Improving quality of life, behavior and function in individuals with dementia through technology-assisted reminiscence

Chantal Kerssens

SimpleC, LLC.

75 Fifth Street, Suite 205

Atlanta, GA 30308 USA

ckerssens@simpleC.com

Jason P. Zamer

SimpleC, LLC.

75 Fifth Street, Suite 205

Atlanta, GA 30308 USA

jzamer@simpleC.com

Abstract

In this paper we make the case that demographic trends emphasize a need for assistive technology supporting seniors with Alzheimer's disease and related dementia disorders (ADRD). Support is specifically needed to alleviate everyday behavioral symptoms associated with ADRD. A reminiscence-based technology solution is then introduced.

Keywords

Reminiscence, technology, personalized care, behavior, dementia, seniors.

ACM Classification Keywords

C.3: Real-time and embedded systems; D.4.7: Interactive systems; H.1.2: Human Factors; H.2.4 Multimedia databases; J.3: Health; K.4.2: Assistive technologies for persons with disabilities.

General Terms

Design, Human Factors.

Introduction

As life expectancy increases and the Baby Boomers age, individuals over 65 years ("young-old") and 85 years of age ("old-old") make up a larger part of society. Consequently, the number of people with age-related cognitive impairment (dementia) is likely to increase both in number and proportion. Today, over 5 million Americans have Alzheimer's disease and related dementia disorders (ADRD) and this number is expected to triple by 2050 [1]. Most individuals with ADRD need help with basic activities of daily living (ADLs, e.g., bathing, dressing, transferring, toileting, eating), but also exhibit a variety of negative behavioral symptoms such as apathy, anxiety, confusion, agitation, resistance to care, and verbal or physical aggression [2-4]. Although the financial, social and emotional burden of caregiving for someone with ADRD is tremendous [1,5], the majority of people with ADRD live, and are expected to live, at home [6]. With the variety of symptoms and individual needs, it is not surprising that managing the care of individuals with ADRD while optimizing their quality of life and functioning is an ongoing challenge.

Drug interventions to promote behavior, function and quality of life in individuals with ADRD may be of some benefit short-term, but are ineffective long-term and associated with significant risks (morbidity, mortality) in the elderly [7-9]. Nonpharmacologic interventions, such as sensory stimulation [2], social contact and conversation [10], exercise [11], and reminiscence therapy [12] have shown modest benefits including improved mood and reduced agitation, but typically lack long-term sustainability as they require extra caregiver skills and time to implement. Clearly, there is a need for behavioral interventions that can be easily implemented and sustained in real world settings. Technology could satisfy these conditions, and there has been a steady increase in reliance on assistive devices and technologies supporting instrumental ADLs (e.g., house cleaning, grocery shopping, mobilization) and basic ADLs (e.g., transferring). Behavioral interventions, however, require an individualized approach that is not necessarily compatible with a blanket technology solution.

Technology-Assisted Reminiscence

We are a behavioral technology company that aims to improve the quality of life, behavior and functioning of individuals with dementia using nondrug interventions, specifically reminiscence. Reminiscence involves 'a process of thinking or telling others about one's past experiences' [13]. As a therapeutic intervention, reminiscence involves the discussion of past activities, events and experiences with another person or group of people, usually with the aid of memorabilia from the past (photo's, items, music and archive sound recordings) [14]. In the elderly, especially seniors with ADRD, reminiscence may promote a sense of comfort, identity, orientation to place and time, self-esteem, and facilitate adaptation to present circumstances [12, 14].

We have developed advanced technology that delivers individually meaningful pieces of information such as old family photos, preferred music, and familiar voices (referred to here as "media") to seniors living in long-term care (LTC) facilities or at home. The system requires internet connectivity and uses cloud computing for information transfer between our offices/servers and individual devices out in the field. Media are brought to residents via an LCD touch screen (Fig 1) and serve in part to engage (entertain) the individual.

In addition, making life history elements available to individuals with ADRD has a comforting effect. Although the person may not recognize the media (e.g., who is in the picture; who composed the music; whose voice was just heard), they often smile in response, start talking or humming, or simply are distracted in a pleasant way by something that looks or sounds familiar, which is generally comforting.

