Using Technology to Engage People with Dementia in Recreational Activities

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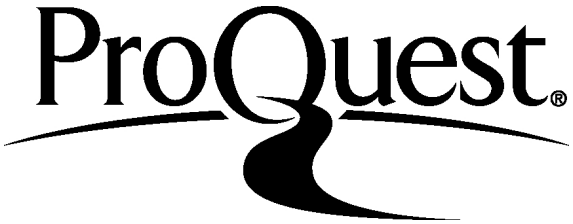

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Abstract

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Dementia is estimated to currently affect almost 15% of US adults over the age of 70. As the population ages, the prevalence of dementia will increase proportionally. The increase in the number of people with dementia will create a corresponding increase in health services required. Structured activities are extremely important for this population, leading to greater well-being and positive affect during activities and long term benefits such as delayed progression of cognitive impairments. Despite the importance of activities in dementia care, many people with dementia lack opportunities for sustained social interactions and stimulating activities. There is a clear unmet need for stimulating activities that do not place an additional financial or time burden on staff or families.

Technology is a promising venue to engage people with dementia in activities. For example, technology can be used to deliver rich multimedia and standardized interventions, increase access to digital archives, engage people in remote care or contact with loved ones, and monitor and log changes.

In my dissertation, I examine the ways technology can support older adults with dementia in engaging in activities in a memory care unit. I discuss existing technologies that support this population in engaging in activities, a six month field deployment of an existing technology, and recommendations for technology design that have been validated with experts in the field of gerontology and human computer interaction. My dissertation furthers our understanding of how to design engaging technologies for older adults with dementia in order to promote meaningful participation in recreational and leisure activities.

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DEDICATION

To my mother and father, whose enthusiasm for and belief in my abilities have formed my foundation. I admire and strive to emulate your integrity, kindness, and zest for life.

Chapter 1. INTRODUCTION

Dementia affects a significant percentage of older adults. As the population ages worldwide, it will become increasingly important to address various facets of the condition. People with dementia often have an unmet need for sufficient engagement in recreational activities. This is in part due to the nature of dementia, as well as the nature of the environment in which people with dementia live. However, recreational activities have significant benefits for people with dementia. Technology has the potential to support people with dementia in carrying out recreational activities, but must be designed with people with dementia in mind as well as those who support them, such as staff and family members.

1.1 Dementia and Memory Care Units

1.1.1 *Dementia*

Dementia is estimated to affect almost 15% of US adults over the age of 70 (Hurd, Martorell, Delavande, Mullen, & Langa, 2013). The prevalence of dementia increases with age, from one in eight people 65 and older to one in two people age 85 and older (Alzheimer's Association, 2012). Although there are several forms of dementia, Alzheimer's disease accounts for 60- 80% of affected individuals (Alzheimer's Association, 2012).

Dementia is characterized by cognitive impairments that progressively limit an individual's ability to engage in activities of daily living. While memory is most commonly impaired, other areas negatively affected by this syndrome include language, visual-spatial perception, judgment, and problem solving (Bird & Miller, 2010). In addition to cognitive impairment, people with dementia may experience behavioral and psychological symptoms of dementia (BPSD), such as agitation, aggression, and mood disorders (Douglas, James, & Ballard, 2004).

1.1.2 *Memory Care Units*

Due to some of the difficulties associated with dementia, thirty to 40% of people with dementia living in nursing or assisted living facilities, compared to only 2% of older adults without dementia (Alzheimer's Association, 2012). Assisted living facilities provide some degree of personal care services, such assistance with activities of daily living such as bathing and dressing, while nursing homes provide more intensive care (Port et al., 2005). One type of nursing home is a memory care unit (MCU), which can also be referred to as a Special Care Unit. An MCU is more specialized than a nursing home in the following ways: 1) admitted residents have cognitive impairment 2) staff are specially selected, trained, and supervised 3) family is involved 4) there is an environment appropriate for people with cognitive impairments, such as secured units, and 5) activity programming is specifically designed for people with cognitive impairments (Berg et al., 1991). A recent report found that the majority of memory care units located in residential care units (91%) do offer activities and programming that take into account the characteristics of people with dementia (Park-Lee et al., 2013). Dementia-specific activity programming is necessary due to some of the difficulties people with dementia experience carrying out activities; some of these difficulties are described below.

1.2 Insufficient Recreational Activities for People with Dementia

1.2.1 *Activity Theory of Aging*

According to the activity theory of aging, people should continue doing as many of the activities they enjoy as possible as they age, and modify or replace activities that they can no longer do (Havighurst, 1961). Researchers, practitioners, and caregivers have adopted the view that meaningful activities can greatly benefit people with dementia in their approach to dementia care (Phinney, 2006). However, people with dementia experience significant difficulties that hamper their ability to modify, replace, and carry out activities.

1.2.2 *Difficulties Carrying Out Activities*

People with dementia experience progressive difficulties in initiating and maintaining activities and interests. They experience these difficulties to the extent that the ability to maintain activities such as hobbies is used as a rating criteria to determine the stage of dementia (Hughes, Berg, Danziger, Coben, & Martin, 1982).

1.2.3 *Unmet Need for Activities*

People with dementia, staff, and family members identify that there are not enough opportunities for people with dementia living in residential care and MCUs to engage in activities (Harmer & Orrell, 2008). People with dementia in long-term care settings have spoken of "long and lonely" days without things to do (Moyle et al., 2011). One study observing residents with dementia in a memory care unit over several days found that for the majority of the day, residents were not engaged in any activity (Wood, Harris, Snider, & Patchel, 2005). Another study assessed over 200 people with dementia in residential care homes and found that while physical and environmental needs were met, the need for social interactions and daytime activities were not met (Hancock, Woods, Challis, & Orrell, 2006).

1.2.4 *Staff Involvement in Providing Recreational Activities*

MCUs and other care settings for people with dementia are often perceived to be understaffed by family members (e.g. Givens et al. 2011) as well as staff (e.g. Harmer & Orrell, 2008). As physical care can take precedence over providing activities as the primary duty for staff, the provision of meaningful activities can fall by the wayside (Harmer & Orrell, 2008). Other reasons staff may not conduct activities include lacking confidence in conducting recreational activities, feeling that they do not having the emotional energy to interact with residents after physical care, and not being aware of the benefits activities have for people with dementia (Pulsford, 1997).

1.3 Importance of Recreational Activities for People with Dementia

1.3.1 *Physiological and Psychological Benefits*

It is especially problematic that recreational activities are lacking for people with dementia, as engaging in activities has a myriad of benefits for this group. Activity programs are advocated as an evidence-based approach to manage behavioral and psychological symptoms of dementia in people with dementia, before pharmacological approaches should be used (Feil, MacLean, & Sultzer, 2007; National Institute for Health and Clinical Excellence, 2006; Vasse et al., 2012). When people with dementia in nursing homes or MCUs engage in more activities, the administration of psychotropic medication has been reduced (Rovner, Steele, Shmuely, & Folstein, 1996; Volicer, Simard, Pupa, Medrek, & Riordan, 2006). Additionally, engagement in certain recreational activities has been found to lead to increased positive affect (Brooker & Duce, 2000; Schreiner, Yamamoto, & Shiotani, 2005) and even to delay the progression of cognitive impairment in people with dementia (Cheng et al., 2014).

1.3.2 *Activities are Desired by All Stakeholders in a Person with Dementia's Care*

In addition to the physiological and psychological benefits of activities, they are greatly desired by people with dementia, staff who care for them, and family members to increase the quality of life of people with dementia. In one study, all three groups of stakeholders identified the provision of meaningful activities as a key component of person-centered dementia care (Edvardsson, Fetherstonhaugh, & Nay, 2010). In another study, nurses in an MCU identified providing opportunities for occupation, including times with play and joy, as an important aspect of promoting a 'good life' for people with dementia.

In addition to the desire that people with dementia, staff, and family members have for activities, the Centers for Medicare and Medicaid Services require long term care facilities receiving aid to provide "an on-going program of activities designed to meet… the interests and the physical, mental, and psychosocial well-being of each resident" (Department of Health & Human Services (DHHS) & Centers for Medicare & Medicaid Services (CMS), 2006).

Given the tremendous benefits of and desire for recreational activities for people with dementia, as well as the dearth of appropriate activities, there is a need to explore novel solutions to increase the accessibility of recreational activities for people with dementia.

1.4 Technology to Support Recreational Activities for People with Dementia

Various researchers have posited the ways technology could support people with dementia for various purposes, such as with stimulation and relaxation and compensation for difficulties due to dementia (Marshall, 1996), communication (Topo, 2009) and facilitating meaningful occupation such as leisure activities (Wey, 2005). Information and communication technologies (ICT) indeed have the potential to support people with dementia in carrying out many of the actions above, many of which can contribute to supporting people with dementia in engaging in recreational activities.

In the following chapters, I explore the following questions:

1) What kinds of technologies are currently being designed and studied to support recreational activities for older adults and what were their purposes?
2) How do people with dementia, family members, and staff use a specific piece of technology to support people with dementia in engaging in recreational activities?
3) How should technologies be designed to assist people with dementia in engaging in recreational activities?

To answer the first question, what kinds of technologies are currently being designed and studied to support recreational activities for older adults, I conducted a systematic review of the literature regarding a specific recreational activity: reminiscence therapy. Reminiscence therapy involves the "the act or process of recalling the past," often using artifacts to unleash memories and prompt conversation (Butler, 1963). The systematic review of these interventions is the first paper of my dissertation.

One of the findings from my review review was that many of the systems in the study were not ready to be used by staff or family members due to technical issues or complexity. Therefore, I decided to explore the way people used a commercially available system designed to support people with dementia in engaging in recreational activities. Another finding was that many of the studies were extremely short in length, limiting our ability to understand changes that take place as the novelty of a system wears off or as users overcome initial barriers in learning to use a system. Consequently, I conducted a six-month field study of a technology system in a memory care unit and a three-month field study with an activity group for people with less severe cognitive impairment. In this study, I interviewed and observed the use of the system with staff, family members, and residents with dementia. The second paper of my dissertation is an overview of the findings of the field test, and the third is a closer look at a dyad resident and family member who participated in the study.

To answer the third question, what types of technologies should be designed to support recreational activities for people with dementia, I analyzed data from the field study to generate detailed recommendations for system designers. I validated these recommendations in two rounds with experts in gerontology and human computer interaction. The fourth paper of my dissertation contains the recommendations and the process by which they were generated.

PAPER 1: A SYSTEMATIC REVIEW OF TECHNOLOGY TO PROMOTE REMINISCENCE FOR PEOPLE WITH DEMENTIA[1]

In this paper, I present a systematic review of technology used to support a common therapeutic recreational activity for people with dementia, reminiscence therapy. I discuss the technologies that have been used for reminiscence with people with dementia, their purposes, and some of the benefits and drawbacks to the different technologies used.

1.5 INTRODUCTION AND RELATED WORK

Standard non-pharmacological therapies for dementia include behavior therapy (addressing triggers of challenging behavior), validation therapy (empathizing with expressed emotions), and reminiscence therapy (involving the "the act or process of recalling the past", often using artifacts to unleash memories and prompt conversation, for present benefit (Butler, 1963)). One of the advantages of reminiscence therapy compared to the other therapies mentioned above is that it can be used with people with varying levels of cognition, including those who have lost ability to speak (Douglas, James, & Ballard, 2004).

Reminiscence therapy has the potential to benefit individuals with dementia and family caregivers. Therapeutic purposes of reminiscence therapy for people with dementia include reducing social isolation, offering an enjoyable and stimulating activity, promoting self-worth, and providing a way to sustain relationships with loved ones (Gibson, 2004). Although reminiscence often involves pleasant memories to promote enjoyment, it can also involve serious or sad memories for therapeutic or cathartic purposes (Parker, 2006). Reminiscence therapy also offers benefits for family caregivers, including new ways of interacting with a relative (Gibson, 2004).

Reminiscence therapy also holds potential benefits for improving staff care and facilitating closer relationships between staff and people with dementia. Engaging in reminiscence therapy with

[1] This chapter is adapted from Lazar, Thompson, & Demiris, 2014

residents with dementia provides an opportunity for staff to better understand the resident's current behaviors and personality (Gibson, 1994).

Several reviews have been published on randomized control trials of reminiscence therapy interventions, both for the general population of older adults (Y.-C. Lin, Dai, & Hwang, 1994) as well as for those with dementia (Cotelli, Manenti, & Zanetti, 2012; Subramaniam & Woods, 2012; Woods, Spector, Jones, Orrell, & Davies, 2009). These reviews identified problems with the available evidence base, including the differing forms of reminiscence therapy, a limited number of studies, and small sample sizes. Despite these methodological issues, reminiscence therapy does appear to be a promising intervention for individuals with dementia, with outcomes including improvements in mood, cognition, and behavior (Cotelli et al., 2012; Woods et al., 2009).

With advances in technology, there can be increased access to tools such as information and communication technology (ICT) for health-related interventions. Benefits of using ICT for people with dementia include the possibility of increasing the pool of study participants, the effectiveness of intervention, and the ability to assess outcomes. ICT has the potential to be a practical way to support the delivery of reminiscence therapy, whether through permitting individuals to stay in their local communities while communicating with others at a distance, presenting engaging and stimulating multimedia, facilitating use by multiple users, and providing interaction through dynamic methods. One review addressed systems that used ICT to deliver reminiscence therapy and concluded that using ICT is feasible for the delivery of reminiscence therapy in a population with dementia (Subramaniam & Woods, 2010). However, this paper did not address in depth how different forms of ICT have been used to benefit the delivery of reminiscence therapy.

Studying the different types of ICT used for the delivery of reminiscence therapy can lead to an understanding how different technologies affect the delivery, quality, and effectiveness of a reminiscence therapy intervention. This understanding can aid future researchers and clinicians when designing or implementing a system that involves reminiscence with older adults with dementia.

The aim of this study is to systematically examine the scientific literature on the use of ICT in conducting reminiscence therapy in order to assess current evidence, make recommendations regarding potential uses and challenges of using technology with persons with dementia, and to identify areas requiring further study. The goal of the study is not to evaluate therapeutic benefits of reminiscence therapy, but rather to examine the applications of ICT to reminiscence therapy.

The key questions explored in this review are:
1) What kinds of technology have been used to facilitate reminiscence therapy?
2) What purpose did the technology serve?

1.6 METHODS

1.6.1 *Sources*

I searched three databases: 1) the ACM (Association for Computing Machinery) guide to computing literature (1954- September 2013), 2) the NCBI's (National Center for Biotechnology Information) PubMed (1966- September 2013) and 3) the APA's (American Psychological Association) PsycINFO (1908- September 2013). All three databases were searched with the keywords "dementia AND reminiscence". Although the focus of this review was on technology use, no reference to technology or ICT was included in the search terms to ensure that interventions using technologies such as audio-platforms for music that may not have been classified as "information technology" could still be considered for inclusion.

Ten percent of the retrieved articles were evaluated for inclusion by another researcher to determine reliability of article inclusion. One hundred percent agreement was obtained.

1.6.2 *Inclusion and Exclusion Criteria*

To be included in the review, studies had to (1) describe the design or evaluation of an reminiscence therapy intervention; (2) include ICT use in the intervention delivery; (3) be

written in English; (4) be targeted towards individuals with dementia (for example, a paper discussing how an intervention benefited a caregiver without discussing how it impacted individuals with dementia would not be included, nor would a study used in a mixed population that did not include subgroup analysis for individuals with dementia). ICT was defined for this review as electronic technology used to present, access, or manipulate media (e.g., computer and TV, as well as older technologies such as cassette players). The study did not need to specifically mention the words ICT or technology if the technology met the definition of ICT that I used. Introductions, letters and comments, abstracts, theoretical/conceptual papers, books and reviews were excluded.

1.7 RESULTS

The initial search returned 386 papers, 115 from the ACM database, 107 from the PubMed database, and 164 from the PsycINFO database. Abstracts and titles were sufficient to rule out papers that did not meet inclusion criteria (1) or (3). One hundred full papers were reviewed when it was not clear whether they included ICT (criteria (2)). 24 ACM papers, 13 PubMed papers, and 7 PsycINFO papers met the inclusion and exclusion criteria, resulting in a total of 44 papers (see Figure 1).

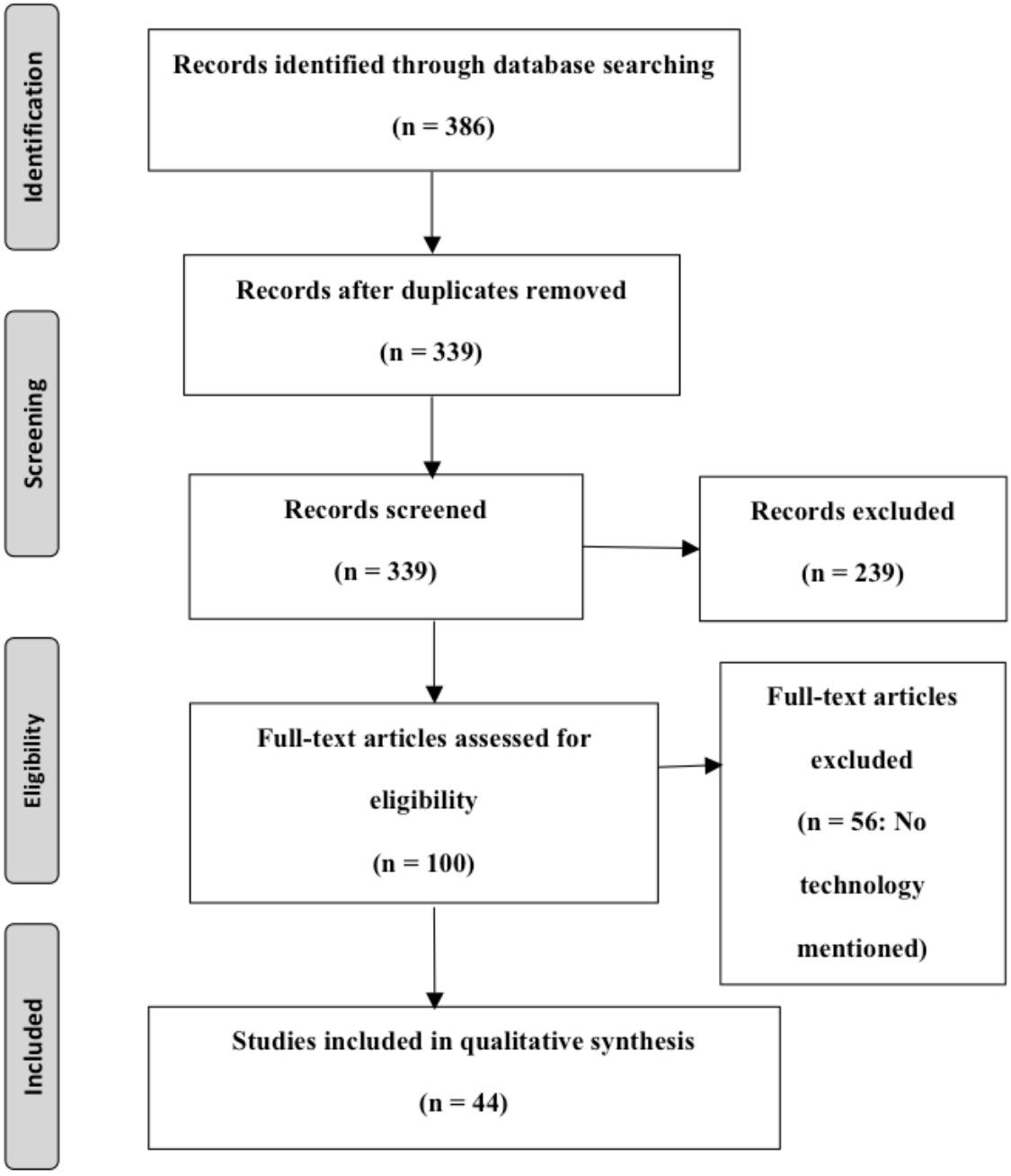

Figure 1: Study selection process

The study details are reported in Table 6. Study Details. Multiple papers describing a single study are grouped together. Below, results are organized below by research question.

