RESEARCH SUMMIT ON DEMENTIA CARE
Building Evidence for Services and Supports

The Use of Assistive Technology to Reduce Caregiver Burden

Issue Brief

May 2017

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Research Summit on Dementia Care: Building Evidence for Services and Supports

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Executive Summary

The Assistive Technology Act of 1998 defines *assistive technology* as any item, piece of equipment, or product system that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities. The most frequently cited goals for assistive technology for persons with dementia living in the community include maintaining independence, helping to ensure safety, and reducing caregiver burden, which, it is hoped, will delay or prevent costly institutionalization.

However, the evidence base for assistive technology that can compensate for cognitive impairment is lacking and little research has been conducted on technologies to address many common symptoms and impairments of dementia other than memory loss. Much of the research to date is methodologically flawed and does not take account of important issues, such as (1) the need to involve persons with cognitive impairment and dementia—and their caregivers—in the identification and development of assistive technology that will make a meaningful difference in their lives; and (2) determining who can benefit from a specific technology and the optimal time for introducing it.

Nonetheless, some commercial assistive technology products are available that may help to maintain independence by helping to orient a person with memory loss to time and place and facilitating the performance of activities of daily living. Importantly, a wide range of monitoring technologies can relieve caregivers from the strain of constant supervisory attentiveness.

However, no product will be effective and beneficial for everyone. Given the lack of research on the effectiveness of most commercially available products, caregivers need to assess whether an individual can use it and benefit from it and introduce the product on a trial basis. Assessment to ensure that an assistive technology product matches a person's deficits, abilities, and preferences must be ongoing because dementia is characterized by progressive decline.

Introduction

More than 5 million Americans have dementia, and the number of people with Alzheimer's disease, the most common cause of dementia, is projected to increase to 13.8 million by 2050 (Hebert, Weuve, Scherr, & Evans, 2013; National Institute on Aging, [NIA] 2016). Currently, no pharmacological treatments can prevent, cure, or significantly delay the onset or progression of Alzheimer's and other diseases that cause dementia (Cummings, Morstorf, & Zhong, 2014; NIA, 2016; U.S. Department of Health and Human Services, 2016).

Dementia affects individuals' cognitive function, behavior, and ability to perform everyday activities such as shopping, paying bills, and managing medications (Alzheimer's Association, 2016; NIA, 2016). As the condition progresses, individuals may need assistance with bathing, dressing, and eating. People living with dementia and their family caregivers face great difficulties in coping with and managing the condition. In particular, common behavioral problems—such as agitation, aggression, and wandering—are a significant source of stress for caregivers (Sales, Mayordomo, Redondo, Torres, and Bendicho, 2016). Caregivers experience high rates of depression and anxiety and are at increased risk for poor physical health outcomes (National Center on Caregiving, 2017).

Assistive technology has been proposed as a means to compensate for specific physical and cognitive deficits of people with dementia and to lessen caregiver burden. At least three additional factors have increased interest in the potential of assistive technology to compensate for cognitive deficits and to substitute for or complement informal and formal caregiving for people with dementia: (1) the projected long-term care workforce shortage, (2) the high cost of institutional care when caregivers can no longer meet an individual's needs at home, and (3) the availability of new technologies (O'Keeffe, Maier & Freeman, 2010; Woolham, Gibson, & Clarke, 2006).

Assistive technology has been defined in many ways. For example, the Assistive Technology Act of 1998 defines *assistive technology* as any technology designed to be used as an assistive technology device or service. An assistive technology device is "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities." Assistive technology services include those that directly assist an individual with a disability in the selection, acquisition, or use of an assistive technology device. Many organizations that support people with disabilities use similar definitions.

