Technology-Driven Interventions for Caregivers of Persons With Dementia: A Systematic Review

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Technology-Driven Interventions for Caregivers of Persons With Dementia: A Systematic Review

Kyler M. Godwin, PhD, MPH¹,², Whitney L. Mills, PhD², Jane A. Anderson, PhD, RN, FNP-BC³,⁴, and Mark E. Kunik, MD, MPH²,⁵,⁶

Abstract
Caregiving for a person with dementia can lead to physical and psychological morbidity. Technology-driven interventions hold the promise of convenient, low-cost methods of delivering psychosocial interventions. This systematic review examined the efficacy of technology-driven interventions for caregivers of persons with dementia. A search of Ovid Medline, PsychInfo, and EBSCO from 1990 to May 2012 resulted in the identification of 295 articles. After removal of duplicates, 271 articles were reviewed, based on the abstract and title alone; 32 were relevant or could not be fully assessed without assessing the entire article. Eight fully satisfied the inclusion/exclusion criteria. Each of these had some positive findings. However, there was large variability in the content and delivery of the interventions and inconsistency in measurement and variability of outcomes. Future studies should employ randomized control trial methodology and measure outcomes with commonly used measures to ensure feasibility of comparisons across the studies.

Keywords
caregiver, dementia, technology, systematic review, intervention

Background
Persons with Alzheimer’s disease (AD) and other dementias usually receive care at home from unpaid family caregivers. Specifically, 15 million Americans provide unpaid care for persons with dementia (PWD). These unpaid, or informal, caregivers bear the financial, physical, social, and psychological burdens of this care.¹ Additionally, it is well known that caregiving for a person with AD or another dementia can lead to physical and psychological morbidity, including caregiver’s burden, depression, anxiety, stress, and strain.¹,²

Because of the high personal cost of caregiving for PWD, numerous interventions have been developed to improve caregivers’ psychosocial outcomes through behavior change and increased social support. Several systematic reviews have evaluated these existing interventions to determine the scientific evidence for the best way to intervene with caregivers of PWD. One systematic review of psychological interventions for caregivers of PWD found caregivers’ psychological health improved with 6 or more individual behavioral management therapy sessions focused on the PWDs’ behavioral problems.³ It also found support for improving caregivers’ psychological health by teaching caregivers coping skills in both individual and group session formats. A review of information and support interventions for caregivers of PWD found group-based supportive interventions to reduce depression; however, the authors cautioned that the clinical significance of the finding was uncertain.⁴ Another review of interventions for caregivers of PWD focused on the clinical, rather than statistical, significance of psychosocial and environmental interventions.⁵ Methods for delivering interventions varied across the studies; often, the caregiver traveled to receive the intervention or an intervention specialist traveled to the caregiver’s home; several interventions also employed some amount of intervention

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delivery via telephone. Home-based interventions are prevalent in the literature and are often less burdensome for the caregiver compared to interventions delivered at another site, though home-based care remains costly and may still be inconvenient for caregivers because of scheduling challenges and disruptions of daily routine.

Technology-driven interventions (ie, interventions that use computer or Web-based applications) offer convenient, low-cost alternatives for delivering interventions to caregivers of PWD. They can provide health information alongside social support or behavioral change support.\(^6\) Interventions that use Web-based and other technological applications can also be used at any time of day or night that the caregiver finds convenient. Other benefits of such interventions include the capability of relaying information in a variety of formats (ie, text, graphs, video, and audio), enabling informed decision making through the provision of information, promoting health behaviors by increasing knowledge, and encouraging information exchange and emotional support among peers.\(^6\) Because of their possible benefits, convenience, and low cost, several interventions for caregivers of PWD have been conducted with various technology-driven components.

Although several systematic reviews of interventions for caregivers of PWD have been conducted, no review of technology-driven interventions for informal caregivers of PWD has been reported to date. This study was a systematic review of the literature to ascertain the effects of technology-driven interventions for caregivers of PWD. Specifically, this study examined the psychosocial effects (ie, depression, burden, stress, and strain) of technology-driven interventions targeted toward informal caregivers of PWD.

