored: (1) current research methods and techniques used to engage SWML in the design process, (2) the evaluation of existing and new design techniques through the facilitation of three pilot studies, (3) and insights and recommendations to engage this population in future work.

Acknowledgments

First, I would like to thank my supervisory team: Katherine Sellen, Assistant Professor at OCAD University, and Paula Gardner, Assistant Professor at Brock University, for their invaluable guidance, motivation, thought provoking questions, and precious time. I want to express my gratitude to my professors, Sambhavi Chandrashekar and Peter Coppin, and to my colleague, Barbara Barbosa Neves, for their encouragement and tutorship in the ethics, research, and reporting processes.

Many thanks to the seniors, their family members, caregivers, and memory care staff for their willingness to participate in this research and offer their time and insights. This research would not have been possible without their willingness to engage in this process. A special thanks to David Coles, Chris Arnold, and Spencer Beacock for their assistance during, and reflections on, the workshop sessions. I would also like to thank everyone at the Technologies for Aging Gracefully Lab (TAGlab) for your enthusiasm and support.

I would like to thank Jutta Treviranus, Program Director, for making this opportunity to explore Inclusive Design possible, and my fellow Inclusive Design cohort that offered a great source of inspiration, education, and friendship. Finally, I wish strength, motivation, and courage to all my friends who are still working on their MRP.

Dedication

To

David Coles and my family, the Crosskey's, who have given me inestimable support, patience, and tolerance these past two years.

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1   Introduction

As the aging population continues to grow (Figure 1, pp.1) and life expectancy increases, so does the number of people experiencing memory loss that can be attributed to aging, such as Alzheimer's disease (AD) (Figure 2, pp.2). In 2010, it was estimated that AD affected 4.2 million people in the United States; 11% of people aged 65 years and older and 32% of people aged 85 years and older (Hebert, Weuve, Scherr, & Evans, 2013). As one of the world's fastest growing diseases, AD could affect triple that number by the year 2050 (American Academy of Neurology, 2013).

Figure 1 - Projected percent of the U. S. population aged 65 and older: 2010 to 2050 (U.S. Census Bureau, 2008)
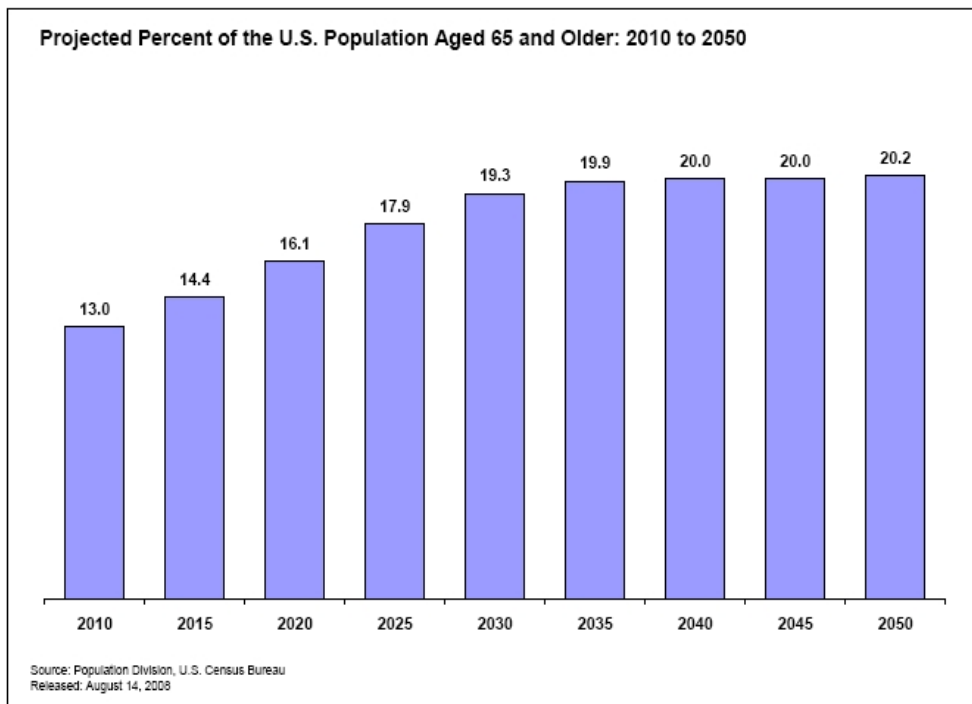
Figure 2. Estimated number of people with Alzheimer's disease (AD) in the U.S.: 2010 to 2050, in millions (Hebert et al., 2013)
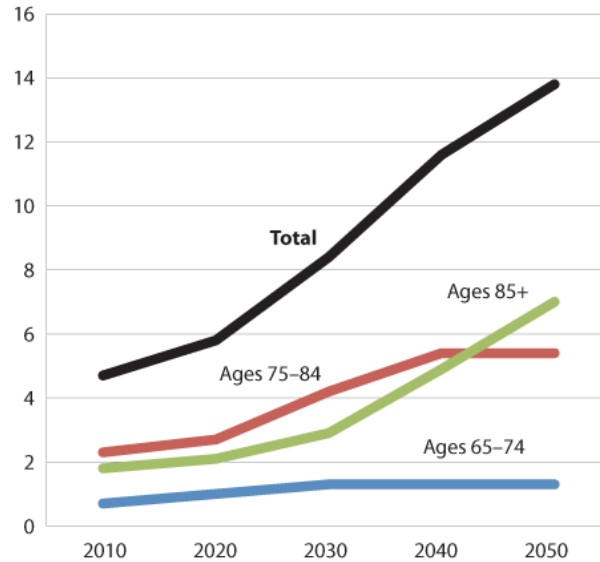
Memory Loss and the Risk of Isolation

The effects of memory loss present communication barriers, such as semantic confusion and pragmatic disruptions (Savundranayagam, Hummert, & Montogomery, 2005), which can have a significant impact on one's ability to initiate and maintain social connections. Despite these barriers, people with memory loss desire both verbal and non-verbal communication (Ward, Vass, Aggarwell, Garfield, & Cybyk, 2008), which is vital to maintaining a sense of self (Sabat, 2002) and personhood (Kitwood, 1997). Unfortunately, they are at greater risk of being excluded from social interaction (Sabat, 2001, 2002), especially if they are hospitalized or residing in specialized units (Ward et al.,

2008). As a result, many people experiencing memory loss may feel isolated or disconnected (Fratiglioni, Paillard-Borg, & Winblad, 2004).

It is estimated that at least 10% and as much as 43% of seniors are socially isolated (Nicholson, Molony, Fennie, Shellman, & McCorkle, 2010; Smith & Hirdes, 2009). Research strongly links poor social connections to negative health outcomes, such as depression (Anderson, 2001), cognitive decline (Beland, Zunzunegui, Alvarado, Otero, & Del Ser, 2005), and increased risk of all-cause mortality (Eng, Rimm, Fitzmaurice, & Kawachi, 2002). Conversely, research reveals that social connections are protective against dementia (Fratiglioni et al., 2004; Wang, Karp, Winblad, & Fratiglioni, 2002) and mortality (Giles, Glonek, Luszcz, & Andrews, 2005).

One of the design challenges in addressing the social isolation of seniors with memory loss is that individually they have varying degrees of abilities and impairments that change over time (Bowes, Dawson, & Greeasley-Adams, 2013). Technology's flexibility and versatility provides opportunities to develop tools that connect these seniors with their family and friends to reduce feelings of isolation. Current technologies' lack of success may be due to the focus on designing for younger populations (Wilkinson, 2002; Joyce, Williamson, & Mamo, 2007; Newell & Gregor, 1997) or the difficulty in

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adequately understanding the needs of people living with memory loss (Gregor & Newell, 2001).

1.1 Theoretical Position – Inclusive Design

In order to better understand the needs of the target population, inclusive design and co-creative approaches have been developed to involve users in the design development process. Inclusive design refers to design that considers the full range of human diversity with respect to ability, language, culture, gender, age and other forms of human difference (*The Inclusive Design Research Centre*, n.d.). Three key principles of inclusive design are: (1) recognizing the diversity and uniqueness of each individual, (2) employing inclusive processes and tools, and (3) having awareness of the broader beneficial impacts of a design. This mindset is particularly useful in designing for and with marginalized populations.

A co-creative lens was also used in this research as a means to realize the inclusive design principles. As depicted by Sanders and Stappers (2012) in Figure 3 (pp.5), co-creation can be used to describe a mindset, a method, or a tool or technique. For the purpose of this paper, co-creation will be used to describe a mindset supported by various research approaches to address the front end of the design development process. The design approaches examined include

participatory design, co-design, and generative research and are discussed in more detail in section 3.1.

Figure 3. Three perspectives on co-creation throughout the development design process (Sanders & Stappers, 2012)
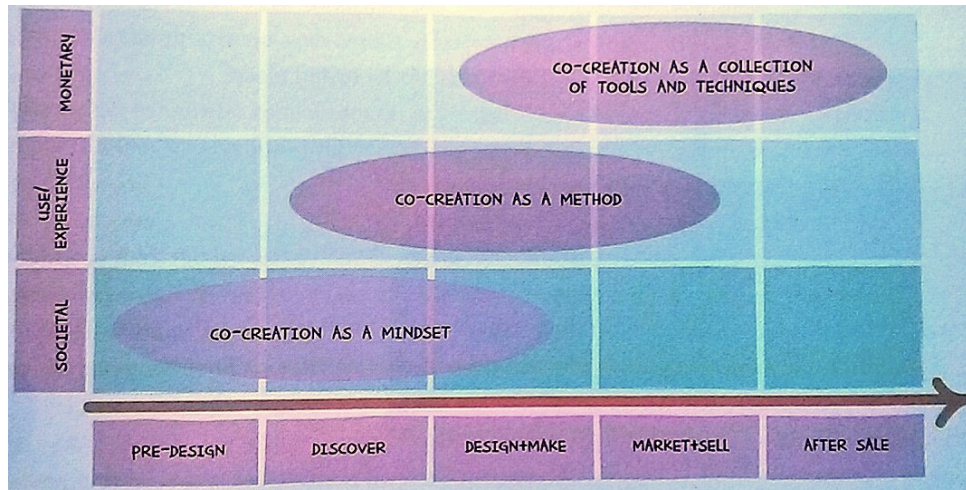
The invaluable benefits of adopting a co-creative perspective to collaborate with people with memory loss include the democratization of the design process, empowering the participants, developing empathy and trust, and shifting the design focus to the needs of the user. The full and equal participation of the users in the design processes has the potential to break down power barriers and show respect for the personhood of the participant living with memory loss (Kitwood, 1992, 1997). Simply having one's voice heard and contributing to the development of new technologies can be empowering and have a positive affect on one's sense of respect and self worth (Murphy, Gray, Van Achterberg, Wyke, & Cox, 2010;

Barnett, 2000). The close contact and extensive time involved in co-creative practices can foster empathy among designers and participants, resulting in a richer understanding of the participants' experiences, which can enable designers to better tailor solutions to this population (Wright & McCarthy, 2008).

The design landscape is shifting its focus from designers, family members, and caregivers as representatives of the senior to engaging the senior throughout the design process. Consequently, the final designs will more accurately reflect the needs and desires of the target population rather than the biases of its representatives (Orpwood et al, 2008).

This research leverages Inclusive Design principles with a co-creative mindset to enable this design shift. The complex design challenge in co-creating with seniors with memory loss is tackled by employing a combination of participatory design (PD) methods, a co-design approach, and generative research techniques in a series of pilot studies. Building on the practices and values of these approaches, this research contributes to the field of participatory design by identifying and developing effective techniques tailored to this unique population.

1.2 Research Questions

1. What research methods and techniques have been explored or developed to engage seniors with memory loss in the design process?

   a. How do you ensure seniors' equal role in engagement and balance the bias of family members and staff?

   b. How are ethical issues of informed consent addressed?

   c. What evaluation tools are most effective for receiving input and feedback from seniors with memory loss?

   d. What factors effect the participation of seniors in participatory workshop activities?

2. What are the barriers and facilitators to engaging seniors with memory loss in co-design workshops that address social connection?

3. How can seniors with memory loss be more effectively engaged in the design process?

2   Literature Review

2.1   Issues in Design

People living with memory loss are one of the most under designed for and excluded populations (Wilkinson, 2002). In a study conducted by Keady and Gilliard (1999) with people with dementia, the participants were amazed that someone was actually taking an interest in them. This neglect is possibly due to various factors including the lack of appropriate and effective research techniques to include people with cognitive impairment, caregivers speaking on behalf of people with memory loss, the challenge in designing for decreased cognitive abilities and a diversity of needs, and/or negative attitudes toward technology among potential users.

Ethical Issues

One of the reasons research ethics guidelines were developed was to ensure the inclusion of vulnerable groups of people, such as seniors with memory loss, and uphold and protect their dignity (Hellstrom, Nolan, Nordenfelt, & Lundh, 2007). Unfortunately, these ethics board processes and requirements can make it very challenging to include seniors with memory loss so researchers often list dementia as exclusion criteria. Consequently, the extent to which people with

dementia have been excluded from having a voice in design processes that affect their lives has raised widespread concern (Bartlett & Martin, 2002). More inclusive design approaches have been developed to address these challenges and are discussed later on in Section 4.1 Techniques Identified in Previous Research.

Caregivers as Representatives

Most research around technology designed for seniors with memory loss is derived from a medical model that results in assistive technologies that address an individual's impairments rather than their social or emotional needs (Dishman, Morris, & Lundell, 2004). Such assistive technologies often focus on supporting independence (DSDC, 2011) and the ability to live safely at home (Doughty & Williams, 2001; Woolham & Frisby, 2002) rather than leisure and quality of life (Dupuis et al., 2012).

One of the primary reasons most technologies address safety rather than feelings of loneliness and isolation is researchers have a tendency to work with caregivers and family members as representatives of the seniors' needs and desires (Lindsay, 2011). Traditionally information communication technologies have targeted family caregivers through professionally run telephone support (Goodman & Pynoos, 1990;

Lindsey-Davies, 1998) rather than considering the communication needs and desires of seniors with memory loss.