Given such a broad definition, research on assistive technology for dementia care covers a very wide range of products from "low tech" items such as grab bars, walkers, and reminder calendars, to "high tech" items such as "smart house" sensors to turn off appliances when they pose a hazard; remote monitoring systems to determine the level of activity and safety of persons in their homes; and GPS tracking technology to enable caregivers to locate individuals who wander and get lost (O'Keeffe, Maier & Freeman, 2010). Some of these assistive technology items—such as walkers and other devices to compensate for physical impairments—are considered to be durable medical equipment by public and private health insurance programs.

The most frequently cited goals for assistive technology products for persons with dementia living in the community include maintaining independence, helping to ensure safety, and reducing caregiver burden, which, it is hoped, will delay or prevent costly institutionalization. However, there is disagreement about the potential for assistive technology to compensate for the cognitive deficits associated with dementia. Some experts believe that computing, consumer

electronics, and telecommunications technologies have the potential to improve the quality of life for persons with dementia and their caregivers. In contrast, the Everyday Technologies for Alzheimer's Care initiative noted that many researchers, family members, social workers, and policy makers often assume that older people in general—and persons with dementia in particular—are incapable of using information and communication technologies (Dishman & Carrillo, 2007). This view is reflected in the marketing of "simplified" versions of widely used technologies, such as mobile phones and television remote controls, for older persons.

Lack of an Evidence Base for the Effectiveness of Assistive Technology in Dementia Care

Review articles on the topic of assistive technology for people with dementia identified several hundred studies published over the last 25 years. However, few of the evaluations met commonly accepted research standards of methodological rigor.

One review article examined the literature between January 1992 and February 2007 (Topo, 2009). After assessing 46 publications, including one review article, the author concluded that research on the role of technology in dementia care is still in its infancy and that much more study is needed to develop methods for assessing the relevant technologies' efficacy, acceptability, and usefulness, and to improve the coherence of study designs and outcome measures.

The most recent review article examined the literature between 1995 and 2011 and found that only 41 of 232 relevant studies met the methodological criteria for inclusion (Fleming & Sum, 2014). Of these, only 7 were considered methodologically strong; 10 were rated moderate, and 24 weak. The methodological limitations of these studies included small samples, high dropout rates, limited statistical analyses, and poor performance of the technology itself. The authors noted a great need for better designed, methodologically stronger studies, along with careful assessment to determine the likely benefit of a technology to an individual. The authors concluded that the research was unable to establish a positive effect of the assistive technologies reviewed in the lives of people with dementia.

Some review articles focus on a single technology, such as motion-based technology to increase physical activity. Motion-based technology is hypothesized to promote activity, improve cognition and physical function, and provide an engaging leisure activity. One type—computer sports games—requires users to wear a transmitter on the wrist so their hand and arm movements affect the motion of a ball or other sports item displayed on the computer monitor. Such games can be played while standing or sitting.

Some evidence suggests that the benefits of physical activity for people with dementia living in the community may include slowed progression of cognitive decline, improved mood and reduction in depression, and improved sleep (Teri, Logsdon, & McCurry, 2008). One systematic review, which analyzed 31 articles on motion-based technology, concluded that people with mild cognitive impairment or dementia can and are willing to learn to use it (Dovel & Astell, 2017). Participants in many of the studies reported a range of positive reactions to the activities, including enjoyment, engagement, stimulation, empowerment, encouragement, and motivation.

Nonetheless, the authors of the review concluded that although the current literature supports the use of the motion-based technology for people with mild cognitive impairment and dementia, this area of research is in the very beginning stages and requires further investigation. They noted the need for research on how to introduce motion-based technology to people with mild cognitive impairment and dementia—and their caregivers—and to train and support them in its use.

Another review article sought to examine the effectiveness of smart home technologies as an intervention for people with a physical disability, cognitive impairment, or learning disability, who are living at home (Martin, Kelly, Kernohan, McCreight, & Nugent, 2008). However, no study met the methodological criteria for inclusion. The authors concluded that the studies do not provide the empirical evidence to support or refute the use of smart home technologies within health and long-term care programs.