**Methods**

**Search Strategy**

Ovid Medline, PsychInfo, and EBSCO databases were searched for all randomized controlled trials (RCTs) of technology-driven interventions for caregivers of PWD between 1990 and May 2012. The following key words and medical subject headings were used: *interactive health communication or IHC or communication or health communication or computers or computer communication networks or Internet or medical informatics or medical informatics applications or decision making, computer-assisted therapy, computer-assisted or software or communications media or telecommunications or multimedia or CD-ROM or compact disks or medical informatics computing or consumer health informatics or world wide web or computer-assisted instruction or interactive technology application or digital TV or digital television or web-based packages or hypermedia or video games or virtual reality AND caregiver or caregiver* or *caregiver AND dementia or delirium or dementia, amnestic, cognitive disorders or dementia, vascular or dementia, multi-infarct or Alzheimer disease AND middle aged or aged AND intervention studies or randomized controlled trials as topic or controlled clinical trial or random allocation or clinical trial or random\$ or follow-up studies or prospective studies. After the above terms were combined, the following terms were excluded: magnetic resonance imaging or signal processing, computer-assisted or image processing, computer-assisted or dose-response relationship, drug or biopsy or cardiac-gated single-photon emission computer-assisted tomography or therapy, computer-assisted or tomography, x-ray computed or screening or mass screening or qualitative research. Studies were limited to those published in English.

**Inclusion and Exclusion Criteria**

Interventions developed for informal caregivers were included in this review. Informal caregivers were defined as anyone who was an unpaid caregiver of the PWD; this could be a spouse, adult child, other family member, or friend. Interventions aimed at paid caregivers (ie, nurse’s aides and other long-term care workers) were excluded. Technology-driven interventions were defined as interventions that used computer- or Web-based applications. Interventions that were decision aids only or that included telephone contact only were excluded. Also excluded were interventions in which the technology was exclusively limited to videotape or CD. Studies that reported only on feasibility or dose of an intervention were also excluded, although follow-up and prospective studies were examined to help inform the discussion.

**Outcome Measures**

The outcome measures of interest were broadly defined as caregivers’ psychosocial outcomes, such as burden, depression, anxiety, stress or strain- common psychosocial outcomes in the caregiving literature. To create the broadest set of studies possible, the initial search terms were not limited by outcome measures. However, outcome measures were considered in the final determination of study inclusion or exclusion.

**Data Collection and Analysis**

Duplicate articles identified in the search were excluded as part of the search strategy. All remaining articles were exported to a reference manager (RefWorks). One author (KMG) screened all titles and abstracts for eligibility. Studies that clearly did not meet inclusion criteria were excluded. Screening erred on the side of inclusiveness; if it was not obvious that the abstract did not fit the criteria, we retained the study for further review. A full-text, paper copy was obtained for all the remaining studies. Both electronic and hard copies were maintained for ease of review.

A review tool based on the Cochrane handbook\(^7\) and the Centre for Reviews and Dissemination\(^8\) was developed in a Microsoft Access database. Two reviewers, KMG and WLM, independently applied the selection criteria to each study and extracted data from studies not excluded upon further review. Reviewers first extracted the following: reviewer initials,
citation, date of review, whether the study was an RCT, whether the study was a technology-driven intervention, whether caregiver’s psychosocial outcomes were reported, and whether the study was truly eligible for review. If the study was considered ineligible for review, the reason for exclusion was noted. If the study was eligible for review, the following additional data were extracted: study aim(s)/objectives; study design; date of study; study inclusion and exclusion criteria; study recruitment procedures; unit of allocation (individual, clinic, etc.); total study duration; number, age, gender, ethnicity, and health status of participants; setting in which the intervention was delivered; description of intervention and control; number of missing participants; outcome measures; and key findings. Extracted data were entered directly into the database for ease of data management and analysis. Any discrepancies between the 2 reviewers were discussed. If discrepancies could not be resolved, the issue would have been referred to a third reviewer; however, this was not necessary. All studies meeting all the inclusion criteria have been included in this review.

Results
Our initial search yielded 295 citations (Ovid = 123, PsychInfo = 30, and EBSCO = 140). After removal of duplicates, we reviewed the remaining articles based on the abstract and title alone and fully assessed the others by reading the entire article. Most were not included in this review for the following reasons: (1) was not an RCT or did not report RCT results; (2) did not report caregiver’s psychosocial outcomes; and (3) not technology driven, as defined in this review (see Figure 1). The 8 articles included in this review are listed in Table 1.