1.7.1 *What Kinds of Technology Have Been Used to Facilitate Reminiscence Therapy?*

I summarize the media types, content, and technologies used in Table 7. Media Type, Content, and Technology by Study. Multiple papers describing evaluations of a single system are grouped together. Media content ranged from generic content to personal content such as photographs; the predominant media type was music. Other content types were based on the era or region in which the individual with dementia grew up or based on personal interest. The studies varied greatly in the degree of detail they reported, especially in regards to the specific technology used. Some were specific in reporting technology details (i.e., brands of monitors used), while others did not mention any details about what ICT was used. Diverse types of technology were used, from technology to monitor brainwaves to identify evocative media to technology to analyze conversations through natural language processing. However, the predominant use was to play multi-media prompts.

Ten papers in this review reported the use of a technological component in a 'reminiscence kit,' a portable selection of non-technological triggers such as old toys, smells, maps, and food, as well as technological triggers such as slides or records. Some studies used kits available commercially (e.g. Bi Folkal kit[2]), while others used reminiscence kits developed by the researchers. Audio was reported as a component of all identified reminiscence kits; eight of the ten identified reminiscence kits mentioned music. With another kit, Namazi and Haynes (1994) used a tape-recorder to play sounds to accompany paper photographs. The use of video (L.-J. Lin, Li, & Tabourne, 2011; Moss, Polignano, et al. 2002) and slides (Moss et al., 2002; Thorgrimsen, Schweitzer, & Orrell, 2002) were also reported. As it was impossible to evaluate the impact of technology components as opposed to the other kit components, the results of these papers are not discussed further in this review.

The authors of eight papers, corresponding to five distinct projects, described systems that utilize ICT for reminiscence therapy, but did not report any evaluation with the target population. These papers have been classified as "system architectures." The projects used diverse types of technology: to deliver reminiscence therapy remotely (Hamada, Kuwahara, et al. 2009; Hattori,

[2] http://www.bifolkal.org/products.html

Kuwabara, Kuwahara, et al. 2007; Kuwahara, Yasuda, et al. 2006), capture, display, and promote reminiscence regarding daily activities (Kikhia, Bengtsson, et al. 2010; Kikhia, Hallberg, et al. 2010), play multimedia (Caprani, Dwyer, et al., 2005), monitor brainwaves of an individual during reminiscence therapy (Gary, 2012) and present conversation facilitator prompts through the use of natural language processing (NLP) (Green, Guinn, & Smith, 2012). These papers are not described in Table 6, as they do not report evaluation with the target population. However, they are discussed in the remainder of the paper, as the novel uses of technology they propose are relevant to the study.

All of the retrieved studies that matched inclusion and exclusion criteria, except for reminiscence kits and system architectures, are reported in Table 6. Study Details. Almost all of the studies were case reports, signifying the early state of research in this area. Due to study heterogeneity, meta-analysis of results was not possible.

Outcomes were diverse and included metrics such as usability, acceptability, interactions between people with dementia and caregivers or staff, and concentration and distraction while using the system. Few studies looked at health outcomes such as impact on mood and cognition or a comprehensive evaluation of wellness or engagement, also signifying the early state of the research.

1.7.2 *What Purpose Did the Technology Serve?*

Below are the purposes for which researchers used the various technologies identified through the systematic review.

1.7.2.1 Accommodating Deficits: Using Technology to Ease Participation

Mitigate Motor and Sensory Impairments

Aging is often accompanied by changes in psychomotor performance and dexterity due to slower response time, tremor or arthritis. The presence of dementia, more often seen in older adults, further compounds these changes as motor impairments become an issue, particularly in later

stages. In several studies, technology was used to accommodate motor impairments through specialized input devices that users with dementia used to interact with the system. Some methods to aid interaction included the use of commercially available gaming devices, touchscreens, and prototype devices.

The MinWii videogame (Benveniste, Jouvelot, & Renaud, 2010; Boulay, Benveniste, et al. 2011) employed a Wii remote as an input device to accommodate motor impairments of users who might have otherwise been unable to play the game. The research team also incorporated computational filtering to accommodate tremors or imprecision by filtering input from the Wii remote and adjusting the output to make their reminiscence game easier for users by 'smoothing' their movements.

Several of the projects in this review used interfaces specifically designed to encourage people with dementia to manipulate and interact with reminiscence materials. One example is the group who created the Computer Interactive Reminiscence and Conversation Aid (CIRCA) (Alm et al., 2003, 2005, 2007; A. J. Astell et al., 2010; Gowans et al., 2004), who found that the touchscreen interface encouraged users with dementia to use the system themselves with little prompting. Cohene, Baecker, & Marziali (2005) explored the design of several prototype input devices meant to be simple and familiar for the user with dementia, such as page turning and a single button control.

Various input devices have different tradeoffs. A touchscreen, as opposed to a Wii Remote, combines navigation and content on one interface, which affects the distance the user must be from a screen and consequently the number of people who can gather around the system. Novel, custom-made devices such as those discussed by Cohene et al. (2005) might be more suitable to the particular cognitive and motor needs of individuals with dementia, but are not yet commercially available.

In addition to motor impairments, sensory impairments such as vision and hearing loss may accompany aging, and many older adults with dementia experience these kinds of impairments (Cohen-Mansfield, Marx, Regier, & Dakheel-Ali, 2009). Shik, Yue and Tang (2009) used

headphones and amplifiers to accommodate hearing impairments and projectors to magnify photographs to accommodate vision impairments. Using technology in this manner allowed participants who might otherwise be excluded to engage in reminiscence therapy with the rest of the group during a group reminiscence activity.

Compensate for Memory Deficits

As memory is both impaired by dementia and necessary for reminiscence, it is important for systems to support individuals with dementia in remembering events that have occured. Many of the projects used materials from the past to prompt remembering and reminiscence. Two projects gathered materials from the users' daily activities using technology such as GPS, cameras, and audio-recorders to compensate for memory deficits during reminiscence (Kikhia, Bengtsson, et al., 2010; Kikhia, Hallberg, et al., 2010; Lee & Dey, 2008). The motivation for one design was to alleviate caregiver strain originating from repeatedly providing details to help someone with dementia recall facts about events during casual reminiscence (Lee & Dey, 2008). Yamagami, Oosawa, Ito and Yamaguchi (2007) used a video at the beginning of the session to remind participants how to use tools from their past. The participants then showed staff how to use these tools, reversing the roles of staff as helper and resident as helped. By using a video instead of having staff instruct the residents, this role-reversal was possible.

1.7.2.2 Taking Advantage of Continuing Abilities: Using Technology to Harness Strengths

The other side of accommodating impairments is taking advantage of abilities. Certain skills, such as sensory awareness, musical responsiveness, and emotional memory have been labeled "continuing abilities" in dementia, as they are thought to persist after others have been compromised (Lawton & Rubinstein, 2000). Sensory awareness is the response to various forms of stimuli (e.g., visual, audio, tactile). Musical responsiveness refers to the strong responses people with dementia can have to music. Emotional awareness refers to the ability of people to experience rich emotions. Below are detailed some of the systems that used technology to draw on these continuing abilities.

Sensory Awareness and Musical Responsiveness

Technology is commonly used to display movies, photographs, and audio. Many of the projects in this review, particularly those using reminiscence kits, used technology solely for this purpose. Media were used as triggers to prompt a positive response in the form of interactions or improved mood. Almost all of the studies in this review used technology to display or play media.

One consideration in creating multimedia reminiscence materials is the degree of stimulation desired. In general, it seemed that researchers shared the philosophy that the more forms of stimulation, the better the product. For example, one group used photographs, background music, narration, panning, and zooming in their reminiscence video slideshows (Yasuda, Kuwabara, Kuwahara, Abe, & Tetsutani, 2009).

Emotional Awareness and Long Term Memory

Projects that focused on these abilities mainly appealed to something personally relevant to the individual. This was done through a range of materials, from materials that were personal only in that they were from the general era in which an individual grew up, to artifacts related to individuals' interests (e.g., football reminiscence groups) (Tolson & Schofield, 2012). At the other end of the spectrum were projects that used materials that belonged to an individual, usually gathered from family members. One project personalized not only materials, but also the reminiscence delivery platform, basing the design of interactive jewelry (e.g., digital photo-displaying locket) on the values and interests of a woman with dementia and her husband (Wallace et al., 2013).

The benefits of using personalized versus generic materials were issues explored in two studies with differing conclusions. One study found that generic photographs prompted more story telling from individuals with dementia (Astell, Ellis, Alm, & Dye, 2010) and note the potential for emotional distress when a person with dementia fails to recognize themselves or others in personal photographs (Gowans et al., 2004). Another study found that people showed more interest and less distraction while viewing personalized photo-videos than while viewing TV shows (Yasuda, Kuwabara, et al., 2009). One explanation for the disparity in findings is that the

first group of researchers had people with dementia involved in conversation, possibly resulting in the person with dementia struggling to remember specific details about pictures from their past. The second study took place with a person with dementia alone in a room viewing photo-videos. By not requiring the participants to generate conversation with another party, the researchers might have enabled the participants to enjoy the personalized photo-videos. Another explanation is that the different findings are due to the higher score on the Mini-Mental State Examination (MMSE) of participants in the first study, possibly leading to more awareness of their difficulty in recalling information and subsequent discomfort.

In addition to distress from not recalling memories, a potential area of discomfort that may arise as a result of reminiscence therapy is the reaction to disturbing photographs, such as wartime photographs or of deceased loved ones. Smith, Crete-Nishihata, Damianakis, Baecker, & Marziali (2009) recommend basing decisions of whether to include images or videos of relatives who had passed away on the wishes of participants, their families, as well as their reactions to that type of media.

1.7.2.3 Easing the Burden of Therapy Delivery

Reminiscence therapy can be time-intensive and costly in terms of preparation and delivery. One issue is gathering the materials for therapy, which may clearly be a barrier when personal materials are needed, but also when desired materials may be hard to find due to their rarity. Technology can assist in gathering these types of materials, as well as assist people in bridging geographic distance and avoiding transportation barriers. Listed below are systems that used technology to facilitate therapy delivery.

Gathering Personal Materials

A potential area for technology to aid in the delivery of reminiscence therapy is in allowing the digital transfer of materials for reminiscence therapy to the therapist. Sarne-Fleischmann, Tractinsky, Dwolatzky and Rief (2011) built a back end into a website-hosted reminiscence intervention that allowed family members to upload personal material to be viewed by their relative with dementia. Piasek, Irving and Smeaton (2012) had a person with early stage dementia wear the Microsoft SenseCam, a device that takes photographs at intervals. A therapist

then used the photographs during reminiscence therapy. The authors found that the individual was not able to remember that he had been wearing the SenseCam and was confused about where the pictures had come from, but was able to engage in richer conversation than when he did not have the photographs as prompts.

Gathering Generic Materials

Digital archives can make a large body of uncommon materials available for reminiscence therapy facilitators in disparate locations. The football reminiscence project (Tolson & Schofield, 2012) consisted of four interventions in different locations. All interventions used digitized images from a historic football picture database for reminiscence therapy with older males with dementia. Giving therapists access to the archives allowed them to accommodate interests of participants.

Remote Therapy

Like other therapies, a downside of reminiscence therapy is that either the individual with dementia or the therapist must travel to be in the same location. One approach that has become popular with the advent of telehealth is the use of technology to bridge geographic distance when delivering care. The set of papers describing the Networked Reminiscence Therapy system describe a system focused on the delivery of therapy from afar. The system is designed to allow a caretaker or therapist to view videos and photos with an individual in another location. Both parties can indicate regions of interest on the photographs, and the therapist or caretaker can control the visual effects that accompany the reminiscence videos. Evaluations of this system have found that most individuals find remote reminiscence therapy enjoyable, and some have had persisting benefits in terms of managing behavioral symptoms such as anxiety, irritability, and restlessness (Kuwahara, Yasuda, Tetsutani, & Morimoto, 2010; Yasuda, Kuwahara, Kuwabara, Morimoto, & Tetsutani, 2013; Yasuda, Kuwahara, & Morimoto, 2009). Though remote reminiscence therapy could reduce some barriers that result from transportation difficulties, it may create new barriers for individuals lacking technical expertise or necessary hardware. The researchers involved in Networked Reminiscence Therapy addressed this concern by setting up the system in the participants' homes and remotely starting applications (Yasuda et

al., 2013). However, it is questionable whether this approach would work with a commercially available system.

Tailoring for Individualization

Some of the systems used technology so that a single device or system could work for different people. One way systems did this was by providing individuals with their own login. Sarne-Fleischmann et al. (2011) accomplished this through selection on the touchscreen (Sarne-Fleischmann, Tractinsky, Dwolatzky, & Rief, 2011). USB sticks were another method by which researchers enabled tailoring, with the authors of the MinWii study recommending that each individual using their system have a USB stick with their configurations and scores (Benveniste et al., 2010). Two other papers proposed using USB sticks to store personal reminiscence materials such as photographs for use with a shared television (Wallace, Thieme, Wood, Schofield, & Olivier, 2012) and a shared laptop (Caprani et al., 2005). USB sticks can prevent requiring someone to memorize a password. However, remembering to carry around the USB device could be an issue for cognitively impaired individuals or overwhelmed staff.

In addition to separate logins, a second way the systems promoted tailoring to diverse interests was by having a large collection of materials organized in ways accessible to users with cognitive impairments. This arrangement might allow individuals with dementia to take more ownership over the topic of conversation than a physical set of materials brought in by a therapist. Gowans et al. (2004) reported surprise at the level of initiative taken by the individuals with dementia to operate the system they created, and as a result made some ergonomic design modifications since the system had originally been designed for caregivers to operate.

A third way material was tailored was through automatically detecting reactions of users to reminiscence content using commercially available brainwave sensors (Gary, 2012). This may be an effective method when people with dementia are unable to express their preferences.

1.7.2.4 Evaluating Progress and Use

Technology can be used to track and monitor progress and system use. Boulay et al. (2011) used logging to report on the speed with which people with dementia learned to use the game they describe in their study, and they mention the capability for therapists to log in and assess client progress as favorable aspect of the system (Benveniste et al., 2010). The interactive wall display project kept track of the number of interactions through radio-frequency identification (RFID) technology (Wallace et al., 2012). Information on progress and system use can be built into many ICT platforms, and may be useful to help health professionals decide when to adjust interventions. This kind of information may also be useful to assist facility administrators in determining which interventions are being used by residents with dementia and staff. However, monitoring progress may require individual logins or accounts, which might not be feasible due to privacy issues involved in using shared machines.

1.8 DISCUSSION

This paper systematically reviewed studies of the use of information and communication technology tools for reminiscence therapy interventions. I answered questions such as the types of available studies in this area, what technologies were used, and why these technologies were used to facilitate reminiscence therapy. The answers to these questions can help guide facilities for people with dementia and therapists who administer reminiscence therapy in deciding whether and how to incorporate ICT into reminiscence therapy, and aid researchers in deciding what elements to incorporate into future designs. The body of evidence for ICT reminiscence therapy interventions is limited by small sample sizes, studies of short duration, limited description of the reminiscence method used, and lack of details on how outcomes varied by level of dementia. These factors, as well as the high variability in technologies used and diverse aims, make a quantitative determination of how different aspects of technology contribute to the delivery of reminiscence therapy difficult. To move the field forward, larger studies are needed to determine whether these systems have a positive effect on people with dementia. Studies rarely described how reminiscence therapy was administered or whether therapists had any training. Future studies should take more care in describing how reminiscence therapy is delivered. Another issue is that results were rarely separated by dementia severity, despite the

differences in people across the spectrum of disease. If researchers include individuals at different stages of dementia, they should separate results by stage or specify if there is no difference.

Despite their limitations, the papers included in this review yield some rich insights on benefits and challenges of using ICT during reminiscence therapy. Challenges include that many of the systems described in the study require technical expertise for setup or operation and may not be ready for independent use by family caregivers. Benefits include the enjoyment derived by people with dementia from viewing reminiscing materials through various forms of multimedia such as video and audio, and that these individuals can benefit from ICT-supported reminiscence therapy by having increased opportunities for interactions and greater ability to take ownership of the conversation. Additionally, ICT can aid the deliver of reminiscence therapy by activity therapists by reducing session preparation time, making available materials impossible for a therapist to find on his or her own, and providing opportunities for remote sessions to reach distant clients.

1.9 CONCLUSION

As the segment of the population 65 years of age or older continues to grow, the number of individuals with dementia increases proportionally, highlighting the need to design engaging activities that meet the social and emotional needs of people with dementia, such as reminiscence therapy. This paper systematically examines the scientific literature on the use of information and communication technology for facilitating reminiscence therapy to assess the current state of the evidence and identify future trends. To review the literature, I searched the PubMed (1966-2013), ACM (1954-2013), and PsycINFO (1908-2013) repositories using the keywords “dementia” and “reminiscence”. My findings suggest that there are both benefits and challenges to using ICT for reminiscence therapy interventions. Some of these benefits of using technology include access to rich, stimulating, and engaging multi-media materials, opportunities for people with dementia to participate in social interactions and take ownership of conversations, and a reduction of barriers due to motor deficits and other impairments during interactions with media. Challenges include a lack of commercially available systems that can be readily adopted by

caregivers of people with dementia and difficulties with setup for individuals without technical expertise.

Chapter 2. PAPER 2: FIELD STUDY OF A TECHNOLOGY TOOL TO PROMOTE RECREATIONAL ACTIVITIES[3]

In the following paper, I present an overview of a field study of an existing technology designed to encourage people with dementia to engage in recreational activities. I examined this technology in a six month study in the context of a memory care unit for people with mild severe dementia and a three month study in an activity group for people with less severe dementia. I discuss benefits and challenges of the use of the technology, as well as factors that influenced participants' experience of use.

2.1 Introduction and Related Work

Many researchers have explored the use of information and communications technologies for individual types of activities for people with dementia, including playing music, exercise games, and conducting reminiscence therapy (e.g. Topo, Mäki, Saarikalle, et al., 2004; Tobiasson, 2009; Yasuda, Kuwahara, & Morimoto, 2009). Though these systems show great promise in providing stimulating and engaging activities for people with dementia, the systems serve a single purpose and therefore require individuals to purchase, learn how to use, and set up each system. This can be both time consuming and costly and can contribute a major barrier to the integration of these systems into care.

One potential solution to overcome these limitations would be the use of a multi-functional technology system. Multi-functional systems have been examined in several studies with people with dementia or mild cognitive impairments. Four systems, AMUPADH (Mokhtari, Aloulou, & Tiberghien, 2012), COGKNOW (Meiland, Reinersmann, et al., 2007), the Companion (Kerssens, Sattler, & Monteiro, 2014) and a study using tablet computers (Yamagata, Coppola, et al., 2013) have applications that engage social and sensory capabilities. The mobileWAY system (Jordan, Silva, et al., 2013) and another tablet study (Lim, Wallace, et al. 2013) have applications that engage sensory and cognitive capabilities, and ISISEMD (Mitseva, Peterson, et al., 2010), a cognitive training program (Haesner, O'Sullivan, et al., 2014) and SOCIABLE systems

[3] This chapter is adapted from Lazar, Demiris, & Thompson, n.d.

(Zaccarelli, Cirillo, et al., 2013) have applications that engage cognitive and social capabilities. While these projects are novel and hold promise, limitations of their ability to be used more broadly include that many of the systems are not commercially available, were designed for people only in the early stages of dementia, and are quite limited in terms of the number of capabilities they support (usually just two or three). Additionally, none of the projects mentioned satisfied cognitive, social, and sensory categories, let alone other activity categories such as exercise. The need for comprehensive systems with a wide range of applications targeting people across all stages of dementia motivated this study, which involves a field test of a multipurpose technology system in a memory care unit.

2.2 METHODS

2.2.1 *Study Design*

The study design used was a mixed-methods, longitudinal, quasi-experimental field study of a commercially available technology intervention. As this was a feasibility study, no controls or randomization were used.

2.2.2 *System Used for the Study*

I used a commercially available computer system designed for older adults in community settings (iN2L Mobile FLEX Lite Package, It's Never 2 Late, Centennial, CO; Figure 2).

