

Personalized Technology to Support Older Adults With and Without Cognitive Impairment Living at Home

American Journal of Alzheimer's Disease & Other Dementias®
2015, Vol. 30(1) 85-97
© The Author(s) 2015
Reprints and permission:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/1533317514568338
aja.sagepub.com



Chantal Kerssens, PhD¹, Renu Kumar, MA¹, Anne E. Adams, PhD^{1,2},
Camilla C. Knott, PhD³, Laura Matalenas, BS^{1,2},
Jon A. Sanford, MArch^{4,5}, and Wendy A. Rogers, PhD²

Abstract

Although persons with dementia (PWD) and their family caregivers need in-home support for common neuropsychiatric symptoms (NPS), few if any assistive technologies are available to help manage NPS. This implementation study tested the feasibility and adoption of a touch screen technology, the *Companion*, which delivers psychosocial, nondrug interventions to PWD in their home to address individual NPS and needs. Interventions were personalized and delivered in home for a minimum of 3 weeks. Post-intervention measures indicated the technology was easy to use, significantly facilitated meaningful and positive engagement, and simplified caregivers' daily lives. Although intervention goals were met, caregivers had high expectations of their loved one's ability to regain independence. Care recipients used the system independently but were limited by cognitive and physical impairments. We conclude the *Companion* can help manage NPS and offer caregiver respite at home. These data provide important guidance for design and deployment of care technology for the home.

Keywords

dementia, nondrug interventions, assistive technology, aging in place, caregiver burden, neuropsychiatric symptoms

Introduction

Dementia and Alzheimer's disease, the most common form of dementia, are increasingly recognized as a public health crisis as they are difficult, costly diseases to manage, and a cure is not imminent.^{1,2} The disappointing success of drug therapies³ has underscored the need for disease management strategies that include nonpharmacological interventions and support for patients and their caregivers in daily life, especially in the home. Over 70% of American seniors live in private homes,⁴ which is where many prefer to be and stay.⁵ Seniors fear loss of independence more than death, and independence is a major factor in quality of life in persons with dementia (PWD).^{6,7}

Managing the care of PWD while optimizing their quality of life is challenging, especially for family caregivers. These caregivers often have full-time jobs yet spend many hours per week caring for a loved one at home.⁸⁻¹⁰ They provide help with instrumental activities of daily living (IADL) such as house-keeping and preparing meals, and with basic ADL such as bathing and toileting. Caregivers of PWD additionally have to cope with a host of neuropsychological symptoms such as apathy, anxiety, and agitation that are common across the dementia spectrum and stressful to handle.^{3,9,11-13} Assistive technologies could fill an important need in the support gap if they promoted

independence, positive mood and behaviors, and quality of life without adding to caregiver burden.

Persons with dementia and their caregivers have indicated they need, but are lacking, support in 4 main areas, namely, (1) symptoms of dementia such as loss of memory, (2) ADL, (3) social contact and company, and (4) health monitoring and safety.¹⁴ Most information and communication technology (ICT) efforts have focused on monitoring and surveillance, which mainly enhance caregiver feelings of safety and security.¹⁵⁻¹⁷ The ICT support for memory deficits and ADL comes primarily from electronic aids that facilitate the organization

¹ Research & Innovation SimpleC, LLC, Atlanta, GA, USA

² School of Psychology, Georgia Institute of Technology, Atlanta, GA, USA

³ Aptima, Inc, Washington, DC, USA

⁴ Center for Assistive Technology & Environmental Access, College of Architecture, Georgia Institute of Technology, Atlanta, GA, USA

⁵ Department of Veterans Affairs, Rehabilitation R & D Center of Excellence, Atlanta, GA, USA

Corresponding Author:

Chantal Kerssens, PhD, SimpleC, LLC, 300 Galleria Parkway, suite 720, Atlanta, GA 30339, USA.

Email: ckerssens@simplec.com

and execution of everyday tasks.^{16,17} These aids can improve prospective memory, that is, remembering to do something in the future, including in PWD.^{16,18}

Technology support for neuropsychiatric symptoms (NPS) is virtually disregarded as yet.¹⁶ NPS are not uncommonly treated with psychotropic drugs, despite regulations to the contrary and questionable efficacy and safety of such drug interventions.^{12,19,20} Nonpharmacological approaches are based on theories that NPS stem from a combination of unmet needs (boredom, loneliness, and sensory deprivation), maladaptive behavior reinforcement (tending to problem behavior only), and low stress thresholds that render PWD vulnerable.¹³ Common psychosocial treatments, therefore, include sensory interventions such as *music*, social contact such as *real or simulated presence* using photos and videos, and *orientation to place and time* using cues and reminders.¹³ *Reminiscence*, additionally, can reduce boredom, stimulate conversation, and preserve personal identity by remembering past events and experiences with the aid of artifacts such as personal photos or objects.²¹⁻²³ Psychosocial interventions are associated with improved NPS and quality of life in PWD and caregivers^{12,13,22-24} but traditionally depend on human interaction. This is a limiting and often unsustainable factor in an already burdened demographic.

The *Companion* (SimpleC, LLC, Atlanta, Georgia) is a touch screen computer (no keyboard and no mouse) that was developed to deliver psychosocial interventions to PWD in their living environment using rich audiovisual programs (“shows”) that combine images, music, and messages from trusted individuals that are relevant and pleasing to the care recipient and thus engages him or her meaningfully and positively. Shows aim to address NPS that are barriers to independence and well-being. Reminiscence and simulated presence are provided through personal photos and videos and by using the voices of loved ones to make announcements or recount personal stories. The Companion cues and primes for important activities and routines through explicit verbal and timed reminders (e.g., “Time to drink some water”) followed by images that are congruent with the expected behavior (e.g., people drinking a glass of water). The reminders are an important source of orientation to time, which is also provided by a clock, date, and day of the week displayed on the home screen that comes on when no show play. Preferred music accompanies each show unless requested otherwise. The Companion was developed in field working with PWD and their formal and informal caregivers, predominantly in assisted living and memory care.

The goal of this study was to test the usability, feasibility, and adoption of the Companion in a home- and community-based setting (i.e., private homes as opposed to formal care communities) in a small sample of dyads. A Companion was personalized for each of 7 households, and subsequently we determined barriers and facilitators to use and usefulness to PWD and their primary, family caregivers through structured observations, interviews, and assessments. Participants used the system for at least 3 weeks.

Methods

Sample

Given the focus on feasibility and usability, this study recruited a small sample ($n = 7$) that is considered adequate in usability and engineering psychology studies to capture the main barriers and facilitators to use of a system and its interface in order to properly inform redesign.²⁵ Caregiver/care recipient dyads were recruited from a network of organizations and institutions, such as retirement communities with an independent living campus, the Georgia Chapter of the Alzheimer's Association, adult day centers, and a senior services center in 1 local county. They were identified from referrals and in response to recruitment flyers or face-to-face group presentations. All participating dyads received verbal and written communication about the details of the study, and written informed consent to participate was obtained from all participants. Ability to sign informed consent was assessed in care recipients²⁶ and if unable to sign consent, care recipients signed an assent form.