Addressing Behavioral Challenges using Technology-Assisted Reminiscence

In addition to presenting personal media that entertains and comforts the individual, we actively use life history details to address common, everyday challenges that involve care events and resident behavior. By knowing what makes someone tick, problem behavior can be successfully redirected and resistance to care subsides.

Key to success in using reminiscence as a therapeutic tool in our experience is:

- Having access to a detailed, accurate life history;

- Having access to accurate dynamic life history information that captures ongoing changes in personality, environment and disease progress;

- Finding media that closely represent a personality and pertinent life events;

- Properly validating the media with the individual to ensure it is engaging and evokes pleasant associations;

- Proper media timing depending on individual traits and preferences (e.g., presentation speed, volume, frequency, time of day).

When properly combined, however, technology and reminiscence provide a powerful, effective nonpharma-

cological intervention for individuals with age-related cognitive impairment.

figure 1. Our technology-assisted reminiscence display that is part of a larger system and personalized service assisting individuals with ADRD and their caregivers.

Process & Vignettes

We carefully collect individual life histories based on standard LTC intake forms and our own queries that address personality, preferences, and routines (daily schedules) plus observations in interacting with the resident. Based on this initial assessment, 10 to 16 individual life history topics are selected and translated into media, for instance, a picture show of Paris is created for somebody who grew up there, and French music accompanies the show. This aims to reactivate the long-term personal memory that was once formed in order create a happy moment/experience. Each show is then 'validated' with the resident, in-person, to ensure a positive response (smile, laughter, relaxation) and engagement. Thereafter, shows may be played to entertain or calm the individual, lift their spirits, or to

simply find a topic that relates to them and can assist in conversation. In addition, shows are used to draw an individual's attention to upcoming care events, in which case the show may be accompanied by a personal voice recording (family member; favorite care staff person) announcing the event) and pictures relevant to the event (e.g., taking a bath). This aims to orient and prepare the resident to help him/her participate in the event rather than being overwhelmed and startled. Shows can be started at any time ('on-demand') by touching the screen or be scheduled in advance based on an individual care schedule or routine (e.g., preferred bedtime).

Two examples of successful interventions include:

John
had advanced dementia and was <u>very</u> <u>withdrawn</u>, which made it difficult to interact and connect with him. Researching his life, we discovered he played football for a Big Ten school in the 1940s. By showing him pictures of the school's team and playing the school's 'fight song', John engaged in limited conversation and would sing part of the song. This made him happy, and it easier for others to relate to him.

Belle
had Alzheimer's dementia and was agitated towards 4PM each day ('<u>sun-downing</u>'). Having grown up on a farm, Belle yearned to go home to 'milk the cows and slop the pigs'. We created a show of Belle's adult siblings, which redirected her attention and was incongruent with running farm chores that were real only when her siblings were young. Belle became less agitated and much less disruptive to others.

Goals
By participating in the workshop we intend to:

▪ Share our experience, process, and setup further in order to inform and instruct others about the use of reminiscence, and technology;

▪ Not feature our product that is commercially available and used by long-term care facilities;

▪ Discuss ongoing research and development based on internal preliminary studies (using reminiscence in combination with activity cuing to motivate residents to attend daily activities and meals), as well as collaborations with established academic partners and institutions.

By attending the workshop we express an interest in:

▪ Learning more about reminiscence practices and theories of memory;

▪ Learning more about similar (technology * reminiscence) initiatives;

▪ Exploring the potential of reminiscence-based interventions for other cohorts with cognitive impairments, such as individuals having suffered a stroke or with post-traumatic stress disorder;

▪ Receiving feedback on our current practices and reminiscence delivery;

▪ Identifying academic partners for funded (small business concern, or otherwise) research collaborations.

