

Chapter 14

Using Technology to Reach Caregivers of Veterans with Dementia

Candice M. Daniel

VA Salt Lake City Health Care System, USA

Bret Hicken

VA Salt Lake City Health Care System, USA & University of Utah, USA

Marilyn Luptak

University of Utah, USA

Marren Grant

VA Salt Lake City Health Care System, USA

Randall Rupper

*VA Salt Lake City Geriatric Research, Education, and Clinical Center, USA
& University of Utah, USA*

ABSTRACT

Caregivers of persons with dementia experience higher levels of anxiety, depressive symptoms, and other mental health problems, as well as increased rates of hypertension, cardiovascular disease, and premature mortality compared to their non-caregiving peers. They also face significant challenges in accessing support from local, state, and VA resources. Several empirically supported treatments have been developed to assist these caregivers. However, accessing these interventions can be difficult given the extent and demand of their caregiving duties. To address this problem, the authors developed a psycho-educational caregiver intervention for use with in-home digital technology that is currently underway at three Veteran's Health Affairs (VA) health care centers. The chapter provides: 1) a brief summary of the background and rationale for intervention development; 2) an overview of the project; and 3) the issues and lessons learned from developing interventions using digital technology for use with older adults.

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INTRODUCTION

Nearly 4 million older adults in the U.S. are currently living with dementia (Plassman, et al., 2007) and this number is expected to increase to more than 7 million people by 2030 (Alzheimer's Association, 2010). Dementia is characterized by impairment in multiple areas of cognition, including memory, resulting in functional impairment that affects daily life. Alzheimer's disease, the most common form of dementia, is a progressive and degenerative disease that involves gradual loss in functioning. Vascular dementia, the second most frequent type of dementia, commonly results in abrupt, stepwise changes in functional abilities. Language and motor impairment are common, in addition to impairment in memory, executive skills, and visuospatial abilities. These functional declines due to Alzheimer's and vascular dementia result in increased need for support and daily care.

Most older adults with dementia reside in their homes and are cared for by nearly 11 million unpaid caregivers (Alzheimer's Association, 2010). Informal caregivers of older adults with dementia are commonly spouses and children. Spouses are frequently older adults themselves, often facing their own chronic illnesses and health declines. Adult children typically have additional responsibilities, such as caring for their own children and working outside the home. As a result, informal caregivers have multiple responsibilities and demands on their time, in addition to their caregiving duties.

Caregivers manage a range of multiple issues related to basic and more complex instrumental activities of daily living for the individual with dementia (i.e., "care recipient"). Basic activities of daily living include basic self-care behaviors, such as eating, bathing, dressing, toileting, and transferring. For the caregiver, assisting with self-care behaviors may involve managing incontinence or assistance with dressing. Instrumental activities of daily living are more complex behaviors that involve the skills needed to function independently

in the community, such as managing finances and medication, driving or utilizing other transportation, and housework. Caregivers often take over these instrumental activities of daily living during the early stages of dementia. In addition to behaviors associated with daily living, caregivers cope with mood changes that the person with dementia may experience, including frustration, irritability, and agitation. Finally, caregivers manage behavioral problems common to dementia, such as wandering and aggression.

Given the extent of caregiving responsibilities identified above, caregiving requires large amounts of time committed to providing care. When compared to their non-dementia caregiving peers, caregivers of people with dementia spend more hours per week providing care (Ory, et al., 1999). The care of a person with dementia can require 24-hour involvement or supervision, while the amount of formal and informal care increases proportionately with the severity of dementia (Wimo, von Strauss, Nordberg, Sassi, & Johansson, 2002). Informal, or non-paid care, is often very time-intensive, measuring four times the amount of formal caregiving that patients with dementia receive (Wimo, et al., 2002). Given these diverse, challenging, and time-intensive caregiving responsibilities, caregivers often face increased stress, depression, and burden associated with caregiving (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999).

Compared to their non-caregiving peers, caregivers experience higher levels of depressive symptoms and other mental health problems (Schulz, O'Brien, Bookwala, & Fleissner, 1995). Caregiving can also take a toll on physical health. The health costs of caregiving include unintentional injuries related to caregiving duties; poorer self-reported health; and compromised immune systems. Increased rates of hypertension, cardiovascular disease (Monin, Schulz, Martire, Jennings, Lingler, & Greenberg, 2010; von Kanel, et al., 2008), and premature mortality (Schulz & Beach, 1999) have also been observed among

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