Decreased Cognitive Abilities

While there has been some research to develop technology that can aid in reminiscence and social interaction (van Rijn, van Hoof, & Stappers, 2010; Massimi & Baecker, 2008), very little technology has been designed for entertainment or communication (Orpwood et al., 2010), in part due to the decreased cognitive abilities of this population. Since many existing communication technologies assume and require a certain level of cognitive ability (van der Wardt, Bandelow, & Hogervorst, 2012), they may be unusable by people with memory loss due to their complex designs (Patomella, Kottorp, Malinowsky, & Nygård, 2011). As Rosenberg (2009) highlighted in a recent study, computers and mobile phone technology were perceived to be one of the most difficult everyday technologies for people with cognitive impairments to use.

Technologies that are designed to support people with cognitive impairments tend to be expensive or are in such early stages of development they are not available or ready for widespread use (Bowes, Dawson, & Greasley-Adams, 2013; Mason, Craig, O'Neill, Donnelly, & Nugent, 2012; van den Wardt, 2012). These socio-

economic barriers and immaturity of technology development can render well-intended technologies inaccessible and inappropriate for people with cognitive impairments, such as memory loss.

Dynamic Changes in Abilities

Another challenge is the need for a flexible and fluid design that can accommodate the dynamic changes in abilities of seniors living with memory loss. Typically designs are static (Nielsen, 1993; Preece, 1994; Shneiderman, 1992) and do not take into account the dynamic and changing nature of the users' abilities over time. Traditional UCD practices do not offer sufficient flexibility for this population, and consequently, most communication and information technology developed to support people with disabilities are special assistive systems that focus on accessibility features for younger, mainly physically or sensorially disabled people (Newell, Carmichael, Gregor, & Alm, 2002).

Attitudes toward Technology

Attitudes towards technology and understanding people's experiences are other key design considerations that are often overlooked. Even among technologies specifically designed for people with memory loss, there are problems with accessibility and usability that result in very low adoption rates (Lindsay, 2011). Designers must value and

understand the attitudes and experiences of users as well as their (dis)abilities otherwise new technologies may have undesired consequences.

Many seniors in the UK rely on writing cheques to make purchases, but as the chip and pin credit card system and online shopping have become more popular, the UK is phasing out the use of cheques. This shift in favor of technology and the termination of the familiar can contribute to seniors' frustrations and negative attitudes towards new technology (AgeUK, 2011). Understanding seniors' attitudes towards technology can help their experiences be understood and valued.

2.2   The Social Model of Disability

The social model of disability sheds light onto why people with changing abilities, such as seniors with memory loss, are being neglected. Over the past three decades, people with disabilities have been challenging discrimination and violations in their human rights (Barnes, 2007). This reconceptualization of disability has led to a paradigm shift from which the social model of disability emerged. The traditional concept of disability is entrenched in a medical model that views disability as an "ill" person with impairments that prohibits them from carrying out every day functions. Conversely, the social model places emphasis on the inaccessibility of a person's environment rather

than the abilities or disabilities of the individual. As discrimination of people with disabilities is an international issue, the World Health Organization (2001) sought to provide a universal definition of 'disability' defined as 'a multidimensional phenomenon resulting from the interaction between people and their physical and social environment.'

From the perspective of the social model of disability, a person is disabled by their environment; therefore, disability is a product of poor design rather than the person's physical or mental state. Since this perspective is not yet widely adopted, there is still a significant amount of discrimination against people with disabilities. Their exclusion from the research process rather than considering ways to redesign the process in a way that accommodates diverse and vulnerable populations is just one example. Consequently, most technologies and services either ignore the needs of seniors with memory loss or are biased towards the desires of caregivers resulting in designs that are inappropriate or inaccessible to the targeted population.

2.3   Summary

The research discussed in this paper addresses the issue of isolation among SWML from a social model of disability lens framed by an inclusive design and co-creation mindset. As the world's aging

population grows substantially over the next three decades, serious consideration needs to be given to the inclusion and participation of seniors with memory loss in the research and design development process. The techniques and tools explored in this research are a combination of participatory design, co-design, and generative design research methods. By drawing on the strength of these methods, the research tackles the design issues highlighted in previous research by identifying the barriers and facilitators to effectively engaging this senior population.

3   Methods

3.1   Research Approach

There were four phases of research in this study: (a) a survey of current literature on techniques, tools and experiences engaging seniors with memory loss; (b) the development of a toolkit based on the current survey of literature; (c) design and execution of a pilot study that explored the research questions through practice; and (d) refinement of the toolkit and methods based on practice-based learning (Figure 4, pp.17).

Figure 4. Diagram of research approach
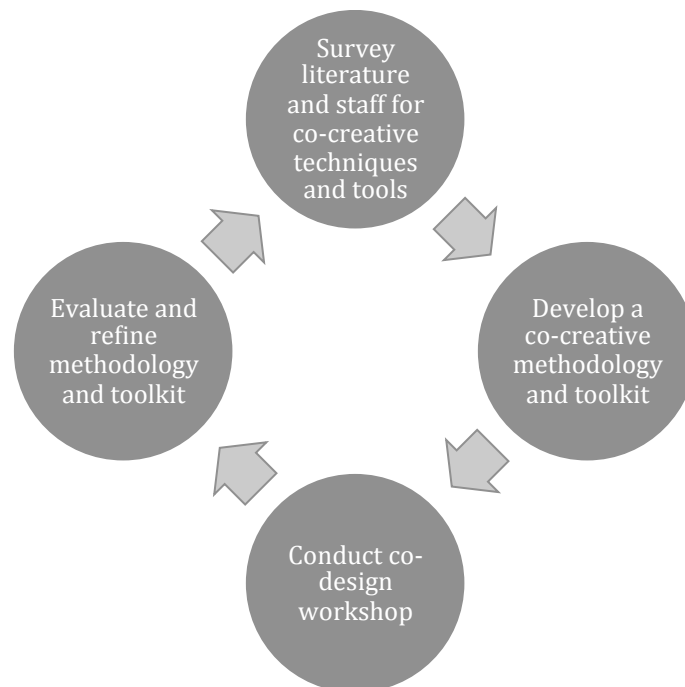
This research draws upon literature from various academic disciplines, such as computer science and design, both of which currently conduct participatory research with seniors and/or people with memory loss. The research methodology and toolkit were a hybridization of participatory design, co-design, and generative research approaches that were then tested and evaluated through five pilot study workshops. A preliminary pilot study of the first workshop was conducted with a group of graduate level design students to run through logistics and test the clarity of the activities.

After evaluating the feedback and revising the preliminary pilot study design, two sets of workshops were conducted to explore the methods and toolkits through practice. Each workshop was held with a senior living with memory loss, a family member, a caregiver, a research facilitator and a research assistant. The workshop activities were designed to encourage discussions about communication preferences (Workshop 1), and social connection and the co-design of a communication tool (Workshop 2).

After each workshop, techniques and tools were refined for the next group of participants and the materials and approaches for the second workshop were tailored to preferences of the participating group. Further evaluation of techniques and tools resulted in

recommendations and new questions that were then explored through a survey of the literature, as well as through dialogues with staff. New insights were used to revise the pilot study designs and this iterative process (Figure 4, pp.17) was repeated four times.

3.2 Survey of Existing Research Approaches

The survey of existing research approaches identified effective techniques and unresolved challenges in working with seniors with memory loss. The review spanned a number of academic domains, including Human Computer Interaction, Social Gerontology, and Design Research. The various PD approaches and techniques used were compared and considered (see Table 1, pp.21). Four PD research papers were closely reviewed to provide guidance in the design of a pilot study design that explored social connection and communication with seniors with memory loss.

Table 1. Survey of Previous Research Approaches in Selected Resources

Researcher	Affiliation	Domain	Article Type	Year	Project	Approaches and Techniques	Recommendations from Literature Implemented in the Pilot Studies
Hendricks, N. Truyen, F. Duval, E.	Katholieke University Leuven, Belgium	HCI & Design Research: Communications, Cultural Studies, and Computer Science	Conference proceedings/ Lecture notes (HCI-Interact)	2013	AToM (A Touch of Memory) Combined guidelines from lit review	• PD through co-design sessions • Context mapping with generative tools • Aggregated PD guidelines (Appendix G, pp.127)	• Avoid using too much fantasy • Avoid offering too much choice • Distinguish the results from family and the senior • Conduct individual PD session • Use caregivers to think beyond single cases
Lindsay, S.	Newcastle University, England	HCI: Computer Science	PhD Thesis	2011	KITE (Keeping in Touch Everyday) and OASIS	• Person Centered Care approach (Kitwood, 2007) embodied throughout the PD process • Evaluate methods with respect to empathetic relationships (Wright and McCarthy, 2008) and the Third Wave of HCI (Bødker, 2006) • Role-playing scenarios as directed by person with dementia	• Use prompting techniques to spark discussion, such as showing storyboards • Work with the same group of people with dementia throughout the design process to build an empathetic relationship • Design new tools for exploring intangible concepts • Accept that the participants are capable of articulating, expanding upon and clarifying their own experiences • Treat the participants as experts in the design domains and pay attention to their narratives
van Rijn, H. van Hoof, J. Stappers, P.J.	ID-StudioLab Delf University, Netherlands	Design Research: Industrial Design Engineering	Journal (American Journal of Alzheimer's Disease & Other Dementias)	2010	"Chitchatters" Game	• PD but still expert led (concept generation with caregivers, product development involves seniors w dementia who test the prototype) • Montessori principles (provide cognitive and sensory stimulation, offer objects that can be manipulated to provide cues) • Cultural Probes (eg. booklets with assignments) • Generative techniques • Context mapping	• Be sensitive – do not to ask questions that are too confronting about the senior's dementia when speaking with the senior and/or their relatives • Design tasks and use materials that give extensive cueing and guidance in terms of what is expected • Collaborate with all stakeholders throughout the design/research process • Use Montessori principles: cueing with physical objects and building on existing skills
Hanson, E. Magnusson, L. Arvidsson, H. Claesson, A. Keady, J. Nolan, M.	University College of Boras & University of Kalmar, Sweden Tolvshillingen Dementia Day Centre, Sweden ACTION Call Centre, Sweden University of Manchester and the Bolton, Salford and Trafford Mental Health NHS Trust, UK University of Sheffield, UK	Social Gerontology: Nursing	Journal Article (Sage publications)	2007	ACTION participatory design model (Magnusson, 2005)	• Scandinavian PD approach • Iterative process, comprising cycles of development and evaluation until an agreed solution is reached • Focus groups and interviews to develop content for ACTION 'Living with Dementia' multimedia education and support program which supports caregivers and PWED	• Prioritize the overall well-being of the participants • Allow ample time for the sessions to enable socializing and repetition of information • Provide active and continuous support by having a family member present, pacing, flexible structuring, and permitting breaks • Choose a satisfactory location for meetings by considering convenience, familiarity, and social status

Search and Selection of Relevant Resources

The search for relevant resources was conducted primarily through Google Scholar and the online university library database Scholars Portal using the search terms indicated in Table 2 (pp.24). The reason specific databases were not searched was to prevent an echo-chamber effect of selecting resources from a specific field or from a particular academic community or discipline. Google Scholar and Scholars Portal were used to produce relevant results from a diversity of sources.

Hundreds of resources were scanned and considered and just over three hundred were selected based on the relevance of their title and abstract. Resources were sorted based on themes and then scanned a second time to determine the most useful resources in each category. This was determined by the level of detail in the methodology, credibility and popularity (were they cited by other relevant papers or within a particular field), published date, and quality of bibliographical references. This filtering reduced the selected resources to roughly fifty. A more in-depth review of each resource involved identifying, retrieving, and reviewing the most relevant citations and bibliographical references, the sources of which were assessed in the same manner as resources found in the initial search.

Table 2. Search Terms Used

(dementia OR memory loss OR Alzheimer OR senior) and (participatory)
(dementia OR memory loss OR Alzheimer OR senior) and (co-design)
(dementia OR memory loss OR Alzheimer OR senior) and (inclusi)
(dementia OR memory loss OR Alzheimer OR senior) and (connection)
(dementia OR memory loss OR Alzheimer OR senior) and (communicat)
(dementia OR memory loss OR Alzheimer OR senior) and (generative)
(dementia OR memory loss OR Alzheimer OR senior) and (empathy)
(dementia OR memory loss OR Alzheimer OR senior) and (action research)
(dementia OR memory loss OR Alzheimer OR senior) and (isolation)
(dementia OR memory loss OR Alzheimer OR senior) and (probes)
(dementia OR memory loss OR Alzheimer) and (ethics OR consent)
(dementia OR memory loss OR Alzheimer) and (personhood OR selfhood)
(dementia OR memory loss OR Alzheimer OR senior) and (tangibl)
(dementia OR memory loss OR Alzheimer OR senior) and (tech)
(including people with dementia in research)

The final review identified four primary research papers that would provide the cornerstones to the pilot study design and approach. The research papers chosen were produced in the past seven years, reflected different perspectives, offered detailed participatory design techniques, and clearly identified gaps and recommendations for future work. One of the primary papers was a thesis, Lindsay (2011), and

was chosen because it was highly relevant to this research. The author of the thesis paper was a co-author on numerous peer-reviewed publications, reflecting their expertise, credibility, and knowledge in their domain, despite the thesis not being objectively peer-reviewed.

Human Computer Interaction Approach

As a relatively new academic discipline, Human Computer Interaction (HCI) was developed on a multi-disciplinary foundation of science and technology studies and ergonomics. By drawing on the different backgrounds, HCI research uses a qualitative and quantitative approach based on a social process. The primarily research approach in HCI is user-centered design (UCD) in which the researcher or designer is still seen as the expert who translates and directs design decisions.

Participatory design methods are often employed to support the primary goal of the UCD design processes, which is to improve the functionality and interaction between a person and an object or concept (eg. Massimi, Baecker & Wu, 2007). In the field of HCI, participatory design has also been referred to as cooperative design (Scandurra & Sjölinder, 2013; Schuler & Namioka, 1993) and a community centered approach (Savitch et al., 2006), reflecting the participant's more active role in the design process.

Social Gerontology Approach

The research in the field of Social Gerontology is more controlled than that of HCI and Design. Research often follows a more scientific process that is based on rational and controlled research design that follows with systemic analysis. After surveying social gerontology papers it is clear that the integration of PD practices in healthcare design is still lacking (Slegers, 2013; Pilemalm & Timpka, T, 2008). Since nursing and psychology are largely associated with medicine, the medical model of disability persists in this field, which arguably discriminates against people with disabilities.