Many other researchers have reached similar conclusions about the lack of an evidence base, noting that the assistive technology research field is in a preliminary stage of development, with a large number of qualitative studies, audits, and service evaluations, but few with sufficient rigor and an appropriate design to allow for any degree of generalizability (Boger, Taati, & Mihailidis, 2016) or agreement about how "success" can be measured (Olsson, Engström, Skovdahl, & Lampic, 2012).

Additional Research Issues

In addition to the methodological issues discussed above, several features of the existing research on assistive technology present barriers to the development of a strong evidence base.

1. Research subjects are not comparable across studies.

To evaluate the effectiveness of an assistive technology for a specific population, research subjects should be comparable to the target population: people with dementia living in the community—with and without caregivers. The effectiveness of an assistive technology device will depend to a great degree on the type and severity of an individual's impairments. Thus, to ensure validity and reliability, researchers need to precisely define the target population and use accurate measures to identify research subjects' type and level of impairment.

Researchers vary considerably in their selection of a target population. A review of 108 abstracts on assistive technology for people with dementia, conducted for this paper, found that research subjects were selected based on the following conditions/diagnoses, using various measures:

- memory complaints
- a memory disorder
- mild cognitive impairment
- cognitive impairment
- mild dementia
- early stage dementia
- mild to moderate dementia
- early stage Alzheimer's disease
- mild to moderate Alzheimer's disease

Even if researchers reached a consensus to study only individuals with mild to moderate dementia, the measures they use to identify research subjects may not always be accurate. For example, impaired executive cognitive function (ECF) is more likely to be the initial symptom of vascular dementia, as opposed to the memory loss often associated with early Alzheimer's disease (Alzheimer's Association, 2017). But a commonly used measure—the Mini Mental Status Examination (MMSE)—can miss people with ECF impairment (Fogel, 2001). If individuals have both memory and ECF impairments, they may be categorized as having mild dementia when in fact they may have moderate to severe dementia.

Additionally, research populations may not be comparable if studies use different diagnostic measures to identify research subjects. For example, one study's inclusion criteria may use *either* a physician's diagnosis of dementia *or* a score on the MMSE, while another may use *only* an MMSE score or *only* a physician's diagnosis. Without knowledge of the measures a

physician used to make the diagnosis, it is not possible to determine if the research subjects are comparable both within and between studies.

Another issue is that researchers using the MMSE or other tests may employ different cut points to determine the stage of dementia. One study mapped MMSE scores onto Clinical Dementia Rating (CDR) categories to determine how well the MMSE performs as a surrogate of the CDR as a timesaving method of staging dementia. (Although the CDR has demonstrated high validity and reliability for this purpose, it requires the collection of a considerable amount of data from both the person with dementia and from an informant.)

The matching MMSE ranges were 0-10 for severe, 11-20 for moderate, 21-25 for mild, 26-29 for questionable, and 30 for no dementia. Yet researchers vary in the cut points they use and not all conform to these scores. For example, to identify individuals with mild to moderate cognitive decline, one study used an MMSE score of 25 ± 3.4 (28.4 - 21.6) (De Luca et al., 2016), while another used an MMSE score of 21.7 ± 2.9 (mean ± SD), (24.6 - 18.8) (Lanza et al., 2014). Neither of these cut points exactly match those that were mapped on CDR categories.

2. Assistive technologies generally focus on compensating for memory loss and do not take account other impairments that may preclude the use of a specific device or of behavioral symptoms, such as wandering, that cause stress for caregivers.

An early review of assistive technology for persons with cognitive impairment concluded that very little is known about the relationship between dementia's clinical features and the characteristics of assistive technology that are most suitable for individuals with specific impairments and behavioral symptoms (LoPresti, Mihailidis, & Kirsch, 2004). One review article noted that the greatest attention has been paid to memory aids, while little research has been conducted on devices that address any of the other progressive impairments associated with dementia such as aphasia, agnosia, apraxia, visuospatial deficits, and executive dysfunction (Bharucha et al., 2009).