Inclusion criteria were formally assessed during an in-home visit (next section) and were living independently in a private home or independent living cottage or apartment containing at least 3 rooms separated by walls and doors, cohabitating couples or caregiving dyads, a dementia diagnosis or assistive need in care recipients, mild to moderate caregiver distress, and limited outside assistance from formal caregivers or otherwise. Care recipients had to be at least 50 years old and caregivers at least 21 years old. Exclusion criteria were a care recipient Mini-Mental State Examination (MMSE) score below 10, a dementia diagnosis in caregivers, severe caregiver distress, comorbid medical or psychiatric conditions in either the care recipient or the caregiver that would prevent or impede completion of assessments or implementation of the trial, and evidence or a suspicion of alcohol or physical abuse.

Screening and Baseline Assessments

Preliminary eligibility criteria were determined in a screening phone interview with caregivers that assessed candidates' ages, living arrangements, support structures, comfort level with technology, medical diagnoses and conditions, the presence of NPS and/or difficulties with ADL in care recipients, and caregiver distress. Caregivers gave verbal informed consent to assess these variables. If participants seemed eligible, an in-home visit was scheduled to formally assess inclusion criteria. Baseline assessments were initiated after written informed consent documents were signed and included the following standardized measures: MMSE, standard version,²⁷ to assess the presence and extent of cognitive impairments in care recipients, Barthel index²⁸ to assess care recipient's ability to complete ADL, Lawton scale²⁹ to assess the presence and extent of difficulties with IADL; Cornell Scale for Depression in Dementia (CSDD)³⁰ to assess the presence of major depressive disorder in care recipients, Neuropsychiatric Inventory (NPI), brief version,^{31,32} to assess the presence and severity of 12 NPS and the associated caregiver distress, Caregiver

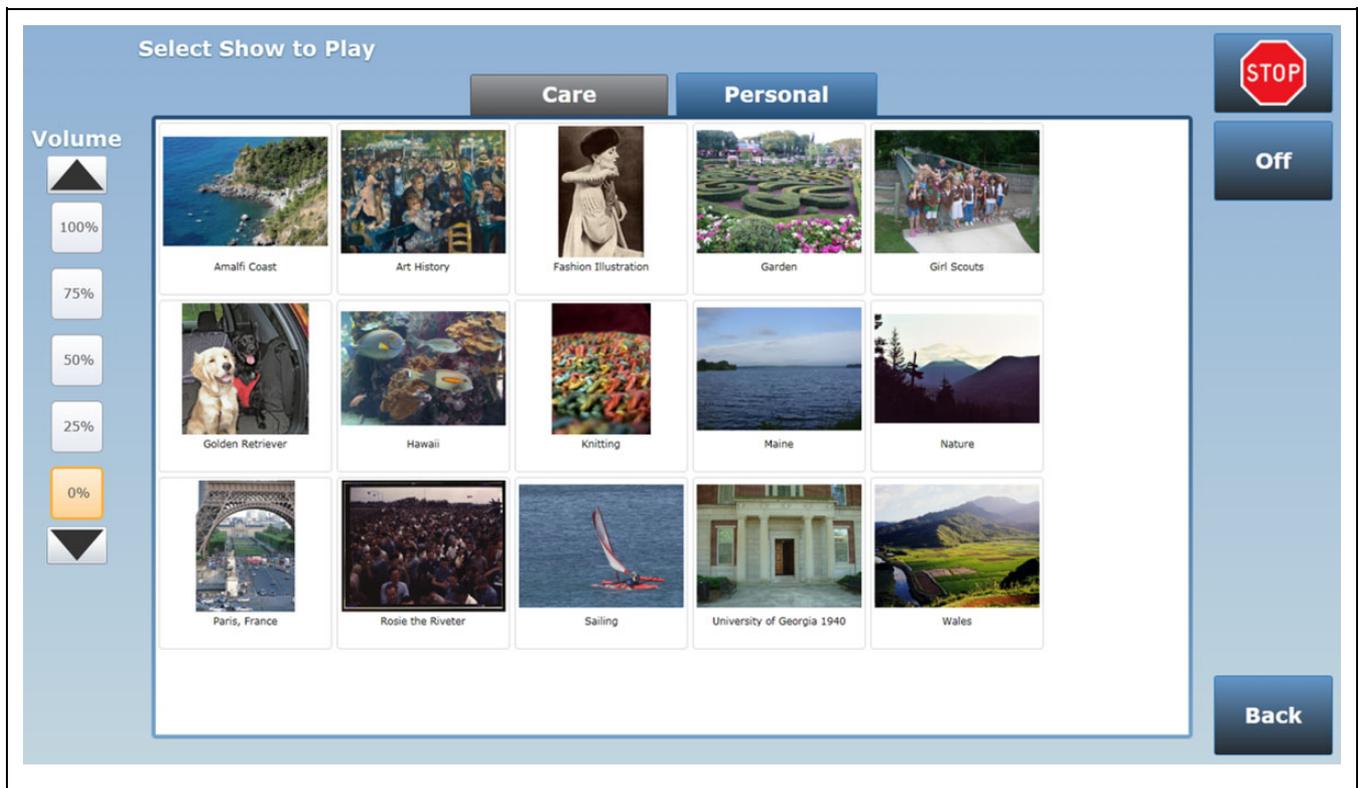


Figure 1. Example (screenshot) of SimpleC Companion Life Story menu.

Strain Index (CSI), modified,³³ to evaluate objective aspects of caregiver burden, and Zarit Caregiver Burden Scale³⁴ to assess subjective aspects of caregiver burden. The MMSE was completed in private with the care recipient. All other assessments were completed based on caregiver report, typically in private conversation (NPI and CSDD) with the responsible investigator (RK).

Life Story and Care Needs Interview

In order to personalize the Companion for individual households and care recipients, a second home visit was scheduled to complete a life story interview preferably with both the caregiver and the care recipient present as well as a care needs interview with the caregiver, preferably in a private conversation with the investigator.

The life story interview aims to identify positive life events, memories, interests, and circumstances that can support meaningful and positive individual engagement. It identifies topics and content conducive to reminiscing and personal wellness, including food preferences and important routines. This interview forms the basis for the Companion's reminiscing feature or "Life Story menu" (Figure 1) consisting of shows on topics that speak to the individual and can be enjoyed by care recipients in isolation or together with others. Personal photos and music are used if available. The life story interview was developed by SimpleC based on reminiscence and dementia care

best practices and our experience of working with older adults with dementia.

The care needs interview aims to identify the most pressing symptoms or needs in a care recipient or household and covers a wide range of challenges common in dementia and late life, including behavior and mood issues (20 symptoms), sleep, eating, and hydration issues (10 symptoms), difficulties with communication and participation in social events and activities (12 symptoms), and difficulties with ADL (9 symptoms). The needs interview was developed by SimpleC and is partially based on formal assessments of NPS in dementia (e.g., Neuropsychiatric Inventory^{31,32} and Nursing Home Adjustment Checklist³⁵) and part on years of experience working with older adults with dementia and their caregivers. In this study, baseline measures helped inform which symptoms were present and most pressing. During the Needs interview, caregivers selected 1 to 4 symptoms to become the target of intervention ("Goal"), and the current status for each target symptom was determined. This served as a reference ("baseline") for future status assessments and goal attainment scaling.³⁶ Meaningful Engagement was made a goal for all participants to encourage Companion use, given the need for caregiver respite.