Over the past decade, there has been a call in nursing literature to adopt the social model of disability in an effort to challenge this discrimination and improve quality of life for seniors (eg. Manthorpe et al., 2010; Kitwood, 1997; Hubbard, Downs, & Tester, 2003); however, these efforts have been relatively unsupported (Scullion, 2010). Clare & Cox (2003) agree that while a more collaborative research approach is starting to appear in the field of dementia (e.g. Sabat, 2001; Arieli, 2013), a genuine participatory agenda has yet to be developed. Despite the efforts towards a collaborative approach in the gerontology field, the involvement of people experiencing memory loss in research

and design requires a more radical shift in perspective; one that is informed by a social model of disability.

Design Approach

The field of Design is rooted in an artistic process where inspiration, emotions, and chaos thrive and yield results that can be difficult to analyze in a systemic and rational manner. This approach is best exemplified in the use and role of cultural probes in the design process. In an effort to disrupt the traditional, expert-led User Centered Design (UCD) approach common in fields such as HCI, designers Gaver, Dunne, and Pacenti (1999) introduced 'cultural probes' as a research technique. Unlike in fields, such as HCI and Social Gerontology that have reductionist research process, probes are used in the Design field to generate and expand upon a multitude of ideas, thoughts, and values. The probes are often physical objects or toolkits designed to provoke and engage participants early on in the design process. Used in combination with the qualitative questions found in User Experience Research, probes offer designers insight into the personal experiences, emotions, and desires of the participants.

Wallace et al. (2013a, 2013b) employ design probes to pose questions and make sense of the participant's experiences together. Despite probes' effectiveness in engaging empathy and reminiscence, they

offer ambiguous insights into participants' experiences and attitudes. This uncertainty leaves the translation of the probes into design to the researcher's subjective interpretation. While the exploratory design phase may be participatory, the design process becomes less participatory and more expert-led. The personalized and subjective nature of the design research process limits insights and artifacts to rhetoric rather than execution since they are not designed to be scalable to a larger population.

Shortly after the introduction of cultural probes, they were adopted more broadly by the field of HCI, which re-appropriated probes to "frame an alternative account of knowledge production in HCI design" (Boehner, Vertesi, Sengers, & Dourish, 2007) rather than providing an alternative source for inspiration. Boehner et al. (2007) explains that HCI repurposed the initial experimental and subversive cultural probes as tools for "impersonal analysis" that inform "small, well-defined requirements and themes."

Fundamental differences in values, reflected in each field's approach, are responsible for the different roles that probes now play in research. Design researchers, such as Gaver, Bouche, Pennington, and Walker (2004), place value in the openness and uncertainty that the probes provoke, while HCI researchers desire more quantitative data and a

certainty in the design process (Boehner et al., 2007). Ironically, the re-appropriating of probes in the HCI field serves the very approach that the critical designers were looking to disrupt.

Multidisciplinary Approach

The tensions between the three different fields (HCI, Social Gerontology, and Design) are evident, but as Treviranus (2013) cautions, "there is now so much that resists defining, that won't be categorized, that escapes our boxes and check marks. Fuzziness, divergence, pluralism, the hybrid, the mongrel, and fusion rule." As we are confronted with more complex phenomena with immeasurable elements, we will continue to see the overlapping of disciplines and the re-appropriation of different methodologies.

Perhaps we will move from a modern system based on logic and reason to, as Barcucci (2013) suggests, "an advanced system, the Advancity, where reason gradually surrenders and becomes a means to suppose even illogical mechanisms, to discuss with a complexity which is so inextricable that seems irrational." This advanced system is emerging through multidisciplinary research teams and various co-creative design approaches, such as Generative Design Research.

3.3 Related Approaches in Co-creative Design

Today's designers are of a different generation than seniors with memory loss and their radically different life experiences make designing technologies with and for this population exceptionally challenging (Lindsay, 2011). The "nothing about us without us" slogan that became popular during 1990s disability movement advocates that policies should be decided with equal participation of all involved stakeholders and people affected by the policy, rather than being determined by a representative.

This democratic and inclusive approach is realized in research through PD practices, which provide an opportunity for users, stakeholders, and designers to collaborate on equal footing. Similarly, co-design and generative research are approaches that engage all stakeholders in the research and design process. Despite the emphasis on user participation in these approaches, there are notable differences rooted in their origins, values, and practices as illustrated in the mapping of current design trends (Figure 5, pp.31).

Figure 5. Current Design Trends (Sanders & Stappers, 2012)
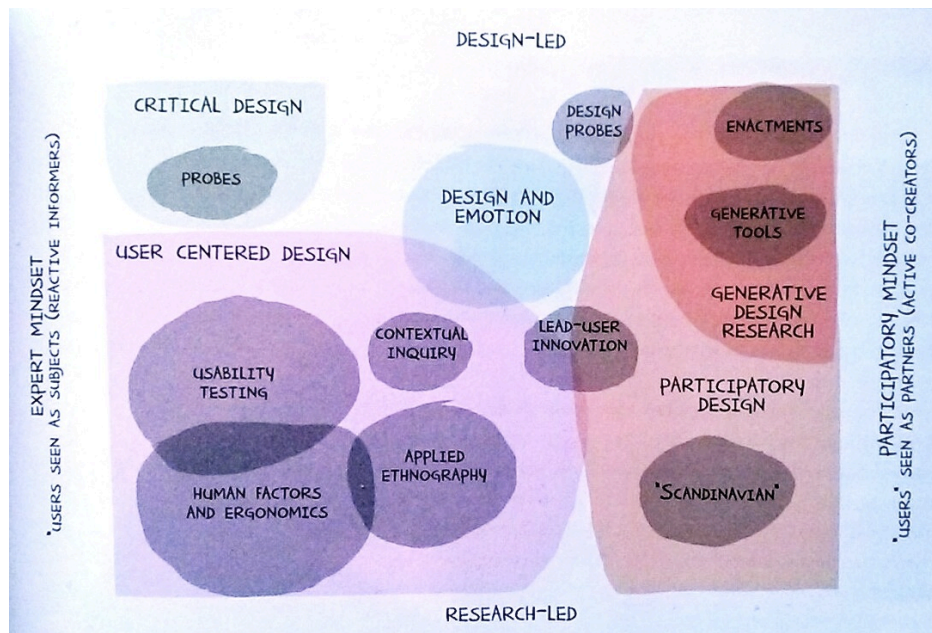
Participatory Design Methods

While the traditional and more widely used User-Centered Design (UCD) approach can be effective at understanding user needs, it still champions the researcher as the expert and is predominantly research-based. By employing a PD approach and generative tools, this design-led research method invites the various stakeholders to be part of the design process, highlighting the value of the users' knowledge gained through their personal experiences. Robinson, Brittain, Lindsay, Jackson & Oliver (2009) involved people with dementia in developing new products and they believe this

collaboration reduced some of the stigma associated with dementia, as well as informed the design.

Originating in Scandinavia in the 1980's, Participatory Design was introduced to help integrate new technologies into the workplace (Bødker, Ehn, Sjögren, & Sundblad, 2000) through a more democratic process. Today in current design trends, PD is becoming more widespread as designers and researchers shift from a UCD approach that emphasizes an end product or design to a PD approach, which focuses on the experiences and involvement of users and relevant stakeholders (Figure 5, pp.31).

When conducting research with people with memory loss, PD can have a number of shortcomings that need to be addressed in order to ensure the methods are effective. PD techniques are by nature goal oriented (Kensing & Blomberg, 1998) and this can be ill fitting for a non-work context (Bødker, 2006), such a discussion about one's personal experiences and preferences. These methods also make assumptions about the cognitive abilities of participants, such as reasoning, memory, abstract thinking, and self-expression, that may not hold when engaging people with memory loss (Wu, Baecker & Richards, 2005).

Another key characteristic of PD is the use of physical artifacts and objects of the workplace as thinking tools throughout the process, which was a common methods used in the research-led Scandinavian tradition. These aspects may need to be modified or reconsidered so that they are appropriate and respectful of the participants' abilities and experiences. Muller (2002) adds that most PD theories and practices require the combination of multiple perspectives in order to address design challenges presented by complex human problems that require a variety of disciplines to develop well-designed solutions.

Co-design Approach

The co-design approach is rooted in North American origins with a focus of involving various stakeholders in the design process without capitalizing on the politicized and democratic nature that is celebrated in the European-based PD. While the co-design approach has the potential to adopt a social action agenda, its focus is on collective creativity that is applied throughout the design development process (Sanders & Stappers, 2012).

In a co-design activity, the traditional UCD roles of researcher and user are switched or neutralized. The researcher or designer assumes the role of a facilitator rather than the role of the expert and the person who will eventually be served through the design process is

given the role as 'experts of their experience' as illustrated in Figure 6 (pp.34).

Figure 6. Shift in roles: the traditional design process and the co-design process (Sanders & Stappers, 2012)
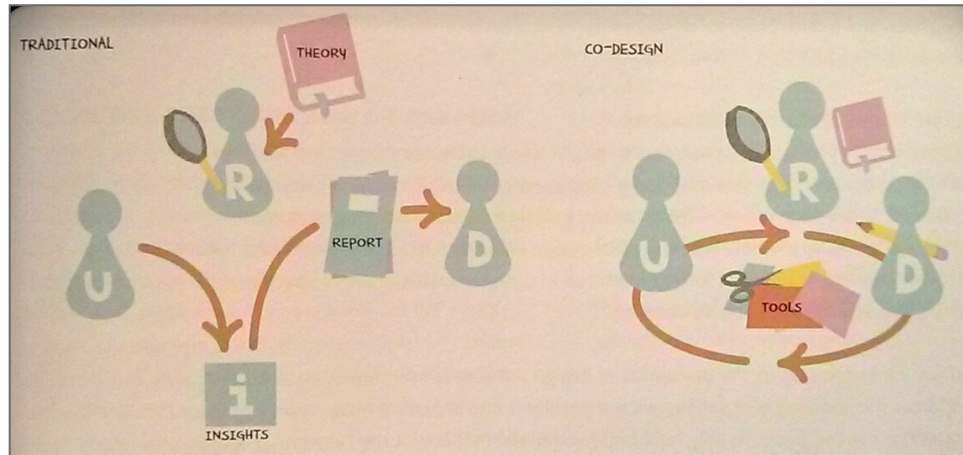
Generative Design Research

Generative Design Research is an approach to participatory design and co-design that focuses on the front end of the design development process (Sanders & Stappers, 2012). As illustrated in Figure 5 (pp.31), generative design research is considered one approach to the larger PD methodology and it is more design-led than the traditional research-led Scandinavian-based PD methods. Muller (2002) reflects on Sanders & Stapper's overall Generative Design Research strategy as a blend of market research ("what people say"), ethnography ("what people do"), and participatory design ("what people make").

One Generative Design Research technique is employing generative tools throughout the research process. Generative tools are simple materials, such as buttons or sketches, which can be used in a co-creation activity to explore experiences and concepts through physical action and working with the materials. This "make, say, do" method offers the opportunity to access tacit and latent knowledge, as well as explicit and observative knowledge (Sanders & Stappers, 2012). These materials can also be used to expand the vocabulary of researchers and everyday people (Sanders & Stappers, 2012). The research discussed in this paper assesses what types of generative tools are appropriate for seniors living with memory loss associated with Alzheimer's disease (AD), other dementias, and aging.

Three-Pronged Approach

This research borrows the democratization of the design process and the use of physical artifacts to use as thinking tools from PD; the collective creativity and participation of all stakeholders and the role of the designer/researcher as a facilitator from co-design; and the exploration of an idea through generative tools and the "make, say, do" approach (Sanders & Stappers, 2012) in Generative Design Research. The implementation of these co-creation techniques in the following pilot study demonstrates how current design practices can be

more inclusive by breaking down the power structures and empowering the users and stakeholders to be a key part of the design development process.

3.4 Pilot Study Design

In an attempt to address the challenges of designing for and with seniors with memory loss, previous research was reviewed and considered to inform the design of a pilot study with this population. Literature was surveyed primarily from the fields of HCI, Social Gerontology, and Design. Research that employed participatory design, co-design, and/or generative tools as research methods with seniors were selected. These papers were reviewed (Section 4– Techniques Identified in Previous Research, pp.49) and most of the recommendations for future work highlighted were explored through a pilot study.

The Significance of a Pilot Study

Pilot studies can be invaluable in testing out a particular research method designed for a larger-scale study. The purpose for conducting a pilot study in this research was to offer insight and advanced warning into aspects of the research methodology, which might fail or have adverse affects (van Teijlingen and Hundley, 2001). Conducting a pilot study provides an opportunity to address logistical issues as well

as the research methodology, increasing the likelihood that the full study will be successful (Kilanowski, 2011; Simon, 2011). For this research, the pilot study will serve to check that the participant criteria and consent process are appropriate, that the workshop activity instructions are comprehensible, that the technology works properly, that the techniques and tools used are effective, and that unexpected issues are addressed.

Pilot Study Approach

Based on insights offered from the relevant resources, a pilot study was designed to experience using the surveyed tools and techniques through practice. The pilot study consisted of two workshops with themes of exploring social connections among seniors with memory loss and their loved ones. Technology was considered as a potential way to provide flexibility and possibilities in design that could offer solutions to design challenges associated with decreased sensory and cognitive impairments. The assumption that technology could offer solutions is based on previous research and speculation.

While this pilot study focused primarily on the research methods, future research in this area should explore whether technology is an appropriate tool to increase feelings of social connectedness and reduce isolation among seniors with memory loss. Through a

combination of participatory design, co-design, and generative tools, this research sought to engage seniors with memory loss and their loved ones in discussions and activities that might offer understanding around the barriers and facilitators to communication, both within a co-creative research setting and in a personal, social context.

The pilot study designed and conducted put this rhetoric into practice-based research. The research tested and expanded existing PD techniques for people with memory loss by engaging the senior, their family member, and caregiver in a series of design workshops that explored social connections. This study involved four phases: two participatory workshop sessions that employed generative tools and informal discussion, and two phases of analysis to evaluate and refine workshop techniques (see Figure 7, pp.39). Each workshop consisted of a group of two to three participants: a senior with memory loss, a family member, and a caregiver. Two groups participated so four workshops with seniors were held in total. A preliminary test of Workshop 1's structure, timing, and activity flow, was held with eleven Masters of Inclusive Design students simultaneously in small groups of three to four people.