The system included: 1) a commercially-available standard interface designed for use with older adults as well as 2) a prototype interface designed specifically for use with people with memory impairment/dementia (see Figure 3). The system included access to freely available web resources such as search engines, commercially available computer programs purchased by the company, as well as a programs developed specifically for the system.

Figure 2. The system deployed in this study

The system is intended to provide access to and opportunities for various recreational and leisure activities, such as social involvement (e.g. video calling, email-access, and Facebook), entertainment (e.g. through games, puzzles, exercise videos, movies, and music), motor involvement (e.g. exercise videos) and cognitive training (e.g. memory games). Applications within the dementia care interface are organized into categories such as ‘reminiscence’, ‘entertain’, and ‘stay connected.’ The system also allows the creation of custom grouping of applications that can be placed under icons for a specific resident or staff members.

Figure 3. The system interface

Features of the unit include a touch-screen monitor that can be plugged into an external monitor. In addition, the unit can be wheeled from room to room and has a webcam, microphone, and speakers. It also comes with additional peripherals such as a video camera, hand/foot pedal for exercise and therapy, joystick, and headset. The height of the unit can be adjusted to allow the unit to be used by people seated or standing.

2.2.3 *Study Setting*

I made the system available for use in two settings within the same 167-apartment senior housing community: 1) a 26-apartment memory care unit (MCU) for people with moderate or severe dementia and a 2) residentially-based activity group (AG) intended for people with signs of cognitive impairment.

The system was placed in the activity/dining room of the memory care unit and was used there by staff. I wheeled the system to a side room or residents' rooms for individual sessions and to

the activity group for biweekly sessions. I was on hand to provide technical support and answer questions about how to use the system.

2.2.4 *Participants and Inclusion and Exclusion Criteria*

Stakeholders from multiple groups were involved, as the perceptions of the various people involved in the lives of the person with dementia are important to understand the use of the system.

Participants (N=21) came from four groups: 1) older adults residing in the memory care unit (R; n=5) 2) family members of older adults living in the memory care unit (FM; n=4) 3) older adults participating in the activity group (RM; n=3) 4) staff members of both the memory care unit and the activity group (S; n=9). As this was a feasibility study, the small sample size in the groups is appropriate (Courage & Baxter, 2005). Older adults in the R and RM groups had to be residents of the participating community, 50 years of age or older and able to understand spoken English. Individuals in the R and RM group were excluded if they were legally blind. Cognitive status of residents was not used as inclusion or exclusion criteria. People with any stage of dementia could participate in the study; however, weekly sessions were only held with individuals who appeared able to sit and focus for an hour. Family members had to be related to the resident, aged 18 or older, have visited their relative residing in the MCU at least monthly in the year preceding the study, be willing to meet at the MCU for interviews, and be able to read and speak in English. Staff had to be aged 18 or older and either interact directly with the individuals with memory impairment/dementia in the study or play a part in activity planning for people with cognitive impairments. Family members and staff were excluded if legally blind or had significant auditory impairments that affected conversations as assessed during consent. All procedures were approved by the University of Washington Institutional Review Board.

2.2.5 *Recruitment*

Due to the residents' cognitive status, those in the R and RM group were not able to provide informed consent for themselves to participate in the research study. Therefore, letters were sent to the legally authorized representative (LAR) inviting study participation. Once LARs consented for their relatives to take part in the study, I approached the residents in the MCU and

AG to discuss study procedures and obtain verbal assent. LARs and residents were also informed that they could choose not to participate or withdraw at any time without affecting care. LARs of MCU residents were asked if they were interested in being a part of the study (family member group). Staff were recruited through on-site information sessions.

2.2.6 *Study Procedures*

2.2.6.1 Procedures: MCU Participants (R)

Participants in the MCU were enrolled for six months. Residents were given the opportunity to use the unit in weekly hour-long sessions with me. The best time for sessions was determined by speaking to family and staff members and took into account times of day residents were most alert while avoiding times favorite activities were scheduled. Sessions took place either in resident apartments or in common areas, depending on resident preference.

Residents were not interviewed given the severity of dementia; it would have been difficult for them to remember details about the system to yield meaningful findings and it could have potentially increased participant fatigue. Instead, I took detailed notes during weekly sessions with residents on aspects such as the features participants chose to use, participants' level of initiation, emotions expressed, barriers and facilitators to using different applications and the overall system, and topics of conversation that were inspired or generated by system use.

Instruments administered to residents and staff proxies included the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975), the Quality of Life in Alzheimer's Disease (QOL-AD) (Logsdon, Gibbons, McCurry, & Teri, 2002), the Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos, 2002), and the Resource Utilization in Dementia – Formal Care (RUD-FOCA, reports the total number of minutes spent caring for a resident with dementia per month) (Luttenberger & Graessel, 2010). I administered the MMSE, an 11-item test that scores people as having mild, moderate, severe, or no appearance of dementia, and the QOL-AD, a 13-item questionnaire that allows people to score elements of their life from poor to excellent, directly to the residents. I and/or staff filled out the CSDD, a 19-item scale that evaluates people for no depression, depression, or major depression. Staff filled out the RUD-FOCA, which assesses the amount of time spent on formal and informal care to assist the

resident in four areas of care. These instruments were administered at baseline, three months, and six months.

2.2.6.2 Procedures: Family Members (FM)

Family members took part in audio-recorded interviews at baseline and six months with an optional interview at three months. During the baseline visit, I administered a demographics form including a section on comfort using technology. During the baseline interview, I also administered the five single-item indicators from the positive affect instrument (PAI) for the family member to fill out regarding their relationship with their cognitively impaired relative (Bengtson, 1982). The positive affect instrument is used to assess the relationship between parents and children. Bengtson et al. found that the instrument has a test-test reliability of .89 and construct and discriminant validity, and designed it to measure affect regardless of the age of those to whom the instrument is administered (Bengtson, 1982). During the baseline interview, I asked questions about applications family members thought residents would enjoy using (in order to help me plan sessions), whether they thought the system as described was appropriate for people with cognitive impairments, whether they had any concerns about the system such as privacy, and their expectations of how their family member would perceive the system. The subsequent interviews focused on use of the system, interactions with the residents using the system and impact of system use on interactions.

2.2.6.3 Procedures: Staff Members (S)

I audio-recorded interviews and administered instruments to staff members monthly over a six month period for staff in the MCU and over a three month period to staff in the AG. During the baseline interview, a demographics form was administered and questions were asked regarding what kind of activities were currently offered in the MCU or AG, what activities would be offered in an ‘ideal world’, and whether they had comments on features of the system. During monthly and exit interviews with staff, staff were asked to provide information about their use of the system and issues they had. I conducted a training session at the beginning of the study for all staff, as I wanted staff who weren’t enrolled in the study to be able to use the system that would be housed on their floor.

Table 1. Memory Care Unit Procedures

Group	Baseline	1 month	2 months	3 months	4 months	5 months	6 months
MCU Residents (R)	Weekly sessions MMSE CSDD RUD-FOCA QOL-AD	Weekly sessions	Weekly sessions	Weekly sessions MMSE CSDD RUD-FOCA QOL-AD	Weekly sessions	Weekly sessions	Weekly sessions MMSE CSDD RUD-FOCA QOL-AD
Family Members (FM)	Interview PAI Feature sheet Demogra-phics			Optional Interview			Interview PAI
MCU Staff (S)	Interview Feature sheet Demogra-phics	Interview Feature sheet	Interview Feature sheet	Interview Feature sheet	Interview Feature sheet	Interview Feature sheet	Interview Feature sheet

2.2.6.4 Procedures: Activity Group Participants (AG)

Participants in the activity group were enrolled for three months. Use of the system in this group consisted of twice weekly sessions lasting two hours each, and staff could choose to use the system or not. I observed these bi-weekly sessions and took notes. Staff were also encouraged to use the device more frequently if they wanted to. Staff in the activity group underwent identical procedures as the staff in the memory care unit, except that their monthly feature sheet was slightly shorter.

I administered the MMSE, QOL-AD, and Geriatric Depression Scale- Short Form (GDS- SF) (Greenberg, 2007) at baseline and three months to residents taking part in the activity group, as well as a demographics instrument at baseline that included questions on participant comfort with technology. I also interviewed activity group participants at baseline and three months. Baseline interview questions included what took place in the activity group and favorite activities. At the exit interview, participants were asked about their experience using the system and whether any applications stood out.

Table 2. Activity Group Procedures

Group	Baseline	1 month	2 months	3 months
Residents in the activity group (RM)	Bi-weekly group sessions Interview MMSE QOL-AD GDS-SF Demographics	Bi-weekly group sessions	Bi-weekly group sessions	Bi-weekly group sessions Interview MMSE QOL-AD GDS-SF
Activity Group Staff	Interview Feature sheet Demographics	Interview Feature sheet	Interview Feature sheet	Interview Feature sheet

2.3 ANALYSIS

Descriptive statistics were performed on questionnaire and instrument data. All audio recordings of interviews and were transcribed and verified. Thematic coding was performed both inductively and deductively. Interviews were coded inductively. Interviews were coded inductively through open coding of the data using a content analysis approach (Hsieh & Shannon, 2005). A subset of the transcripts was coded by a second member of the research team for validation. Data management was facilitated using NVivo Version 10.

2.4 FINDINGS

2.4.1 *Demographics*

Demographics of participants are shown in the following tables.

Table 3. MCU Resident (R) Demographics

ID	Sex	Age
R1 (R1 and RM1 are the same individual)	Female	86
R2	Male	86
R3	Female	92
R4	Female	93
R5	Female	82

Table 4. Family Member (FM) Demographics

ID	Sex	Age	Race/Ethnicity	Relation to R	Comfort with Technology
FM1	Female	60	Asian/Pacific Islander and White/Caucasian	Daughter	Very comfortable
FM2	Female	87	White/Caucasian	Wife	Very comfortable
FM3	Female	59	White/Caucasian	Daughter	Very comfortable
FM5	Male	51	White/Caucasian	Son	Very comfortable

NOTE: R4 did not have an accompanying family member in the study

Table 5. Staff (S) Demographics (S1-7 in MCU, S8-9 in AG)

ID	Sex	Age	Race/Ethnicity	Job Title	Time at Facility	Time working w/ people w/ dementia	Comfort with technology
S1	F	40	Asian/Pacific Islander	MCU Manager	2 years	6 years	Very comfortable
S2	F	24	White/Caucasian	Activity planning assistant	10 years	9 years	Very comfortable
S3	F	39	White/Caucasian	Activity planning Assistant	3 years	14 years	Somewhat comfortable
S4	M	25	Other (Pakistani)	NAC	1 year	1 year	Not very comfortable
S5	F	26	Asian/Pacific Islander	CNA/Med Tech	13 months	13 months	Very comfortable
S6	M	42	Asian/Pacific Islander	Resident Assistant	17 months	3.5 years	Very comfortable
S7	F	26	Asian/Pacific Islander	CNA, Activity planning Assistant	10 months	14 months	Somewhat comfortable
S8	F	24	White/Caucasian	AG lead	1 year	7 years	Very comfortable
S9	F	24	White/Caucasian	AG Assistant	1 year	4 years	Very comfortable

Activity Group Participant (RM) Demographics

ID	Sex	Age	Race/Ethnicity	Comfort with technology	Interest in technology
RM1	Female	86	Asian/Pacific Islander and White/Caucasian	Very comfortable	Very interested
RM2	Female	86	White/Caucasian	Not at all comfortable	Somewhat interested
RM3	Male	89	White/Caucasian	Somewhat comfortable	Not at all interested

2.4.2 *Descriptive Statistics*

Descriptive statistics for MCU and activity group participants at the various time points can be found in Table 8. Descriptive Statistics of MCU Resident (R) Scores and Table 9. Descriptive Statistics of Activity Group Participant (RM) Scores. These measurements are not intended to provide any evidence about the effectiveness of the intervention, but rather to provide a full picture of each of the residents. Five MCU residents were enrolled initially, with four residents still enrolled at three months. One resident completed all six months of study procedures. One participant with an MMSE of 2 did not appear able to understand instructions and was deemed unable to take part in weekly sessions. He was transferred to another facility shortly after, leading to his and his corresponding family member's withdrawal. A second participant was also transferred to another facility and she and her corresponding family member were withdrawn from study participation. Two additional residents were admitted to the facility during the course of the study, and completed procedures out to 3 months before the study ended. R1 participated in 26 sessions, R2 in 0, R3 in 9, R4 in 13 sessions, and R5 in 5.

At baseline, family members scored an average of 22.3 (SD 4.8) on the five single indicator items (rated from one, "don't agree with closeness items", to six, "agree with closeness items") on the PAI.

2.4.3 *Trends*

Tables in the appendix (Table 10. Averages of MCU Resident (R) Scores and Table 11. Averages of Activity Group Participant (RM) Scores) includes averages to illustrate changes scores over time. R2 is not included in this table as he was withdrawn from the study shortly after baseline. Note that R5 is excluded from the averages for the QOL-AD and R4 is excluded from the averages for the RUD-FOCA due to missing instruments. MCU participants show a beneficial trend in all instruments measured except for the RUD-FOCA. One explanation for that and the large standard deviation may be due to different staff members estimating the amount of time spent caring for resident. AG participants showed a beneficial trend for the QOL-AD and a detrimental trend with the MMSE and GDS. Again, these measurements are not intended to provide any information about the effectiveness of the intervention.

2.4.4 *Themes*

Qualitative themes are organized into the following categories: benefits, challenges, and influencers on use of the evaluated system.

2.4.4.1 Benefits

Benefits were identified from transcripts for all parties involved: residents, family members, and staff.

Interaction Facilitation

Residents, family members, and staff all benefited from the way the system facilitated interactions. These interactions occurred between staff and residents, family members and residents, and also between residents in the memory care unit. One application that especially promoted interaction was a library of links to YouTube videos. S2 noted: “the baby videos got them talking about their own kids and how many kids they had and stuff like that. ‘My baby used to do this,’ ‘my baby did that.’ And they started talking to each other, almost like a new mom parenting group.’”

In addition to residents conversing spontaneously with each other in response to an application, staff engaged and elicited responses from residents while utilizing materials on the system. Staff

benefitted from these interactions as well. S5 noted that playing music that residents and staff liked "bridges the age gap and the generation difference," leading to a sense of connection between the two groups. Family members also benefited from interactions facilitated by the system: family members who used the system with their relatives noted positive experiences. While enjoyable, these new interactions were not reported to affect the relationship in a larger sense: FM3 said, "it's given us something to do together, but I don't think it's really changed the relationship."

Learning About Residents

Staff and family members benefited from learning more about residents through use of the system. S5 noted, in reaction to seeing a resident playing blackjack on the unit and learning that she was a "card shark", that learning things about residents "is good because especially here in the memory care, you can hear things from them but you don't necessarily know if it is true." Another reason that getting to know residents better was seen as beneficial was because it informed staff of residents' likes and dislikes, which they used to plan and tailor activities. Family members also valued learning more about their relatives through use of the system; FM1 learned that her relative enjoyed karaoke by observing one of our sessions and then scheduled her to be engaged in more singing activities.

Enjoyment

Both residents and staff benefited through enjoyment when using the system. For example, when asked how the system had led to changes in R1's quality of life, FM1 said that R1 was "always happy when she thinks about it… And it brings a big brightness to her life." FM3 less enthusiastically noted that R3 was "relatively engaged in enjoying it." Staff reported that residents in the MCU (not only those enrolled in the study) enjoyed specific applications. Staff also noted that some applications, such as YouTube videos, were especially fun to use.

Something to which to look forward

Residents benefitted by having something to which to look forward. This was only noted by FM1 about R1, as other family members said that their relatives most likely did not remember them occurring.

Having something different to do

Residents and staff benefitted from using the system by having something different to do. RM2 specified that using the computer in the activity group would be a good idea because "it would be something different than what we've been doing." Staff noted that they enjoyed the novelty of the content. Discussing using a music application during lunch, S5 said "it's not the same thing all the time, which is good… because [before] you're like 'oh it's that CD again' whereas now it's like something different all the time. You can change it up." Novelty of content as well as the novelty of the system itself was appreciated by residents and staff.

Mental and physical stimulation

Residents benefited from the system prompting mental stimulation. Both staff and family members perceived applications as being beneficial for exercising residents' cognitive functions. S6 mentioned that observing the first author using the system with residents convinced her that "it's exercising their mind." When I told RM3 that I would be bringing the unit to the group activities, he stated that the unit might "get your noodle working." Cognitive stimulation occurred not only during the use of applications such as memory games, but also during other applications that are not traditionally considered to be cognitive exercises, such as casino games. FM1 mentioned that while she had originally perceived using the casino application on the system as having "no brain thing going on" for her mother, taking her mother to the casino and seeing her struggle there made her say "now I'm back to 'play the casino'… there was a lot happening and I didn't realize it. Because it's second nature for me and you." After recognizing that even the simple casino brain promoted mental stimulation, FM1 asked that this activity continue to be used with her mother during the weekly sessions. Another benefit was related to physical stimulation: FM2 saw the system as useful for helping her mother recover physical mobility after a stroke she had experienced during the study.

Reminiscence

Residents benefited through reminiscence that occurred with use of the system. The system's applications reached participants through the variety of applications (so one was bound to be relatable to residents) as well as through the wealth of materials from past eras. Each of the

residents that participated in weekly sessions chose to return over and over to applications relevant to activities that they had done in the past (e.g., casino/card games and slideshows with images of horses). These applications brought back individual memories for the residents, and FM1 explained that R1 “absolutely loves the casino one, and that's because she used to… meet her favorite sister in Las Vegas. So it’s brought back memories.”

Staff spoke frequently about playing older movies and TV shows for residents. S5 explained that she used the movie application often because “... they shouldn’t really be watching the news, it will stress them out and confuse them. Right now… they’re just playing Christmas movies and I don’t know if it’s really relevant to them because they’re newer. So I feel like I should put on something that they may know at least it’s from their generation…and [they] might remember it.”

Though staff appreciated the older movies, shows, and music, it is important to note that content did not have to be older for residents to relate to them. In some cases, older content was frustrating to residents. S2 commented on a trivia slideshow on the system, saying that: “They do love trivia, but it’s a double-edged sword, when they start not being able to remember things, but they know they know it, then it frustrates them. And so… they’re like ‘well I lived in the forties, why don’t I know this?’ ‘Who came up with these questions?’ Then it gets indignant.” Residents were frustrated knowing they should recognize materials from a certain era but not being able to do so. Another way older materials were not appreciated involved changes in taste. S9 noted that they were “watching the ‘Three Stooges’… the other day, and [a resident stated] 'this used to be funny back in 1930', that's what people found funny, but [the resident has] been here long enough to know that the humor has changed… I'm sure there are some older shows that they'll still like, probably Johnny Carson…[but] they like some up to date stuff.” Although older materials can evoke memories and stimulate meaningful conversation, not all older materials were appreciated.

Accommodation of individuals along the dementia spectrum

The system benefited a larger number of residents by accommodating individuals along the dementia spectrum. Music was particularly meaningful to people with different levels of

dementia: S3 said: “Music's always probably the top thing, because no matter what level someone is at mentally, it's very soothing and it usually brings people together.”

Attention and visual memory aided

Another benefit to residents of the MCU was that the system aided attention and served as a visual memory aid. This benefit was identified by staff and participants in the activity group. Family members also identified this as a potential benefit. The following is the response of a participant (RM1) to the addition of the system into the activity group program: “I think that's a very good idea…you have to concentrate on it. You have to look at it, and try to figure what's on and what it's doing and all that….I think that's very good [for] keeping their attention.” The system was also useful as a visual aid when staff or residents did not know an exercise but wanted to do them. Such was the case with Tai Chi where S5 said “they’ll copy what they see.” By having a video with someone performing moves, staff were able to provide the opportunity for residents to engage in a novel and beneficial activity.

The system also assisted facilitators in making sure a group of residents were ‘on the same page.’ S9 mentioned how typically “A lot of times [residants will] lose their place when they have the sing-along [which was done in the facility previously using CDs and paper songbooks] in front of them, so it's kind of nice to just look at it. And it's right on the words and they can follow on there, so I think that does help.”