Creating Companion Shows and Menus

Based on the Life Story and Care Needs interviews, a menu of Life Story and Care shows was created and compiled by trained care specialist using proprietary methods and ICT systems.

Depending on the available media, shows included personal photos and music, personal voice recordings and messages, or “generic” photos and music from our media library that do not belong to individual users but nevertheless are relevant to their life story or care need. If requested, specific times were scheduled for the shows to come on automatically as opposed to starting them on demand by touching the screen. Two investigators (RK and CK) checked and approved the final offering after which the in-home install was scheduled.

Equipment Placement and Installation

Although the Companion was personalized, an expert in assistive technology and environmental access visited participants in home to evaluate the presence of environmental and other barriers in the home that could limit individual access to the technology. Based on this assessment, recommendations for Companion placement in the home were made. During the install, both the caregiver and the care recipient were observed using a scripted protocol as they used and saw the Companion for the first time. Participants completed basic operations and tasks to inform the degree of technology usability or “user-friendliness” and to get them acquainted with the system. Based on observations of individual performance, additional feedback and training were provided as necessary to make sure participants had a basic understanding and comfort level operating the Companion before investigators (AA and RK) left the residence. In addition, caregivers were asked to fill out a questionnaire about their expectations of the technology’s usability and usefulness to themselves and care recipients. Questions were adopted from Davis scales of Perceived Ease of use and Perceived Usefulness,³⁷ which have repeatedly shown to predict technology acceptance.³⁸ Caregivers were given a diary to fill out daily during the intervention period. The primary purpose of the diary was to facilitate use of the system, enhance caregiver’s comfort level with the system by having them complete a simple task every other day, and to document personal observations and experiences. Caregivers reported that maintaining the diary was easy and required little time each day to complete.

Follow-Up Phone Calls and Diary

Caregivers received a phone call within a few days of installation to make sure the Companion was working properly and nothing prevented participants from using it. The purpose of specific shows was reviewed to remind caregivers of target symptoms and the interventions that had been created accordingly. Subsequently, caregivers were contacted once a week by phone to see how things were going, if they were using the technology, and if they had any questions or concerns.

Final Status, Goal Attainment, and Exit Interview

At the end of the intervention period, a final home visit was scheduled to discuss participants’ experiences using a

semistructured interview. Questions were based on the diary and a technology adoption questionnaire that both the caregiver and the care recipient filled out postintervention. Caregiver questions were based on the preimplementation questionnaire which was put in past tense to assess caregiver experiences and perceptions as they looked back on the intervention period. Answer categories (7 in total) ranged from *very true* to *very untrue*. Care recipient questions were adapted with permission from Tiberio and colleagues who assessed attitudes and experiences with a robot in individuals with cognitive impairment.³⁹ Care recipients answered with *yes* or *no*.

To assess goal attainment, caregivers were asked to rate how care recipients were doing with respect to the target symptoms identified at the outset of the study (“better,” “stable,” “worse,” and “not applicable”) and whether the current level of functioning, postintervention, was as expected or not (“much less than expected,” “somewhat less than expected,” “as expected,” “somewhat more than expected,” and “much more than expected”).³⁶

Results

Descriptive Data

Sample. Twelve dyads were screened between September 2012 and August 2013 and completed baseline assessments. Five (42%) dyads were excluded over the course of the investigation because either the care recipient died ($n = 2$, 17%), the care recipient deteriorated and was transferred to a nursing home ($n = 1$, 8%) and the caregiver deteriorated and was hospitalized repeatedly ($n = 1$, 8%), or the spouses could not agree on the focus and goal of the intervention and how to proceed ($n = 1$, 8%).

Included dyads ($n = 7$) were all married couples and either lived in a house (57%) or apartment (43%). In all, 4 (57%) couples were living in a continuing care retirement community and 3 (43%) in private homes. Sample characteristics are shown in Table 1.

Physical status. Care recipients had fewer reported comorbid conditions than caregivers (Table 1), but medical frailty varied substantially between individuals and couples and was not formally assessed through medical records. Two (29%) care recipients used a walker inside the home and had limited mobility. Three (43%) others moved slowly and used a cane or walker outside the home. The vast majority of participants wore glasses, but despite this 1 (14%) care recipient had blurred and double vision. In both subgroups, 2 (28%) individuals wore hearing aids. One (14%) care recipient had fine motor problems as reflected in difficulty holding a pen and with writing, and 1 (14%) caregiver had a numb left hand but was right handed. Two (14%) care recipients had a history of depression.

Cognitive status. All care recipients had completed high school; 6 (86%) went to college and 2 (28%) completed advanced degrees. Four (57%) care recipients had received a diagnosis

Table 1. Sample Characteristics.^a

	Care Recipients (n = 7)	Caregivers (n = 7)
Age, yr	77 (60-88)	79 (63-86)
Gender, F/M	3 (43%)/4 (57%)	4 (57%)/3 (43%)
Walking difficulties, Y/N	5 (71%)/2 (29%)	0 (0%)/7 (100%)
Vision difficulties, Y/N	1 (14%)/6 (86%)	0 (0%)/7 (100%)
Hearing difficulties, Y/N	2 (29%)/5 (71%)	2 (29%)/5 (71%)
Fine motor problems, Y/N	1 (14%)/6 (86%)	1 (14%)/6 (86%)
Psychiatric history, Y/N	2 (29%)/5 (71%)	0 (0%)/7 (100%)
Comorbid conditions, n	1 (0-5)	2 (0-6)
Comorbid conditions	Hypertension (n = 4, 57%) Diabetes (n = 2, 29%) Congestive heart failure (n = 1, 14%) High cholesterol (n = 1, 14%) Hydrocephalus (n = 1, 14%) Hypothyroidism (n = 1, 14%) Open heart surgery (n = 1, 14%) Urinary incontinence (n = 1, 14%) Vascular stent (n = 1, 14%)	Hypertension (n = 4, 57%) Allergies (n = 2, 29%) Urinary incontinence (n = 2, 29%) Diabetes (n = 1, 14%) Diverticulitis (n = 1, 14%) Enlarged prostate (n = 1, 14%) Gout (n = 1, 14%) Heart arrhythmia (n = 1, 14%) High cholesterol (n = 1, 14%) Knee problems (n = 1, 14%) Macular degeneration (n = 1, 14%)

Abbreviations: F, female; M, male; N, no; Y, yes.

^a Data are median (range) or frequency counts (percentage).

of dementia or mild cognitive impairment (MCI) in the recent years, which their MMSE scores reflected (Table 2). Two (28%) care recipients had not received a diagnosis, but their MMSE scores suggested the presence of MCI or moderate dementia. One (14%) care recipient scored in the normal cognitive range but exhibited several NPS, which we considered an assistive need and eligibility for study inclusion. None of the participants had difficulty with the Reading item on the MMSE instructing them to close their eyes (Table 2).

Functional status and dependence. The median score on the Barthel Index was 90 (range, 30-100), suggesting an overall high level of independence in completing ADL. In all, 3 (43%) care recipients were fully independent, 3 (43%) largely independent (sum scores, 70-90), whereas 1 (14%) care recipient was largely dependent on his wife to complete ADL. The most common ADL difficulties observed were getting dressed and getting up or down stairs (both n = 3, 43%).