Figure 7. Pilot Study Approach

Workshop 1: Attitudes and Preferences	Analysis and Evaluation	Workshop 2: Exploring Connection	Analysis and Evaluation
Phase 1	**Phase 2**	**Phase 3**	**Phase 4**
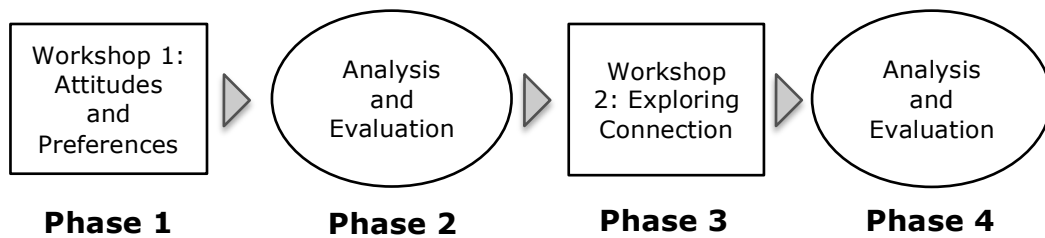
Phase 1: Workshop 1 – Communication Technology Attitudes and Preferences

This phase engaged a senior with memory loss, a family member, and caregiver in a workshop that explored perception of connection between the senior and their loved one or caregiver. First the senior was invited to express their attitudes and share personal narratives around five different communication tools: a postcard, a letter, a landline telephone, a mobile telephone, and a computer (email). Communications tools, such as a mobile phone, and generative tools, such as stickers, emoticons, and sticky notes, were used as tactile objects that could facilitate discussion and provide grounding for abstract concepts.

The family member was also asked about their communication preferences and styles. Their attitudes and narratives were mapped next to the senior's on a piece of poster board with a black and white sketch of the communication tool being discussed. In the final activity,

the senior and then the family member were asked to rate their first, second, and third preferences for communication tools. Lastly, participants were invited to provide feedback on all aspects of the workshop: workshop storyboard, generative toolkits, topics discussed, rating preferences activity, etc.

Phase 2: Data Analysis and Design Insights

This phase involved the analysis and evaluation of techniques used in Workshop 1, documentation of design insights, and the tailoring of materials and approaches for the next activity, Workshop 2. The personal experiences and narratives of the participants and their responsiveness to various techniques and tools were used to expand the toolkit, refine the research approach, and tailor the scenarios in Workshop 2.

Phase 3: Workshop 2 – Exploring Connection: Current and Idealized

This phase engaged the senior with memory loss and a family member, and caregiver in a workshop that explored perception of connection between the senior and a loved one. Participants were invited to create a visual map of their current communication practices, discuss challenges and barriers, and choose the most important barrier to address. Using generative tools to brainstorm

solutions, the participants and the researcher discussed elements of a new communication tool and attempted to create an initial model. In this workshop the role of the family member and staff was to provide insight into their current communication patterns with the senior and offer assistance and support in exploring and building new solutions.

Phase 4: Analysis and evaluation of techniques used in Workshop 2 and documentation of design insights.

The collected data was analyzed using open coding to evaluate the effectiveness of PD methods and guidelines used. Design insights were organized and documented based on the different phases of the PD process.

3.5   Participatory Workshops

Two sets of design workshops were conducted; one explored attitudes and preferences and the other explored current and idealized communication. Both workshops engaged a senior, a loved one, and a caregiver in informal discussions and activities based on the theme of social connection. The seniors that were invited to participate in this study were people living with memory loss on the memory care floor of a retirement residence. In circumstances where the family was not in direct contact with the senior, only the senior and a caregiver participated.

Each workshop lasted approximately 1 hour and engaged two to three participants, one research facilitator, and one research assistant. Participants were offered generative tools, such as stickers and illustrations of people (see Figure 8, pp.42), to express their preferences for different communication tools, illustrate how they currently communicate with one another, and discuss design preferences for new solutions.

Figure 8. Workshop 1 – initial generative toolkit

All workshops were held on the Alzheimer's floor of an urban retirement residence, which accommodates approximately forty memory care residents. Each session was conducted with a research assistant who assisted in data capture and facilitation when necessary. The workshop set-up involved a still camera, an audio recorder and

one video camera to capture the workshop activity and the participants' body language and interactions. Still photographs of the workshop activity were be taken by the research assistant throughout the session.

3.6   Recruitment of Participants

Working through one of the staff members on the residence's memory care floor, five participants for this research study were recruited: two seniors living with memory loss, one family member, and two caregivers. In this research, the phrase "seniors living with memory loss" refers to seniors affected by Alzheimer's disease (AD) and other dementias.

Eligible participants met the following criteria:

1. Adult with memory loss who is 65 years of age or older, or the caregiver/friend/family member who is 18 years of age or older
2. Minimal English-speaking proficiency (participants with English as a second language were encouraged to participate)
3. Living in the Greater Toronto Area
4. Living in a long-term care home or retirement residency

Recruitment and Consent Procedure

One of the program directors at the retirement residence was assigned to be the point of contact (POC) for the researcher and participants. The POC recruited five participants by selecting clients from each

group (senior, family member/friend, and caregiver) and arranged for a suitable date and time for the first workshop. The Information and Consent Form was sent to the POC who informed residents and their family members about the opportunity to participate in a research study. Based on the interested participants, the POC obtained verbal consent to participate and confirmed a date and time for the first workshop. This allowed time for participants to consider their participation and reflect on questions or concerns they might have.

The information and consent form were reviewed at the beginning of each workshop session and any questions and/or concerns were addressed before consenting took place. Throughout the study, the senior's consent to participate was assessed by the researcher and the family member and addressed verbally if necessary. At the end of the first workshop, the researcher scheduled the date and time for the second workshop. Both participating senior residents were living with moderate-dementia on the residence's memory care floor.

3.7   Exploratory Meetings

Previous research had been conducted at this retirement residence by the researcher, so the building, culture, and some of the staff and residents were familiar. Prior to conducting the workshop, the researcher made two exploratory visits to the retirement residence.

The first meeting consisted of an introduction to the memory care floor and staff, and provided an opportunity to review the study design and materials with both the Program Director POC and one of recreation facilitators.

The snoezelen room on the memory care floor was identified as a private and suitable location where the workshops could be held. The second visit involved assessing the space (adjusting the heating, controlling the snoezelen lamps, identifying the nearest restroom) and determining the best set-up and arrangement of people and objects (number of chairs and tables, the location of the camera and workshop storyboard). The development of the toolkits themselves was informed by these exploratory meetings, which are discussed in more detail in Section 5.1 Exploratory Meetings.

3.8 Data Collection

Data consisted of notes, photos of the workshop, audio recordings (recordings at each individual group's table during the workshop), and video recordings (of the all the participants in one frame during the workshop.)

Audio and video: All workshops were recorded using both audio recorders and a digital video recorder. The audio and video recordings were reviewed after the workshop session to capture any participant

gestures or statements that may not have been noted during the workshop.

Photos: Still photos captured the participants engaging in the workshop activities and were used to document any workshop artifacts, such the communication maps.

Notes: The research assistant took notes throughout the workshops to capture insights that may be difficult to capture through video, audio or photographs.

3.9   Analysis and Design Insights

After each workshop, materials and techniques were reviewed and discussed by the researchers to improve the workshop activities for the next group of participants. The design insights identified in Workshop 1 were also used to tailor materials and approaches for the same group of participants in Workshop 2. Both the participants and the researcher assessed the activities, techniques, and tools at the end of each session.

After all four workshops were conducted the researcher reviewed the videos and photographs to identify particular challenges and successes in engaging the senior with memory loss in the workshop activities. Careful attention was paid to verbal, physical, or visual cues captured

in the recordings of the workshop sessions. Open coding and thematic analysis were used to categorize research insights based on themes.

These pilot study insights and themes were compared to the guidelines and recommendations offered in the four closely surveyed papers to confirm or build on their findings. It was also discussed whether possible new techniques or tools were identified through the pilot that could address gaps and challenges highlighted in previous research.

4 Techniques Identified in Previous Research

Over the past decade, more researchers and designers have recognized the importance of involving seniors with memory loss (SWML) in design processes that affect them. In order to appropriately engage this population, researchers have developed guidelines and PD techniques tailored to their strengths. Critical to the PD approach, empathy is the platform that most PD researchers build upon to create an inclusive, beneficial, and effective research environment. With empathy as the backbone, the following techniques and tools have been used to engage SWML in the research process: ongoing consent, supporting selfhood through narrative, drama improvisation, action research, design probes, structured research sessions, storyboards, videos and third person narratives, aggregated guidelines, and generative toolkits.

4.1 Ongoing Consent

Before research can begin all participants must give informed consent and this ethical process can be a barrier in working with people with memory loss or other forms of cognitive impairment. Dewing (2007) explores process consent with people experiencing memory loss and advocates assessing consent throughout the research process either through verbal or observational cues, or a familial person's insights.

She notes that the more impaired a person is, the more in-depth the process for gaining and ensuring consent needs to be. Clare & Cox (2003) explain that process consent "requires a continual dialogue between researcher and participant, and considers ways of enhancing communication to support decision-making."

Morrissey (2012) discusses ethical issues around conducting research with people with disabilities more broadly, such as confidentiality, anonymity, disclosure, and context of interviews. She argues that the benefits of including people with disabilities in research outweigh the risks, and encourages critical consideration of the ethics and consent processes.

4.2   Empathy

Wright & McCarthy (2008) champion the dialogical nature of empathy that can enable shared experiences and meaningful interactions beneficial to participants, researchers, and future designs. Coombes, Wallace, Blythe, & Wilson (2013) promote the following techniques to weave empathy in the design process: listening and getting to know the participants, using empathetic design probes to facilitate multifaceted dialogue as discussed in section 4.6, and focusing on developing the psychological and emotional environment so that it supports feelings of trust and safety. Their work exemplifies how

developing empathy can facilitate conversation around complex emotions and experiences.

Empathy was a key pillar in Lindsay's (2011) thesis research, which served as one of the four primary resources surveyed. Lindsay discusses the fundamental role of empathy in the process of co-designing guidelines for the Keeping In Touch Everyday (KITE) project (Robinson et al., 2009) and the OASIS project.

4.3   Supporting Personhood and Dignity through Voice

Kitwood (1997) stresses the importance of respecting the personhood and dignity of the SWML and notes that it is critical to developing empathic and trusting relationships. As identified in Cotrell & Schulz's research, (1993) (as cited by Clare & Cox, 2003) one of the barriers in adopting this approach is that historically, dementia was viewed as a loss of self and the perspective of the person with dementia was largely ignored. Today, it is widely understood that personhood is retained even when cognitive functioning and many everyday abilities are lost (Sabat, 2001).

This newfound understanding has encouraged people to consider how personhood and dignity can be supported to improve quality of life (eg. Manthorpe, 2010). Hubbard et al. (2003) and Wilkinson (2002) suggest privileging the voice of the person with dementia as one

technique. Hubbard et al. (2003) offer a range of strategies including: using different methods bespoke to each person with dementia; greater flexibility and time; preliminary meetings with the person with dementia; discussions with formal and informal caregivers; and research training.

4.4   Drama Improvisation

Practicing drama improvisation techniques and flexibility - "be obvious," "accept offers," and "fail cheerfully" (Johnstone, 1987) - can create an emotionally safe environment that encourages openness. Multifaceted dialogue, verbal and gestural, can foster imaginative empathy through objects and narrative. This method proved effective and enjoyable in research activities designed to make social media tangible to senior citizens (Foverskov & Binder, 2012).

4.5   Action Research

Another important aspect is getting to know the participants by spending time in their everyday environment and by listening to them fully and respectfully. One technique that embodies this approach is Action Research, which can offer a better understanding of a person's experiences and their context. Arieli (2013) used Action Research as a way to maintain and negotiate challenges in a relationship with a loved one living with dementia. Her research provides an alternative to

understand coping situations and experiences that are usually described in medical terms and addressed through therapeutic approaches.

The Action Research cycle was comprised of fours phases that reflect AR's 'living in the world as a question' mindset (Marshall & Reason, 2008). The four phases presented by Arieli (2013) are: (1) negotiating the diagnosis; (2) sliding between reality and delusion; (3) reflecting on the mental experiences of dementia; and (4) positioning herself in relation to the loved one and the institutional setting. This approach attempts to maintain an equal and mutual personal relationship with a person with dementia, rather than one that is authoritative or patronizing.

4.6   Design Probes

Wallace et al. (2013a, 2013b) use empathy in the process of designing tangible bespoke probes that aid in reminiscence, scaffold reflection, and spark dialogue around personhood. Their research demonstrated that the act of making the probes was effective in initiating discussions. They were also useful in structuring the exploration into personhood and framing questions to which the participants and the designer sought answers. Central to their methods was the focus on the participants' lived experiences throughout the design process, the

quality of those experiences, and how they were triggered by the empathetic design probes.

4.7 Formalized Meeting Structure and Storyboards

Lindsay (2011) highlights the importance of formalizing the design process for each research session to prevent structural breakdown and to ensure that all meeting items were touched upon. The support of a visual storyboard that illustrated each phase of the workshop proved to be effective tool for engaging participants, focusing their attention, and reinforcing the structure of the session.

4.8 'Invisible Design' Videos and Third Person Scenarios

In order to address abstract concepts, such as hypothetical scenarios, Lindsay (2011) created invisible design videos during the OASIS project. These videos were produced with a professional acting crew and then shown to participants to help illustrate intangible concepts, such as research ethics and future scenarios, in an effort to make them more accessible to participants. Third person scenarios depicted in these videos proved to be an effective technique for engaging participants in discussions around imagined scenarios and potentially sensitive topics.

4.9   Aggregated Participatory Design Guidelines

In an effort to reconcile disparate but related guidelines for people with memory loss, Hendricks et al. (2013) aggregated different PD guidelines into one document. This set of guidelines combined effective design techniques for people with Alzheimer's disease, amnesia, dementia, and aphasia into one set of guidelines while preserving the relevance to the individual subgroups through an abbreviation at the end of each recommendation. These guidelines were divided into six categories that reflected the PD process and were refined through PD sessions with people with dementia and their family members. These guidelines were intended as a resource for researchers and designers to more effectively engage this population.

4.10   Generative Toolkits

The workshop sessions conducted by Hendricks et al. (2013) began by using a "MAP-(k)it" toolkit that invited participants to use icons and basic text to map out their daily routines around the home. Next a "superhero" was introduced to overcome a problem faced by the participant in this environment. The person with dementia continued by explaining how the superhero could resolve their problem and together the designer and participants sketched possible solutions.