Author Backgrounds
Jason Zamer received his B.A. from the University of Pennsylvania where he studied economics and psychology. While teaching computer classes to novice seniors with cognitive impairments in Philadelphia-area

community centers, Jason noticed how images of individual life events (e.g., home town) or family members (grandchild) would often engage the senior, lift their spirits, and prompt them to talk for extended periods of time where they normally would not participate in conversation. This led him to develop the notion that people with ADRD may benefit from exposure to life history details through images and sound, and how technology could play a role in bringing this information to people when human interaction is limited or unavailable. The first prototype of his technology solution was launched in early 2009 and that same year, the company joined the Advanced Technology Development Center (ATDC), a Georgia Institute of Technology start-up accelerator.

Chantal Kerssens trained as an experimental and cognitive psychologist at the University of Amsterdam (MSc) and Erasmus University Rotterdam (PhD) in the Netherlands, where she specialized in human memory function. Upon completing her PhD, she moved to Emory University in Atlanta to pursue research into the effects of anesthetic drugs on the human brain and memory function. Over the years she completed and directed a number of clinical-behavioral studies in surgical patient populations and studies in volunteers using functional neuroimaging. She joined SimpleC late 2010 to direct the internal and external research efforts in order to demonstrate the efficacy and usefulness of technology-assisted reminiscence for individuals with dementia and other forms of cognitive impairment, and their caregivers.

References

[1]   Alzheimer's Association. *2010 Alzheimer's Disease Facts and Figures*.

[2]   Cohen-Mansfield, J. Nonpharmacologic interventions for inappropriate behaviors in dementia: a review, summary, and critique. *Am J Geriatr Psychiatry 9,* 4 ((2001), 361-381.

[3]   Minati, L., Edginton, T., Bruzzone, M.G. and Giaccone, G. Current concepts in Alzheimer's disease: a multidisciplinary review. *Am J Alzheimers Dis Other Demen 24*, 2 (2009), 95-121.

[4]   Monastero, R., Mangialasche, F., Camarda, C., Ercolani, S. and Camarda, R. A systematic review of neuropsychiatric symptoms in mild cognitive impairment. *J Alzheimers Dis 18*, 1 (2009), 11-30.

[5]   National Alliance for Caregiving. e-Connected Family Caregiver: Bringing Caregiving into the 21st Century, 2011.

[6]   Doty, P. The Evolving Balance of Formal and Informal, Institutional and Non-Institutional Long-Term Care for Older Americans: A Thirty-Year Perspective, in *Public Policy & Aging Report*, National Academy on an Aging Society (2010), Washington, DC, USA, p. 3-9.

[7]   Sink, K.M., Holden, K.F., and Yaffe, K. Pharmacological treatment of neuropsychiatric symptoms of dementia: a review of the evidence. *JAMA, 293*, 5 (2005), 596-608.

[8]   Ballard, C. and Waite, J., The effectiveness of atypical antipsychotics for the treatment of aggression and psychosis in Alzheimer's disease. *Cochrane Database Syst Rev*, 2006 (1), p. CD003476.

[9]   Ballard, C.G., Gauthier, S., Cummings, J.L., Brodaty, H., Grossberg, G.T., Robert, P. and Lyketsos, C.G. Management of agitation and aggression associated with Alzheimer disease. *Nat Rev Neurol 5*, 5 (2009), 245-255.

[10] Tappen, R.M. and Williams, C.L. Therapeutic conversation to improve mood in nursing home residents with Alzheimer's disease. *Res Gerontol Nurs, 2*, 4 (2009), 267-275.

[11] Williams, C.L. and Tappen, R.M., Exercise training for depressed older adults with Alzheimer's disease. *Aging Ment Health, 12*, 1 (2008), 72-80.

[12] Woods, B., Spector, A., Jones, C., Orrell, M. and Davies, S. Reminiscence therapy for dementia. *Cochrane Database Syst Rev*, 2005 (2), p. CD001120.

[13] Cappeliez, P., O'Rourke, N., and Chaudhury, H., Functions of reminiscence and mental health in later life. *Aging Ment Health, 9*, 4, (2005), 295-301.

[14] Pittiglio, L., Use of reminiscence therapy in patients with Alzheimer's disease. *Lippincotts Case Manag, 5*, 6, (2000), 216-20.