Self-Esteem Gained

Another benefit was the residents gaining self-esteem through the use of the system. This was due to pride associated with using a computer as well as satisfaction from winning games.

Convenience and availability of information and media

Staff benefited from using the system because of the convenience and availability of information and media. S1 noted that “they like those older movies, and it’s hard to get them from Netflix… we can click on any one of them and we would know that hey, that’s an older movie, they’ll like that.” Staff members also mentioned the convenience of having multiple types of materials on a

single system, which was seen as reducing the chance of losing peripherals such as DVDs or the remote.

Pressure Relieved

The system was also seen as relieving pressure from staff. Staff were able to engage in new activities that they did not necessarily have expertise in through use of the system:

"On Mondays we don't have an activity [director present] so we have someone that comes up… and we have our schedule already. And she's like 'what's Tai Chi?' and I'm like 'we actually have this computer thing'. We taught her how to set that up, so she does Tai Chi with them."

The MCU has a very involved activity director, and S1 mentioned that "We use the [system] more when [activity director is] not here. It's helpful, at least when we're trying to struggle to figure out what to do, what kind of activity… And we know that it's always available for us to use." Having the system available when it was needed was seen as beneficial by staff.

Replacement or augmentation of activities

Another benefit was that the system replaced or augmented activities. The system did not necessarily need to provide new activities: many features of the system were noted by FM3 to be "what they [staff in the MCU] do already." Similarly, S5 noted "it's just an improvement on what things they were already using." However, staff also appreciated when the system provided new types of activities and interactions. S3 noted that having the system "helps me thing of some things outside of the box that I wasn't thinking about."

2.4.4.2 Challenges

In addition to the many benefits of using the system, there were also significant challenges associated with its use.

Technical and Usability Issues

The most problematic challenge pertained to technical and usability issues. These issues were especially significant in the first few months of the study and staff reported that these types of issues this reduced their use of the system in early interviews. S2 explained how the difficulty

MCU residents had staying focused affected her likelihood to use a system with technical issues. She said: “I think it’s not getting used as much as it could be because of the frustration of it freezing or going too slow, because they’ll lose interest so quickly. And start getting antsy and want to do other things… I would be more willing to use it if I knew the games I had talked up were going to work when I opened them.” Issues also arose relating to staff not knowing how to use features or where applications were located.

Once the technical issues were resolved and staff became more familiar with where applications were located, staff reported more use and had better opinions of the system.

Both staff and family members noted that usability or technical issues would be especially frustrating for people with dementia. S3 noted “if we’re having a hard time using it, it’s definitely gonna be hard for [residents]”.

Lack of resources

The next most significant challenge with using the system was the lack of resources, especially time and personnel. The additional needs of residents due to cognitive impairments compounded this need: S1 said “I really wish I just [had] more people to actually use it with the resident. And I'm pretty sure [we should] have one dedicated person to use it with the resident, because our residents won't just go there and use it by themselves. They have to be guided.”

Challenges related to cognitive impairment

Many challenges related to the cognitive impairments of residents arose. Applications that might be well designed for the general population were ill-suited for some of the residents. For example, one set of exercise videos had three people on the screen doing the same exercise at varying levels of intensity, which staff mentioned was confusing to residents.

Challenges due to disease-related disabilities

In addition to challenges due to cognitive-impairments, challenges arose due to disease-related disabilities. Two of the participating residents were in wheelchairs, and the station height did not decrease enough for one participant to comfortably reach the keyboard, and the footpads of the

wheelchair had to be moved to the side so another could get close to the system. Additionally, R3 had a stroke during the study and no longer had use of her dominant hand, and her hand would tire quickly when using the system. FM3 suggested that the system should "have the screen on maybe some kind of arm where you can swing it down." Other difficulties related to functional level arose when using specific applications: some exercise videos were viewed as too strenuous for residents; S3 said "I was feeling it after doing it… so I knew they must have been feeling it, and they were complaining a little about that".

Several applications had writing that was too small or sound that was not loud enough. Conversely, some applications were appreciated as they were able to magnify writing: S8 mentioned that "when we do the games [RM3] will answer some of the questions, when if we play the board game he probably wouldn't have played along… because it's more visual seeing it on a screen then seeing it on a board because you don't have that same visual with the board. And it's bigger and it's probably easier for him to see."

Ethical Concerns

An additional challenge using the system was ethical concerns staff and family members had about the system. Some of these concerns were assuaged as the study went on. S5 had initially seen the use of the system as yet another instance of technology replacing humans: "technology just seems to be replacing things that people normally do. Not just in activities but at the post office or in hospitals with robotics and surgery", but she noted 'I don't think that's going to happen with this... especially with this in dementia, and just working with people, and trying to keep them active and involved. I think you need a person to facilitate that. But I think the [system] is a good tool to help with that. But I don't think it'll replace a human.' S5 described her change in her perception of the system, saying '[at first] the idea seemed like would that then replace an activity person, if we already had this machine that had all these programs with it? But I think it just enhanced it or made it easier, just made it better, not necessarily replaced it.'

S3 said that she could imagine staff in a different facility using the system as a "babysitter" if they weren't comfortable working with people with dementia.

Another concern, brought up by FM1, was that R1 would be very upset once the sessions ended. This reflects a concern of implementing an intervention with vulnerable populations only to withdraw it when the study ends. Another issue, voiced by S3 during several interviews, was that clicking on links to the internet might result in something inappropriate "Cause it might say something like laughing babies but then you get some something weird, sexual or something." Family members did not mention concerns about inappropriate content.

Uninteresting Content

Other challenges arose regarding content, with some content seen as boring to both staff and residents. Staff appreciated that some content, such as movies and TV shows, was rotated monthly, but many found that there were too few episodes or movies. S5 said having a small number of episodes of a show was an issue "Because they probably don't remember that they've already seen it… but I've played this three times already in the past day." Though residents may not have noticed the repetitiveness of content due to their memory impairments, staff were bored by limited content.

Physical aspects of the system

Finally, some challenges arose related to physical aspects of the system. One such issue was ownership, as the content was all on a single system (as opposed to a service that could be accessed from various computers). FM3 said she used the system with R3 a few times without the authors, but "a lot of times it's just kind of difficult because they're either using it to show a movie to the group, so then I'm not going to interrupt that, or it just doesn't seem like there's a time and place where I can pull it…" On the other hand, S5 said that having the system unavailable when the first author was using it with residents was not problematic because "we could find something else to do." As opposed to staff, FM3 found it more important to use the system at a specific time, perhaps because she came at specific times of day.

Other issues related to the physical nature of the system was that it was considered ugly and flimsy by S3 and bulky by FM1.

2.4.4.3 Influencers

A third theme that arose from analysis of the transcripts was that many factors affected the experience of use of the system. I will refer to these factors as influencers.

Facilitator

One influencer I identified was that the facilitator who used the system with the resident greatly affected the experience of the resident. The facilitator was typically a staff member or myself, and occasionally family members who came to sessions or used the system with residents independently. The involvement of a facilitator was key because, as both I and staff noted, residents were unable to use the system on their own due to cognitive impairments and the complexity of the system. Residents needed frequent instruction to use the system and did not usually retain information between sessions. Thus they required prompting from another individual to successfully interact with the system. Who the person was that assisted the resident and their relationship with the resident was important. FM3 recalled: “One time when I was using [the system], and [R3] was playing blackjack, I had to leave, and I said 'you know you can still keep playing' and she's like 'no, I don't want to.' And one of the staff members even said 'well, I'll watch you for a while' but I think she just lost interest after I left.” In this case, the presence of FM3 may have been an essential component that made the activity enjoyable for R3.

FM1 highlighted the importance of the personal characteristics and personality of the person assisting residents in using the system, stating that in order for optimal use of the system, a facility needs to “have to have the right person [to use the system with a resident]. If you don't have… someone with a nice personality that is enthusiastic about it, if you took one of the employees here that is assigned to do it and they don't want to do it or they are scared of technology and don't know how to do it themselves, it's gonna be a complete failure. You have to have someone that's knowledgeable with the equipment, someone that has a good personality to deal with people with dementia, and someone that has just the right overall attitude.” As the above quotes indicates, facilitators were important not only to assist the resident in the technical aspects of using the system, but also to provide encouragement in its use.

One-on-one or in a Group

Another influencer of a positive experience was whether the system was used one-on-one or in a group. Many staff pointed out that the system would probably be more beneficial in a one-on-one setting or small group. They attributed this in part to the varying levels of dementia of residents: S3 said the games on the system would be more beneficial in a one-on-one setting "Because, you know where that person's at, physically and mentally. When you're in a group, I have such a variety of levels and it's hard to meet everyone's need." Additionally, many of the applications, such as puzzles, could only be used by one person. Staff noted that "unless [the residents are] the ones that have the mouse, it's easier for them to kind of sit there and not get involved in it."

Attitudes towards or experience with computers

Another factor believed by staff and family members to influence and mediate system use were attitudes towards or experience with computers. RM1 mentioned that she thought she would enjoy using a computer as she had fond memories of using a typewriter for work; in contrast, RM2 said, "I think that would be good for some of the people who know how to use the computer. I don't. I wouldn't know what to do with it" and that "I've talked about this with some of my older friends, and we've all said we weren't too interested in learning about it. We're of an age where we don't feel it's important to us." Both her inexperience with and disinterest in computers contributed to her hesitance in wanting to use the computer in the activity group. Experience did not always facilitate the desire to use the computer: RM3 said "I had a computer in business from before you were born. And it was a very necessary thing. But as I got older and as I got out of business and sold everything, I didn't need it any more. And I divorced myself of it."

Two family members said that since their relatives were not familiar with modern technology, they might be uninterested or unable to use the technology. Additionally, S2 brought up an incident where the system did not work and residents said "'why do we have to use computers all the time'… It gets them riled up and then they start complaining about computers and stuff like that." Residents' negative attitudes of technology may have contributed to them being more impatient or expressing more negative thoughts about the situation. On the other hand, FM1 thought R1 enjoyed using the computer "because she knew computers are a big deal and only

young kids can do those but she was smart because she could use a computer." During sessions with residents, however, it was not obvious to us that negative (or positive) attitudes affected their enjoyment of the system.

Familiarity with computers also appeared to be a facilitator for staff, as S9 said: "I don't know why it takes a little bit of difficulties off of us to just have the computer there to kind of be helping… maybe since I've grown up working with computers or being around computers, maybe I'm just more comfortable with it, having something there."

Frequency of use

Some influencers had to do with the continued use of the system, such as frequency of use. FM3 thought she hadn't seen any effects on the quality of life for her relative "just because she hasn't been using it consistently enough". FM5 said that one hour a week would have " absolutely minimal effect." On the other hand, FM1 thought that having the first author come weekly for an hour a week had huge benefits for her relative- however, her relative participated in more sessions and more consistently than the other residents.

Effect of time

Another influencer related to continued use of the system was the effect of time. Staff had a strikingly different attitude towards the system at the beginning of the study and at the end, including their assessment of the usability of the system and whether they thought the system would replace human care. As S3 said, there was also a "learning curve," as might be expected for any new technology.

2.5 DISCUSSION

This study has contributed to the body of research on multi-functional systems for dementia in several ways. First, it involved individuals with mild to moderate dementia where previous studies have focused mainly on people with early dementia. I do note, however, that this inclusion led to increased subject withdrawal from the study due to residents moving to more involved care settings. This should be a consideration for future investigators to consider in

either the environment or the length of procedures. Second, staff used the system in an immersive MCU for six months, which is a long-term study with this population. The length of the study allowed me to see how staff opinions changed over time, which was very valuable as many staff members initially had negative opinions of the system which became much more favorable as the study went on. Another strength of this study is that I evaluated the tool with three users groups where other studies typically examined just one or two of these user groups. One especially important finding from the perspective of the family member and reinforced by the staff was the importance of the facilitator's personality in using the tool with people with dementia. Future work using systems in these settings should report on the specific role and qualifications of the facilitator/interventionist. Additionally, this study included a system with many different applications, thereby allowing me to see which types of activities were used and how.

Another important finding was that the though the system may not alter the fundamental elements of the relationships family and staff have with the person with dementia, it did provide opportunities to support interactions, particularly around reminiscence. In particular, the finding that others benefited from the use of the system through finding out new information about people with dementia is echoed in a study by Gowans et al. who found that when caregivers used a system to support reminiscence therapy with a person with dementia, they heard stories they had not heard before (Gowans et al., 2004).

Utilizing a device to support interactions between people with dementia and caregivers is a very different usage of a device than done in some other studies, such as by Lim et al., whose motivation to have people with dementia use tablets was to provide them with an activity to do on their own to provide respite to caregivers (Lim, Wallace, Luszcz, & Reynolds, 2013). Though it is certainly important to facilitate activities that people with dementia can do on their own, I found that having the caregivers using the system with residents was actually a way for them to engage in a mutually enjoyable activity. This may be partially attributable to the family members in this study being distant caregivers, who did not have the same need for respite, as well as some self-selection in who decided to take part in the study and attend sessions with relatives in the MCU.

Finally, the use of a tool with many applications allowed me to tailor the activities in order to involve and capture the diverse interests of a group of individuals. With a variety of applications on a single device it was possible to use with both individuals and groups, and to meet interests in a more personalized fashion which may not have been possible with a different device. Consistent with activity theory, which posits that people should continue doing as many of the activities they enjoy as possible as they age, and modify or replace activities that they can no longer do (Havighurst, 1961) people with dementia in this study were able to find meaning in applications that were tailored to their interest and which often reflected past interests.

Many studies have used older materials with people with dementia to prompt reminiscence (e.g. Gowans et al., 2004, Yasuda, Kuwahara, & Morimoto, 2009). Though older materials were greatly enjoyed by many residents, not all content should be from past eras, as interest in activities change over time and the introduction of novel media such as "zoo cams" (live streams of animals) was also found to be highly enjoyable. I also found that certain applications such as music, videos, and TV were used with larger groups, while games were used and said to be more feasible one on one.

Facilities that might be interested in using similar systems should realize that staff may take several months to adopt a system and integrate it into their activity planning. Further, to support increased uptake it is extremely important to determine if technical and usability issues are affecting use at the onset and to remedy them as soon as possible. It is also very important in introducing such a system to be clear on the intent of use, as fears related to the system replacing staff may reduce its acceptability and create a barrier to use and adoption. This type of device may also be of particular benefit in settings with fewer available resources, where a full time activity director is not available, as activity directors may have a complete set of activities that they already find beneficial for residents and may have little need for a new system. Lastly, during planning for rollout of similar systems, facilities should plan on the need for staff, volunteers, or family members to work with residents, as it is unlikely that persons with cognitive impairments will use the system on their own. It should also be decided whether staff will be given time to use the system in one-on-one settings or in smaller groups.

Limitations of the study include the small sample size, which did not power for statistical analysis of the quantitative measures as well as lack of a control group. Additionally, only one resident in the MCU group completed six months as residents either dropped out or enrolled several months into the study. Future research should overenroll and involve multiple communities to increase sample size in order to make quantitative measurements more interpretable and test such systems against control (e.g. attention group) to draw out whether positive effects of the intervention are due to the role of the facilitator or the system itself. Additionally, the study took place in a single facility catering to people in the upper socioeconomic strata, with limited diversity in terms of family member racial and ethnic groups. Further work should look to examine perceptions of other racial/ethnic groups and other socioeconomic levels of system use and integration.

2.6 CONCLUSION

In this paper, I discuss a field deployment of a multi-functional technology tool used in a memory care unit for six months and an activity group for three months. I analyzed interviews with family members, staff, and individuals with dementia to generate themes regarding perceptions and use of the system. I describe benefits such as enjoyment for residents and staff, mental stimulation for residents, and the facilitation of interactions for residents, family members, and staff. Challenges of the system such as technical issues as well as ethical issues are also discussed. Finally, I outline influencers of system use such as single or group use. Findings can inform researchers using multi-media and multi-functional technology systems in MCUs as well as designers and users of such systems.

Chapter 3. PAPER 3: INVOLVING FAMILY MEMBERS IN A FIELD STUDY OF A TECHNOLOGY FOR PEOPLE WITH DEMENTIA: A DYAD CASE STUDY[4]

In this chapter, I explore the experience of a dyad resident and family member who took part in the field study described in chapter three. I discuss the ways the family member integrated the system used in the study into her care for her relative with dementia.

3.1 Introduction and Related Work

To date, technology has been overwhelmingly used to relieve caregiving burden rather than creating opportunities for people with dementia to engage in meaningful activities (Smith & Mountain, 2012). Previous research has involved family members at various stages of the design process of technologies that support caregivers in caring for people with dementia or that assist people with dementia with functional limitations. In one project, researchers gathered requirements from informal caregivers to design a device to reduce repetitive questioning (Hawkey, Inkpen, Rockwood, Mcallister, & Slonim, 2005).

Some studies have involved informal caregivers and relatives in the design of technologies to support recreational andleisure activities for people with dementia. The CogKnow Day Navigator is an application that runs on a desktop and mobile phone and was designed to assist people with mild dementia in functional, social, and recreational areas (e.g. through a simplified music player). The developers of the system included informal caregivers in the design process by having them prioritize needs and possible solutions. In evaluating this technology, Meiland et al. found that informal caregivers were able to discuss the kinds of technology they would want to use with their relatives with dementia (Meiland, Dröes, Sävenstedt, Bergvall-Kåreborn, & Andersson, 2010). Another project involved distant family members of a woman living in a long-term care facility as proxies for participatory design and found that family members wanted to

[4] This chapter is adapted from Lazar, Demiris, & Thompson, 2015.

significantly contribute to the design and research process (Cohene, Baecker, Marziali, & Mindy, 2007).

While the studies described above do involve informal caregivers, they lack in-depth perspectives of family members over the course of technology deployments designed to support activities of people with dementia. Given family members' willingness to take part in design and research studies and their unique perspective about the ways dementia affects their loved one and themselves, it is important to solicit their feedback and perceptions during technology deployment. In this paper, I utilize a case study approach to explore the experience of a family member along with a relative with dementia living in an MCU who took part in the study described in Chapter 3.

3.2 METHODS

This paper involves a participant dyad from the field deployment described in chapter three. In this paper, I focus on one family member and resident dyad to explore their perceptions of the intervention as well as its impact on their relationship. Interviews were administered to the family member at baseline, midpoint, and exit. The interviews were transcribed and verified and then coded using open and axial coding. As themes emerged, they were entered into a codebook and iteratively grouped as sub-themes for larger themes that emerged.

3.3 FINDINGS

3.3.1 *The Case Dyad*

The dyad described in this paper consists of an 86-year-old woman, referred to as Kay, and her 60-year-old daughter, referred to as Flora. Both described themselves as very comfortable using computers. Kay's score on the MMSE was 16 at baseline (a score associated with having moderate dementia) and 21 at the midpoint and end of the study (an improvement) (Folstein, Folstein, & McHugh, 1975). Kay resided in the MCU but was also a part of the activity group. On the Positive Affect Index, which measures aspects of closeness through questions such as

how well relatives get along, Flora scored 29 on five single-item indicators of the Positive Affect Index at baseline, indicating a high degree of closeness (Bengtson, 1982). This score did not change substantively at six months.

3.3.2 *Qualitative Results*

Several themes emerged through our analysis of the data. Flora maintained an awareness of Kay's interests and abilities, facilitated activities for Kay by scheduling them and personally taking a role in the activities, and acknowledged and found ways to avoid external barriers. Flora also cultivated Kay's positive emotions and attempted to reduce instances of negative emotions. Finally, Flora attempted to fit technology into Kay's routine to enhance her activity schedule and quality of life.

3.3.2.1 Awareness of Activity Preferences and Abilities

Awareness of interests

When asked what types of things Kay might like to do with the system deployed in this study, Flora was able to easily answer the things Kay would and would not like to do. She actively discovered Kay's interests by staying in touch with the people running the activity group, saying since Kay had been there "I never knew that about my mom, but since she's been here… she's quite the little crafty gal."

Flora continued to discover Kay's interests through use of the system. She encouraged me to send a summary of session activities to her and she also attended some sessions. One discovery Flora made was that Kay enjoyed singing: "One of the first times we sat there and did the karaoke, and I saw that she really liked that… then I started noticing the singing on the [activity group] calendar so I started having her go to those… I'm learning more and more." The system exposed Kay to new activities and Flora appreciated learning more about Kay's interests so that she could incorporate these activities into Kay's schedule.