The "MAP-(k)it" was made up of small icon stickers paired with text that depicted daily routines. These icons were made ahead of, and during, the session to support participation in a non-verbal way. Often the active mapping proved physically challenging for many seniors and so the telling of the story received more attention (Hendricks et al., 2013). The ability to make choices also proved to be another challenge, especially when presented with open-ended questions. As the tools became more conceptual, such as the use of the Superhero, the activity became more complex rather than playful and transparent. In creating a toolkit for future sessions, Hendricks et al. (2013) advise against offering too many choices and appealing to the senior's fantasy.

5   Research in Practice

In an attempt to address the challenges of designing *for* and *with* seniors with memory loss (SWML), previous research was reviewed and considered to inform the design of a pilot study with this population. Papers were surveyed primarily from the fields of HCI, Social Gerontology, and Design. The research methods specific to SWML were identified and reviewed (section 4. Techniques Identified in Previous Research, pp.49), and the recommendations for future work were considered. Based on these insights, a pilot study was designed to understand social connections between SWML and their loved ones. Two exploratory meetings with staff were held at the seniors' residence to refine the design of the workshop activities, material, and logistics.

Through a combination of participatory design, co-design, and generative tools, this research addressed the high risk of isolation among seniors, specifically those living with memory loss. The pilot study design consisted of five participatory workshop sessions. The first was conducted with a class of design students and the following four were held with two groups each made up of a senior with memory loss, a family member, and a caregiver. After each session, the

methods were critiqued, refined, and tailored to the participants' second workshop session.

5.1 Exploratory Meetings

The initial phase of the pilot study began with two exploratory meetings at the long-term care home. The first meeting was with the Recreation Director and a staff member who facilitated group activities. After discussing the workshop designs and showing the proposed toolkit, they provided invaluable feedback that was used to revise the study design, the toolkit materials, and the language used. The second visit provided an opportunity to survey the snoezelen room and determine the best set-up for effective workshop sessions.

Refining the Workshop Designs

The initial plan was to hold the workshops with three seniors, their family members, and staff in a focus group style session. This shifted to a more one-on-one approach with the individual groups (a senior, a family member, and a caregiver) having their own workshops. This allowed the researcher to be more focused and engaged with the participants, reduced the stress and difficulty of finding caregivers that could participate at the same time, and offered a more flexible workshop schedule for seniors and their family members.

The original approach for Workshop 1 was to present all five communication tools to the participants at once and invite them to share their experiences, attitudes, and preferences. The staff thought this might be overwhelming, so they recommended showing one or two tools at a time to reduce chances of distraction and confusion. The decision to hold the workshop sessions in the snoezelen room, which had a door and only one window, was chosen because it offered an easily accessible, quiet, and uninterrupted space that would help to minimize distraction.

The memory care staff also stressed the importance of conveying the session as graduate level research rather than an arts and crafts activity. Framing the workshop with this level of status would respect the senior's dignity and the perceived meaningfulness of the activity might increase their engagement and commitment. As a token of appreciation, the staff recommended that the seniors be given the option to keep what they had made at the end of the workshop. Seniors participating in the residence's programmed activities often appreciated being able to keep what they had created.

Refining the Toolkit

A variety of materials were chosen to cater to participant preferences, to express different types of emotions or attitudes, and to illustrate

various scenarios and relationships. Materials offered a range of textures, colors, associations, and levels of abstraction. The overall emphasis was to create a fun and playful environment that encouraged an open, informal discussion. Materials were chosen initially based on the topic of discussion, but throughout the research process they became more specialized to reflect the participants' preferences and socializing practices.

Four different toolkits were created: a toolkit for mapping preferences and attitudes and a communication device toolkit (Workshop 1), and a mapping toolkit and a generative toolkit (Workshop 2). These toolkits were reviewed by the memory care staff and the research advisor and were further critiqued by the preliminary pilot study with the design students. A unanimous consensus was that it was overwhelming because there were too many materials to choose from, but having materials with varying levels of abstraction was very appealing. The memory care staff also indicated that in the programed arts and crafts sessions seniors were particularly drawn to bright colors, but some seniors would be offended if the materials were too childish.

Based on this feedback, the toolkit was reduced to less than half its contents (Figure 9, pp.61; Table 3, pp.62) and the excluded tools (Table 4, pp.63) were kept as backup materials to augment the

60

activities or provide alternatives if necessary. The tools were not included because they were potentially too infantile, too complex, or too abstract for the population.

Figure 9. Workshop 1 – sampling of the revised toolkit

The toolkit for Workshop 1: Communication Technology Attitudes and Preferences (Figure 9, pp.61) offered explicit, suggestive, and open materials that could be used to illustrate attitudes, preferences, and scenarios in which the five communication tools were used. Explicit materials included chocolate coins that could express affordability; party-themed stickers that could illustrate gifts, surprises, and food; and emoticon stickers to express feelings. Glittery stars were included as a suggestive tool that could express preference or act as a rating

system, and colored sticky notes, markers, and blank oval stickers were provided as open-ended tools to enable customization.

Table 3. Workshop 1 – Revised Toolkit

Tool	Level of Abstraction	Potential Associations	Material Properties
Coins	explicit	expensive, money, payment	smooth, shiny, 3D, edible (chocolate)
Party stickers	explicit	celebration, gifts, surprise, food	foam stickers, squishy, smooth
Line-drawn characters	explicit	family members, relationships, portrayal of self	flat, colored line drawings
Photos of people	explicit	family members, relationships, portrayal of self	flat, colored, newspaper photos
Rosettes	explicit	rating preferences	satin ribbon, smooth cardboard
Emoticon stickers	explicit	happiness, indifference, confusion, sadness	glittery, rough, pastel colors
Padlock & 'private' icons	explicit	security, trust, privacy	flat, black and white icons
Star stickers	suggestive	ranking, emphasis, positive	glittery, rough, foam/squishy, sticky, bright colors
Sticky notes	open	anything, words, sketch	sticky, smooth, neon colors
Markers	open	write words, draw images	smooth, smelly
Blank oval stickers	open	draw a facial expression, represent an object	glittery, rough, foam/squishy, pastel colors, sticky

Table 4. Workshop 1 – Backup Toolkit

Tool	Level of Abstraction	Potential Associations	Material Properties
Smiley face stickers	explicit	happy, family, friends, positive	flat, smooth, sticky
Pirate stickers (treasure chest, sharks, skulls boats, maps, islands)	explicit	excitement, surprise, danger, insecurity, negativity, travel, mapping	flat, smooth, sticky
Outer space stickers (aliens, planets, stars, rockets)	explicit	adventure, alien, unfamiliar, futuristic, travel, magical	flat, smooth, sticky
Wooden cut outs (birds, flowers, sun, moon, robot)	explicit	happiness, familiarity, spring/newness, music, day, night, futuristic	wooden, smooth, 3D
Dinosaur	explicit	ancient, archaic, cumbersome, heavy, comforting	stuffed, soft, fuzzy fabric, 3D
Smiley face stress relief balls	suggestive	happiness, stress, relief	squishy, 3D, smooth
Alphabet stickers	suggestive	grading for ranking ("A, B, C"), writing a name or phrase	glittery, smooth, sticky, colorful
Feathers	suggestive	liberating, delicate, independence	colorful, soft, delicate
Paint color samples	open	emotions, intimacy level	smooth, matte, colorful

In addition to the generative toolkit, Workshop 1 also included communication tools to scaffold the discussion, provide a focal point, and provide as a reference or prop for demonstration of how the object is used. Five communication tools were presented one at a time: a postcard, a letter, a landline telephone, a mobile phone, and a desktop computer (Figure 10, pp.64). These objects were chosen to be aesthetically neutral as possible. Brand names and superfluous details were covered to reduce bias and distraction. In some cases, such as the postcard and the desktop monitor, the communication tool was recreated as a model.

Figure 10. Communication toolkit: desktop computer, mobile phone, landline phone, letter, and postcard

One toolbox created for Workshop 2 included materials for mapping current communication practices and tools for discussing and exploring

new communication tools. The mapping tools (Figure 11, pp.66) were predominantly explicit materials such as arrows, line-drawn characters, and communication device icons, and the sticky notes and markers offered and open-ended material for personalization. A magic wand tool (a glitter star attached to a stick) was introduced at the end of the mapping session as a tool that could be used to indicate a problem area or a part of the communication that the senior wished to improve.

The second half of Workshop 2 introduced more abstract and suggestive materials as part of a generative activity that explored possible new communication tools (Figure 12, pp.66). This included a phone handset, cardboard dial pads, bristle blocks, silhouettes of people, a letter and an envelope, black flat 'screens' of varying sizes, and functionality indicators such as "talk to me."

In addition to toolkits, both Workshop 1 and Workshop 2 used tools to facilitate structure and scaffolding throughout the sessions (see Figure 13, pp.67). An "overview of today's activity" storyboard was hung on the wall and illustrated each stage of the activity with a number, a simple line drawing, and a couple words of text. Scenario cards were also used during discussions to present and explore different

scenarios. These cards were black and white line drawings or photos mounted on green poster board.

Figure 11. Workshop 2 – sampling of the mapping toolkit

Figure 12. Workshop 2 – sampling of the generative toolkit

**Figure 13. Scaffolding tools used in all workshop sessions:
Workshop storyboard (left), scenario cards (right)**

As the workshop sessions progressed, these tools and materials moved from theme-based materials towards more customized materials that could better express the participants' experience, preferences, and ideas.

Refining the Language

As noted in the literature, using appropriate language that both empowers the senior and respects their personhood is crucial to developing a trusting and open relationship (Kitwood, 1997; Lindsay, 2011). When talking about the participants with the staff, the researcher used the phrase "people with memory loss" rather than

"dementia" and this appeared to be acceptable terminology. Regarding other vocabulary, the staff provided helpful insights.

When inviting the senior to participate, as well as throughout the workshop sessions, staff strongly recommended using the phrase "would you help me" as an effective and empowering way to initiate an activity or question. This request for help worked every time and proved invaluable at times when the senior appeared lost or confused.

Since talking about the future is often challenging for SWML, the staff suggested phrasing questions about possible solutions and future designs by grounding them in the present. For example, "what would make it easier to use" or "what do you like about your current communication tool." Despite these being viable alternatives, engaging participants in thinking about hypothetical solutions proved remarkably difficult.

Creating a Supportive Environment

The small size of the snoezelen room provided a cozy and private environment, but required careful consideration in terms of tripod setup and furniture arrangement. Three regular chairs around a square table provided seating for the participants and two small foldable stools provided seating for the researcher and assistant. The three participants and the researcher sat around the table and the research

assistant sat just off to the side where the tripod and video camera were set up. The off-center setup of the video camera and the low stool that the researcher sat on, kept the video camera out of the senior's central field of vision to reduce the likelihood of it being distracting.

Another attempt to minimize distraction was to sit the senior with their back to the outside window. The small, low stools were chosen for the researcher and the assistant due to space restrictions; however, this proved a useful mechanism to reinforce the proposed hierarchy and empowerment of the senior leading the discussion as an expert in their experiences.

5.2   Characteristics of Participants

There were five participants in total: two seniors living with memory loss, one family member, one personal caregiver, and one staff member (see Table 5, pp.70). While the staff attempted to recruit male residents and staff, there were proportionally fewer men than women. This gender imbalance combined with the availability and families' willingness to participate resulted in all the pilot study participants being female. Three of the participants were over 75 years old, one was around forty years old, and one was 20 years old.

Table 5. Summary of Participant Details

P = Participant	F = Family member		S = Staff	C = Caregiver
Code	Role	Age	Estimated Stage of Dementia	Current Communication
P01	Senior	81	moderate to late	in-person visits with sister 2-4 times per week
F01	Sister	75	none	some landline phone use, mostly in-person connections, no cell phone or internet
C01	Caregiver	20	none	in-person communication with senior and family only
P02	Senior	80s	moderate	communicates with family through caregiver as a proxy
C02	Caregiver	40s	none	uses smartphone to communicate and share photos of senior with senior's daughter

Of the three participants over the age of 75, none used a mobile phone, a smart phone or the internet, and only one of the three used a landline telephone (the sister who did not live at the retirement residence). There was a strong preference and practice of in-person communication among the SWML, but both caregivers had personal smartphones that that they used to communicate with their family and friends by sending text messages, photos, and using Skype. When

communicating with the seniors, family did so by visiting in-person or by calling the residence's front desk to relay a message.

Both seniors live on the memory care floor in a retirement residence in the Greater Toronto Area. This floor is secured by keypad locks to address concerns about residents' safety. Most of the residents were observed to be spending time in the communal areas.

5.3   Analysis of Pilot with Inclusive Design Students

A preliminary pilot study of Workshop 1 was held with eleven graduate Inclusive Design students. This diverse group of students represented a range of cultures, ages (25-50), genders, and educational backgrounds. While this group of participants was cognitively and generationally different to the seniors that would participate in the full pilot study, this workshop was useful in formalizing the structure and facilitation of Workshop 1 and refining the toolkits.

The graduate students expressed the need for improvement on the structure, overall clarity of the workshop activity, and setting expectations. A storyboard was made for each workshop to highlight each activity phase using numbered steps, descriptive text, and a simple illustration to address and communicate the workshop structure. The wording and the presentation of the research goals and workshop activity were developed further and an example of one of

the activities was created to help set expectations and clarify the activities.

Regarding the toolkit, the students noted that the stickers were useful as icebreakers because they were explicit, but once they were comfortable with the activity, they were less useful. Instead, the markers, sticky notes, and blank ovals (for facial expressions) were preferred as open-ended tools that could be used to create personalized expressions. There was also a unanimous decision to reduce the amount of tools offered because having so many tools made the participants feel overwhelmed.

Despite the students being a very different user group than the pilot study participants, their insights proved to be relevant more generally and were helpful in refining the structure, facilitation, and materials used in the pilot study with seniors with memory loss, their family, and caregivers.

5.4 Analysis of Workshop 1 & 2 with Seniors, Family, and Staff

Two pilots studies, each comprised of two participatory workshop sessions, were conducted using the revised pilot study design and toolkits. Each session was comprised of a small group – a SWML, a family member and a caregiver. The exploratory activities conducted in these sessions were captured through video, audio, and photographs.

Thematic analysis of these sessions began by reviewing the videos and photographs to identify particular challenges and successes in engaging the SWML in the workshop activities. Careful attention was paid to verbal, physical, and visual cues captured in the recordings of the workshop sessions.

