

The Role of Technology in Supporting Family Caregivers

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Abstract. In the United States and in many other countries, family members represent the primary source of support for older adults with a chronic disease or disability. While caregiving is associated with positive outcomes such as personal growth or the sense of helping someone in need, evidence has shown that caring for a relative/friend with an illness or disability causes distress in family caregivers and compromises their health and survival. Thus, there have been many intervention programs designed to aid family caregivers and many of these programs have proven beneficial in terms of alleviating caregiver burden and distress. Unfortunately, due to lack of awareness of the existence of these programs or logistic problems accessing these programs, many caregivers do not take advantage of or receive the benefits of evidenced-based interventions. This paper will discuss and demonstrate with examples from our research, how Information and Communication Technology (ICTs) can support family caregivers.

Keywords: Family caregiving · Social support · Information and communication technology

1 Introduction

The growth in the number of older people, especially the old-old, in both developed and developing countries has important implications for society and the healthcare system. Worldwide, the number of older persons was 841 million in 2013, and will almost triple by 2050, when it is expected to surpass the two billion mark [1]. The likelihood of developing a chronic disease or disability and the need for support and healthcare services generally increases with age. For example, about 36 million people worldwide have Alzheimer's disease (AD) or some other form of dementia and this number is expected to increase to 66 million by 2030 [2] (Fig. 1). In the U.S. alone about 92 % of older adults (aged 65 +) are living with one chronic condition such as high blood pressure, diabetes or heart disease and many 77 % have at least two [3].

Most people with a chronic condition such as AD or a disability are cared for at home by family. Although caregiving can have positive benefits, caregiving often creates negative consequences for the caregiver. Overall, the existent literature indicates that caregiving can result in psychological distress, the adoption of poor health habits, sleep disruption, psychiatric and physical illnesses, and mortality. Caregiving also often disrupts social

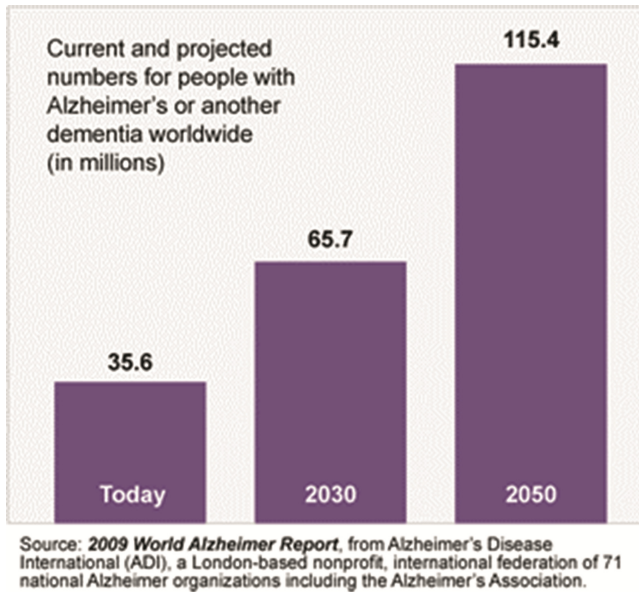


Fig. 1. Projected increase in the number of people with Alzheimer's Disease worldwide

and other family relationships and employment activities [4, 5]. Given these consequences, there has been a broad range of intervention studies aimed at decreasing caregiver stress and enhancing the caregiver experience. Several of these intervention studies have demonstrated beneficial effects for the caregiver such as in reductions in caregiver burden and depression and enhanced caregiving skills and social support. In fact, many of these programs such as the Resources for Enhancing Alzheimer's Caregiver Health (REACH II) [6], are now considered to be an evidenced-based interventions and are being broadly implemented in the community. However, despite the proliferation of these interventions many caregivers are unaware of or do not have access to these programs. For example, services are not always available to caregivers in some communities or their availability is not well advertised, further many caregivers are unwilling to use services that are available because of issues such as cost, logistic problems, or lack of help from others to care for the older adults when they are engaging in an activity such as attending a community support group. Information and Communication Technologies (ICTs) offer the potential of removing these barriers and providing support and delivering services to caregivers. Existing evidence suggests that the use of technology to deliver intervention programs and support to family caregivers is feasible and acceptable to caregivers and technology-based interventions can prove to be beneficial. However, this issue is just beginning to be explored and there is a need for a more robust evidence-based with diverse populations of caregivers. This paper will explore this issue and provide examples of technology-intervention programs.