Another review noted that common neuropsychiatric symptoms—such as agitation, aggression, rummaging and hoarding, wandering, disinhibition, apathy, resistance to daily care, and disruptive vocalizations—cause considerable stress for caregivers (Niedens, 2012), yet few if any assistive technology devices/interventions are available to help manage these symptoms (Kerssens et al., 2015).

Many studies focus on assistive technologies that prompt people to perform an activity that it is assumed they have "forgotten" how to do. Devices designed to prompt and remind people to perform specific activities—from hand washing to cooking to eating—are viewed as a means to compensate for memory loss. But other impairments unrelated to memory loss—such as impaired ECF—can preclude the use of such "reminder" devices.

Individuals may fail to wash their hands after using the toilet not because they have forgotten how to but because they no longer understand the need to perform the task or have lost the ability to follow instructions to carry out a task. Thus, they may become combative when a caregiver attempts to make them perform these activities. Providing prompts and even step-by-step instructions in such a case will not result in the desired behavior.

Another example of an assistive technology device that assumes memory loss is the only impairment is the design of an "easy-to-use" telephone with photos of friends, family members, and caregivers. These phones have several auto-dial buttons with photos of the person to be called. However, people with dementia may not recognize the phone, or be able to identify the photo or

the voice of the person called, or have the ability to follow through on a plan to call someone. They also may have aphasia—the inability to communicate with speech.

3. The target population may be too impaired to use an assistive technology device.

If researchers evaluate an assistive technology device for memory impairment among people with mild or moderate dementia, they may find that is not effective. But it may be effective for persons with mild cognitive impairment, approximately 60 to 65 percent of whom develop clinical dementia during their lifetime (Busse, Angermeyer, & Riedel-Heller, 2006). Introducing assistive technology devices at the very early stages of cognitive impairment would give the person time to learn to use and become familiar with it, and establish behavioral routines for using it that might persist into the early and moderate stages of dementia (Royall, 2010). Whether this learning would persist is currently unknown.

4. People with cognitive impairment or dementia living alone—with or without caregivers "on call"—are rarely included as research subjects.

A major goal of assistive technology is to help people live independently. However, one review article found that assistive technology research was conducted most often in residential care settings, such as assisted living facilities and nursing homes; only a few studies involved people with dementia living alone in the community (Topo, 2009). Devices that work in residential settings may or may not be effective in community settings.

5. Factors that affect the adoption and continued use of assistive technology are rarely considered.

Few studies consider factors that may affect the adoption and continued use of assistive technology. A key factor is the lack of information about what products are available and guidance for verifying manufacturers' claims because of an absence of agreed-upon standards (Woolham, Gibson, & Clarke, 2006).

Affordability is also a major factor. Although some basic devices such as reminder aids are low cost, sophisticated electronic monitoring systems may not be affordable for many people, and insurance coverage for assistive technology for people with dementia is very limited. Caregivers need to be educated about how assistive technology may or may not benefit a person with dementia—and themselves—before making a purchase.

Individual factors may also influence the adoption of assistive technology devices. For example, people with dementia may reject assistive technologies that need to be worn around the neck or wrist—such as a personal emergency response system or a tracking device—because it is uncomfortable or stigmatizing. If they have initially accepted it, as their condition deteriorates they may no longer recognize it or understand its purpose and discontinue its use. Several researchers argue that to achieve greater acceptance of—and satisfaction with—assistive technology devices, persons with dementia and their caregivers need to be involved in their development and design—termed a user-centered design approach (Zwijsen, Niemeijer, & Hertogh, 2011).

Finally, even if an assistive technology has been adopted, it can fall into disuse because of poor assessment of client needs, inappropriate choice of equipment, lack of client and caregiver instruction and support, and failure of the assistive technology to meet clients' and caregivers' expectations or needs (Bonner & Tahir, 2012).