The median score on the Lawton IADL Scale was 1 (range, 0-8) for female care recipients and 2 (range, 1-5) for male care recipients. One male and 1 female care recipient were high functioning and independent, but the majority (71%) of care recipients depended on their caregivers for IADL. The most common challenges, corrected for gender bias, were shopping (n = 5, 71%) and preparing and taking one's medications (71%).

Neuropsychological status. Table 3 lists the number and kinds of NPS observed in care recipients per caregiver self-report. The median NPI sum score was 9 (of 96 maximum), the median number of symptoms reported was 3 (of 12 maximum), and the median distress sum score was 5 (of 60 maximum). This

confirmed that care recipients were experiencing NPS that gave rise to caregiver distress but not extremely so. The most common symptoms were agitation, depression, and sleep difficulties (n = 3, 43%). None of the care recipients exhibited delusions, hallucinations, disinhibition, or motor disturbances at the outset of the study.

One (14%) care recipient showed evidence of significant depressive symptoms (CSDD sum score over 6, Table 3), but in none was major depressive disorder likely or obvious. The most common depressive symptoms (43%) were irritability, multiple physical complaints, and difficulty falling asleep. None of the care recipients were suicidal per caregiver report.

Caregiver distress. Table 4 details the level and source of caregiver distress. The median distress score on the modified Caregiver Distress Scale was 5 (range, 0-9) of 26 maximum. Most distress was generated by the confining nature of caregiving, restricting caregivers' free time, and free movement (n = 5, 71%).

The median Zarit sum score was 19 (range, 0-34) of 88 maximum, which suggested little to no caregiver burden overall. On an individual level, however, 4 (57%) caregivers showed evidence of mild to moderate burden. Caregivers most commonly felt Afraid about what the future holds for their loved one (n = 6, 86%), that their loved one is dependent on them (71%), that they lost control over their own lives (71%), and they feel uncertain about what to do about their loved one (71%).

Outcome Data

Technology implementation and feasibility. All couples (caregivers) had cell phones and the majority a computer (71%) and wireless Internet at home (86%). Few (14%) owned a

Table 2. Cognitive Profile of Care Recipients as Measured by the MMSE.^a

Care Recipient	Dementia or MCI Diagnosis	MMSE Sum Score	Registration	Orientation to Time	Orientation to Place	Recall	Attention Calculation	Naming	Repetition	Comprehension	Reading	Writing	Drawing
1	Yes	12											
2	No	25											
3	No	27											
4	Yes	16											
5	Yes	11											
6	Yes	22											
7	No	16											

Abbreviations: MCI, mild cognitive impairment; MMSE, Mini-Mental State Examination.

^a Cells highlighted in gray reflect impaired (imperfect) performance.

Table 3. Neuropsychological Symptoms as Measured by the NPI and CSDD.

Care Recipient	Tool	Number of Symptoms (Sum Score)	Severity sum Score ^a	Distress Sum Score	Symptoms
1	NPI	3 (10)	4	6	Agitation, anxiety, nighttime behaviors
	CSDD	0 (0)	0	n/a	None
2	NPI	0 (0)	0	0	None
	CSDD	3 (4)	1	n/a	Difficulty falling asleep, diurnal variation of mood, multiple physical complaints
3	NPI	4 (10)	4	6	Appetite and eating, agitation, elation or euphoria, irritability
	CSDD	1 (2)	1	n/a	Weight loss
4	NPI	4 (7)	5	2	Depression, anxiety, irritability, nighttime behaviors
	CSDD	4 (4)	0	n/a	Multiple awakenings during sleep, difficulty falling asleep, multiple physical complaints, irritability
5	NPI	0 (0)	0	0	None
	CSDD	2 (3)	1	n/a	Early awakening, lacks energy
6	NPI	3 (9)	4	5	Depression, apathy, agitation
	CSDD	3 (5)	2	n/a	Irritability, poor self-esteem, sad
7	NPI	4 (11)	6	5	Depression, apathy, nighttime behaviors, appetite and eating
	CSDD	7 (7)	0	n/a	Anxiety, sad, irritability, multiple physical complaints, loss of appetite, diurnal variation of mood, difficulty falling asleep

Abbreviation: NPI, Neuropsychiatric Inventory; CSDD, Cornell Scale of Depression in Dementia.

^a The severity score reported for CSDD reflects the number of symptoms that were rated as severe, receiving the maximum score (2).

Table 4. Caregiver Distress as Measured by the mCSI and Zarit Caregiver Burden Scale.^a

Caregiver	Tool	Sum Score	Sources of Distress
1	mCSI	3	Caregiving is confining, changes personal plans, upset by changes in person
	Zarit	10	Angry around loved one, afraid for future, strained around loved one, social life suffers, uncomfortable to have friends over
2	mCSI	0	n/a
	Zarit	0	n/a
3	mCSI	0	n/a
	Zarit	11	Loved one asks for more than needs, embarrassed over behavior, afraid for future, loved-one dependent on me, should be doing more, could do a better job
4	mCSI	8	Caregiving is confining, family adjustments, changes personal plans, emotional adjustments, upsetting behaviors, upset by changes in person, overwhelmed
	Zarit	34	Loved one asks for more than needs, no time for self, angry around loved one, afraid for future, loved-one dependent on me, strained around loved one, no privacy, social life suffers, loved one expects me to take care of him, could do a better job
5	mCSI	9	Sleep is disturbed, caregiving is confining, family adjustments, changes in personal plans, upset by changes in person, overwhelmed
	Zarit	21	No time for self, afraid for future, loved-one dependent on me, social life suffers, loved-one expects me to take care of her, lost control life
6	mCSI	5	Physical strain, caregiving is confining, family adjustments, changes in personal plans, time demands
	Zarit	30	Loved one asks for more than needs, no time for self, afraid for the future, loved one dependent on me, strained around loved-one, no privacy, should be doing more, could do more
7	mCSI	6	Sleep disturbed, physical strain, caregiving is confining, time demands, overwhelmed
	Zarit	19	Stressed meeting other Responsibilities, afraid future, loved-one dependent on me, loved one expects me to take care of him, lost control life

Abbreviations: n/a, not available; mCSI, modified Caregiver Distress Scale.

^a The maximum sum score on the mCSI is 26, suggesting *regular* distress. The maximum score on the Zarit Caregiver burden scale is 88, suggesting the caregiver *nearly always* feels burdened.

smartphone, tablet, or e-reader. The majority (57%) of caregivers identified themselves as “Tending to wait until a technology is widely adopted before you try it.”

Companions were installed in the home between February and October 2013. Although the intervention was scheduled

to last 3 weeks, the median trial period was 31 days (range, 24-57 days). Longer trial periods accommodated unforeseen circumstances and interventions needing revisions per caregiver request. All participants accepted the intervention and no adverse events occurred.

Table 5. Intervention Goals and Goal Attainment Ratings at the End of the Intervention Period.