Awareness of Limitations

Flora demonstrated an awareness of the things Kay found difficult due to her cognitive impairments. For example, she scheduled activities for Kay as she realized "She's not going to be able to look at those calendars [distributed by staff] and go 'today is the seventh, they're singing at ten thirty, I'd better be there'. She can't do that anymore."

Her understanding of Kay's limitations in regards to the computer used in the study came across in her assessment that "She could never [use the system on her own], really." She realized that Kay was not able to remember how to use the system but benefited in other ways. She also understood the importance of having a single volunteer returning to use the system with Kay. She also noted that if Kay were to use the system on her own, without a facilitator, it would have to be "a thousand percent easier then what it is now." She suggested having a smaller number of applications and fewer steps to go to applications for individual use by people with cognitive impairments.

3.3.2.2 Facilitation of activities

Promoting Ongoing Engagement

Flora scheduled activities, particularly those involving technology, for Kay to ensure that her weeks would be filled with enjoyable activities. Flora signed Kay up for the activity group as soon as it was brought to the facility, and said "And of course, as with this [study], I signed up mom right away…" Flora was able to expose Kay to a variety of beneficial activities by proactively discovering and facilitating opportunities.

Personally participating in activities

Flora personally participated in many of the activities she scheduled for Kay. For example, when Kay was living independently, Flora attended Wii bowling when there were not enough people for Kay to play.

Flora took it for granted that she would attend sessions for this study, saying "of course I'll go and help her do it a couple of times to get her going." In part, she saw her presence as a way of

helping Kay feel comfortable using certain applications such as Skype, saying “she’d want me to do it with her, she wouldn’t do it by herself.” Flora did attend several sessions with me and Kay, and used it once alone with Kay. Though Flora said that Kay enjoyed using the computer, Flora also said that “She's in this building twenty four seven, 365, unless I take her out. So when I come, she wants to go somewhere.” Despite being enthusiastic about the system used in the study, Flora chose to do activities with her mother outside of where Kay lived as she recognized Kay’s desire to go outside the facility.

Emotional Activation

Along with scheduling and participating in activities with Kay, Flora would motivate Kay to partake in activities. For example, she motivated Kay to learn to use a cellphone by telling her she could use it to call her sister, with whom she enjoyed long conversations.

In the context of this study, Flora motivated Kay by speaking to her before and after sessions with the system. She said “I would always try and jog her memory… knowing that if I got an email from you that said that you did that [activity], then I could say 'you must of had some fun' and she goes 'we had so much fun…' But it takes the supporting cast to really do that. Because I can't just say 'did you have fun with [Amanda] today', she'll say 'yes', that's the end of that conversation...” Likely in part due to Flora’s enthusiasm, Kay looked forward to sessions and was able to relive some of the positive interaction afterwards by talking to Flora.

Acknowledgment of Individual Barriers to Adoption

Flora expressed disappointment in the ways she perceived that the facility did not share her enthusiasm for activities, including technology-based activities. For instance, she stated “the workers on mom's floor, they're either overwhelmed, overworked with everyone, and can't even think about something that might be fun.” In general, she saw commitment from staff members as essential for activities, saying, “you have to have buy-in from the top, everyone has to be excited about it, you have to really get the activity director and their staff jazzed about it… And if there's no buy-in, you might as well take your toys and go home. Because it's just not going to work here or anywhere.” Flora understood the need for staff to be enthusiastic and comfortable with technology for a technology-based activity intervention to work.

Flora felt frustrated about the lack of enthusiasm and knowledge she perceived staff had for the system used in this study. Flora took it upon herself to tell the activity group about the system when she realized that there was not communication between the MCU and the activity group about its existence, which initiated my implementing use of the system in the activity group as well.

3.3.2.3 Cultivation of emotions

Empowerment and Self-esteem

Flora emphasized both with system use and other activities the need to encourage positive emotions for her mother. Flora called the MCU the "gold medal floor" and told her mother that "…she's in the first class section, like on an airplane." Additionally, Flora empowered her mother by giving her choices in decisions such as whether to go to activities: "I tell her now… 'you're in charge. If you don't want to do something today, don't. If you want to stay in your room, you get to.'"

Flora appreciated the ways the system helped Kay feel special and empowered. When asked what specific types of applications Kay would enjoy, Flora answered but also said "I think we just have to see what she likes. She's in charge," thereby indicating that Kay was the ultimate arbiter of what she liked to do. Once the study began, Kay pointed out that using the computer helped Flora have a sense of accomplishment and feel good about herself, "Because even if [people with dementia are] not with everything that's going on in the world around them, they all have in their brain that computers are it, and if they get to be on a computer, they're gonna feel good about that." Additionally, she said that Kay benefited from sessions "Because it was one-on-one with her. So she was special."

Reduction of Negative Emotions

In addition to promoting positive feelings in Kay, Flora attempted to reduce negative emotions. One way she did this was through avoiding bringing up sad memories. Consistent with this,

Flora was wary of pictures of Kay's husband being shown to Kay on the system due to her fear that they would bring up negative emotions, as Kay had taken some time to remember and come to terms with her husband passing away. Just as Flora protected Kay from negative emotions daily in their face-to-face or phone interactions, she did so during the use of the system.

3.3.2.4 Fit of technology into routine

Utilization and Expectations of Technology

Flora had a history of encouraging Kay to use technology, such as asking Kay to take a computer class at age 65. Flora had specific reasons for wanting Kay to learn to use different technologies, such as being able to stay in contact with her, and she saw technology as a solution to these needs. She also encouraged Kay to use technology for fun, with applications such as Wii bowling. Consistent with her expectations of technology as useful, Flora thought that the technology would be beneficial during the baseline interview. For example, she asked if she could email pictures to Kay so she would not have to print pictures to bring to show her. Flora indicated that the system in this study would be fun before ever seeing it or using it, consistent with her conception of technology as being enjoyable.

Technology to help people with dementia

In addition to seeing technology as useful and enjoyable, Flora saw technology as a key to her own care plan if she got dementia: "and if it turns out to be hereditary, I'm going to be like [my mother]… so I'm trying to do everything I can to not get down the road like that, and computers I think are a huge way [to prevent that]." One way she saw the system used in the study as beneficial for people with dementia was in helping those who had lost verbal abilities. Flora said, "…[a] lot of the dementia people I've noticed can't speak. That doesn't mean there's not a light on behind their eyes, and if they could communicate, they would. And if this [computer] program could do that, help them point to it and say 'water' or… 'I wanna play cards'… I think it could really help." Flora saw the system used in the study as helpful for people with dementia to communicate.

3.4 DISCUSSION

I explored the experience of a dyad from a study of a system introduced to an MCU and activity group to support engagement in activities. This study adds to the body or research demonstrating that family members can benefit from being more involved with relatives in an MCU (e.g. Kellett, 2007). The distant caregiver benefited from using the system by being able to augment her usual care. Some ways she did so were through awareness of her mother's activity preferences, facilitating activities the she enjoyed, and fitting technology into her routine.

Researchers and product designers should be motivated to accommodate and invite the involvement of family members in studies with people with dementia and as a user group who may be using technologies with people with dementia. The impetus to do so lies in the benefits experienced by family members such as those in this study. Also, family members may see uses for technology that others may not. Koch stresses the role family members may play in recognizing the capabilities of technology to serve as assistive aids for older adults (Koch, 2010). The case I describe is an example of this, as Flora found a myriad of benefits and uses for the system employed in this study. Thus, family members should be included as targets of both research and product development, not instead of, but in addition to people with dementia. Many studies have found that older adults are willing to use new technologies (e.g. Demiris et al., 2004; Heinz, Martin, & Margrett, 2013; Parker, Jessel, Richardson, & Reid, 2013) and this dyad's enthusiasm for using the system in the study is yet another conformation that age and ability do not preclude technology use. Researchers and developers should continue to design and test new technologies with older adults and family members and not assume that these technologies will be rejected due to their novelty.

] Flora felt that her mother could not obtain sufficient meaningful engagement in activities on her own due to the limited level of enthusiasm she perceived from staff. In a different setting where Flora felt that staff's involvement was sufficient, she might have taken a less involved role. Designers should understand the settings where the technology may be introduced, and understand the needs of and possible skepticism of staff and be prepared to address it proactively. Additionally, staff and family members may be interested in different kinds of

applications and features (e.g. family members may wish to use one-on-one games intimately with a relative, where staff would wish to use group games to engage a large number of residents). Technologies of this kind should be designed and tested accordingly. Finally, it may be of interest to researchers to identify whether family members take a more involved role when staff members appear more involved.

It may be important to investigate in detail some of the most salient motivators that encourage family members to be interested in using technology with relatives with dementia. These motivators can then be emphasized in recruitment materials or study design. For example, I saw that Flora was interested in adding an activity to Kay's schedule: in the future for similar interventions, I may emphasize in recruitment materials that taking part in the study could provide a weekly activity for residents.

As this is the analysis of a single case study, it is not meant to be representative of other's experiences. However, it does contribute to the body of research stating that some family members of people with dementia are willing and enthusiastic to be in studies that involve technology (Cohene et al., 2007) and can contribute to the research process. Future researchers should examine whether some of the factors that motivated Flora to participate in this study are present in other family members, and the other types of motivating factors that encourage family members to participate in research involving existing and novel technological systems to encourage people with dementia to take part in recreational activities.

3.5 CONCLUSION

In this paper, I present a dyadic case study from a six-month study evaluating a system designed to engage people with dementia in activities in a memory care unit (MCU). Findings include that the family member used the computer in a manner consistent with her usual style of interaction and supportive care. For example, she continued to maintain an awareness of her relative's activity preferences and cultivated her mother's quality of life, fitting the technology into these efforts. These findings demonstrate a use case for such technologies to support activities of older

adults with dementia while engaging family members, and provide future directions for technology design and research in this population.

Chapter 4. PAPER 4: RECOMMENDATIONS FOR DESIGNERS OF SYSTEMS TO PROMOTE ENGAGEMENT IN RECREATIONAL ACTIVITIES FOR PEOPLE WITH DEMENTIA

In this paper, I present recommendations for designers of ICT systems to promote recreation for people with dementia in memory care units. Recommendations were generated from fieldwork and refined in two rounds of feedback from experts in the field of human computer interaction and gerontology. Recommendations aim to increase the autonomy and empowerment of people with dementia and take into account factors such as the time pressure staff often experience when working in a memory care unit. Areas covered include hardware, content, applications, and navigation. The importance of creating a system usable by people with dementia and the need for a diversity of materials on the system are also discussed.

4.1 Introduction and Related Work

Tak et al. created a framework for tailored computer activity interventions for people with dementia (Tak, Zhang, Patel, & Hong, 2015). According to the framework, when designed with individual characteristics in mind, three components- format, content, and procedure- affect engagement and, consequently, health outcomes. This framework is useful to guide researchers and designers, but there is a need for specific, concrete, actionable recommendations within these different categories.

Researchers have generated recommendations for designers of systems for people with dementia, primarily as a set of requirements guiding the design of an intervention or as part of a discussion of an evaluation of an intervention. Gowans et al. identified several criteria for a system that can meet the needs of people with dementia, families, and caregivers, such as supporting intuitive navigation, supporting customization and supporting people with dementia in having an equitable role in the conversation (Gowans et al., 2007). Mayer et al. generated guidelines based

on a survey of existing research, focus groups, and the evaluation of a prototype of a touch screen device to assist people with dementia in performing daily activities (Mayer & Zach, 2013). The authors stressed the importance of having clear instructions and a learnable system, as people with dementia may forget how to use the system each time they use it. Other guidelines include the need to involve others in using the system with the person with dementia, as it can be too difficult for the individual with dementia to use it alone as the condition progresses. Guidelines also address the need to minimize the complexity of the system. Boman et al. highlighted the need for simple and intuitive systems in their user requirements, which are organized in terms of the Universal Design principles (Boman, Rosenberg, Lundberg, & Nygård, 2012). Another group of researchers also used the Universal Design Principles as a framework to structure recommendations and to design a system that resembles a karaoke application for people with dementia (Outi & Päivi, 2009). Outi et al. summarized principles to guide the design of technology to create opportunities for meaningful and pleasurable activities, including providing positive feedback only, and promoting a sense of independence in users with dementia.

Though the above recommendations are useful as guiding principles for designers of systems for people with dementia, the guidelines are either too broad to be actionable or are not comprehensive. Additionally, they do not focus specifically on design for the memory care unit environment, and many appear to refer to design for individual use of the system, as opposed to a shared system. As 30-40% of people with dementia live in assisted living facilities such as MCUs (Alzheimer's Association, 2012), there is a need for recommendations that focus on systems specifically for the memory care setting.

4.2 METHODS

4.2.1 *Fieldwork*

The initial draft recommendations were generated based on a field test of a commercially available system designed to promote engagement in recreational activities for people with dementia. The system was evaluated with multiple groups of stakeholders in multiple settings:

one on one with individuals with dementia in weekly sessions, during group use with staff, and in a smaller activity group for people with less severe cognitive impairments than those in the MCU. The general findings of this study are described in Chapters 3 and 4. The recommendations described in this paper were generated through content analysis of interviews with staff, residents with cognitive impairments, and family members who used the system in the study, as well as detailed notes taken in observations of system use in these settings. Interviews and notes were analyzed using Nvivo Version 8.

4.2.2 *Assumptions and Guiding Principles for Recommendations*

A number of principles that emerged from the data and literature guided the recommendations. These principles relate to the role of the facilitator, control over the system, the importance of the technology being ability-focused, and the setting guided the recommendations.

For the implementation of these recommendations, it is assumed that, given the cognitive impairments of people in MCUs, there will need to be a facilitator present to use the system with the person with dementia. A facilitator might be a staff member of the MCU, a family member, or a volunteer visiting the unit. In addition to ensuring the person with dementia can use the system, it is important to have a facilitator present to avoid the technology being used to replace human care.

The second principle is that despite the presence of the facilitator for assistance, the recommendations are designed to give the user with dementia as much ownership and control over the system as possible in order to reinforce the user's autonomy.

The third principle is that the recommendations are ability-focused, taking into account the strengths of people with dementia such as their ability to engage in certain activities that they enjoy.

Finally, the recommendations take into account aspects that are likely to exist in an MCU, such as the need for mobility and flexibility given factors such as the time pressure felt by staff in this

setting. One element of flexibility in this setting is the possible scenarios in which such a system might be used: it is possible that they system would be used with a group of users with dementia, as well as with an individual user.

4.2.3 *Expert review*

The draft recommendations that derived from the field study were then vetted with a group of experts in two areas: gerontology (n=3) and human computer interaction (n=4). Inclusion criteria for experts were that they had published several first authored papers in their field (similar to criteria for experts in Delphi studies, e.g. Jeste et al., 2010; Snelson, Rice, & Wyzard, 2012). The average age of the experts was 44.2, with a standard deviation of 12.7. Three of the experts were female, four were male, and all were based in the US. All participants were professors of research universities.

I solicited feedback from experts in two rounds: in the first round, experts took part in a 30 minute audio-recorded interview during which they were asked to review the recommendations and offer feedback on their clarity, usefulness, and validity. The recommendations were then revised based on expert feedback and a second draft was sent to experts to review along with an online survey which asked experts to rate the clarity, usefulness, and validity of the recommendations on a five point Likert scale (with increasing scores corresponding to increased clarity, usefulness, or validity), as well as provide additional feedback.

The average of expert's scores for usefulness was 4.3; clarity 4.4; and validity 4.6. Recommendations were revised again to incorporate feedback from the second round.

4.3 FINDINGS

The complete text of the recommendations can be found in Appendix C. The text includes an introductory section that discusses underlying assumptions and guiding principles that arose from the data and the literature that guided the recommendations. The recommendations below are grouped into five categories: hardware, content, applications, specific applications (games

and media), and navigation. Below, sections of the recommendations are described and expanded upon.

4.3.1 *Hardware*

I recommend a touchscreen system over a traditional mouse and keyboard interface. The touchscreens was intuitive for the participants in the field study that these recommendations are based on as well as several other studies (e.g. S. Smith, Mountain, & Hawkins, 2013). Though touchscreen is the main type of input I recommend for users with dementia, I also suggest including a wireless keyboard that facilitators can use to be further away from the system during group use. Additionally, though the touchscreen is appropriate for one-on-one use with people with dementia, it is likely that facilitators will want to plug the system into a large monitor for group use to enlarge content. I recommend making the process of connecting the system to a monitor as seamless and intuitive as possible to lower barriers staff experience due to time pressure.

4.3.2 *Content*

I recommend that designers include access to a large body of applications. People with dementia will have very diverse interests and cultural backgrounds. Additionally, dementia affects people across a number of decades, so content that evokes reminiscence needs to be specialized to appeal to people from different generations. It is especially important to include content that is diverse enough that some application is sure to appeal to most individuals interested in using the system. This is, in part, because as dementia progresses, people's interests are likely to become restricted (Hughes, Berg, Danziger, Coben, & Martin, 1982). However, interests can remain quite consistent and people will be able to experience enjoyment from using applications that are centered on certain areas of interests.

Recommendations in this section also pertain to the forms of media use (e.g. audio, video, text, and images). It is recommended that if using multiple forms of media, the message communicated by the different media forms is congruent to minimize confusing the user.

4.3.3 *Applications*

Some of the recommendations in this section pertain to accessibility. Older adults with dementia are likely to have vision and hearing impairments (Cohen-Mansfield, Marx, Regier, & Dakheel-Ali, 2009). Therefore, it is important to have large font sizes and images. It is also important to enable size and contrast increases, as well as an intuitive way for the person with dementia to adjust audio.

Many of the other recommendations in this section assist system designers in designing to avoid highlighting some of the difficulties people with dementia may have with comprehension and attention. Some of these recommendations address appropriate language by suggesting that designers avoid complex language, abbreviations, metaphors, and technical jargon. It is also important to minimize the amount of text that appears on the screen, as it has been found that people with dementia are likely to read irrelevant information in addition to relevant information (Passini, Pigot, Rainville, & Tetreault, 2000) (e.g. people with dementia may read instructions of how to use an application every time they appear, even if they are for a game they had just played). In general, I recommend eliminating on-screen instructions whenever possible. One way to eliminate instructions is by scaffolding applications such that it is obvious what to do next. Other alternatives are to have instructions available through a consistently placed and intuitive icon (such as a question mark), or to have instructions appear as they are needed, rather than all at once at the beginning of an application.

4.3.4 *Specific Applications: Games*

As games are a popular and effective recreational activity, and many recommendations arose from the data regarding games, I have a section of recommendations specifically about games. The games that designers choose to put on their systems may be diverse, including puzzles, trivia, group games such as “Family Feud”, and individual games such as Solitaire which come preloaded on many computer systems. One recommendation is that regardless of the game, feedback on scores should be kept kept positive or neutral, as I saw participants react with self-criticism to poor scores. I do not recommend hiding low scores, but rather framing them in a

positive way, such as writing ‘seven right’ instead of ‘63% right’. If it is important to track progress for cognitive training, keep scores somewhere the facilitator can access it. This recommendation in particular is suited more to people with moderate to severe dementia, as people with very mild dementia may wish to view scores and progress.

I also suggest that games include challenging elements and clear goals, as these components can make games more enjoyable. Though some games designed for people with dementia are designed as ‘failure-free’ games (e.g. popping bubbles), in my experience, these were not appreciated (though perhaps they might be appreciated by people with more severe dementia). Involving challenging elements does bring additional issues, as a balance must be found: games that are too easy may be found boring, but games that are too difficult will most likely be frustrating. I recommend that difficulty is not configured at the time of play, as people with dementia may misestimate the difficulty level they will be able to play at and then feel frustrated and wish to end a session. Instead, I recommend a learning system that automatically adjusts to find an appropriate difficulty level. If this is not possible, it is advised to allow a facilitator to select a difficulty level ahead of time.