6. Very different types of studies are conducted by researchers in diverse fields—with varying purposes and outcomes.

Because the definition of assistive technology is so broad, the literature on its use and effectiveness spans markedly different types of technologies with researchers from very different fields, including engineering, computer science, mathematics, robotics, rehabilitation, psychiatry, social work, nursing, and occupational therapy. As one author noted, the studies are difficult to compare because of the large variety of aims, technologies, research designs, and outcome measurements (Topo, 2009). Such a fragmented approach to determining the effectiveness of assistive technology in dementia care is a barrier to developing evidence on its effectiveness.

Using Assistive Technology in "Real World" Settings

Many assistive technology products are available that may help compensate for memory impairment and disorientation. Some products are available to facilitate communication, exercise, entertainment, and relaxation, which may help to decrease behavioral symptoms. Importantly, a wide range of monitoring technologies is available to relieve caregivers from the strain of constant supervisory attentiveness. They include technologies to alert caregivers when an individual gets out of bed during the night or attempts to leave the home at unexpected or inappropriate times, and to help ensure safer walking and address wandering problems. The availability of wireless technology has increased the range of products available and reduced the price of many (O'Keeffe, Maier, & Freeman, 2010).

However, to be useful, an assistive technology product must be both effective *and* beneficial. A product that is effective (i.e., achieves its intended purpose) but causes distress is not beneficial. Because individuals have different needs, abilities, and preferences, no product will be useful for everyone with dementia. Even if an assistive technology product is effective in a research setting, its usefulness may be limited when used in the home of a person with dementia or when used inappropriately (O'Keeffe, Maier, & Freeman, 2010).

The features of dementia that can influence the acceptance, use, and effectiveness of assistive technology include a person's

- specific pattern of cognitive abilities and deficits,
- specific emotional and behavioral changes,
- personality characteristics and attitudes toward technology,
- attitude regarding assistive technology that appears to exert "external control," and
- physical and social environment (LoPresti, Mihailidis, & Kirsch, 2004).

Any of these factors can result in an assistive technology product not being used effectively or *at all*—even if it has been proven to be useful in a controlled research setting. An individual must be both willing and able to use a product and comfortable with its use. Research has indicated that the use and acceptance of an assistive technology product may also depend on individuals' personality, motivation, and insight into their deficits (Jones, 2004).

Prior to introducing an assistive technology product or monitoring system, a thorough assessment of the individual and the physical and social environment must be performed to determine if the person can use it and will benefit from it. Assessment to ensure that an assistive

technology product matches a person's deficits, abilities, and preferences must be ongoing because dementia is characterized by progressive decline (O'Keeffe, Maier, & Freeman, 2010).

Given the lack of research on the effectiveness of many commercially available products, caregivers need to introduce such products on a trial basis to determine for themselves whether they are useful—that is, both effective and beneficial. Monitoring technology to ensure safety can be of benefit to caregivers, but its use needs to be carefully implemented so that it does not cause distress to a person with dementia. For example, when a person opens an exterior door, the sound of an alarm or a voice recording that warns the person not to leave the house could be frightening or disorienting.

Conclusion

The evidence base for assistive technology that can compensate for cognitive impairment is lacking, and little research has been conducted on technologies to address many common behavioral symptoms and impairments other than memory loss. Research on assistive technology would benefit from the following:

- greater involvement of persons with cognitive impairment and dementia—and their caregivers—in the identification and development of assistive technology that will make a meaningful difference in their lives;
- greater awareness of the clinical manifestations of dementia other than memory impairment;
- a better understanding of technology's potential and limitations in supporting persons with dementia and their caregivers in the community;
- a better understanding of the complexities of matching people and technology, with a focus on the factors that determine who can benefit from a specific technology and the optimal time for introducing it;
- some consensus about the target population and the selection of research subjects—taking account of the type and severity of their impairments—and about the most accurate methods to identify them; and
- interdisciplinary research: researchers in engineering, computer science, mathematics, and robotics would benefit from collaboration with professionals in gerontology, psychiatry, social work, nursing, and occupational therapy, with direct experience providing services to people with dementia living in the community.

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