Dyad	Goal 0	Goal 1	Goal 2	Goal 3	Goal 4	Caregiver Objectives for Care Recipient
1	Meaningful engagement	Medications	Confusion, event	-	-	Takes medicines independently each day and understands when caregiver is out twice each week.
2	Meaningful engagement	Trouble falling asleep	-	-	-	Falls asleep smoothly
3	Meaningful engagement	Eating, (consume food)	Demanding, agitated	-	-	Increase daily food consumption and improve everyday mood
4	Meaningful engagement	Solitary activities	Physical exercise	Evening routine	Hydration	Occupies himself and completes routines independently
5	Meaningful engagement	Confusion, time	Bathing	Socialization	-	Knows what day of the week it is and is reminded of care and social events.
6	Meaningful engagement	Sad or down	Solitary activities	-	-	Is positively and meaningfully engaged independently.
7	Meaningful engagement	Frequent daytime NAPS	Sad or down	Falling asleep	Hydration & healthy food	Positive engagement during the day, improve sleep, meal, and hydration routines

	Less than expected
	As expected (goal)
	more than expected
	N/A, did or could not use as directed
GOAL	status "better," but goal attainment "less than expected"

Companions contained on average 8 life stories with personal media (range, 0-14 Stories), 29 life stories with personalized, but generic (nonpersonal) media, 2 care shows with personal media (range, 1-10 shows), and 2 care shows with generic media.

Five (71%) of 7 couples kept the Companion beyond the intervention for at least 45 days or more. Two couples are still using it after 33 and 65 weeks, respectively.

Goals and subjective attainment. Table 5 shows the intervention goals caregivers selected based on symptoms and needs. Goal attainment is shown in different colors. Postintervention, 11 (44%) of 25 goals were as expected or better than expected, whereas 8 (32%) goals were less than expected in the eyes of caregivers. Importantly, in 4 (50%) of these instances, caregivers rated the care recipient's status as "better" but goal attainment as *less* than expected. One finding of note is that all 6 dyads who were able to use the Companion as intended reported that Meaningful Engagement was as expected or better than expected.

Positive experiences included many couples using and enjoying the reminiscing feature together, which some indicated they would not have done otherwise. All but 1 couple said the reminiscing was a positive experience and 1 caregiver stated after 8 months, long after the official trial ended: "The Companion is truly living up to its name these several months that [care recipient] has been in the nursing home". Other positive experiences included the intervention helping caregivers be reminded of giving medications and feeling more secure and at ease when they were out, knowing the Companion was playing at home.

Barriers to use and usefulness included care recipients' inability to use the Companion independently due to physical limitations (2); the Companion not offering a feature the caregiver had counted on (1), caregivers ignoring or muting all scheduled shows, and not using interventions on demand (2); care recipients ignoring interventions even when they noticed them and perceived them as positive (2); care recipients' unwillingness to share experiences with the caregiver (1); and couples not having enough time or availability to experience the interventions due to circumstances (1). Three caregivers had hoped their loved one would use the technology more even when he or she did use it independently.

Technology adoption. Figure 2 shows adoption metrics for care recipients. They perceived many aspects of the Companion and intervention positively, including ease of use and contents. The majority indicated it helped them relax, enjoy life, and reminisce, whereas it did not make them feel monitored or watched, nor did they find it to be irritating.

Caregivers were overwhelmingly positive in their assessment of the technology (Figure 3) and felt it made their daily lives easier and made helping their spouse easier. However, this did not necessarily make caregivers more efficient or effective in daily life nor helped them have more time to themselves. Respondents were more cautiously optimistic in these areas, suggesting that while assistive technologies such as the Companion can help mitigate symptoms and address needs in PWD, care burden and challenges remain. Perhaps most compelling is the ultimate question "I would miss the Companion if I no longer had it"

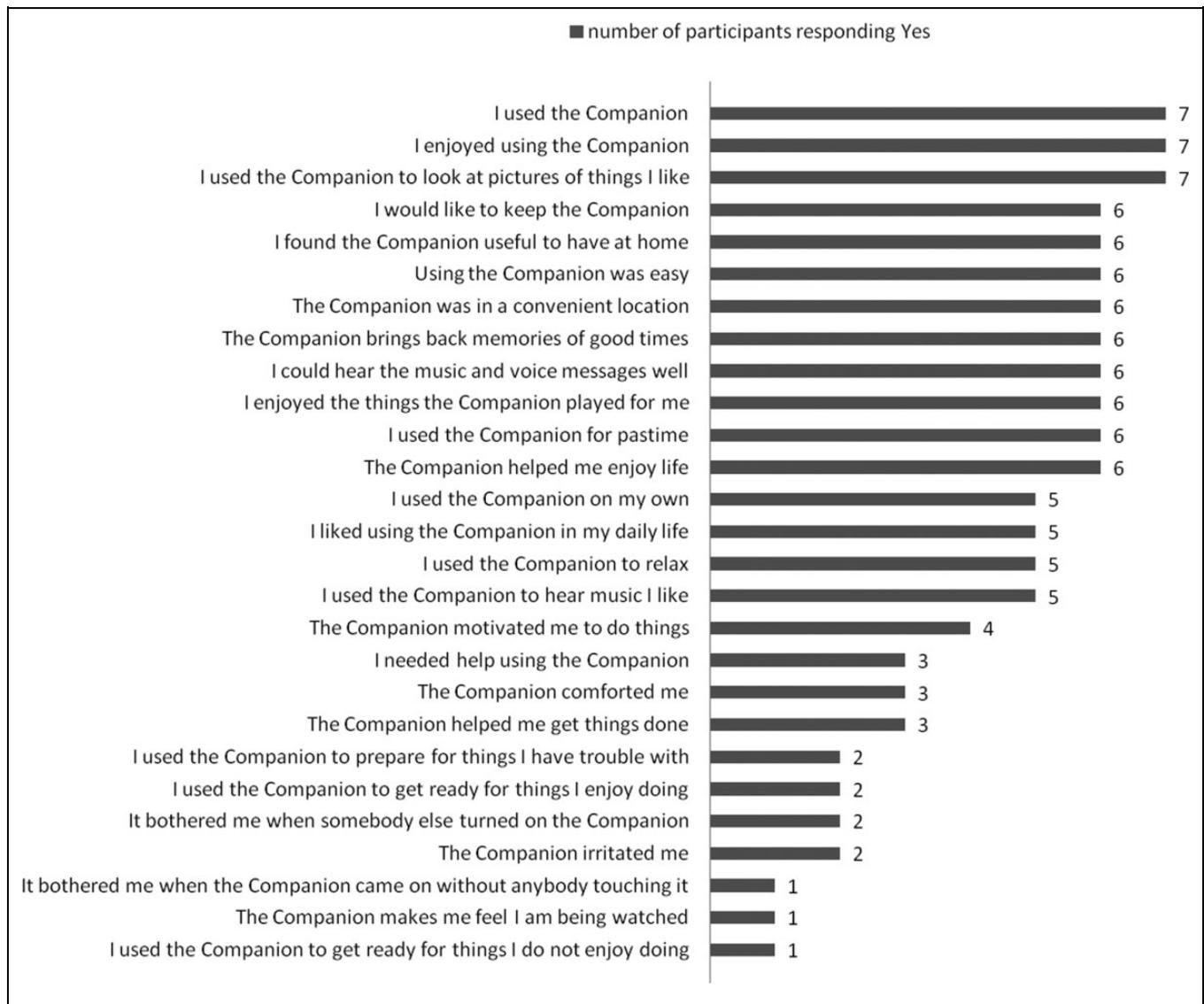


Figure 2. Care recipient (n = 7) technology adoption.

to which 86% of caregivers responded positively. This data point indicates the value of the system in the home.