2 Objectives

The focus of this paper is on demonstrating how ICTs can be used to support family caregivers and enhance their access to services and resources and their ability to provide care. A case example will be presented to demonstrate feasibility and efficacy of using technological interventions for caregiver populations. Issues of cost-effectiveness, barriers to implementation and privacy will also be discussed.

3 The Role of Technology in Support Family Caregivers

To provide a context for what follows we begin by providing a definition of family caregivers offered by Schulz and Martire [7], who define caregiving as the provision of extraordinary care outside of the bounds of what is considered typical for a relationship – e.g., a spouse does not typically bathe, feed and dress their partner. Caregiving typically involves a range of tasks such as care coordination, assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), provision of emotional and in some cases (e.g., dementia) provision of cognitive support. Caregiving also increasingly involves assistance with healthcare tasks previously performed by trained specialists such as delivering injections or interacting with a blood glucose monitor or an infusion pump. Thus, caregiving involves tasks that may be unpleasant and uncomfortable; are psychologically stressful and physically exhausting; and involve significant expenditures of time, effort, energy, and financial resources over potentially extended periods of time. Further, the demands of caregiving are not static and many change over the course of their loved ones' illness.

Due to the increased reliance on family caregivers to help manage the growing population of older adults and the documented consequences of caregiving on the caregiver, there have been a broad range of intervention trials aimed at decreasing the burden of caregiving and providing support to the family caregiver. These interventions included counseling, skills training, case management, and social support. They are also delivered in a variety of formats and contexts such as individual and group sessions delivered in the home or in clinical settings. Unfortunately because many caregivers remain unaware of these programs or confront barriers to accessing these programs, the benefits of these programs are often not experienced by many family members in the caregiving role. Thus there is a need for innovative methods to bring services and support to caregivers – clearly ICTs offer this potential.

Overall, ICTs hold several advantages over more traditional methods of intervention delivery such as: increased ability to deliver and access information on demand and in a time efficient manner, over long distances and asynchronously; increased access to resources and healthcare providers; and increased flexibility with respect to information format. For example, the Internet and mobile devices can enhance caregivers' access to information and resources. A challenge facing many caregivers is having the necessary knowledge about the care recipient's illness or disability, how to provide care, and how to access and utilize available services. There are a vast number of websites available that can provide caregivers with information on illnesses/diseases, medications and

treatments, healthcare providers and health resources. These applications can also enhance direct access to experts and professional organizations, which can also facilitate decision-making by the caregiver. Recent data from the Pew Internet and American Life Report [8] indicates that among caregivers in the U.S. who have access to the Internet, 84 % indicated that they went online to research health topics such as information about their loved ones illness, medication safety, and medical procedures. Fifty-nine percent of these caregivers said that the online resources enhanced their ability to provide care and 52 % indicated that these resources have been helpful in their ability to cope with caregiver stress. Of course a concern is the quality, quantity and usability of the information offered by Internet resources. Our data shown that Internet health information can be challenging to use and understand (e.g., [9, 10]).

Network applications can also link caregivers to other family members or long distant caregivers to the person for whom they are providing care. They also offer caregivers the opportunity to engage with other caregivers and participate in support groups.

Monitoring and sensing technologies are increasingly being used to monitor the functional health and activities of older adults, and to assist with the management of chronic conditions, may also be beneficial to family caregivers. Develops in microelectronics and digital wireless technology now make it possible to integrate wireless sensors and network capabilities so that the information collected from the sensors can be transferred to clinicians and family caregivers at remote locations. These systems include a wide variety of technologies such as home-based safety monitoring systems (e.g., fall detection systems, sensor-embedded environmental systems); embedded or integrated activity-monitor sensory systems that track behaviors such as movement patterns, sleep behaviors or simpler systems that track activities such as medication adherence; and systems that monitor vital signs and other health indicators or provide reminders about health-related activities.

However, despite these benefits there are also potential challenges associated with technology use such as lack of “meaningful access” to technology systems for some segments of the population (e.g., older adults, individuals of lower socio-economic status), usability problems, the dynamic and constant evolution of technology, cost and reimbursement, and the possibility that using technology to deliver an intervention may not be a comparable substitute to the face-to-face interactions between caregivers and interventionists, other caregivers, or healthcare providers [11, 12]. To overcome these challenges requires larger robust trials to gather evidence about the benefits and pitfalls of technology and the consideration of caregiver characteristics, needs, and preferences.