4.3.5 *Specific Applications: Reminiscence Media and Other Media*

Recommendations regarding reminiscence media and other types of media (e.g. current and older movies, music, recent pictures, or travel videos) are grouped, as it can be difficult to draw a line at what should be considered reminiscence media and what should not. Newer materials may evoke strong memories in people with dementia, and older materials may not necessarily be evocative or even remembered.

Recommendations include what kinds of question types are appropriate for this population, as some media designed for people with dementia (particularly for reminiscence) contain questions and prompts to elicit conversation. I suggest that designers avoid prompts that rely on people with dementia remembering specific facts, as it can be distressing for a person with dementia to be asked a question that they think they should know an answer to but do not (such as the name

of a sibling). It is also suggested that designers stay away from yes and no questions, and instead use questions that can lead to a conversation.

4.3.6 *Navigation*

Recommendations for navigation take into account the assumption that the system will be used in multiple ways: one-on-one with a resident directing use, as well in a group with a facilitator directing use. Therefore, I recommend that there be multiple modes for accessing applications. Users with dementia should navigate via a free explore screen (which shows certain applications divided into categories), as they may not remember the name of the application they wish to access. However, facilitators may appreciate a search function in the event that they are looking for a specific application to use.

Though I recommend touchscreens over other modes of interaction such as mouse and keyboard, the use of a touchscreen can result in difficulties for people with dementia. It may be difficult for the user to learn the precise kind of touch that is accepted by a touch screen: the system should accept double taps, touches with tremor, and longer or shorter touches. Additionally, interactive elements should be far enough apart that it is unlikely for a user to accidentally tap the wrong one, as it can be difficult for a user to recover from errors.

4.4 DISCUSSION

These recommendations are consistent with the tenants of activity theory, which emphasizes the benefits of activities for older adults and recognizes the need to modify activities that they have difficulty doing due to age-related factors, and in this case, cognitive impairment (Havighurst, 1961). Information and communication technology tools have the potential to facilitate modified activities that are better suited to the needs of people with dementia, particularly when attention is paid to supporting autonomy and control, avoiding usability issues that make activities difficult to carry out, matching activities to an individual's unique interests, and negotiating the role of the facilitator.

The role of the facilitator is highlighted within the recommendations, as one of the guiding assumptions is that a facilitator will be present. Though one reason for this is that it is assumed that it would be difficult for the person with dementia to operate the system completely independently, it is also beneficial for the purpose of increasing opportunities for people with dementia to interact with others. Though movies and television shows are sometimes suitable activities, it is important that the technology is not used solely to provide entertainment that decreases a person's active engagement level. Indeed, an ethical concern of using technology for people with dementia is that the technology will replace staff and, consequently, interaction with others (Marshall, 1996). These considerations also highlight the need to balance how engaging applications are to an individual with how much they enable conversation and interactions between the facilitator and the person with dementia.

People with dementia can experience frustration at a loss of abilities (Kitwood, 1997). One way of restoring or reinforcing a sense of autonomy, dignity, and self-esteem is by giving people with dementia decision-making power and control when possible (Zingmark, Sandman, & Norberg, 2002; van Gennip, Pasman, Oosterveld-Vlug, Willems, & Onwuteaka-Philipsen, 2014). This has been identified as important within the design of technology systems by Outi et al., who emphasize that the "experience of competence is crucial to users" (Outi & Päivi, 2009, page 73). Indeed, technology systems have been specifically identified as a way to help people with cognitive impairments retain independence and control (Newell, Carmichael, Gregor, & Alm, 2002). A guiding tenant of these recommendations is to provide the person with dementia control over the system to the maximum extent possible. Some of the recommendations on how to do so may seem extremely minor, such as making the audio control easy to use for the person with dementia so that a facilitator does not need to provide assistance. However, even minor instances of helping people with dementia do something they can do themselves (referred to by Kitwood as "disempowerment"), when repeated, can damage the self-esteem and emotional wellbeing of people with dementia (Kitwood, 1990). Therefore, I stress the importance of making the system as usable for the person with dementia as possible, even though there will likely be a facilitator present to provide assistance as needed. It is important for future research to investigate how system design can encourage the facilitator to hand over control to the person with dementia, as it is possible that facilitators will take control even if the system is usable by the person with

dementia if they are perceived as taking too long or the variety of other factors that lead people to do things for people with dementia that can be done by the individual with dementia if given the right type of support (Kitwood, 1990).

One element that greatly impacts whether the system will be usable by the person with dementia is the amount of technical or usability issues in the system. I emphasize the importance of not taking technical risks, for example by beta-testing applications with this population, particularly in the memory care unit setting. Though there are benefits to using early versions of applications or including additional applications that have usability problems but might be otherwise enjoyable, the difficulty this population experiences recovering from errors is too high to justify doing so. Technical and usability issues also need to be minimized for the sake of staff, who may feel an intense sense of time pressure (Edvardsson, Sandman, Nay, & Karlsson, 2009) and abandon applications that do not work well the first time.

I stress the need for diversity of applications and content for several reasons. First, people with dementia have varying interests and backgrounds and respond to different kinds of activities (Smith, Kolanowski, Buettner, & Buckwalter, 2009). Second, the ability to engage with and the level of interest in different applications can vary with severity of dementia (Tak, Zhang, & Hong, 2015), and people with a wide range of dementia severity may live in the same MCU. Individualized activities that match the interests, abilities, and self-identity of people with dementia can increase the positive affect and enjoyment experienced (Cohen-Mansfield, Parpura-Gill, & Golander, 2006; Gitlin, Winter, Earland, Herge, Chernett, Piersol, & Burke, 2009; Tak, Zhang, Patel, & Hong, 2015; Van Haitsma, Curyto, Abbott, Towsley, Spector, & Kleban, 2015). Finally, people with dementia may be unlikely to take initiative or be able to overcome usability issues to use the system on their own, especially as the condition progresses.
Diverse content can also make the experience more enjoyable for the facilitator. It is essential to make the system usable and enjoyable for the facilitator (Mayer & Zach, 2013), and one element of what makes a system enjoyable for staff is diverse content, as staff note that though people with dementia may not remember content, staff tire of using the same content repeatedly (Lazar, Demiris, et al., n.d.). Thus having a wide variety of content can benefit users with dementia as well as facilitators.

The recommendation to include a large body of applications that is discussed above is at odds with some of the other recommendations, such as those that stress keeping the system as simple as possible for use by people with dementia. Though this tension is somewhat resolved with several proposed ideas (e.g. only showing a subset of the applications), in general, there are tensions that the designer will have to resolve based on the specifics of the environment and users.

4.5 CONCLUSION

In this paper, I present recommendations for designers of recreational technology systems for people with dementia in memory care units. These recommendations were generated through a six-month study deploying a technology tool in a memory care unit and evaluated and revised with expert input. Recommendations encompass areas of design such as hardware, content, applications, and navigation.

Chapter 5. CONCLUSION

5.1 OVERVIEW

In this dissertation, I explore appropriate design of technology to support engagement in activities for people with dementia in memory care units.

In my first paper, I describe existing technologies that have been created to support engagement in a particular activity, reminiscence therapy, for people with dementia. I discuss the purpose the technologies served, such as harnessing the strengths of people with dementia such as the ability to appreciate sensory input and emotional memories. Other purposes technology served include accommodating deficits such as memory and sensory impairments. I also discuss common pitfalls of these technologies, such as difficulties staff and family members had setting up and using them, and challenges with study designs, such as short studies involving limited stakeholders.

In my second paper, I describe a study deploying an existing technology in a memory care unit with a range of dementia severity over six months, and an activity group for people with less severe dementia over three months. I involved people with dementia, their family members, and staff at the memory care unit and activity group. In this paper, I discuss benefits of the system to people with dementia, family members, and staff, such as promoting reminiscence and facilitating interactions. I also describe challenges of the system, such as the great extent to which technical issues affected the use of the system due to the time-pressured nature of an MCU. Finally, I describe influencers such as the facilitator, who enormously impacted the experience of the people with dementia who used the system.

In the third paper, I examine a dyad consisting of a resident and family member from the study described in paper 2. I discuss the ways the family member used the system in the study to care for her relative with dementia and the benefits of involving family members in the evaluation of technologies with people with dementia.

In the fourth paper, I generate recommendations based on findings from the study described in the second paper as well as the input of experts in human computer interaction and gerontology over two rounds of review. The recommendations are intended for designers of systems that promote engagement in recreational activities for people with dementia in memory care units. The recommendations take into account and explicitly acknowledge the importance of accounting for the time pressure experienced in a memory care unit and the various ways cognitive impairment affects people with dementia's ability to utilize a technology system and engage in activities.

5.2 CONTRIBUTIONS

Below, I detail my contributions and the literature that I expand upon through my dissertation work.

5.2.1 *An understanding of how technology impacts activities with people with dementia*

In my first paper (Chapter 2), I explore the literature on how technology has been used to support a specific activity with people with dementia, reminiscence therapy. Previous reviews on the topic have not included a nuanced understanding of the way different types of technology affect the experience of use (Subramaniam & Woods, 2010). I expand on the existing literature through a detailed analysis of how technology can improve the delivery of activity interventions such as reminiscence therapy.

5.2.2 *Recognition of changes over the long term*

Many studies that take place in a memory care unit setting last several weeks at maximum. However, changes occur during longer time spans that cannot be captured in short-term studies. By conducting a field deployment over six months, I was able to understand the way this greater length of time affected staff's willingness to use and comfort with using the system in this study. I contribute to the body of literature through findings related to how staff and family member perceptions of a technology tool in a memory care unit change over time. Some of my findings, such how staff's concern that technology would replace human care was alleviated over time, are

novel and can be acted upon in future interventions (for example, by stressing that the technology is not intended to replace human care in the first few months of a deployment).

5.2.3 *Field deployment of a multi-functional system*

Studies that examine technology for recreational activities with people with dementia typically deploy a system with a single application for a single type of activity (e.g. see systematic reviews on reminiscence therapy (Lazar et al. 2014, Subramaniam et al. 2010)). In papers two and three (chapters three and four), I describe a field deployment of a system with a large variety of activities. By doing so, I was able to see the effects that different types of activities had on staff, family member, and resident experiences. This is a significant contribution to the field that advances the literature through an evaluation of a system with multiple components. This is especially important given the constraints experienced in MCUs (such as limited space to store items and little time for setup and cleanup).

5.2.4 *Involvement of multiple stakeholders and settings*

Studies of technology for dementia may just involve people with dementia, staff, or family members, but rarely all three. In particular, studies often do not include the perspective of people with dementia (Span et al. 2013). In papers 2 and 3 (chapters three and four) of this dissertation, I involve stakeholders from all three groups, and therefore am able to have a comprehensive view of the key players in the care of the person with dementia. By conducting regular sessions using a system with people with dementia as well as soliciting perspectives during sessions and interviewing participants in the activity group, I contribute to a field which does not sufficiently involve the perspective of people with dementia despite designing for them (Span et al. 2013) and even when including their perspectives, rarely involves an individual with dementia actually using the technology (Topo 2009).

In addition to involving multiple stakeholders, I examined the use of the system in multiple settings, such as one-on-one use, use in a large group, and use in a smaller group. By doing so, I was able to see benefits and challenges that emerged in each of these settings, as well as a comprehensive view of how a system would be used in a memory care unit outside of a study. As the setting in which a system is used greatly affects the experience of a person with dementia

(Hagen et al., 2004) and studies in this setting often lack detail on the setting in which a study took place (Topo, 2009), my work presents a nuanced addition to our understanding of how people with dementia and those that care for them use technology in the different settings in which they find themselves.

5.2.5 *Recommendations for a challenging setting*

In paper 4 (chapter 5), I present recommendations for designers of systems to encourage recreation for people with dementia.

There are significant methodological and ethical issues with designing for a population with dementia. Recruitment and conducting studies is extremely difficult (Lazar, Thompson, & Demiris, n.d.), and it may be unethical to test designs on vulnerable populations such as people with dementia if they will not receive direct benefit (Berghmans & Meulen, 1995). Recommendations and heuristics can reduce the number of times people with dementia will be involved in iterations of designs. Currently, recommendations for designers of systems for people with dementia are embedded in papers (often framing the intervention or in the discussion section). Usually, the authors propose small number of recommendations, often at an abstract level that requires a designer to interpret them on their own in order to make them actionable (e.g. see Gowans et al., 2007; Mayer & Zach, 2013; Boman et al., 2012; Outi & Pävi, 2009). Therefore, my contribution to the field is presenting detailed and comprehensive recommendations for system designers. These recommendations in particular take into account constraints that exist in memory care units, such as time pressure staff experience, thereby expanding on the current state of the literature. Additionally, by focusing on giving people with dementia as much control over the system as possible, designers who use these recommendations can increase the likelihood that their design will espouse the values of increasing the autonomy of people with dementia.

5.3 LIMITATIONS AND TRADEOFFS

In addition to their contributions, each paper has several limitations.

For the first paper, due to the large body of literature on technology systems for people with dementia, the review only covers technology for people with dementia for one purpose, reminiscence therapy. Additionally, there may be many commercial systems that are designed to promote reminiscence for people with dementia that have not been studied in peer-reviewed literature.

The second paper involves a field deployment of a technology with people in a memory care unit and activity group for people with less severe cognitive impairment. The sample size for this study does not allow for quantitative analysis of administered instruments, so I am unable to determine if the system had any effect on cognition or mood. Additionally, there was no control group. Finally, the study took place in a single MCU with a sample of limited racial diversity. Given the enormous impact the environment has on a successful deployment in this setting, it is difficult to know what may have happened with this technology in a different setting.

In the third paper, I examine a single dyad. Though the case study format lends itself to a detailed understanding of the dynamics of the use of a technology, it is not possible to generalize findings to the broader population.

In the fourth paper, I discuss recommendations generated for designers of systems for people with dementia. A limitation of this study is that a relatively small number of experts were involved. Additionally, I did not produce designs using these recommendations to test to validate the recommendations.

5.4 Opportunities for Future Work

Below, I outline several areas of future work that my dissertation research points to:

5.4.1 *Designing to validate recommendations*

Though I have generated recommendations based on field experience with an actual technology and the input of experts in related fields, I have not tested the ease with which system designers can apply them. It would be beneficial to have designers create designs based on these recommendations to refine their actionability.

5.4.2 *Design to deploy*

I have deployed an existing system to evaluate its benefits and challenges in a memory care unit with people with dementia. Future work points to designing an improved system based on the recommendations I have generated, and iteratively designing it during a deployment in a similar setting.

5.4.3 *Design for interactions between people with dementia*

In my dissertation work, I have deployed a system that, due to its complexity, requires a facilitator alongside a person with dementia. However, there are potential benefits to a system that does not require a staff or family member and can be used by multiple individuals with dementia. Benefits include reducing the dependency on staff of people with dementia's ability to engage in activities, as well as increasing social interactions between people with dementia in an MCU. I would like to explore how a system should be designed to support these types of interactions through a technology system. To do so, I would meet with activity directors and other individuals who regularly and successfully conduct activities with people with dementia to understand how they design activities to avoid frustration due to cognitive impairment and capitalize on the abilities that people with dementia excel in. Then, I would design a technology, iteratively refining it based on observations of individuals with dementia using the technology.

5.4.4 *Investigate Technology to Support Recreational Activities in the Home*

Though there is a scarcity of recreational activities in memory care units and other forms of nursing facilities and assisted living, there are a significant number of people with dementia living in the community without sufficient activities to engage in. It is important to identify

whether these design recommendations apply to systems for this setting and what additional recommendations need to be added.

5.5 Concluding Remarks

In this dissertation, I present papers that expand our understanding of how to design technologies for people with dementia. I take into account the various stakeholders involved in a person with dementia's life, as well as the setting in which a person with dementia in a memory care unit finds themselves. Only by including the people most central in a person with dementia's life and staying focused on the desires, opinions, and experiences of people with dementia themselves, can we appropriately offer recreational activities that will engage and delight people with dementia.

APPENDIX A: TABLES

Table 6. Study Details

Reference	Study Design	*N*	Age (m)	Dementia severity	Place	Study Aims	Technology related Findings
CIRCA (Alm et al. (2003, 2005)	Case-control	30 (18 PWD, 12 CGs)	81.9	MMSE 2-23 (mean 15.4)	UK	Participation, engagement, and enjoyment. Effectiveness of prototype	Improved enjoyment, participation (more equal footing), stronger and prolonged engagement
Alm, Astell et al. (2004)	Case report	12 (6 PWD, 6 CGs)	74.3	MMSE 10-25 (mean 15.6)	UK	Assess reaction to system and identify usability issues	Enjoyment. Staff liked choosing materials (but wanted variety) and that PWD spoke more. FMs liked videos and ease of use.
Alm et al. (2004)	Case report	18 (9 PWD, 9 staff)	83	MMSE 8-22 (mean 16)	UK	How does system affect interest and involvement of PWD and enjoyment of CG?	All PWD enjoyed using system. Participants wished there were personal materials. Touch screen easy to use.
Alm et al.	Case	NS	NS	'people	UK	Acceptabili	Digital RT doesn't

(2007)	Report			with dementia ’		ty & reactions to different interfaces	have to mimic scrapbook. Videos appreciated only when triggered memories (photos and music appreciated regardless) System idea acceptable.
Astell et al. (2010b)	Case report	22 (11 PWD, 11 staff)	83.5	MMSE 9-23 (mean 15.9)	UK	Effect on relationship between CG and PWD	Improved interactions when using CIRCA
Astell et al. (2010a)	Case-control	20 (10 PWD)	Group A: 82.8, Group B: 72.	Group A: MMSE 9-25(mean 20.4). Group B: 12-24 (mean 16.8)	UK	How does what and how much PWD say change based on viewing personal or generic photos?	Generic prompted more conversation, personal more labeling (which limited the amount of information PWD produced)
Bass & Greger (1996)	Case report	12 (6 PWD)	68.5	6 rated ‘confused ’ by nursing staff	US	Does the addition of music as an additional stimulus during RT decrease depression?	No advantage in addition of music reported

Benvenist e et al. (2010)	Case report	9	NS	MMSE 10-25 (mean NS)	France	Usability, what people liked and did not like about the system	Users felt empowered during use and enjoyed recollections spurred by music. Based on results, researchers focus on RT.
Boulay et al. (2011)	Case report	7	88.5	MMSE 12-22 (mean 16.7)	France	Usability, whether PWD could learn to use system, whether they found it satisfying	System usable and satisfying. 3 participants showed significant learning.
Cohene (2005)	Case report	1 PWD and family	NS	'mid-stage AD'	Canada	Whether & how PWD react to life stories, gather life story materials, system interactions	PWD enjoyed using system and needed less prompting with time.
Glynn (1992)	Case report	20	84	All rated 'severe' on GDS	US	Inter-rater reliability of instrument, responses to different music	Acceptable inter-rater reliability. Low spontaneous (2.5%) or prompted (50%) reminiscing to nostalgic music.

						genres (including nostalgic music for reminiscence)	
Kuwahara et al. (2006a): Study 1	Case-control	7 (5 PWD)	84.6	Mean Hasegawa score: 8.8 (1 Mild, 1 moderate, 3 Severe)	Japan	Experience using system, usefulness, usability	All but one subject was able to concentrate during sessions. RT content improved remote reminiscence.
Kuwahara et al. (2006a): Study 2	Case report	9	77	MMSE 10-25 (mean 19)	Japan	How does use of videophone compare with in person RT in PWD's time to respond & eagerness?	Videophone acceptable (no significant difference in terms of eagerness or time to respond)
NR [Kuwahara et al. (2010); Yasuda et al. 2009b)]	Case report	4	79	MMSE 16-27 (mean 22)	Japan	Effect on 'psychological stability' (measures from GBS such as anxiety),	NR was effective for 2 PWD, with persistent effects for 1. CGs reported that system caused anxiety (n=3) and enjoyment (n=2)

						caretaker observation	
Lee & Dey (2008)	Case report	6 (3 PWD, 3 CG)	NS	Early stage of AD	US	Usability, whether system supported interaction	CGs enjoyed using system but uncertain about selecting cues for PWD. PWD able to use system. More details recalled with system than with CG using photos.
Piasek et al. (2012)	Case report	2 (1 PWD, 1 CG)	87	Early stage of dementia	Ireland	Effect of viewing SenseCam photos on PWD's sense of self, interactions with CG, and conversations	No change in psychosocial measures. Didn't promote positive interactions between PWD and CG but led to richer conversation with therapist. Source of pictures confused PWD.
Sarne-Fleischmann et al. (2011)	Case report	3	NS	AD diagnosis	Israel	Usability	Some visual components needed to be changed to reduce distraction and confusion
Shik et al. (2009)	Case report	NS	NS	'mild dementia'	Hong Kong	How to design and deliver reminiscen	No results specific to technology

						ce to Chinese older adults in Hong Kong	
Smith et al. (2009)	Case report	12 (6 PWD)	85	Stage of (AD) dementia: Early (2), Mid (3), Advanced (1)	Canada	Feasibility of making personal multimedia biography videos with people with cognitive impairment	Project feasible, but time CGs must invest potential barrier. Music appreciated. Videos for PWD required FM involvement, so PWD may miss on benefits (self-reflection, esteem) other participants experienced.
Smith et al. (2009)	Case report	12 (6 PWD)	85	Stage of (AD) dementia: Early (2), Mid (3), Advanced (1)	Canada	Feasibility of producing personalized multimedia biography videos with people demonstrating cognitive impairments	Project was feasible, but time CGs must invest might be a barrier for some. Music highly appreciated. Videos for PWD required FM involvement, so they may miss on benefits of self-reflection and self-esteem improvements that came with contributing to the

							project that occurred for other participants.
Tolson & Schofield (2012)	Cohort Study	NS	NS	'men with dementia'	UK	What can be learned analyzing 4 case studies using context, mechanism, and outcome?	No results specific to technology
Wallace et al. (2012)	Case report	NS	NS	Clients with psychiatric disorders - mostly dementia	UK	Staff's experiences using art to evoke reminiscence with PWD	Art used for several purposes, including reminiscence, relaxation, and to assess a PWD's memory and life history
Wallace et al. (2013)	Case report	2 (1 PWD, 1 CG)	'early 60s'	'early stage dementia'	UK	How to use design probes to empathically engage a PWD and CG in designing digital jewelry to support personhood	The design process helped the researchers understand how it was to live with dementia and co-design meaningful jewelry for the PWD.