Discussion

This study demonstrates that nondrug, psychosocial interventions can be delivered to seniors with dementia or assistive needs and their spouses at home using computer technology and help address symptoms and needs common in dementia and late life. Cohen-Mansfield and colleagues have argued and found that personalizing such interventions to meet individual needs and preferences is key to their success and efficacy by virtue of engagement, which is necessary for behavior change.^{13,40} As this study illustrates, advanced technology can be personalized in many ways by collecting and using personal facts and information and individually relevant audiovisual stimuli. In the future, if these items and data, including progress to wellness and intervention goals, are collected electronically

and automatically, technology-based interventions can truly live up to their potential and make chronic conditions management available with ease. Chronic disease will never be easy, but disease management can become easier with the help of smart technology.

We found that care recipients with MCI as well as moderate dementia were very interested in the possibilities of technology and could be tested using it for short as well as extended periods of time. Although the sample was small, technology adoption was excellent among both care recipients and caregivers as reflected in postimplementation questionnaire responses and a tendency to keep the Companion long after the official trial had ended. A third (2 of 6) of care recipients indicated they did not use the Companion independently. This did not necessarily relate to observed levels of cognitive impairment and suggests personal motivation and curiosity play a role. Physical limitations such as visual impairments and ambulation did affect independent technology use, which underscores the need for

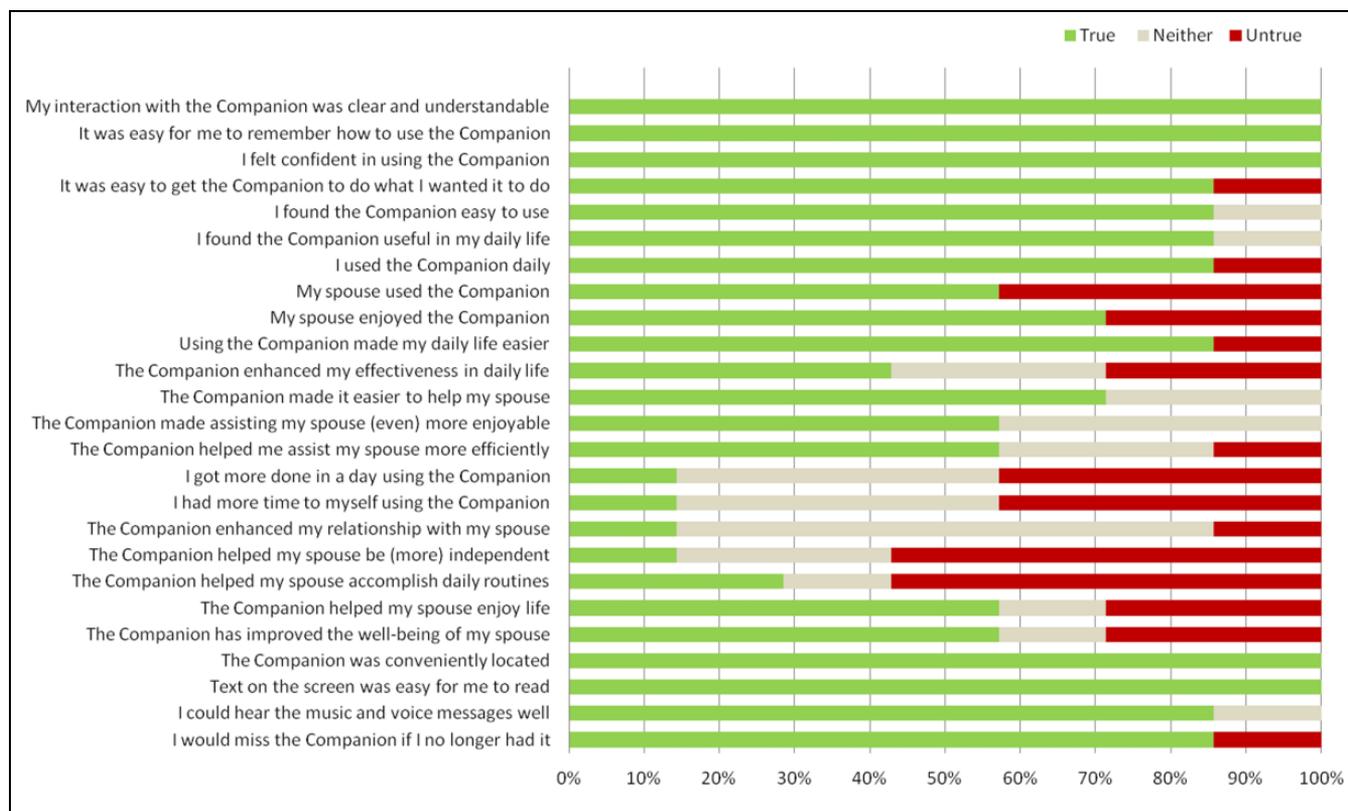


Figure 3. Caregiver (n = 7) technology adoption.

user screening and for systems that adapt to common user impairments, for instance by enlarging captions and graphics automatically if vision is impaired. Developing mobile applications and devices, in addition, will help accommodate ambulation difficulties, and it is encouraging to see older adults adopting tablet technology in great numbers.⁴¹ It remains to be seen how seniors use mobile health care devices and applications in the home and daily life and accordingly whether assistive technology can effectively address dementia symptoms and needs and relieve caregiver burden on a large scale.

A majority of care recipients in this study indicated they enjoyed the Companion shows, that they used it as a pastime and it brought back good memories and that it helped them relax and enjoy life. This suggests the intervention facilitated meaningful and positive engagement, as intended, and supports quality of life, although none of these constructs were measured formally with standardized, dedicated questionnaires. Our findings are consistent with the work of other laboratories using technology to promote reminiscing and quality of life⁴²⁻⁴⁵ and confirm that psychosocial interventions can be delivered using computer-based tools and digital media as opposed to a human being. The scope and depth of this positive engagement effect, for instance, on symptoms such as depression and apathy, remains to be seen. There is some evidence to suggest that technology-assisted interventions can benefit mood and mood disorder symptoms, but most studies to date have included young rather than older adults.⁴⁶ Technology studies

with older adults tend to focus on security and monitoring, not disease and symptom management, or NPS are addressed using nontechnological solutions such as environmental design.^{17,46} The current work did not focus on efficacy and, therefore, did not include postimplementation tests of NPS, quality of life, cognitive function, or caregiver distress. If efficacy was the objective, more dyads would need to be studied over longer periods of time, which we are in the process of doing. However, we question the usefulness of the repeat (pre-post) measurement of constructs such as cognitive function, ADL, and NPS using standardized tools, given that most symptoms, impairments, and the underlying disease state are unlikely to change if not deteriorate in the face of a progressive neurodegenerative disease such as dementia. Even if a symptom or function was to improve, standardized tools are unlikely to reflect this, as the tool's overall score includes a number of items that will not have improved or are irrelevant and thus remain stable regardless of an intervention. Rather, it seems relevant to ask which specific symptoms or needs are an issue for a caregiver and patient and to focus on those symptoms and needs specifically and exclusively in terms of the intervention as well as outcome assessment. By definition, this requires an individualized metric of success or outcome, which we used and advocate here in the form of goal attainment scaling (discussed further subsequently).