Overall analysis of the pilot studies identified and examined four themes: methods, facilitation, toolkit design, and participants. The following subsections highlight the details and insights associated with each theme:

Methods

The combination of participatory design, co-design, and generative tools used to engage seniors with memory loss worked only marginally well. The participatory elements were most effective, possibly because the researcher was able to refer to the insights and guidelines offered by Hendricks et al. (2013) and Lindsay (2011) on conducting participatory research with this particular population. The object-based nature of this approach helped ground and focus all participants. It provided a clear, concrete, physical focal point in Workshop 1 when discussing preferences for different communication tools (Figure 14, pp.74).

Figure 14. SWML and her sister discussing a letter as a communication tool in Workshop 1

Unfortunately, the workshop activities and discussion topics still proved challenging for participants to engage. In Workshop 2, hypothetical scenarios were offered to understand how participants communicated in different situations and what their preferences were. One example was discussing a communication challenge(s) that might arise if a friend residing at the retirement home became ill and had to be relocated to a separate floor. These possible scenarios were met with confusion, irritation, and/or lack of a direct response from both of the SWML and the reason is not entirely clear why.

P02 said the answer seemed so obvious, "well I would go visit them" despite the fact that her mobility was restricted to the memory care floor without staff assistance. When asked how they would prefer to communicate in a possible scenario, P02 became irritated and exclaimed, "I could leave a note, go visit . . . it's so simple I don't

understand." When asked which means of communication she preferred, the senior repeated what she said previously rather than expressing a preference. It is unclear whether the senior had difficulty imagining what she might do in this hypothetical situation, whether the purpose of the question was unclear, whether she didn't have a preference, or whether it was difficult to make a choice.

These hypothetical situations were also challenging for P01 who often looked to her sister for answers. P01 seemed to have difficulty making sense of the present - she forgot where she was during the sessions and that she no longer used the telephone to communicate – and this might have made it difficult to imagine other scenarios. Previous research also found that seniors with Alzheimer's had a real struggle trying to comprehend hypothetical scenarios (Lindsay, 2011; Hendricks et al., 2013) and envision new technology (Massimi & Baecker, 2008) during participatory design sessions, in part because they often have difficulty perceiving and making sense of the present.

Conversely, engaging the senior in the story telling of past personal narratives and experiences was particularly effective in understanding the context of use and the person for whom the design was aiming to serve. Engaging in personal narrative also built trust and supported the senior's personhood. Finding ways to effectively trigger the senior's

memories and engage them in sharing personal narratives proved to be a greater challenge than anticipated. The role of the family member became particularly important in these situations.

Facilitation

In this research, the researcher assumed the role of facilitator offering tools and scenarios to support the participants in the workshop activity and discussion. Physical cues, such as scenario cards and a workshop storyboard, were used to help facilitate structure, focus, scaffolding, and participant empowerment throughout the sessions. Appropriate language and responses when engaging participants helped to respect their personhood and encourage a more open discussion. The location and set-up of the workshop session, and having a research assistant provide support were also important considerations in creating an engaging workshop.

Physical cues such as nametags, communication tools, workshop activity map, and scenario cards were effective means of establishing and maintaining the workshop structure, empowering the participants, and in scaffolding and grounding the activity and conversation. The nametags and workshop storyboard, in particular, were referenced often by P02 and provided knowledge that bolstered her self-confidence and empowered her to participate in the conversation as an

equal. The second time P02 met with the research facilitator she referred to their nametag and said, "It's good to see you again, [facilitator's name]." This type of information was clearly useful in supporting the senior's confidence and engagement throughout the social interaction.

Similarly, the workshop storyboard titled "Today's Workshop" (Figure 13, pp. 67) was referred to at the beginning and throughout the session. In fact, when the facilitator said they would give an overview of the workshop session, P02 immediately looked at the workshop storyboard and told *the facilitator* what the different phases of the workshop were. Having this knowledge readily available not only helped to scaffold and set expectations for the workshop session, it enabled the participants to be on more equal footing with the facilitators since they had access to the same information.

Other physical cues that proved moderately effective in scaffolding abstract concepts were the scenario cards. These black and white sketched images mounted on green poster board (Figure 13, pp. 67) were used to illustrate potential scenarios for discussion, such as reaching out to loved ones or celebrating a birthday. While these cards successfully portrayed the representation of a hypothetical situation, they did not help to elicit memories about what was done in the past,

nor did they elicit potential actions. It is possible that these scenarios were not personalized enough for the senior participants to relate to or to recall memories. Using personal photos or objects that represent past events may be more successful in sparking conversation and offering insight.

The effectiveness of using "help me" language was advice given by the staff and proved invaluable. This empowering language recognized the knowledge and purpose of what the resident had to share. It celebrated and validated their personal experiences and supported their sense of personhood and individual voice. This was especially useful in situations where the participants expressed irritation or insecurities because the phrase was empowering for the SWML.

When P02 responded with irritation because the question asked seemed so simple, the facilitator acknowledged the senior's feelings and restated the intention of the inquiry by saying, "I understand that these questions may seem simple, but I do not want to make any assumptions about how you communicate and what your preferences are. I am hoping that you can help me understand what would you would do in this situation." After hearing this, her face lit up and she leaned in with a sense of eagerness as she started talking. Her disposition was more relaxed and contemplative this time.

When discussing hypothetical situations, language used was based in the present, such as, "What would you improve?," rather than talking explicitly about the future, with questions like, "If this device could do anything to enhance your communication, what would it be?" Unfortunately, this did not make it easier for either of the senior participants to discuss hypothetical scenarios.

In managing unexpected responses and reactions, a drama improvisation mindset of being flexible, positive, and humorous was helpful in diffusing tensions and keeping the discussion moving forward. Having a research assistant to manage the technology and as neutral support to both the participants and the facilitator was another important element of successful facilitation. One of the senior participants turned to the research assistant to side against the facilitator when they found a question confusing or too simplistic. After discussing how she might communicate with a loved one in a given scenario, the senior turned to the research assistant and said, "I like him; he's smart," as if to imply that the facilitator was not since they were asking simple questions. This may have helped to create an environment in which the facilitator was the odd one out, not the SWML. It was also helpful in having an assistant so that they could rephrase a question or chime in if the discussion became awkward or was derailed by an unexpected response.

The location for the workshop session was also a key factor in facilitating an effective and engaging workshop. The snoezelen room worked well since it was a small, intimate, closed space that was on the memory care floor and had minimal distractions. One disadvantage was it was tucked away and unfamiliar so one of the senior participants was hesitant to enter the room because there were no windows and she could not see what was on the other side. As we approached the door she stopped and asked, "Why are we going in there?" Another small downside to using this space was that it had a window to the outside parking lot. This was a minor distraction for one of the senior participants even though they sat with their back to the window. Overall, it proved to be an effective and convenient space to hold the workshop sessions.

Toolkit Design

The toolkits for each of the workshops offered a diversity of textures, forms, associations, and levels of abstraction. The communication tools, such as the mobile phone and letter, were tools that proved useful in grounding and focusing the discussion; however, despite being placed in front of the participants no one touched or interacted with the tools; they only looked at them. Similarly, the senior participants expressed little or no interest in engaging with the tactile

hands-on materials to express preferences or illustrate their communication. Perhaps the level of abstraction was too high, as noted in research conducted by Hendricks et al. (2013), or perhaps there were other reasons the senior participants were not touching or participating in the tactile, generative activities.

As the toolkit materials become less abstract they should become more personalized. When P02 was asked to choose something form the toolkit to represent them in the communication mapping activity, they chose not to participate. P02 expressed difficulty in choosing a tool because the line drawings and smiley faces looked too infantile and the photographs of people didn't look like them. Requesting such an explicit representation of oneself may only have been achieved by offering them their own photo.

Conversely, the other senior participant was drawn to the cartoonlike illustrations and smiley faces to represent herself and illustrate her communication. Both participants found the open-ended tools, the sticky notes and markers, to be useful since they offered an opportunity for personalization. The mixed responses to the materials showed the importance of having a diversity of materials in the toolkits and the ability to customize and personalize them (see Figure 15 pp 82).

Figure 15. Differences in tool preferences used to express attitudes, preferences, and scenarios associated with connecting with loved ones through letters, Workshop 1
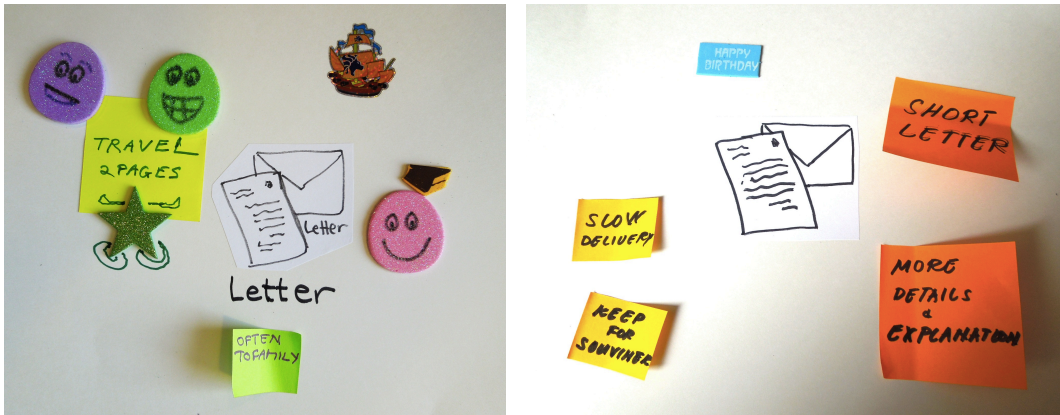
Another consideration is the age-appropriateness of the materials. While different responses were expressed to the cartoon-like line drawn character and the smiley faces, it is important that the materials are appropriate for the participant population and prevalent sensitivities that may exist. When one of the participants saw the smiley faces, she immediately rejected them by laughing and saying that it was "child's play." When offered alternatives, such as sketches of people and photographic images, she openly rejected the entire activity as something "a 4-year old would do."

The rejection and sensitivity of child-like and playful activities is possibly due to the struggle the senior may be experiencing as they age, lose their memory, and experience a more child-like dependence. In order to assert their personhood and separate themselves from the

other memory care residents, one of the participants put down the others living on the memory care floor before the start of the session saying, "What can you do with those people? There's nothing up there," tapping her hand on her head. This demonstrated the sensitivity to being treated like someone with a cognitive impairment or like a child.

At the end of Workshop 1, participants were asked to rate their communication tool preferences using 1st, 2nd, and 3rd place rosettes. The purpose of these tools was clearly understood, but neither participant awarded a 3rd choice, either because they had difficulty deciding between the five communications devices, or because they did not use or had not used the other devices. It is possible that there was confusion around how the objects were being rated. When asked to rate their preferred communication device, one senior selected a computer, which she had only used for writing reports at work, never as a personal communication device. When asked why this device was selected, she said it was accurate and "secure." Even though the device awarded first place had not been used to communicate with loved ones, it highlighted the importance of trust in the design of a communication tool for this senior.

Participants

Family was key to triggering memories and personal narrative that offered a better understanding of context, feelings, and preferences for communicating with loved ones and offered richer data. One of the seniors participated without a family member and no personal stories were mentioned or shared. The caregiver that attended the session had only known the senior for a year, so she did not share memories or experiences with the senior, and as a result, was not able to assist the senior in remembering.

On the other hand, the two sisters that participated in the study had spent a lifetime together and it was very easy for the family member to ask a simple question or mention part of a story that would trigger the senior's memory. One such instance was when the sister asked, "Do you remember the green scooter?" This was followed by chuckling as they recalled their experience traveling through Europe together and sharing their adventures with loved ones by writing letters. The family member's cues were especially helpful in moving the discussion forward when the senior was unable to recall memories when questions or scenario cards were offered.

The family members, caregiver, and staff also offered psychological as well as cognitive support to the SWML. Having a trusted family

participate in the workshop was critical to the creation of a safe environment and created a sense of ease. When one of the seniors was skeptical about entering the unfamiliar workshop room, the family member re-explained the nature of the activity. Since there was already trust established between them, the residents expressed relief and proceeded towards the room.

It was also noted that the same senior followed the cues and comfort level of her family member. If the family member was comfortable and trusted the facilitator, then the senior was also more likely to feel the same. The only time the senior engaged with the tools in the toolkit was when her sister selected a character to represent herself and began coloring it in. This may have been due to their history of sharing fun experiences together so this may have seemed an appropriate and acceptable activity. The other senior who participated with a caregiver was more protective of how she was perceived, less relaxed, and less open to sharing her personal experiences. It is possible that having not developed a long and trusting relationship with anyone in the room contributed to this senior's more distant disposition.

Since neither senior was engaged or actively involved in the tangible aspects of the toolkit, the family member and caregiver played an important role in capturing the perceptions and narratives of the

senior. In the scenario with the family member, the senior provided direction and expressed material preferences and her sister realized those through the hands-on activity. The other senior, accompanied by the caregiver, was willing to engage in the discussion but made it clear that she would not use the toolkit in any way because she thought it was too childish. The caregiver played an important role in capturing the discussion, but the artifacts created were more an expression of the caregiver's perspective rather than that of the senior's. The artifacts created by the two sisters were more reflective of the senior's perspective than the family member's.

Both participating seniors were living with moderate memory loss and this made it especially challenging for self-reflection. Recalling experiences was also a challenge even with the cues offered by a family member and with the use of the scenario cards. Both participants stayed engaged for the first 45 minutes of the session, but after that time they either began to fidget or become easily distracted. Conducting a workshop longer than 45 minutes may be a barrier to engagement. It may also be beneficial to have seniors with early stage memory loss that are still capable of self-reflection to participate and co-design the methods and toolkits for seniors with more advanced memory loss.

This guidance and feedback was also requested from the caregivers at the end of each session to help situate the experience and insights offered by SWML and their family more broadly. Their comments helped to refine and personalize the study design and toolkits, as well as make distinctions between unique scenarios and more general ones.