Yamagami et al. (2007)	Case report	22 (14 PWD)	82.2	CDR= .5 (2), 1 (9), 2 (3)	Japan	To examine the effectiveness of activity reminiscence therapy	No results specific to technology
Yasuda et al. (2009a)	Case report	15	77.3	MMSE 0-23 (mean 14)		Whether personalized videos get more attention than generic TV shows	More concentration during personalized videos, especially for moderate and severe dementia
Yasuda et al. (2013)	Case report	4	78.8	MMSE 14-29 (mean 19.5)	Japan	Effect on 'psychological stability' and caretaker observations	NR effective for 1 participant with effects persisting for three hours. 3 CGs reported that that PWD enjoyed using system.

NOTE: NS = not specified; PWD = person/s with dementia; MMSE = mini-mental state examination; GDS = global deterioration scale for assessment of primary degenerative dementia; AD = Alzheimer's Disease; CG = caregiver; NR = networked reminiscence therapy; GBS = Gottfried-Brane-Steen scale; CDR= Clinical dementia rating

Table 7. Media Type, Content, and Technology by Study

Reference	Media Type	Media Content	Technology Specified
Astell et al. (2010a)	Photographs	Group A: personal (from FM), Group B: Era and Region	Laptop
CIRCA [Alm et al. (2003, 2005, 2007); Astell et al. (2010b); Gowans et al. (2004)]	Music, photographs, text, video	Era and region	Laptop, monitor, speakers [Astell et al. (2010b)]
Alm et al. (2004: Study 1)	Sounds, photographs, video	NS	NS
Alm et al. (2004: Study II)	Music, photographs, video	Era and region	Touchscreen
Azcurra (2012)	Music	NS	Recordings
Bass & Greger (1996)	Music	NS	Audiotape
MinWii [Benveniste et al. (2010); Boulay et al. (2011)]	Music, images	Era (nursery rhymes)	Computer, TV screen, sensor bar, Wiimote, PC software
Caprani et al. (2005)	Music, photographs, text, video (movies)	Era, personal	Proposed system: touchscreen laptop, USB, Audio connection, CD-RW and hard drive
Cohene et al. (2005)	Audio, images, photographs, video	Personal (from FMs and researchers)	Multimedia DVD, remote control
Crispi et al. (2002)	Audio	Generic	Cassette player and tapes, talking toy parrot
Gary (2012)	Audio, photographs, video	Personal	Touchscreen PC or tablet, brain sensing hardware, cloud

			server, phone
Green et al. (2012)	NS	Personal	NLP system
Glynn (1992)	Music	Generic and Era	Cassettes, stereophonic equipment
Networked Reminiscence Therapy [Hamada et al. (2009); Hattori et al. (2007); Kuwahara et al. (2006b); Kuwahara et al. (2010); Yasuda et al. 2009b)]	Photographs (as a photo video), audio (narration, background music), video (video call)	Personal	PC (videophone), monitor, USB cameras, microphones, speakers, internet
Memory lane [Kikhia et al. (2010a, 2010b)	Audio, photographs, text, video	Personal	GPS, camera, audio recorder, door sensor, mobile phone, desktop
Kuwahara et al. (2006a)	Video (video call)	Era	PC, TV conferencing software, monitors, USB cameras, microphones, speakers, internet
Lee & Dey (2008)	Photographs	Personal	SenseCam, digital voice recorder, GPS location logger, software, Tablet PC
L.-J. Lin et al. (2011)*	Music, video ("movies")	Era and Region	Records
Moss et al. (2002)*	Music, video, photographs	Generic and Era	Cassette, slides

Namazi et al. (1994)*	Audio	Generic and Era	Tape recorder
Piasek et al. (2012)	Photographs	Personal	SenseCam, laptop, software
Politis et al. (2004)*	Music	Generic	NS
Sarne-Fleischman et al. (2011)	Music, photographs, text, video clips (described in Sarne-Fleischmann & Tractinsky (2008))	Generic and Personal (from FMs)	Touchscreen, Web-based application
Shik et al. (2009)	Photographs, audio	Generic and Era	Headphones with amplifiers, projector
Smith et al. (2009)	Video (with photographs, video clips, narration, and music)	Personal (from PWD and FMs)	Video cameras, scanners, computers, printers, video editing software, DVDs, DVD players and remote controls
Su et al. (2012)*	Music	Era	NS
Thorgrimsen et al. (2002)*	Photographs	Generic and Era	Slides
Tolson & Schofield (2012)	Photographs	Interest	Digitized archive
Wallace et al. (2012)	Photographs (slide show), video	Personal (from FMs and friends), Era and Region	Computer, accessible volume dial, USB, RFID
Wallace et al. (2013)	Audio (music and voice recordings), Photographs	Personal (from FMs and PWD)	Camera, screen with USB port, RFID ampoules and reader,

			microphone, speakers, computer
Themed Group RT [Wang et al. (2009); Wang (2007)]*	Music	Era	NS
Yamagami et al. (2007)	Video	Era	Video
Yasuda et al. (2009a)	Photographs (photo video), audio (narration, music)	Personal (from FM)	NS
Yasuda et al. (2013)	Same media as Kuwahara et al. (2010)	Same content as Kuwahara et al. (2010)	Touchscreen, web camera, server, scanner, internet, Firefox, Skype

NOTE: FM = family member; NS = Not specified; PWD = Person with dementia; RFID = Radio-frequency identification

* indicates that researchers used a reminiscence kit

Table 8. Descriptive Statistics of MCU Resident (R) Scores

ID	Timepoint	Mental Status (MMSE)	Quality of Life (QOL-AD)	Depressive Symptoms (CSDD)	Resource Utilization (RUD-FOCA) (min/month)
R1	Baseline	16	48	0	976
	3m	21	47	0	380
	6m	21	49	1	220
R2	Baseline	2	25	8	10920
R3	Baseline	20	37	1	700
	3m	21	36	0	Not filled out
R4	Baseline	21	39	4	1036
	3m	19	46	1	1960
R5	Baseline	17	41	3	420
	3m	20	Not filled out	2	1540

Table 9. Descriptive Statistics of Activity Group Participant (RM) Scores

ID	Timepoint	Mental Status (MMSE)	Quality of Life (QOL-AD)	Geriatric Depression Scale (GDS)
R1	Baseline	22	48	0
	3m	21	49	1
R2	Baseline	20	42	0
	3m	16	41	1
R3	Baseline	17	33	3
	3m	12	35	3

Table 10. Averages of MCU Resident (R) Scores[a]

MMSE Baseline	MMSE 3 month	QOL-AD Baseline[b]	QOL-AD 3 month[b]	CSDD Baseline	CSDD 3 month	RUD-FOCA Baseline[c]	RUD-FOCA 3 month[c]
18.5 (SD 2.4)	20.3 (SD 1)	41.3 (SD 5.9)	43 (SD 6.1)	2 (SD 1.8)	.8 (SD 1)	810.7 (SD 340)	1293.3 (SD 818.4)

[a] Measurement for R2 only at baseline, so R2 was excluded from analysis

[b] Instrument missing for R5, so R5 was excluded from analysis

[c] Instrument missing for R4, so R4 was excluded from analysis

Table 11. Averages of Activity Group Participant (RM) Scores

MMSE Baseline	MMSE 3 month	QOL-AD Baseline	QOL-AD 3 month	GDS Baseline	GDS 3 month
20 (SD 2.5)	16.3 (SD 4.5)	41 (SD 7.5)	42 (SD 7)	1 (SD 1.7)	1.7 (SD 1.2)

APPENDIX B: STUDY MATERIALS

FAMILY MEMBER DEMOGRAPHICS FORM

1. What is your age? ____

2. What is your gender? ☐ Male ☐ Female ☐ Other

3. How do you describe your race?

☐ American Indian

☐ Asian / Pacific Islander ☐ White / Caucasian

☐ Black / African American ☐ Other: _____

4. Do you consider yourself Hispanic/Latino?

☐ Yes ☐ No

5. Generally speaking, **how comfortable** do you feel using a computer?

Very Comfortable	Somewhat Comfortable	Not very Comfortable	Not at all Comfortable
☐	☐	☐	☐

6. Which best describes how often you use a computer? (check one)

☐ Once or more per day

☐ A few times a week

☐ A few times a month

☐ Less than once a month

☐ Never

7. For which of the following do you use a computer? (Check all that apply)

☐ Email
☐ Social Networking (e.g. Facebook)
☐ Listening to music
☐ Playing games
☐ Tasks/ documentation at work
☐ Shopping
☐ Reading the news
☐ Video calls (e.g. Skype)
☐ Watching movies or TV shows
☐ Looking at photos of family or friends
☐ Financial management

8. Do you have access to a computer at home?

☐ Yes ☐ No

FAMILY MEMBER BASELINE FEATURE SHEET

Do you think your **family member** would **enjoy** using technology to:

	Very Unlikely	Unlikely	Neutral	Likely	Very Likely
Watch recently released movies and TV shows	☐	☐	☐	☐	☐
Watch classic movies and TV shows	☐	☐	☐	☐	☐
Listen to current music	☐	☐	☐	☐	☐
Listen to music from a past era	☐	☐	☐	☐	☐
Look at current pictures of family and friends	☐	☐	☐	☐	☐
Look at pictures of family and friends from the past	☐	☐	☐	☐	☐
Play games	☐	☐	☐	☐	☐
Solve puzzles	☐	☐	☐	☐	☐
Keep up with the news	☐	☐	☐	☐	☐
Look up information online	☐	☐	☐	☐	☐
Learn something new	☐	☐	☐	☐	☐
Play memory games	☐	☐	☐	☐	☐
Communicate through video with family or friends	☐	☐	☐	☐	☐
Communicate through email with family or friends	☐	☐	☐	☐	☐
Use a social networking site such as Facebook	☐	☐	☐	☐	☐
Play exercise games	☐	☐	☐	☐	☐
Engage in meditation or relaxation techniques	☐	☐	☐	☐	☐
Keep track of medications	☐	☐	☐	☐	☐

Do you think **you** would **enjoy** using technology **with your family member** to:

	Very Unlikely	Unlikely	Neutral	Likely	Very Likely
Watch recently released movies and TV shows	☐	☐	☐	☐	☐
Watch classic movies and TV shows	☐	☐	☐	☐	☐
Listen to current music	☐	☐	☐	☐	☐
Listen to music from a past era	☐	☐	☐	☐	☐
Look at current pictures of family and friends	☐	☐	☐	☐	☐
Look at pictures of family and friends from the past	☐	☐	☐	☐	☐
Play games	☐	☐	☐	☐	☐
Solve puzzles	☐	☐	☐	☐	☐
Keep up with the news	☐	☐	☐	☐	☐
Look up information online	☐	☐	☐	☐	☐
Learn something new	☐	☐	☐	☐	☐
Play memory games	☐	☐	☐	☐	☐
Communicate through video with family or friends	☐	☐	☐	☐	☐
Communicate through email with family or friends	☐	☐	☐	☐	☐
Use a social networking site such as Facebook	☐	☐	☐	☐	☐
Play exercise games	☐	☐	☐	☐	☐
Engage in meditation or relaxation techniques	☐	☐	☐	☐	☐
Keep track of medications	☐	☐	☐	☐	☐

FAMILY MEMBER SEMI-STRUCTURED BASELINE INTERVIEW

Preferences

We are studying the use of a multi-purpose technology tool. It functions like a computer, is touch-screen, and has different programs on it that could be used for entertainment, health, or keeping in touch. What do you think of using this system for people with cognitive impairments or dementia? What do you like or not like about the idea?

Are there any other features of programs you think the system should have?

What do you think they would like or not like?

Features

Hand family member baseline feature sheet to family member. Walk participant through sheet and give 5-10 minutes to fill it out.

Do you have any questions or comments on any of the features?

Please circle the top three features you think your family member would especially like, and put an X by the three you think your family member would especially dislike.

Now that you have looked at these features, can you think of any other that might be useful?

Activities

Can you tell me about what you do during your visits with your relative?
What kind of activities do they enjoy?
What do you enjoy?
Do you ever participate in the activities offered here?
Does your relative ever talk about the activities offered here?

Do you have any other comments or questions?

Family Member Semi-Structured Optional Midpoint Interview

Are there any general observations about the study, the system, or your family member's use of the system you wish to share?

Have you discussed the system or any features with the staff?
Is there anything you want to tell us about those conversations?
Are there any specific applications or aspects of the system that came up?

Have you discussed the system or any features with your family member?
Is there anything you want to tell us about those conversations?
Are there any specific applications or aspects of the system that came up?
How do you feel about the system in general? What do you like or not like about it? Do you have any suggestions for ways it could be better for you?

Have you used the system?
Could you tell me about your experiences with the system?
Which of the features did you use? Can you tell me what you liked or didn't like about those features?
Do you think your use of the system has led to any changes in the behaviors, mood, or quality of life of your family member in the past 3 months? If so, could you describe how it has changed?
Has your use of the system led you to learn anything new about your relative in the memory care unit?
Have you felt that your relationship or interactions with your family member changed in the past 3 months in any way related to the use of the system? If so, could you describe how it has changed?

Can you describe previous ways your family member has used technology (after being diagnosed with cognitive impairments/started having memory issues) [prompt: computer, iPad, TV shows]?
Have you noticed any differences in how your family member used the system in this study? Do you have any thoughts on what they might be due to?

Do you have any other comments or questions about the system or study?

Family Member Semi-Structured Exit Interview

Have you noticed any changes in the attributes or behaviors of your family member in the past 6 months? If so, could you describe these changes?

Have you felt that your relationship with your relative changed in the past six months? If so, could you describe how it has changed?

Have you discussed the system or any features with your family member or the staff? If so, is there anything you want to tell us about those conversations?

Have you used the system? If so, could you tell us about your experiences with it? Which of the features did you use?

How do you feel about the system? What do you like or not like about it?

Do you have any final comments or questions about the system or study?

Staff Demographics Form

Demographic Survey

1. What is your job title? _____

2. How long have you worked at this facility? _____

3. How many years have you worked with cognitively impaired older adult or individuals with dementia? _____

4. What is your age? _____

5. What is your gender? ☐ Male ☐ Female ☐ Other

6. How do you describe your race?

☐ American Indian

☐ Asian / Pacific Islander ☐ White / Caucasian

☐ Black / African American ☐ Other: _____

7. Do you consider yourself Hispanic/Latino?

☐ Yes ☐ No

Technology Use

1. Generally speaking, **how comfortable** do you feel using a computer?

Very Comfortable	Somewhat Comfortable	Not very Comfortable	Not at all Comfortable
☐	☐	☐	☐

2. Which best describes how often you use a computer? (check one)

☐ Once or more per day

☐ A few times a week

☐ A few times a month

☐ Less than once a month

☐ Never

3. For which of the following do you use a computer? (Check all that apply)

☐ Email ☐ Reading the news

☐ Social Networking (e.g. Facebook) ☐ Video calls (e.g. Skype)

☐ Listening to music ☐ Watching movies or TV shows

☐ Playing games ☐ Looking at photos of family or friends

☐ Tasks/ documentation at work ☐ Financial management

☐ Shopping

4. Do you have access to a computer at home?

☐ Yes ☐ No

STAFF BASELINE FEATURE SHEET

Do you think **residents** would **enjoy** using technology to:

	Very Unlikely	Unlikely	Neutral	Likely	Very Likely
Watch recently released movies and TV shows	☐	☐	☐	☐	☐
Watch classic movies and TV shows	☐	☐	☐	☐	☐
Listen to current music	☐	☐	☐	☐	☐
Listen to music from a past era	☐	☐	☐	☐	☐
Look at current pictures of family and friends	☐	☐	☐	☐	☐
Look at pictures of family and friends from the past	☐	☐	☐	☐	☐
Play games	☐	☐	☐	☐	☐
Solve puzzles	☐	☐	☐	☐	☐
Keep up with the news	☐	☐	☐	☐	☐
Look up information online	☐	☐	☐	☐	☐
Learn something new	☐	☐	☐	☐	☐
Play memory games	☐	☐	☐	☐	☐
Communicate through video with family or friends	☐	☐	☐	☐	☐
Communicate through email with family or friends	☐	☐	☐	☐	☐
Use a social networking site such as Facebook	☐	☐	☐	☐	☐
Play exercise games	☐	☐	☐	☐	☐
Engage in meditation or relaxation techniques	☐	☐	☐	☐	☐
Keep track of medications	☐	☐	☐	☐	☐

Can you think of any other ways residents might enjoy using technology?

_____

_____

_____

_____

Do you think **you** would **enjoy** using technology **with residents** to:

	Very Unlikely	Unlikely	Neutral	Likely	Very Likely
Watch recently released movies and TV shows	☐	☐	☐	☐	☐
Watch classic movies and TV shows	☐	☐	☐	☐	☐
Listen to current music	☐	☐	☐	☐	☐
Listen to music from a past era	☐	☐	☐	☐	☐
Look at current pictures of family and friends	☐	☐	☐	☐	☐
Look at pictures of family and friends from the past	☐	☐	☐	☐	☐
Play games	☐	☐	☐	☐	☐
Solve puzzles	☐	☐	☐	☐	☐
Keep up with the news	☐	☐	☐	☐	☐
Look up information online	☐	☐	☐	☐	☐
Learn something new	☐	☐	☐	☐	☐
Play memory games	☐	☐	☐	☐	☐
Communicate through video with family or friends	☐	☐	☐	☐	☐
Communicate through email with family or friends	☐	☐	☐	☐	☐
Use a social networking site such as Facebook	☐	☐	☐	☐	☐
Play exercise games	☐	☐	☐	☐	☐
Engage in meditation or relaxation techniques	☐	☐	☐	☐	☐
Keep track of medications	☐	☐	☐	☐	☐

Can you think of any other ways you might enjoy using technology with residents?

_____

_____

_____

_____

_____

STAFF SEMI-STRUCTURED BASELINE INTERVIEW

Existing programs

What kinds of activities or programming does this facility offer for the residents in the MCU? How often are those activities offered?

What kinds of programming do residents seem to like?