3.1 Case Study: The Videocare Study [13]

The VideoCare Study was a randomized pilot trial that evaluated the feasibility and efficacy of a technology-based intervention among an ethnically diverse sample of family caregivers of patients with Alzheimer’s disease. Following a baseline assessment a sample of 110 caregivers (56 Hispanic Americans and 54 African Americans) were randomized into: (1) the videophone intervention condition; (2) a nutrition attention control condition; or (3) an information only control condition. Those assigned to the intervention group received a Cisco videophone that was installed in their home and

connected to a DSL line and a secure server at the host site (Fig. 2). The Videophones were used to conduct individual skill building sessions with a certified interventionists and facilitator led support groups. The support groups were conducted via the videophone in English and Spanish and followed a structured education/supportive format. This included an introduction to and discussion of themes related to the caregiving experience. The group themes included: (1) Introduction to Dementia; (2) Managing Behavioral Problems; (3) Caregiver Well Being; and (4) Communication; and Planning for Life Transition. The support group sessions were closed, 60 min in duration, and were interspersed with the individual videophone skill building sessions. The caregivers participated from their own homes via videophone. Other features available on the videophones included an annotated resource guide, caregiver tips: educational seminars. The features were presented in hierarchical menus in a multi-modal format (speech and text). Caregivers received training in the use of the videophone, were provided with a help card and access to technical support. There was also a help feature on the menu. All features were available in English and Spanish (Fig. 3). The intervention duration was 5 months, followed by a post intervention assessment.



Fig. 2. The Videophone technology

The results of the study are encouraging and indicate that the intervention was beneficial in terms of alleviating caregiver distress and increasing social support and positive feelings about caregiving among the caregivers assigned to the Videocare intervention arm (Czaja et al. 2014). The majority of caregivers (82 %) also found participating in the on-line support groups was valuable, and that participation in the groups improved their knowledge about caregiving and their caregiving skills. All of the caregivers

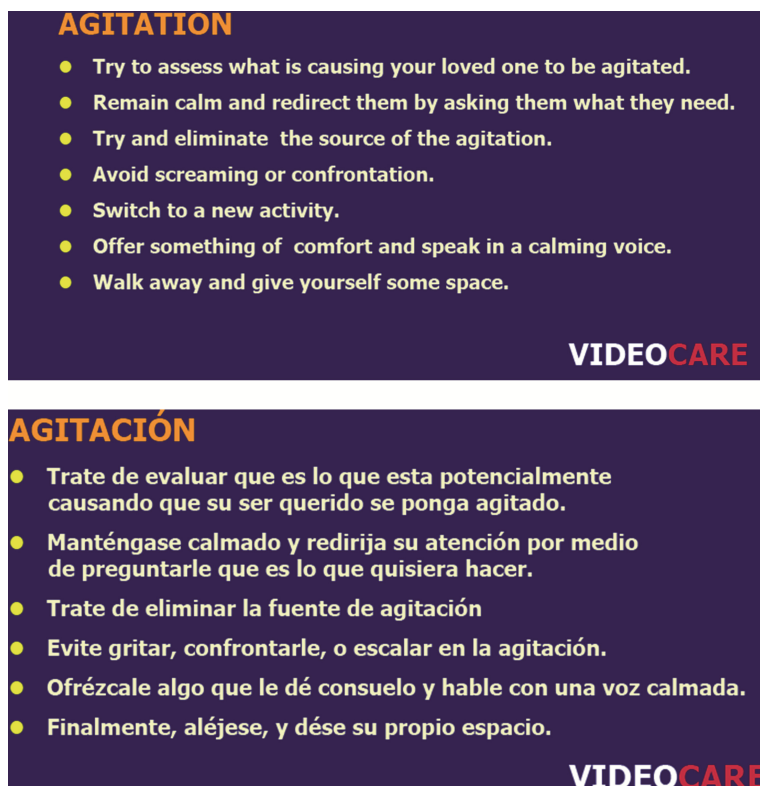


Fig. 3. A sample of a caregiver tip screen in English and Spanish

(100 %) indicated that participation in the groups helped them share their feelings about being a caregiver. In addition, the caregivers were able to use the videophone system and the majority indicated that the videophone was understandable and easy to use. Overall, the findings from the study demonstrate that technology is a viable and valuable option for delivering intervention programs and conducting support groups with diverse caregiver populations. The caregivers were enthusiastic about the program and were able to use the technology. They also found it useful in terms of enhancing their access to resources.