Questionnaire data did indicate that interventions helped care recipients prepare for things they have trouble with or they

enjoy doing or do not enjoy doing, which supports the notion that technology can prompt and motivate people to accomplish important health and wellness routines, such as daily oral hygiene, hydration, and exercise. This is consistent with the small body of work on personal digital assistants and cognitive prosthetics.^{18,47,48} Our study makes an important contribution to the field, as it tested in field a technology solution that integrates various nondrug interventions such as cuing, priming, reminiscing, and simulated presence in 1 customizable system that meets an important, unaddressed need, that is, managing common neuropsychological symptoms and care needs in the home.

These data also provide reason for cautious optimism. Although caregivers embraced the technology in terms of its ease of use and it facilitating and simplifying daily life, this did not necessarily translate into caregivers having more time to themselves or getting more done in a day. Caregivers were frequently instrumental in starting the Companion, and many would reminisce together with care recipients. Although very positive, this cost caregivers time rather than freeing it up. Benefits to caregivers' well-being arguably also take time to manifest themselves, which longer and larger prospective trials should address.

It is further notable that the majority of caregivers did not feel the intervention made their loved ones more independent, which is what many are looking for. Some expressed this quite clearly when we discussed and set intervention goals at the outset of studies and a loved one's dependence emerged as a prime psychological stressor from the Zarit caregiver burden scale in this sample. A key challenge for care technology and disease management systems, therefore, is to balance the requirement for personalization, which requires caregiver and care recipient input, with the requirement for caregiver respite. Caregivers are looking to simplify their lives, which is irreconcilable with the need to keep information and interventions up to date, relevant, and personal. The disconnect between aspirations and actualization of independence and simplification may partially explain why goal attainment ratings by caregivers at the end of trials were surprisingly harsh in a number of cases and did not necessarily reflect the progress care recipients had made. This highlights the importance of setting realistic expectations (goals) on one hand and collecting objective, measurable outcomes on the other. In this trial, we relied on caregiver's *subjective* perception of goal attainment but did not define a goal attainment scale (GAS) as some formal care providers have done in nursing home settings.³⁶ Family caregivers have difficulty defining such a scale in our experience and tend to set unrealistic goals, often unknowingly. Based on these experiences, we now define goals and help set an attainment scale in conversation with families, which works well and provides a more objective measure of progress and outcome. We also note that some goals (e.g., "I want Joe to be less agitated") are harder to define and accomplish than others ("I want Joe to drink more water"). Goal setting and attainment scaling, in conclusion, takes time and consideration but is a valuable method that lends itself well for measuring individual

intervention effects in geriatric and long-term care environments³⁶ but also education,⁴⁹ where needs vary greatly between individuals and within individuals over time. Focusing on standardized, group-based outcomes in these circumstances is frequently irrelevant and even unhelpful. Moreover, effective use of technology in older adults depends on whether or not a new technology satisfies an unmet need,⁵⁰ which reinforces the need not only for personalization but also for an individualized measure of outcome, which GAS provides. Recommendations to ensure methodological quality in applying this promising measurement approach can be found elsewhere.⁴⁹

With respect to the home setting, we note that these initial results suggest that a computer-based assistive technology can become part of the living environment and household routine. The size of the homes in this study was not an obvious barrier to hearing or seeing the interventions, but care was taken to make the Companion accessible to the care recipient by placing it in a convenient and relevant location. We also note that participants were considerably more frail than expected and study recruitment was a challenge, given high attrition rates due to participant frailty and the sensitivity and complexity of the subject matter. Dementia is surrounded by myth, confusion, and stigma, and something people need time to cope with if given a diagnosis. This hampers recruitment. In addition, many seniors, especially males in our experience, shy away from discussing difficulties they are experiencing and it is not always clear that something is wrong. This reluctance and uncertainty raises ethical dilemmas during recruitment and requires investigators to tread carefully. We also observed a general desire to focus on wellness and ability as opposed to disease and dysfunction. Consequently, the interventions in this demographic (independently living older adults) tend to focus on regaining independence and wellness rather than maintaining function and avoiding decline. The implication is that great care must be taken when implementing research and interventions that focus on assistive and wellness needs in seniors.

In conclusion, this field test indicated that a personalized computer-based tool for managing symptoms and needs common in dementia and late life was feasible, usable, and useful. The intervention facilitated meaningful and positive engagement in the home and helped care recipients and caregivers cope with symptoms and needs in daily life. Although a number of intervention goals were met, improving care recipient and caregiver independence is challenging and requires setting the right expectations as well as collecting objective measures of outcome.

Acknowledgments

We thank all our community partners for their support of this project and invaluable help with recruitment. No partner is named specifically to protect the identity of study participants.

Authors' Note

Part of this work was presented at the Gerontological Society of America 66th Annual Scientific Meeting, New Orleans, Louisiana, November, 20–24, 2013 (Abstract ID: 1692269).

Declaration of Conflicting Interests

The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: Chantal Kerssens, Renu Kumar, and Anne Adams are employees of SimpleC, LLC. The latter two positions were funded exclusively by grant 1R44AG042206-01. Camilla Knott (Aptima, Inc) is a contractor on grant 1R44AG042206-01. Jon Sanford and Wendy Rogers are consultants on grant 1R44AG042206-01.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by a Fast-Track Small Business Innovation Research (SBIR) grant from the National Institute on Aging (1R44AG042206-01) awarded to Kerssens and SimpleC, LLC.