Ideal Programs

What do you think residents might to do that is not currently available (in an ideal world, what kinds of activities or programs would you have for the residents?)

Reminiscence Activities

To you knowledge, has the facility ever engaged in reminiscence activities? [If necessary, provide examples such as 'watching older movies' or 'talking about the past]

Features

Hand staff baseline feature sheet to staff. Walk participant through sheet and give 5-10 minutes to fill it out.

Do you have any questions or comments on any of the features?

Now that you have looked at these features, can you think of any others that might be useful?

Do you have any other comments or questions?

STAFF MONTHLY FEATURE SHEET

1. Please complete A **before** B and C.

   A. Rank the following features by **how often** they were used in the past month, starting with 1 for the most used feature. If you did not see a feature used in the past month, write an X on the line.

   For the remaining features (those without an X):

   B. Estimate the number of residents who used the feature in the past month.

   C. Check 'Yes' if the feature was mainly used by a group (more than one resident at the same time), and 'No' if the feature was mainly used by one resident at a time.

A Rank	**B** # res.	**C** Group Yes	No
___	___	o	o
___	___	o	o
___	___	o	o
___	___	o	o
___	___	o	o
___	___	o	o
___	___	o	o
___	___	o	o
___	___	o	o
___	___	o	o

2. Please rate your agreement with the following statements.

In the **past month**, **residents** seemed to enjoy using this feature.					
	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
1.	O	O	O	O	O
2.	O	O	O	O	O
3.	O	O	O	O	O

In the **past month**, **I** enjoyed using this feature with residents.					
	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
1.	O	O	O	O	O
2.	O	O	O	O	O
3.	O	O	O	O	O

In the **past month**, I felt that I **got to know the residents better** by using this feature.					
	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
1.	O	O	O	O	O
2.	O	O	O	O	O
3.	O	O	O	O	O

STAFF SEMI-STRUCTURED MONTHLY AND EXIT INTERVIEW

Features

Hand monthly feature sheet to staff. Walk participant through sheet and give 5-10 minutes to fill it out.

Why do you think some of the features are used more than others?

[If a feature is marked as not easy to use] Can you tell me what makes this hard to use?

Do you think there are features that are missing? [Is there anything you would like to use the system for that isn't there now?]

Do you have any other thoughts or comments about any of these features?

System

In general, are there any issues using the system?

Do you have any specific examples of interactions with the system (anecdotes of use)?

Do you have any other comments? Is there anything else you think is important for us to understand about how the system is being used?

[At exit visit only] Could you see this program becoming part of your facility/programming?

[At exit visit only] Do you think that system has had an impact on how you or others interact with the residents?

ACTIVITY GROUP PARTICIPANT DEMOGRAPHICS

1. How long have you been living at the [retirement community]? _____

2. How long have you been a participant in the activity group program? _____

3. What is your age? _____

4. What is your gender? ☐ Male ☐ Female ☐ Other

5. How do you describe your race?

☐ American Indian

☐ Asian / Pacific Islander ☐ White / Caucasian

☐ Black / African American ☐ Other: _____

6. Do you consider yourself Hispanic/Latino?

☐ Yes ☐ No

Technology Use

1. Generally speaking, how comfortable do you feel using a computer?

Very Comfortable	Somewhat Comfortable	Not very Comfortable	Not at all Comfortable
☐	☐	☐	☐

2. Generally speaking, how interested are you in using a computer?

Very much Interested	Somewhat interested	Not very Interested	Not at all Interested
☐	☐	☐	☐

3. Which best describes how often you use a computer? (check one)

☐ Once or more per day

☐ A few times a week

☐ A few times a month

☐ Less than once a month

☐ Never

4. For which of the following do you use a computer? (Check all that apply)

☐ Email

☐ Social Networking (e.g. Facebook)

☐ Listening to music

☐ Playing games

☐ Tasks/ documentation at work

☐ Shopping

☐ Reading the news

☐ Video calls (e.g. Skype)

☐ Watching movies or TV shows

☐ Looking at photos of family or friends

☐ Financial management

5. Do you have access to a computer at home?

☐ Yes ☐ No

Activity Group Participant Semi-Structured Baseline Interview

Activities

Can you tell me about some of the activities you do during the activity group? What do you especially like or dislike? [Prompt: What do you look forward to?]

Do any of the activities make you feel closer to other people in the group? If so, which?

Do any of the activities make you feel closer to the staff? If so, which?

System

We are studying the use of a multi-purpose technology tool. It functions like a computer, is touch-screen, and have lots of different programs on it that could be used for entertainment (ex. games), health (ex. exercise videos), or keeping in touch (for ex. Skype). What do you think of using this system during [name of activity group]? What do you like or not like about the idea?

Ideally, what would you want the system to do? What features or applications would you want it to have?

Do you think you would enjoy using this system? What do you think you would like or not like?

Do you have any concerns? [Prompt: privacy, hard to use…]

Activity Group Participant Semi-Structured Exit Interview

Overall, do you have any comments about using the computer system in [name of activity group] sessions?

Are there any applications that particularly stood out? [prompt: as fun/enjoyable, as not fun, as hard to use, as something the whole group liked to do. Can also list some of the applications that were used as a prompt]

Would you want to keep using something like computer system this in [name of activity group]? What about at home (not in a group)?

Are there any things the system didn't have that you wished it had? Is there anything it has that you think it shouldn't have?

Is there anything else you want us to understand about your experience using the computer system in [name of activity group]?

APPENDIX C: RECOMMENDATIONS

These recommendations are intended for designers of systems for people with dementia/cognitive impairments (CI) in memory care units (MCUs). Though some systems for people with dementia are designed for cognitive training or other purposes, the intended use of these recommendations are for systems that promote recreational and leisure activities.

It is assumed that, given the level of CI of people in MCUs, there will need to be a facilitator present to use the system with the person with dementia (who will be referred to as the user). The facilitator may be a staff member of the MCU, a family member of the user, or a volunteer. Though acknowledging the presence of the facilitator, these recommendations are designed to give the user with CI as much ownership and control over the system as possible in order to reinforce the user's autonomy. Additionally, recommendations are ability-focused, taking into account the strengths of users with CI such as their ability to engage in certain activities that they enjoy.

These recommendations take into account aspects that are likely to exist in an MCU, such as the need for mobility and flexibility given the time pressure felt by staff in this setting. One element of flexibility in this setting is the scenarios of use: it is possible that the system would be used with a group of users with CI, as well as with an individual user. The recommendations below are grouped into five categories: hardware, content, applications, specific applications, and navigation.

HARDWARE

System

Consider using a touchscreen system: Several studies have found touch screens to be intuitive for older adults with CI (e.g. (Smith, Mountain, & Hawkins, 2013)).

Take into account the tradeoffs of different types of systems: A handheld tablet is more mobile and enables more privacy than a larger screen, but may be difficult for collaborative use or for a user to hold.

Try to make the system robust: In MCUs, it is important to have a waterproof system that is easily cleaned, and can be dropped (e.g. in a case) or does not drop easily (e.g. affixed to a sturdy cart).

Make the system approachable: Users may hesitate to use systems that appear complicated or unfamiliar. Systems that appear similar to known systems (e.g. TV) can be less intimidating.

Peripherals

Consider including a wireless keyboard: A wireless keyboard may be easier for users and facilitators than a wired keyboard that must be within a close proximity of the system.

Consider simple alternate forms of input: Regular keyboards can be confusing for users with CI; keyboards with large characters and clearly labeled keys is more suitable. Simple individually held devices (e.g. Wii remote) may be helpful to engage and empower users in controlling the system.

Make it easy to hook up a monitor: Many structured activities in MCUs are done with a group, often using monitors. Staff should be able to plug the system into a monitor in as few steps as possible.

System Elements

Make system mobile: If used in a group setting, it is essential that a single facilitator can move the system from room to room (between a common area and individual users' rooms). One way of doing this is securing the system to a cart that can be wheeled. If the system must be plugged in, the cord should be long enough that the system can be placed in a variety of locations.

Avoid large and bulky systems: Systems that are large and bulky can be difficult for facilitators to move. Additionally, storage space may be limited in MCUs, and staff may already have many materials they use with residents; the system should not take up too much room when stored.

Accommodate seated people: 9 in 10 people with CI may have mobility impairments (Williams et al., 2005); many affect users' abilities to stand. Accommodate seated users and wheelchairs.

Accommodate reaching issues: Given the high level of mobility impairments, some users may have impairments that affect their ability to reach. Systems can be made more accessible with a system that can be moved to various positions, or with a device that extends reach (e.g. straw).

Design for the environment of use: Various aspects of the environment that may affect use of the system, such as the light, glare, and the amount of noise in the background.

Simple on and off: Make it easy to turn the system on/off for the facilitator (as it is likely that they will be the ones turning the system on and off). However, it should not be easy do so accidentally.

CONTENT

Appropriate content

Include options for applications and content: Dementia affects people across a number of decades, interests, life experiences, and cultural backgrounds. Not all users will have experienced the same historical events or appreciate materials from the same era. Include content that can be used by people along a spectrum of ability, as well as content that is diverse in terms of interests, culture, and gender (e.g. content traditionally perceived as masculine as well as feminine).

Accommodate consistent interests: As dementia progresses, people's interests often narrow, but stay consistent. Include a variety of content that pertains to different interests or utilize a learning system that understands user interests and presents content that is likely to be desired by the user.

Screen content: Staff can be wary of what they perceive to be inappropriate (e.g. sexual content), particularly when accessing the internet. Consider screening applications and making this clear to staff.

Senses engaged

Make different forms of media congruent: Multiple forms of media used together (e.g. audio, video, images and text) can be engaging, but may be extremely confusing if presenting different messages (e.g. historical audio playing while different text is shown on the screen).

Include images and music: Pictures and music can be especially evocative for people with CI.

APPLICATIONS

Accessibility

Use large sizes and enable size and contrast increases: People with CI are likely to have vision impairment (Cohen-Mansfield, Marx, Regier, & Dakheel-Ali, 2009), so providing the ability to adjust size and contrast (and starting out with large sizes) is important.

Intuitive audio control: Hearing impairments are common for people with CI, and this combination can result in decreased likelihood to join activities (Cohen-Mansfield et al., 2009). Allow the user to easily adjust the audio (e.g. on-screen control or a clearly marked knob). Additionally, consider having individual audio headsets for users with severe hearing impairments.

Provide a way to turn off background music: When a system is being used in a large group, background music in applications may drown out users.

Language

Use language that provides context: An icon that says 'next' may not be understood if users do not realize that there is additional content. Instead use 'Next picture' or 'next question.'

Use short simple sentences and familiar language: Avoid complex language, abbreviations, metaphors, and technical jargon, as many people with CI experience difficulties with language (e.g. 'click' will cause a user to look for a mouse rather than realizing it refers to a touchscreen).

Words and Indicators

Avoid words that are not essential: Users may read everything that appears on the screen, so avoid any written information that is not absolutely necessary.

Keep orienting information present: Include information about content to orient users during use of an application (e.g. the country in a travel video). However, users may read text every time it appears. If the information is more than a word or two or stands out and will be read each time, consider an icon such as a question mark that can be tapped for more information.

Distinguish similar content: Users may become confused if there are similar items on a screen (e.g. the amount of money won in a game and the numerical value of a bet made in a game). Eliminate similar content or distinguish clearly between them (e.g. through clear labels or icons).

Avoid indicators that do not assist the user in understanding or lead to engagement: Avoid making changes on the screen that are not essential (e.g. highlighting the last pressed icon).

Instructions

Embed instructions: The pathway for next and possible next steps (as well as the objectives) should be scaffolded and obvious, as users with CI may not be able to remember instructions.

Provide precise instructions: If instructions cannot be embedded, utilize step by step instructions, with steps only appearing when they are to be used. If this is not possible, have instructions accessible by an icon that is consistent in placement and appearance throughout the applications.

Avoiding Issues

Avoid taking technical risks: Users may become bored or frustrated easily or lose track of what they are doing when a system freezes or takes long to load. Additionally, facilitators in an MCU are likely to stop using applications that do not consistently work due to a sense of time pressure. Pre-load content rather than depending on internet access, and use well-established applications rather than beta versions. When technical issues are unavoidable, offer an easy way to switch to a working application.

Avoid interruptions: Screens should not popup during use, as this can cause an interruption that makes it difficult for a user to remember what they had been doing. Instead, overlay text over a blurred background so the user does not become disoriented.

Employ consistency across and within applications: Users with CI are able to learn, but can have significant difficulty changing modes of interaction. Use consistent elements and interactions (e.g. if most applications use the touchscreen, do not require a mouse for another application).

Additional opportunities

Enable remote asynchronous content loading: Allow people such as family members to load content remotely and asynchronously for additional opportunities for interaction with family.

Embed additional information and interactions in applications: Users may seek out additional ways to learn or interact with applications. Provide additional opportunities for interaction (e.g. make images in slideshows clickable). However, some users may find additional opportunities confusing, especially if the application has an overarching goal (such as a game); consider an alternative mode with additional interaction opportunities where the goal of the application is less important.

SPECIFIC APPLICATIONS

Specific Applications 1: Games

Evaluating Gameplay

Keep feedback neutral to positive: Users with CI may misestimate their abilities and become distressed if they receive low scores. If scores are needed to monitor progress, store them where they can be retrieved by the facilitator instead of showing that percentage at the time of play. Another way to minimize failure is utilizing an avatar; that way it is the avatar doing something wrong, not the user.

Employ positive feedback: The system should demonstrate enthusiasm when the user has succeeded. Varying feedback (more points resulting in louder cheering) can help the user identify what actions are more successful. If a user is not successful, use encouraging feedback (such as 'You're almost there!').

Elucidate scoring and why a user's input is correct/incorrect: Avoid games with complex scoring (e.g. a game where different arrangements of icons lead to varying amounts of points, such as a slot machine). Additionally, users may wish to know why an answer was wrong, especially with facts from everyday life (such as trivia).

Difficulty

Involve challenge: Though there is sometimes a focus on 'failure-free' design for people with CI, games without goals can be perceived as boring (e.g. a game where the goal is to tap shapes on the screen). Casino-style games, where success or failure is dependent on chance, can be especially engaging.

Determine appropriate difficulty levels: An MCU will have people with varying levels of cognitive ability, and users' cognition will fluctuate due to various factors throughout the day. Approaches to finding the correct difficulty level include having a learning system automatically adjust to find an appropriate level of difficulty and allowing a facilitator to select a difficulty level ahead of time. Avoid setting the difficulty at the time of play, as users with CI may misestimate their abilities significantly.

Scaffolding

Reduce need for memory of past actions: Do not rely on users to remember previous guesses, even those made seconds before (e.g. in a game like “Family Feud”, list previously guessed words).

Provide example round: Users with difficulty understanding written instructions may appreciate experimenting with a game without 'keeping score' or viewing a virtual user playing a round.

Utilize clues: Assist users by providing clues or scaffolding guesses to provide guidance and support. One way of doing so is using an additional medium (e.g. pictures in addition to words).

Provide secondary information: Audible cues are an especially effective way to provide this type of information (e.g. a sound when a puzzle piece clicks into place).

Recap: Users with CI may forget what action they had just made in a game. Consider providing information about the previous action (e.g. “Correct! Scissors can cut paper!”).

Types of games

Include games that do focus on CI: Users may be aware that they are not able to play certain games as well as they think they should. Games that require creativity may place a user and facilitator on equal footing (as opposed to a game alphabetizing words).

Promote collaboration: Seek games that encourage collaboration between facilitators and a single user, as well as between facilitators and a group of users.

Error Avoidance

Consider allowing error correction: Users may wish to correct errors to feel a sense of having learned.

Support synonyms: In word games, systems should accept similar words as users with CI may have an especially difficult time coming up with the exact right word.

Avoid cascading errors: Games should not rely on prior steps being correct (e.g. crossword puzzles).

Make things work the way they work in the real world: Users may bring in notions of how things should work from real life and have a hard time remembering the alternate way the game words (e.g. users may have difficulty understanding that puzzle pieces cannot rotate in a puzzle game).

Minimize number of steps: Added steps increase complexity and likelihood of error. Aim for one to two steps by avoiding steps like confirming choices (instead offer 'back' buttons).

Additional Features of Games

Provide pause: Provide users or facilitators with a way to pause a game. This is especially important when a system is used in an MCU and staff must interact with users during system use.

Show how many questions or items are left in a game: Providing information about how much is left may help users decide if they wish to keep going or do something else.

Specific Applications 2: Reminiscence Media and Other Media

Media Content

Utilize mysterious content: Content that leaves room for imagination (e.g. a picture that shows a group of people having some type of party) can place users with CI on equal footing with facilitators, create opportunities for conversation, and encourage 'figuring it out' together.

Utilize CI-friendly question types: If reminiscence media includes questions, avoid fact-based questions (e.g. 'What are your sisters' names') and yes or no questions (e.g. 'Do you have sisters'). Instead, use questions that encourage discussion (e.g. "What was it like growing up with sisters?).

Be aware that not all memories are good memories: For example, reminiscence materials may focus on wartime, but some users will have negative memories of this period. Even seemingly innocuous material can trigger distress; have a facilitator on hand to comfort users.

Length and Timing

Include highlight or shorter clips: Longer media (~20 minutes) may be appropriate for group use, but short highlight reels (30-60 seconds) may be more useful in a one-on-one setting.

Avoid intros: Sequences that play at the beginning may cause confusion in users (who may think they have seen a certain video if the intro is the same as a video they have seen).

Consider repetition: Having media repeat may help bring out new memories or allow a user to embellish a story. However, this may be inappropriate for some users or facilitators tire of content.

Provide control of timing of media: Allowing control of playback speed and a skip function will allow more talk about evocative media and less about uninteresting media (e.g. in a slideshow).

Consider autoplay or continuous content: Autoplay or scrolling content reduces the numbers of steps required. Consider an interface that gives the user/facilitator time to exit, then plays the next segment.

Additional Features

Consider previews: Clearly marked previews of content can help users decide what to choose.

Use ad blockers: Much free and internet content have advertisements designed to draw attention. These are likely to distract users with CI, which affect the ability to direct attention.

NAVIGATION

Access to Applications

Include multiple methods of access: Free exploration (e.g. via categories of applications) is suitable when users are navigating, though staff may prefer a search function to find a specific application.

Provide intuitive way to exit: Make it easy and obvious how to exit out of an application.

Make it easy to switch within an application: For applications with a variety of content (e.g. a casino application with several slot machines), allow users to switch content with ease.

Presentation of Applications

Provide a way to easily hide applications: Users may forget that they did not like an application and repeatedly attempt to use it. Provide an intuitive way to hide the application during use.

Present a subset of the available options: A large body of applications and content can provide novelty, meet diverse needs, and give users choices. However, users with CI have difficulty choosing between options. Ways to reduce the number of options yet offer choices include allowing facilitators to customize user profiles with favorite applications, or using a learning system that finds content similar to favorites. Consider introducing random content occasionally to discover unexpected interests.

Avoid many layers: Multiple sub-folders may cause confusion for a user. Limit to 1-2 layers. Make it clear where users are within they system (e.g. utilize breadcrumbs).

Include history of enjoyment: Users with CI will often not remember if they enjoyed an application. Allow users or facilitators to note enjoyment and have this information affect which applications appear.

Interactive Elements and Icons

Use icons that precisely represent the application or content: Users may assume that icons represent an application (that clicking on a dog image will lead to a dog picture, not a dog puzzle).

Make interactive elements obvious, large, and far apart: Make interactive elements large and far apart (at least 1") so users are unlikely to tap the wrong one accidentally.

Have different types of touches register: Given users' likely physical impairments, permit touches that are short or long, as well as double taps, taps with multiple fingers, and touches with tremor.

Clarify what is interactive: Users may have difficulty distinguishing between interactive and non-interactive elements, especially for interactive images (e.g. images that link to videos).

Make it clear whether an action was completed: Users may otherwise not realize when their touch isn't registered on a system.

Touchscreen

Do not make it necessary to use the mouse: As the mouse requires coordinated activities (clicking and dragging) it may be more difficult for users than a touch screen.

Simplify scrolling: A touchscreen scroll bar may be easier to use than dragging a page up or down.

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