Included in this review are 8 articles representing 4 unique RCTs, resulting from 3 parent studies: “Caregiver’s Friend: Dealing with Dementia,”9 “ComputerLink,”10-12 and “Resources for Enhancing Alzheimer’s Caregiver Health (REACH).”13-16 In all the studies, caregivers were caring for someone with AD or a related dementia. Most caregivers were white women with an average age of more than 60 years (with the exception of the study of Caregiver’s Friend, which involved caregivers with an average age of 46.9 years). The articles have been combined by study to gain a better overall picture of the impact of technology-driven interventions on caregivers of PWD.

Studies
ComputerLink used a computer network with 3 main components: information, communication, and decision support.10-12 Information on AD management and treatment, community services, and caregiver’s self-care was provided via an electronic encyclopedia. Caregivers could communicate with other caregivers through a public forum or privately through email. An anonymous question-and-answer forum was moderated by a nurse. The decision support component guided the caregiver in exploring his or her values and the trade-offs associated with self-selected decision problems. ComputerLink did
<table>
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<tr>
<th>Authors</th>
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<th>Outcome Variables</th>
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<td>Beauchamp et al</td>
<td>To evaluate the efficacy of multimedia support program delivered over the Internet to employed family caregivers of PWD</td>
<td>Caregiver’s Friend $n = 299$, 46.9 years (avg), 73% female, 80% white, 4% African American, 8% Hispanic</td>
<td>Caregiver strain; caregiver gain; depression; anxiety</td>
<td>Significant improvements in depression, anxiety, stress, strain, self-efficacy, intention to seek help, and perceptions of positive aspects of caregiving.</td>
</tr>
<tr>
<td>Bass et al</td>
<td>To determine whether access to ComputerLink had greater reductions in caregiver strain</td>
<td>ComputerLink $n = 96$, 60 years (avg), 68% female, 28% African American</td>
<td>Caregiver strain; activity restriction; ComputerLink use</td>
<td>No reduction in overall strain. Reduction in relationship strain for spouses and in emotional strain and activity restriction for caregivers with more informal support. Decrease in activity restriction was greater for caregivers not living alone with PWD.</td>
</tr>
<tr>
<td>Brennan et al</td>
<td>To examine the impact of ComputerLink use on caregiver’s decision-making confidence, skill, and isolation</td>
<td>$n = 102$, 64 years (median), 67% female, 72% white</td>
<td>Decision-making confidence; decision-making skill; social support; depression; burden; service utilization; patient’s functional status</td>
<td>Significant improvement in decision-making confidence. Functional status declined similarly in both the groups. No significant changes in decision-making skills or perception of social isolation.</td>
</tr>
<tr>
<td>Casper et al</td>
<td>To examine the impact of ComputerLink on caregiver’s decision confidence and skill</td>
<td>$n = 102$, 60 years (avg), 67% female, 28% African American</td>
<td>Decision-making confidence; decision-making skill</td>
<td>Significant improvement in decision-making confidence. Access to and length of time on ComputerLink were correlated with decision-making confidence.</td>
</tr>
<tr>
<td>Eisdorfer et al</td>
<td>To examine efficacy of SET and SET + CTIS to reduce depressive symptoms</td>
<td>REACH $n = 225$, 69 years (avg), 75% female, 51% Cuban Americans, 49% white Americans</td>
<td>Depression; burden; satisfaction with social support</td>
<td>Combined family therapy and technology intervention (SET + CTIS) resulted in significant reduction in depressive symptoms at 6 and 18 months.</td>
</tr>
<tr>
<td>Finkel et al</td>
<td>To evaluate the effectiveness of technology-based caregiver psychosocial intervention modeled after the REACH SET + CTIS intervention</td>
<td>$n = 46$, 64.6 years (avg), 68% female, 92% white, 8% African American</td>
<td>Depression; caregiver’s health behavior; social support; change in problem behaviors</td>
<td>Caregivers in the intervention had a significant decrease in burden overtime. Compared with controls, those with high depression at baseline had improvement in depression; those with high support at baseline were able to maintain support and had improved caregiving confidence and ability to provide care.</td>
</tr>
<tr>
<td>Gitlin et al</td>
<td>To determine the pooled treatment effect of 15 different REACH interventions on burden and depression</td>
<td>$n = 1222$, (age, gender, and ethnicity not reported in this article)</td>
<td>Depression; burden</td>
<td>Intervention improved caregiver’s burden. The family therapy plus computer technology intervention reduced depression.</td>
</tr>
<tr>
<td>Mahoney et al</td>
<td>To determine the main outcome effects of a computer-mediated automated interactive voice response intervention</td>
<td>$n = 100$, 62 years (avg), 80% female, 79% white</td>
<td>Bother; anxiety; depression</td>
<td>Significant intervention effect on bother, anxiety, and depression for caregivers with low mastery at baseline. Wives also had a significant intervention effect in reducing bother.</td>
</tr>
</tbody>
</table>

Abbreviations: PWD, persons with dementia; REACH, Resources for Enhancing Alzheimer’s Caregiver Health; SET, structural ecosystems therapy; CTIS, computer telephone integrated system.
not reduce overall strain but was successful in reducing certain types of strain for spouses, those with more informal support, and caregivers who did not live alone with the PWD. Additionally, ComputerLink improved caregivers’ decision-making confidence.