6   Discussion

6.1   Reflecting on Approaches, Techniques, and Tools

Borrowing techniques from the three different approaches - PD, co-design, and Generative Design Research - helped to address the gaps identified in previous research and was useful in the design of a pilot study that explored the social connections of seniors with memory loss (SWML). Based on the literature's recommendations for future work (Table 6, column 1, pp.91), solutions were proposed that could be tested through conducting a pilot study (Table 6, column 2, pp.91). The in-practice effectiveness for each proposed solution was evaluated as low, moderate, or high (Table 6, column 3, pp.91), and based on the pilot study insights, recommendations for future research methods and techniques are offered (Table 6, column 4, pp.91). In an effort to provide more granularity, researcher comments are noted to address each technique (Table 6, column 5, pp.91).

Table 6. Gaps in research identified in literature, my proposed solutions and their in-practice effectiveness, researcher comments, and recommendations for future research

Gaps Identified in Surveyed Literature	Solutions Explored in Pilot Studies	In Practice Effectiveness	Researcher Insights and Comments	Recommendations for Future Research
Conveying abstract and intangible concepts (Hendricks et al., 2013) (Lindsay, 2011)	• Use simple sketches of various scenarios, such as a 'reaching out' scenario card (Figure 13, pp.67) • Relate specific tasks and concepts to a larger picture and context through verbal discussion of the research goals • Provide visual examples	Low - Moderate Low Moderate	• While these prompts appeared to be understood, they did not trigger memories or personal experiences that could be used to inform the activity. • Understanding the purpose of the co-design activities and how they related to the overall research goal was difficult to convey relying solely on verbal communication. • A visual example appeared to be useful in demonstrating the mapping activities to participants	• Use personalized content, materials, photos, or objects to trigger narratives and discuss various scenarios, • Explain verbally and nonverbally what co-design is and how the workshop activities will be used to inform design. • Consider highlighting context more explicitly in the "Today's workshop" storyboard (Figure 13, pp.67) • Explain the context of each activity and provide visual examples or demonstrations
Development of scaffolding techniques (Lindsay, 2011)	• Use of communication probes • Use of scenario cards • Use of workshop storyboard • Use of context mapping	Moderate - High Moderate Moderate Moderate	• In many circumstances these techniques and tools were effective, in others the senior did not appear to reference them verbally or physically. • The context mapping appeared to be the most effective scaffolding tool and reference for everyone, but it was not something the seniors physically participated in making.	• Consider having visual or physical maps to provide an overview and document the research activity. • Use physical props and probes to help focus, ground, and initiate the discussion.
Assessing the guidelines in various contexts; home vs retirement setting (Hendricks et al., 2013)	• Test the guidelines (Appendix G, pp.127) in two pilot studies with seniors living in a long-term care setting	High	• These guidelines were extremely useful and critical to creating the pilot study design. • The pilot study supports the effectiveness of these guidelines applied in a long-term care setting.	• Consider using the guidelines provided by Hendricks et al. (2013) in different contexts.
Revisions of methods are left to researchers, would be worth knowing the participants' opinions (Hendricks et al., 2013) **Development of a process to evaluate the effectiveness and impacts of the modification of PD methods** (Lindsay, 2011)	• Invite participants to provide feedback at the end of the session. Ask what they enjoyed the most and the least. • Ask about whether or not specific materials and tools were useful or appealing. • Observe participants' behavior and comprehension	Moderate - High	• P02 was very open and vocal about her feedback on various aspects of the workshop session • P01 seemed unable to reflect or recall most of the session, but she left in a positive mood and was happy to take the artifacts she created with her • F01 and C02 said it was a good session but were not critical of the session • S01 suggested that the questions asked be shorter and simpler to make it easier for the senior to understand and follow. • Participant feedback is insightful when they are able to recall the workshop activities.	• Encourage participant feedback on the materials, structure, etc. throughout the session while they are experiencing it, rather than expecting them to reflect and recall at the end of the session. • Consider involving seniors at different stages of memory loss in the co-creation, co-analysis, and refinement of the research methods and tools. • Consider using personal items and materials in the workshop toolkit to spark reminiscence, empathy, and engagement. • Observe the reactions and engagement of the participant. While this is very effective, but mindful that this is based on the researcher's perspective.
Need for the development of leisure activities (van Rijn et al., 2010)	• Explore participatory design opportunities for communication tools to support social connection among seniors with memory loss	Low	• The goal of this research was defined by problems and gaps identified in previous research rather than by the seniors. • The seniors expressed some difficulty in relating to the research goal because they did not consider social connection to be a problem.	• Consider involving senior in the co-identification of their needs and the co-construction of the research goals so that the research is focused on their desires and priorities. This may increase participants' engagement and commitment in contributing to the research study and activities.

A number of effective techniques and tools were identified that facilitated the participatory design sessions. The use of physical cues, such as a workshop storyboard, helped to address abstract concepts and scaffold activities. Involving various stakeholders, such as the family and caregivers, proved to be critical. They offered another perspective on the communication loop, provided emotional support to the senior, captured the discussion through the hands-on activities, and helped trigger the senior's personal memories and experiences. Additionally, having a dynamic and iterative design process that used drama improvisation techniques and offered flexibility was critical to increasing the effectiveness of the participatory session.

While the toolkit and generative activities were helpful in scaffolding the activity and moving the discussion forward, this was not something in which the senior was highly engaged. One senior rejected the idea of doing a generative activity and the other senior took some persuasion to participate in the hands-on activity. Since the family member or caregiver predominantly used the generative tools, consideration should be given to how the toolkit and techniques can be adjusted to better engage SWML. Combining other techniques with the generative tools, such as action research and design probes, may increase effectiveness. The input of seniors with early stage of memory loss may also be helpful in the co-design of the toolkit and techniques.

Addressing issues of isolation and social connection as a research topic was particularly difficult since the senior residents did not directly communicate with the family, did not initiate social interactions, or they had a regularly scheduled meetings with family so communication was in-person. If changes were made in social activities these would be communicated and coordinated by caregivers or staff. Based on these two pilot studies, social isolation and feelings of connection did not appear to be a problem because they either had reliable assistance (caregiver with smartphone sending photos and messages to family) or regular contact with nearby family (afternoon visits and dinner every other day).

The overall lack of interest in the hands-on activities and the relevance of the research topic could be addressed by involving the senior in the co-identification of the research question, the co-design of the activities, and the co-creation of the toolbox, especially if it is customized to that individual. The development of a simple, lightweight sensitizing kit for the participants could gather meaningful materials that could help trigger personal narratives and offer insights during workshop sessions or meetings.

Another important consideration is as memory loss progresses, people experience a decline in cognitive ability and the way in which memory

loss affects each person can vary greatly. To address these variations and reduced abilities, it could be beneficial to engage people at different stages of memory loss in the research process. Seniors with early stage memory loss may be able to fill in the gaps and address barriers to participation in a way that could inform the research techniques and tools for working with seniors with moderate to advanced memory loss. Seniors with early stage memory loss may also be able to help the researcher grasp the feeling of the existing social connections before they start to become more difficult for the senior to recall.

Future research should allow time to develop a trusting and personal relationship with the senior participants. Conducting the workshop session in the senior's room or home should be considered, as it is a familiar environment to the SWML. It also affords the researcher the opportunity to refer to personal objects in the room that could potentially be used to engage the SWML and their family in discussion or storytelling.

6.2   Challenges Identified

Despite having identified a number of effective techniques and tools to engage seniors with memory loss in the participatory design process, there are still a number of barriers that need to addressed:

1. **Difficulty in identifying opportunities for improvements and moving beyond the "I am fine. There isn't a problem" response**. This may be addressed by spending more time with the participant to build a trusting relationship. It may also be beneficial to involve the senior in the co-identification of the research goals to ensure that the research is working towards something they find meaningful and relevant.

2. **Heightened sensitivity and resistance to childlike materials and activities.** One of the seniors with memory loss resisted participating in what they felt was a childish activity that involved infantilizing elements. This makes the need for customization and co-design even more critical in ensuring that the research process builds on the senior's abilities and supports their insecurities. The role of material aesthetics in the research process should be carefully considered and deliberately chosen. As the materials become less abstract, they should become more personalized.

3. **Participatory design is a time-intensive process**. Not only do the workshops and activities take longer than expected, meetings can be missed or postponed due to personal or health-related issues, which may impact the overall research study. It is also time intensive to foster long-term relationships with the

participants necessary to develop empathy, understand who they are, and build trust.

4. **Address tensions between the designer/researcher's role and the user/participant's role**. The different roles of the stakeholders must be clear, explicit, and balanced to ensure equal participation and to ensure that the artifacts and designs accurately reflect the user/participant's desires rather than the designer/researcher's potentially more academic aspirations (eg. design probes). It is critical to clarify goals and activity objectives so they can be fully understood by all participants. When working with seniors with memory loss there is a risk of information being presented in a way that is too abstract or unclear and this can amplify tensions between the different stakeholder roles.

5. **Need for more granularity when designing toolkits for seniors with memory loss**. Many research papers do not discuss the granular details of the methods, techniques, or tools that were used. When working with this population the details are significant, such as the aesthetics of the materials. Sharing photographs and excerpts of the transcripts are particularly useful.

6. **Development of tools for more abstract concepts**, such as hypothetical scenarios, as identified by Hendricks et al. (2013) and Lindsay (2011). While storyboards, videos, and scenario cards offered moderate success, other techniques and tools should be explored to help engage SWML in the design process.

6.3 Considerations and Recommendations

It is critical to build an authentic partnership, empathy, and trust between the stakeholders and the seniors through long-term relationships. Participatory design, co-design and generative tools can offer techniques and tools that support an open and dynamic dialogue beyond verbal communication where seniors with memory loss can have an equal voice in the design process using tools and techniques that are meaningful to them. Stakeholders must think about the person with memory loss beyond their disease in order to understand their experiences and desires, and believe in their capacity to fulfill those desires in a meaningful way. Adopting this social model of disability lens with a co-creative mindset would begin the necessary shift from designing *for* people with memory loss to designing *with* people with memory loss.

Involving the participants in the co-identification of the problem and the co-design of the methods and toolkit helps to minimize the risk of

them feeling infantilized and potentially increases their interest and engagement. The sensitivities and the abilities of the participants must be considered throughout the research process using techniques like ongoing consent. Research goals should be clearly defined and communicated verbally as well as nonverbally, such as through a storyboard or video, and they should be supported by a flexible and iterative process. The role of family members as emotional and cognitive support should not be underestimated, although the clear distinction of roles should be established to ensure equal participation.

7 Implications and Contributions

7.1 Significance of Research

This research offers methods, techniques, and tools for conducting participatory design research, providing care, and engaging in collaborative co-creative activities with seniors with memory loss. It identifies techniques and tools that empower people whose voices and personhood have been marginalized and largely neglected. It challenges all stakeholders - designers, researchers, family and friends, healthcare providers, and nursing staff - to critically reflect on their assumptions of seniors living with memory loss and how those assumptions may enable or restrict social connection and engagement, which ultimately affecting the seniors' quality of life and wellbeing.

7.2 Future Work

The research questions explored in this study build on previous research and introduce participatory design and co-design techniques during the exploratory, design, and analysis phases. Future work could be more engaging and meaningful to seniors with memory loss if it involved seniors in the co-identification of the research goals and the co-design of the activities and a personalized toolkit. Based on these

insights, it is highly recommended to involve this population from the very beginning of the research process.

It would also be beneficial for future research to consider bridging the gap between critical design and co-design. If the work conducted in critical design, such as the design probe work explored by Wallace et al. (2013a), considered using participatory design as a follow-up phase to the research process, research could move from the academic realm into practice. Cultural and design probes could be used first to inform the researcher about the participant's experiences and perspectives and then co-design could be used to co-identify the participant's needs and co-construct the participatory design objectives, activities, and prototypes. This blending of approaches may bridge the gap between academic rhetoric and a functioning tool.

Similarly, the integration of techniques practiced in other fields could be married with this hybrid HCI-Design approach. Social scientist Pia Kontos at the Toronto Rehabilitation Institute is exploring "embodied selfhood," which emphasizes the importance of the body and its movements and gestures for self-expression through research-based drama. Her work, as well as that by cognitive scientist Clayton Lewis, explores less traditional methods that are proving effective in engaging people with dementia and cognitive disabilities.

As complex and wicked challenges continue to present themselves, innovative, multi-disciplinary, and co-creative approaches will offer the most viable techniques, tools, and solutions.

8 Bibliography

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9   Appendix A – REB Approval Letter

Research Ethics Board

March 11, 2014

Dear Sarah Crosskey,

RE: OCADU 178, "Making social connections tangible for seniors with memory loss."

The OCAD University Research Ethics Board has reviewed the above-named submission. The protocol and the consent forms dated March 11, 2014 are approved for use for the next 12 months. If the study is expected to continue beyond the expiry date (March 10, 2015) you are responsible for ensuring the study receives re-approval. Your final approval number is **2014-20.**

Before proceeding with your project, compliance with other required University approvals/certifications, institutional requirements, or governmental authorizations may be required. It is your responsibility to ensure that the ethical guidelines and approvals of those facilities or institutions are obtained and filed with the OCAD U REB prior to the initiation of any research.

If, during the course of the research, there are any serious adverse events, changes in the approved protocol or consent form or any new information that must be considered with respect to the study, these should be brought to the immediate attention of the Board.

The REB must also be notified of the completion or termination of this study and a final report provided before you graduate. The template is attached.

Best wishes for the successful completion of your project.

Yours sincerely,

Tony Kerr, Chair, OCAD U Research Ethics Board

10 Appendix B: Recruitment Instructions for Staff

Recruitment Criteria:

Working through one of the retirement residence's Program Directors at the, six participants for this research study will be recruited: three seniors living with early stages of memory loss and three family members, friends, or caregivers associated with the selected seniors. The same six people are expected to participate in all three workshops.

For this research study the following three types of participants will be recruited:
1. Seniors living with memory loss,
2. Family members or friends related to the selected seniors, and
3. Caregivers or volunteers supporting the selected seniors.

Eligible participants will meet the following criteria:
1. Adult with early stage memory loss who is 65 years of age or older, or the caregiver/friend/family member of an adult with a person with memory loss and who is 18 years of age or older
2. Minimal English-speaking proficiency (participants with English as a second language are encouraged to participate)
3. Living in the Greater Toronto Area
4. Living in a long-term care home or retirement residency (not in a hospital environment)

The purpose of including these criteria is to allow the Program Director to select a diverse set of participants from a pool of interested candidates. Beyond these criteria we encourage choosing a variety of people with differences, such as in age, gender, ethnicity and socioeconomic status.
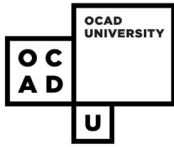
Timeline

Workshop 1: Perception of Connection – Date (one week after REB approval)
A one-hour workshop will be held with three pairs of seniors and either their family member, friend or caregiver. This workshop involves creative activities and discussions about their current communication with one another.