4 Conclusions

This paper provides examples of various technologies and their potential benefits for family caregivers. However, for the benefits of these technologies to be realized by caregivers, it is important that the technology is useful and useable by these populations and that systems are reliable and responsive. If a system is unavailable it cannot be used, and if it is unreliable users will become frustrated and avoid using the technology regardless of potential benefits. All technology involves potential barriers to acceptance

that must be overcome to facilitate widespread acceptance, adoption and continued use. These include a broad range of user characteristics (socio-demographics, health status, social support, experience with and attitudes towards technology) and resources (sensory, cognitive, psychomotor); system characteristics (user interface, instructional support, aesthetics, engagement, functionality); and the fit between the user and the system.

One issue that remains is technology access. Although the rate of technology adoption is increasing across age groups existing data indicate that there are still age-related gaps in usage especially among caregivers and older adults of lower socio-economic status.

Other issues relate to privacy issues and data integration, management and sharing issues. It is essential to investigate sources of potential for harm inherent in some technologies such as privacy intrusions, false perceptions about the capabilities and safety of technology systems, the proliferation of too much and inappropriate information and miscommunications between caregivers, patients and healthcare providers. Optimal strategies for combining technology with other types of interventions and healthcare interactions need to be identified. More rigorous studies are also needed to evaluate the effectiveness of technology-based interventions with large and diverse caregiver populations and on the cost effectiveness of technological interventions.

It is also important to note that many caregivers are also increasingly need to perform medical/nursing tasks, which also means that they have to interact with complex medical technologies such as catheters blood glucose monitors, and injection equipment. In addition, they may have to interact with telemedicine technologies and Personal Health Records (PHRs). Thus it is important to insure that caregivers have the requisite skills and instructional support to use these technologies and that these technologies conform to usability guidelines. All too often ICT technologies are designed without consideration of user populations.

References

1. United Nations, Department of Economics and Social affairs, Population Division: World Population Ageing 2013. ST/ESA/SER.A/348 (2013)
2. World Alzheimer Report 2010. <http://www.alz.co.uk/research/files/WorldAlzheimerReport2010.pdf>
3. National Council on Aging: Healthy Aging Facts. <https://www.ncoa.org/news/resources-for-reporters/get-the-facts/healthy-aging-facts/>
4. Pinquart, M., Sörensen, S.: Correlates of physical health of informal caregivers: a meta-analysis. *J. Gerontol. B Psychol. Sci. Soc. Sci.* **62**, P126–P137 (2007)
5. Schulz, R., O'Brien, A.T., Bookwala, J., et al.: Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *Gerontologist* **35**, 771–791 (1995)
6. Belle, S.H., Burzio, L., Burns, R., Coon, D., Czaja, S.J., Gallagher-Thompson, D., et al.: Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: a randomized, controlled trial. *Ann. Intern. Med.* **145**, 727–738 (2006)
7. Schulz, R., Martire, L.M.: Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *Am. J. Geriatr. Psychiatry* **12**, 240–249 (2004)

8. Fox, S., Duggan, M., Purcell, K.: Family Caregivers are Wired for Health. Pew Research Center. http://www.pewinternet.org/files/old-media/Files/Reports/2013/PewResearch_FamilyCaregivers.pdf
9. Czaja, S.J., Sharit, J., Nair, S.N.: Usability of the medicare health web sites. *J. Am. Med. Assoc.* **300**, 790–791 (2008)
10. Taha, J., Sharit, J., Czaja, S.J.: Use of and satisfaction with sources of health information among older internet users and nonusers. *Gerontologist* **49**, 663–673 (2009)
11. Berkowsky, R., Czaja, S.J.: The use of technology in behavioral intervention research: advantages and challenges. In: Gitlin, L., Czaja, S.J. (eds.) pp. 119–136. Springer Publishing Company, LLC, New York (2016)
12. Czaja, S.J., Lee, C.C., Schulz, R.: Quality of life technologies in supporting family caregivers. In: Schulz, E. (ed.) *Quality of Life Technology Handbook*, pp. 245–260. Taylor & Francis, New York (2012)
13. Czaja, S.J., Loewenstein, D., Schulz, R., Nair, S.N., Perdomo, D.: A videophone psychological intervention for dementia caregivers. *Am. J. of Geriatr. Psychiatry* **21**, 1071–1081 (2013)