Caregiver’s Friend: Dealing with dementia used a Web-based multimedia intervention to deliver positive caregiving strategies via text and video messages to caregivers of persons with substantial memory loss. Caregivers were able to personalize the program, based on their specific concerns and their family member’s degree of memory loss. Caregiver’s Friend was unique from the other studies in this review in which it targeted caregivers employed at least part time in addition to providing care for their family member. This study found that Caregiver’s Friend significantly increased the self-efficacy, intention to get support, and perception of the positive aspects of caregiving in caregivers who received the intervention. Caregivers in the intervention group, when compared to the control group, had statistically significant reductions in stress, strain, anxiety, and depressive symptoms.

The REACH study had 15 different conditions, including 9 active and 6 control conditions. Four articles were found which used technology and reported RCT results. In all, 1 of the 4 summarized all REACH interventions and control conditions. One reported on the REACH-Telephone-Linked Care (TLC). Two reported on the slightly different versions of REACH structural ecosystems therapy (SET) or SET plus a computer telephone integrated system (SET + CTIS). The REACH-TLC consisted of a telephone network system with interactive voice response that provided caregiver stress monitoring and counseling information on managing problem behaviors, personal voice linkages to AD experts, a voice mail telephone support group, and a distraction call for PWD. The REACH SET + CTIS provided family therapy using SET or SET + CTIS. The SET provided home-based weekly sessions for the first 6 months and then biweekly sessions over the next 2 months and monthly sessions for the final 6 months. In the SET + CTIS condition, caregivers received the same intervention, except the final 6 months were delivered via the CTIS. Both the REACH-TLC and the REACH SET + CTIS interventions significantly improved caregiver’s depression. Specifically, the REACH-TLC intervention had a significant effect on bother and anxiety (in addition to depression) for those with low mastery at baseline. The REACH SET + CTIS intervention not only improved depression but also enabled those in the intervention with high social support at baseline to maintain their support. The intervention also resulted in significant improvement in caregivers’ confidence and ability to provide care to the care receiver.

Outcomes

As is often the case with caregiving interventions with psychosocial outcomes, each of the studies focused on different outcomes. Although there was some overlap, no single statement about particular outcomes can be made about all 3 studies because of the focus on different outcomes and the different measurement tools used. All the interventions included measures of social support, but not all studies conceptualized social support as an outcome measure. Two studies reported on caregiver’s strain, while 2 others reported caregiver’s depression and anxiety.

Social Support

Social support was measured with a different instrument in each intervention. Caregiver’s Friend reported an improvement in intention to get social support as measured by the Revised Ways of Coping social support subscale. The ComputerLink intervention reported social support in 2 ways, as a risk factor and an outcome variable. As a risk factor for caregiver stress, social support was measured by the number of close family members and friends in the caregiver’s support network. An outcome variable, social support was measured as the inverse of the Instrumental and Expressive Social Support Scale and was used as a measure of social isolation; no significant changes in social isolation were reported. The CTIS component of REACH showed no significant difference in satisfaction with social support when combined with the SET. However, when the CTIS component was used alone, those caregivers with higher levels of social support at baseline were more likely than controls to maintain that support over time, as measured by the Received Social Support scale.

Strain

The 2 interventions that reported on strain did use the same Caregiver Strain Index but had conflicting findings. One study reported significant improvement in strain, while the other reported no improvement in overall strain but reductions in relationship strain for spouses and reductions in emotional strain for caregivers with increased informal support.

Depression

Depression was consistently measured by the Center for Epidemiologic Studies Depression Scale. The study of Caregiver’s Friend reported a significant decrease in depression for caregivers in the intervention group. Regarding REACH, the SET + CTIS condition showed significant reductions in depressive symptoms at 6 and 18 months. Caregivers who had increased depression at baseline and who were in the CTIS-only group had significant reductions in depression compared to caregivers with lower depression at baseline. Caregivers who received the interactive voice-response condition and had low mastery at baseline also had greater reductions in depression. ComputerLink did not measure depression.