Workshop 2: Idealizing Connection – Date (two weeks after REB approval)
A one-hour workshop that through creative activities explores idealized communication between the senior and either their family member, friend or caregiver that participated in the first workshop.

Workshop 3: Exploring the Prototype & Providing Feedback – Date (five/six weeks after REB approval)
A one-hour workshop, with a family member, friend or caregiver, will explore an early-stage design and invites participants to provide feedback on that design.

11   Appendix C: Informed Consent

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Invitation / Consent Form Template

Date: [Insert Date]
Project Title: Exploring participatory design methods for seniors with memory loss

Principal Investigator:
Sarah Crosskey, Master in Inclusive Design
Candidate
OCAD University
Phone: 647-447-0189; Email:
sc12xh@student.ocadu.ca

Faculty Supervisor:
Katherine Sellen, Professor
Faculty of Design
OCAD University
Email:
ksellen@faculty.ocadu.ca

INVITATION
You are invited to participate in a study that involves research. The purpose of this study is to understand how to design technologies that aid seniors in communicating with family/friends.

WHAT'S INVOLVED
As a participant, you will be invited to engage in two design workshops and one feedback workshop to help design a potential tool that makes it easier to have regular contact with family and friends. Participation will take approximately one hour of your time for each workshop session, which will take place over the course of six weeks.

POTENTIAL BENEFITS AND RISKS
The overall goal of our study is to improve our understanding of and ability to design technologies for socially isolated individuals. As such, participants may benefit from future technologies that these results enable us to design. These benefits will also apply to society more broadly. There also may be risks associated with participation. As the workshops will include personal

conversations and communication, it is possible that participants will discuss matters that may cause slight anxiety, embarrassment or other emotional reactions. The research team is highly sensitive to these issues and has experience dealing with participants experiencing these reactions. Such reactions will be dealt with as they arise, typically by re-assuring the participant that they need not talk about anything they do not wish to discuss, that outside the workshop the data will be kept confidential, and that the audio recorder may be paused at any time.

CONFIDENTIALITY
All information you provide will be considered confidential and grouped with responses from other participants. Given the format of this session, we ask you to respect your fellow participants by keeping all information that identifies or could potentially identify a participant and/or his/her comments confidential.

Data collected during this study will be stored on a password-protected computer accessible only to the Principal Investigator. Physical data will be stored in a locked cabinet located at OCAD University and will be accessible. At the end the study, the data and code list will be secured in locked cabinet, and digital data stored on a secure server, located at OCAD University. Three years after the termination of the study, the data will be destroyed to conform to the Personal Information Protection and Electronic Documents Act (PIPEDA.) Access to this data will be restricted to the research team.

VOLUNTARY PARTICIPATION
Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time, or to request withdrawal of your data (prior to data analysis on March 25th) and you may do so without any penalty or loss of benefits to which you are entitled.

PUBLICATION OF RESULTS
Results of this study may be published in reports, professional and scholarly journals, students theses, and/or presentations to conferences. In any publication, data will be presented in aggregate forms. Quotations from interviews or surveys will not be attributed to you without your permission.

Feedback about this study will be available by contacting the Principal Investigator, Sarah Crosskey at sc12xh@student.ocadu.ca. Feedback will be made available by the end of May and can be requested from the Program Director or by contacting the Principal Investigator directly.

CONTACT INFORMATION AND ETHICS CLEARANCE
If you have any questions about this study or require further information, please contact the Principal Investigator, Sarah Crosskey, or the Faculty Supervisor, Kate Sellen, using the contact information provided above. This study has been

reviewed and received ethics clearance through the Research Ethics Board at OCAD University **2014-20.** If you have any comments or concerns, please contact the Research Ethics Office through jburns@ocadu.ca.

CONSENT FORM

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Participant's Printed Name

_____

Participant's Signature

_____

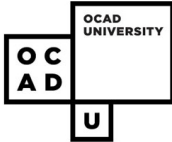OR

Participant's Printed Name:

_____

Power of Attorney's Printed Name:

_____

Power of Attorney's Signature:

_____

Date: _____

Thank you for your assistance in this project. Please keep a copy of this form for your records.

12 Appendix D: Audio/Video/Photo Consent Form

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Audio/Video/Photography Consent Form

Date: [Insert Date]
Project Title: Exploring participatory design methods for seniors with memory loss

As part of this study, we would like to use audio, video, and photographs to understand some of the challenges and ideals around your communication with family members and friends. Sometimes we like to show photographs and videos to audience at conferences to explain what we do in our research. We will always ask you first before starting audio or video recording. You may also request that the recording device be turned off for as long as you like, at any time.

Do you grant permission for us to **audio record** your participation?

       ☐   Yes   ☐   No

Do you grant permission for us to **video record** your participation?

       ☐   Yes   ☐   No

Do you grant permission for us to **photograph** your participation?

       ☐   Yes   ☐   No

Participant's Printed Name

_____

Participant's Signature

_____

OR

Participant's Printed Name:

_____

Power of Attorney's Printed Name:

_____

Power of Attorney's Signature:

_____

Date: _____

13   Appendix E – Workshop 1 Protocol

**Understanding attitudes and preferences towards
different modes of communication**

Hi [participants' names],

Thank you so much for taking the time to meet with me today. I am a graduate student at OCAD University and I am working to design a better way for seniors with memory problems to communicate with their family and friends.

Today, I would like to invite you to participate in an activity that explores your thoughts and attitudes towards different types of communication, such as sending letters vs. making phone calls. We will discuss 5 different communication methods and I would like you to help me understand what you associate with each method and what you like and what you don't like.   We can do this through a conversation and through using various materials, such as smiley faces or stars.

After you [senior] talk about your preferences, I will invite your family member [name] to share how they feel when they receive those types of messages. I am hoping you sharing this kind of information will help me design a communication tool for someone in your situation.

[To family member] [name] I would like you to participate by assisting your family member use these materials to express their preference and attitudes if they would like assistance. It would also be helpful if you were willing to share your experience and preferences receiving messages through different methods.

I am hoping to design a communication tool that [the senior] can use independently, but that works well for both of you – as sender and as recipient.

[Research Assistant] is a [where are they from] will be helping capture the session so that I can review it later to make sure I didn't miss anything. We will be using a video and voice recorder for research purposes only. We will also be taking photos, which may be used in a research paper or an academic presentation. You can ask that we stop recording at any time. Does that sound ok to you?

You are also welcomed to request a break, skip any questions, or withdraw from the study at any point in time.

The board behind me illustrates the different parts to today's activity.

1. **Introduction & Overview** of today's activity

2. **Example** of today's activity

3. **Sharing** attitudes towards sending and receiving different types of messages

4. **Ranking** different communication methods – My favorite way to communicate

5. Activity **Feedback:** How can I make this activity better for the next person I meet with? [confusing language?] What part was the most enjoyable?

Probing questions:

* Indicates ones expected to reiterate often.

Can you think of a time when have you used [] that you would be willing to share with me?

What do you associate with []? Feelings? Status? Personal? Impersonal?

How does it make you feel when you use []?

What could represent that?

What is the conversation like when using []? Personal or impersonal? Long or short?

How does using this feel? In your hand? To pick up? To read the message?

*Is there an image or something here that represents that? (if not, would you help me by showing me by either drawing or writing something here?)

*I am interested in understanding what your attitude/feeling/ preference/ thoughts are about using this type of communication to connect with your family and friends. Would you be willing to help me understand that?

I would like to invite you to two more sessions. In the next couple of days I would like to meet with you again for about an hour to start discussing some of the challenges faced and solutions that can be designed to help you send and receive message more easily and more enjoyably. Then I will create some models of potential communication tools and a couple weeks later I will invite you both back again to ask your for your feedback and input on these designs.

Do you have any questions?

Now I will show you an example of my attitudes regarding my camera so you can have an idea of what this activity will be like.

Show example. Follow through the rest of the activity showing two communication methods together at a time to help speed the process and discuss preferences. Make sure to indicate where you are in the activity on the activity map on the wall.

14   Appendix F – Workshop 2 Protocol

Current and Idealized Communication

1. Illustrate how you currently communicate with one another
[Materials: illustrations of people and modes of transport, colored shapes, arrows, blank faces, sticky notes, markers, construction paper, glue stick).
- When do you communicate?
- Where are you when you communicate?
- How do you initiate the conversation?
- Can you help me understand by walking me through the different steps?
  We can map it out together.
- What makes you feel connected?

In the event that the resident does not communicate with family or friends, try:
a. Third person scenario:
   - Imagine there was resident living here named James who has memory loss. How do you think he might communicate with his son?
   - Can you show me by helping me create a map of what that interaction would look like?
   - Use scenario cards.
b. Is there someone that lives here that you are close friends with?
   - If that person or yourself became ill and had to stay in bed, how would you like to be able to communicate with them?
   - What types of things would you like to communicate? What types of things do you currently communicate?
   - What would make you feel connected?

2. Identify some of the communication challenges in these scenarios.
[Materials: red arrows, exclamation marks, or circles]
- What might make it difficult to communicate? (time of day, physical ability, rules, medication)
- Is there anything **currently** that makes it difficult to communicate?
- How do these challenges make you feel?

3. **Using this magic wand, select a challenge** that you would most like to change.
[Materials: star sticker on wooden skewer]
- Which challenge frustrates you the most?
- If you could change anything what would it be?
- What do you think the most difficult part will be in communicating?

4. **Brainstorm some solutions and try and build them**
[Materials: foam screens, dials, construction paper, silhouettes, bristle blocks, keyboard, handset, words]
- If you could create a tool to communicate with [] what would it look like?
- Would you be willing to use some of these materials to show me?

If the resident isn't interested in building use:
- **Probing scenarios** (green cards)
    - o Can you think of a time when you wanted to talk to [] but you were unable to?
    - o How did that make you feel?
    - o Ho would you like to connect with [] in that situation?
- **Probing questions**
    - o Would you like to communicate with []?
    - o If you could create a way to communicate with [] and it could be any way you like, doesn't have to be realistic, how would you like to communicate with her?
    - Feelings:
    - o What kinds of things make you feel connected with []?
    - o What makes you feel close to []?
    - o Is there a particular object or thing (photo) that reminds you of []?
    - o When you feel lonely, upset or sad, what makes you feel better?
- **Design - Offer to help make something**
    - o How would you interact w it – press buttons, talk w it, touch it
    - o Would you hold it or would it hang on the wall, stand on a table?
    - o Where would you keep it - one place? pocket? purse? wear it?
    - o What type of messages/conversation – short? informational? personal? photos? stories?

- **Look for preferences around the different elements** - dial pads, screen sizes, voice/gesture interactions etc.
    - o Screens: out of these screens which one do you think you would like to see photos or messages on – size, which one would be best size to hold?
    - o Dial pads – big/small, round/square?
    - o Voice commands: What do you think about being able to speak to the device and have it write for you? Have it call the name of the person for you?
    - o Gestures: Would you like be able to wave or point and have the tool respond accordingly?
    - o Haptics: Touch if it vibrated to indicate you had pressed a button

5. Feedback
- What did **you think** of the activity?
- What was the **most enjoyable** part of the session?
- What was the **least enjoyable** or part that was difficult to understand?
- What **materials** did you find most useful to make the map with?
- Did you find making the **map useful**?
- What **materials** did you like for creating or talking about an ideal communication tool?
- What did you think of the **'Today's Workshop' board**? Useful? Distracting? Confusing? Indifferent?
- How can I make this **activity better** for the next person?

Reminders:
- Short questions
- Redirect focus by asking the question again or rephrasing
- Refer to 'Today's Workshop' board
- Remind them they are helping understand ways to improve their connections with loved ones

15 Appendix G – Combined Guidelines for Participatory Design with Persons with Dementia

4.1 Preparation

1. Search for and connect to existing groups and (patient) organizations (ap4)
2. Get to know your target group, try to understand their cognitive deficit and become sensitive to their needs and situation (ap5/am2)
3. Try to get the consent of the person with dementia on various moments throughout the research process (de9)
4. If possible, try to assess each participant in a formal way (am1/ap6)
5. Give yourself enough time for general practicalities (ap11)

4.2 Method

1. Participatory design methods should address experiential aspects (el4)
2. Each chosen (set of) method(s) should be tuned towards the persons' background, interest and specificities of the deficit (de3/am3)
3. If working in a group, modify your method taking into account the different impairments each member of the group is facing (el5)
4. Adapt your method so that it will take into account the difficulties in the comprehension and production of language, both verbal and textual (ap1)
5. Adapt your method so that it will take into account the difficulty in envisioning intangible concepts or abstract notions (el3/ap7)
6. Adapt your method so that it can overcome impairments of memory (am3)
7. Adapt your method so that it aids in following a chain of action/reasoning (ap8)

4.3 Moderator

1. Researchers should clearly explain the purpose of events and the role of the participants (el8)
2. It helps the participants to hold well-planned and structured meetings (am6, el7)
3. Foresee enough time for getting to know each other, for repetition and constant reviewing of the different research/design phases (de6/am5)
4. During a participatory design session try to minimize distraction and keep participants on focus (el1/ap9)

4.4 Tools

1. The location should hold an appropriate social status (de8)
2. The choice of location should take into account the deficits of the participants and ensure easy access to the meeting room (ap10)
3. As the verbal might be a problem, make use of non-verbal elements such as visual stimuli like photos of objects or physical artifacts (notes etc.) (de1)
4. Use distinctive contextual cues (like nametags) (am7)
5. Use fictive 3rd person stories to consult a person in an indirect way (de2)
6. Use easy to understand wording (el9)

4.5 Participants

1. Give the family member or trusted caregiver an important role during each session in aiding the person with dementia in his/her participation (de7/am8)
2. Work in small groups of persons with dementia (6-8) (de5/am4)
3. Try to overcome deficits by pairing persons with different deficits into one subgroup (el6)
4. Use persons who do not suffer from a deficit to get rid of general design problems (ap2)
5. Participants might fail to stay in the research track. Make sure there is some flexibility in participants (de4/ap3)

4.6 Analysis

1. Try not to over-analyze the utterances of your participants (el2)
2. Be critical towards the representativeness of your participants (ap12)