References

- Alzheimer's Association and Centers for Disease Control and Prevention. *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*. Chicago, IL: Alzheimer's Association; 2013:64.
- Alzheimer's Association. 2012 Alzheimer's Disease Facts and Figures. *Alzheimers Dement*. 2012;8(2):131-168.
- Minati L, Edginton T, Bruzzone MG, Giaccone G. Current concepts in Alzheimer's disease: a multidisciplinary review. *Am J Alzheimers Dis Other Dement*. 2009;24(2):95-121.
- Doty P. The evolving balance of formal and informal, institutional and non-institutional long-term care for older Americans: a thirty-year perspective. *Publ Pol Aging Rep*. 2010;20(1):3-9.
- Prince Market Research. *Attitudes of Seniors and Baby Boomers on Aging in Place*. Nashville, TN: Prince Market Research; 2007.
- Mathew Greenwald & Associates Inc. *These four Walls . . . Americans 45+ Talk About Home and Community*. Washington, DC: Mathew Greenwald & Associates Inc; 2003.
- Andersen CK, Wittrup-Jensen KU, Lolk A, Andersen K, Kragh-Sørensen P. Ability to perform activities of daily living is the main factor affecting quality of life in patients with dementia. *Health Qual Life Outcomes*. 2004;2:52.
- Alzheimer's Association. 2011 Alzheimer's Disease Facts and Figures. *Alzheimers Dement*. 2011;7(2):208-244.
- National Alliance for Caregiving. *e-Connected Family Caregiver: Bringing Caregiving into the 21st Century*. Bethesda, MD: National Alliance for Caregiving; 2011:64.
- MetLife Mature Market Institute and Louis Tenenbaum. *Aging in Place 2.0: Rethinking Solutions to the Home Care Challenge*. Westport, CT: MetLife Mature Market Institute; 2010.
- Monastero R, Mangialasche F, Camarda C, Ercolani S, Camarda R. A systematic review of neuropsychiatric symptoms in mild cognitive impairment. *J Alzheimers Dis*. 2009;18(1):11-30.
- Gauthier S, Cummings J, Ballard C, et al. Management of behavioral problems in Alzheimer's disease. *Int Psychogeriatr*. 2010;22(3):346-372.
- Cohen-Mansfield J. Nonpharmacologic interventions for inappropriate behaviors in dementia: a review, summary, and critique. *Am J Geriatr Psychiatry*. 2001;9(4):361-381.
- Lou CR, Giuliano A, Mulvenna MD. State of the Art in Electronic Asssitive Technologies for People with Dementia. In: Mulvenna MD, Nugent CD, eds. *Supporting People with Dementia Using Pervasive Health Technologies*. London: Springer; 2010:23-35.
- Baruch J, Downs M, Baldwin C, Bruce E. A case study in the use of technology to reassure and support a person with dementia. *Dementia*. 2004;3(3):371-392.
- Lauriks S, Reinersmann A, Van der Roest HG, et al. Review of ICT-based Services for Identified Unmet Needs in People with Dementia. In: Mulvenna MD, Nugent CD, eds. *Supporting People with Dementia Using Pervasive Health Technologies*. London: Springer; 2010:37-61.
- Lauriks S, Reinersmann A, Van der Roest HG, et al. Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Res Rev*. 2007;6(3):223-246.
- Jamieson M, Cullen B, McGee-Lennon M, Brewster S, Evans JJ. The efficacy of cognitive prosthetic technology for people with memory impairments: a systematic review and meta-analysis. *Neuropsychol Rehabil*. 2014;24(3-4):419-444. <http://dx.doi.org/10.1080/09602011.2013.825632>.
- Ayalon L, Gum AM, Feliciano L, Areán PA. Effectiveness of nonpharmacological interventions for the management of neuropsychiatric symptoms in patients with dementia: a systematic review. *Arch Intern Med*. 2006;166(20):2182-2188.
- Ballard CG, Gauthier S, Cummings JL, et al. Management of agitation and aggression associated with Alzheimer disease. *Nat Rev Neurol*. 2009;5(5):245-255.
- Pittiglio L. Use of reminiscence therapy in patients with Alzheimer's disease. *Lippincotts Case Manag*. 2000;5(6):216-220.
- Woods B, Spector A, Jones C, Orrell M, Davies S. Reminiscence therapy for dementia. *Cochrane Database Syst Rev*. 2005;(2):CD001120.
- Webster JD, Bohlmeijer ET, Westerhof GJ. Mapping the future of reminiscence: A conceptual guide for research and practice. *Res Aging*. 2010;32(4):527-564.
- Olazarán J, Reisberg B, Clare L, et al. Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. *Dement Geriatr Cogn Disord*. 2010;30(2):161-178.
- Nielsen J. *Usability Engineering*. San Francisco: Morgan Kaufmann; 1993.
- Resnick B, Gruber-Baldini AL, Pretzer-Aboff I, et al. Reliability and validity of the evaluation to sign consent measure. *Gerontologist*. 2007;47(1):69-77.
- Folstein MF, Folstein SE, McHugh PR. Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975;12:189-198.
- Mahoney FI, Barthel DW. Functional evaluation: The Barthel index. *Md State Med J*. 1965;14(2):61-65.
- Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. *Gerontologist*. 1969;9(3):179-186.
- Alexopoulos GS, Abrams RC, Young RC, Shamoian CA. Cornell scale for depression in dementia. *Biol Psychiatry*. 1988;23(3):271-284.
- Cummings JL, Mega M, Gray K, Rosenberg-Thompson S, Carusi DA, Gornbein J. The neuropsychiatric inventory: comprehensive

- assessment of psychopathology in dementia. *Neurology*. 1994; 44(12):2308-2314.
32. Kaufer DI, Cummings JL, Ketchel P, et al. Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. *J Neuropsychiatry Clin Neurosci*. 2000;12(2):233-239.
 33. Thornton M, Travis SS. Analysis of the reliability of the Modified Caregiver Strain Index. *J Gerontol B Psychol Sci Soc Sci*. 2003; 58(2):S127-S132.
 34. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*. 1980; 20(6):649-655.
 35. Brandt J, Campodonico JR, Rich JB, et al. Adjustment to residential placement in Alzheimer disease patients: does premorbid personality matter? *Int J Geriatr Psychiatry*. 1998;13(8): 509-515.
 36. Gordon JE, Powell C, Rockwood K. Goal attainment scaling as a measure of clinically important change in nursing-home patients. *Age Ageing*. 1999;28(3):275-281.
 37. Davis FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. *MIS Quarterly*. 1989; 13(3):319-339.
 38. Venkatesh V, Davis FD. A Theoretical Extension of the Technology Acceptance Model: Four Longitudinal Field Studies. *Manage Sci*. 2000;46(2):186-204.
 39. Tiberio L, Cesto A, Cortelessa G, Padua L, Pellegrino AR. Assessing affective response of older users to a telepresence robot using a combination of psychophysiological measures. In: *2012 IEEE Ro-Man: The 21st IEEE International Symposium on Robot and Human Interactive Communication*. Paris, France. 9-13 September 2012; 2012:833-838.
 40. Cohen-Mansfield J, Dakheel-Ali M, Marx MS. Engagement in persons with dementia: the concept and its measurement. *Am J Geriatr Psychiatry*. 2009;17(4):299-307.
 41. Pew Internet & American Life Project. Tablet and E-book reader Ownership Nearly Double Over the Holiday Gift-Giving Period. In: *Pew Research Center's Internet & American Life Project*, ed. *Pew Internet*. Washington, DC: Pew Research Center; 2012:1-11.
 42. Alm N, Dye R, Gowans G, Campbell J, Astell A, Ellis M. Designing an interface usable by people with dementia. In: *Conference on Universal Usability*. Vancouver, British Columbia, Canada; November 10-11, 2003; 2003:156-157.
 43. Yasuda K, Kuwabara K, Kuwahara N, Abe S, Tetsutani N. Effectiveness of personalised reminiscence photo videos for individuals with dementia. *Neuropsychol Rehabil*. 2009;19(4):603-619.
 44. Mihailidis A, Blunsden S, Boger JN, et al. Towards the development of a technology for art therapy and dementia: definition of needs and design constraints. *Arts Psychother*. 2010;37(4):293-300.
 45. Astell AJ, Ellis MP, Bernardi L, et al. Using a touch screen computer to support relationships between people with dementia and caregivers. *Interact Comput*. 2010;22(4):267-275.
 46. Westphal A, Dingjan P, Attoe R. What can low and high technologies do for latelife mental disorders? *Curr Opin Psychiatry*. 2010;23(6):510-515.
 47. Alm N, Astell A, Ellis M, Dye R, Gowans G, Campbell J. A cognitive prosthesis and communication support for people with dementia. *Neuropsychol Rehabil*. 2004;14(1/2):117-134.
 48. Mihailidis A, Boger JN, Craig T, Hoey J. The COACH prompting system to assist older adults with dementia through handwashing: an efficacy study. *BMC Geriatr*. 2008;8:28.
 49. Ruble L, McGrew JH, Toland MD. Goal attainment scaling as an outcome measure in randomized controlled trials of psychosocial interventions in autism. *J Autism Dev Disord*. 2012;42(9): 1974-1983.
 50. Lin D, Hsieh C. The role of multimedia in training the elderly to acquire operational skills of a digital camera. *Gerontechnology*. 2006;5(2):68-77.