Anxiety

Anxiety was consistently measured by the State Anxiety Inventory and reported by 2 studies. Caregiver’s Friend significantly decreased anxiety for caregivers receiving the intervention.
Caregivers who were in the interactive voice-response arm of REACH had low mastery at baseline and significant decreases in anxiety compared to controls.

Although the outcome measures differed by study, there were some similarities between studies. All studies included multiple components in their interventions. All interventions contained an information component as well as a social-support component. Both REACH and ComputerLink used their respective technologies to foster the caregivers’ social support, while Caregiver’s Friend used affective learning techniques to model social-support skills. Additionally, all the interventions could be tailored to the specific needs of the caregiver.

**Discussion**

This review found 8 articles representing 3 parent studies of 4 unique RCTs that reported intervention effects of technology-driven interventions for informal caregivers of PWD. While all studies included an information and social-support component, the content and delivery differed across the studies. The only variable that was consistently reported across all the studies was social support, and it was measured differently in each study and used either as a risk factor or as an outcome variable. Of the studies that measured depression and anxiety, some demonstrated reductions in depression (n = 4) and anxiety (n = 2) for caregivers in the intervention group. Although each of these studies had some positive findings, there is currently insufficient evidence to support or refute technology-driven interventions for caregivers of PWD.

The evidence represents 4 interventions conducted over the last 17 years. The total number of participants was 772. Robust conclusions cannot be drawn about the effects of technology-driven interventions for caregivers of PWD because of the small number of RCTs, the large variability in the content and delivery of the intervention, and the inconsistency in measurement and variability of outcomes.

The results of this review show that there is a dearth of RCTs of technology-driven interventions for informal caregivers of PWD compared to other areas of dementia caregiving research. A previous review of interventions that used technology with PWD and their caregivers reported mostly on interventions for persons with moderate and severe dementia in residential care settings. Of the 66 studies included in the review, only 15 reported on the needs of family caregivers; 7 of those were RCTs and only 4 of the RCTs included technology other than telephone. The existence of only a few RCTs of technology-driven interventions for caregivers of PWD reveals a gap in the literature between the numerous feasibility studies of technology-driven interventions and the efficacy of those interventions. Several studies have reported on the feasibility and acceptability of technology-driven interventions, but few report outcomes from randomized intervention and control groups.

Although several studies identified in the initial search were subsequently excluded from the review, they do provide important information about technology-driven interventions for informal caregivers of PWD. Technology-driven, computer-based interventions have been found to be acceptable and feasible among caregivers of PWD. Specifically, caregivers have responded positively to online education, Internet-based support groups, computer-mediated interactive voice-response systems, and online skill building. In addition, many of these nonrandomized studies of technology-driven interventions have shown promising results regarding reductions in burden and improvement in overall mental health, increased confidence in caregiving skills, and increased competence. However, no follow-up controlled trials of the feasibility studies were found; without further testing, the strength of the results remains a question.

**Limitations**

The conclusions drawn from this review must be considered in the context of several limitations. This review contained a small number of RCTs. Although other trials of technology-driven interventions for caregivers of PWD were identified during the search, we limited our review to RCTs because they produce the strongest conclusions in terms of efficacy. This review was also limited to studies published in English and indexed in the 3 databases searched, although the search terms used in this review were broadly inclusive to capture all possible studies. Additionally, because technology changes rapidly, early technology-driven interventions may be less applicable to technology-driven interventions of the future. However, as technologies continue to become more commonplace and “user friendly,” some of the early technological challenges may diminish.

Technology-driven interventions for caregivers of PWD continue to hold promise for the future of intervention research because of their convenience and variety of delivery formats for both information and support (ie, text, graphs, video, and interactive voice response). However, to date, too few RCTs of such interventions have been conducted to fully evaluate their merit. Additionally, of the studies that have been conducted, heterogeneity in outcome measures prevents comparison across the studies. Although large RCTs of promising technological interventions will provide the strongest evidence, they are not always feasible. Future studies could include quasi experimental studies, large demonstration projects, or participatory action research to elucidate the best technology-driven interventions for caregivers of PWD.

**Authors’ Note**

The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs, the US government or Baylor College of Medicine.

**Declaration of Conflicting Interests**

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