The Impact of Technology-Based Interventions on Informal Caregivers of Stroke Survivors: A Systematic Review

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Abstract

Objective: This article is a systematic review of the impact of technology-based intervention on outcomes related to care providers for those who survived a stroke. **Materials and Methods:** Literature was identified in the PubMed, PsycINFO, Scopus, and Cochrane databases for evidence on technology-based interventions for stroke survivors' caregivers. The search was restricted for all English-language articles from 1970 to February 2015 that implied technology-based interventions. This review included studies that measured the impact of these types of approaches on one or more of the following: depression and any of the following—problem-solving ability, burden, health status, social support, preparedness, and healthcare utilization by care recipient—as secondary outcomes. Telephone or face-to-face counseling sessions were not of interest for this review. The search strategy yielded five studies that met inclusion criteria: two randomized clinical trials and three pilot/preliminary studies, with diverse approaches and designs. **Results:** Four studies

have assessed the primary outcome, two of which reported significant decreases in caregivers' depressive symptoms. Two studies had measured each of the following outcomes—burden, problem-solving ability, health status, and social support—and they revealed no significant differences following the intervention. Only one study assessed caregivers' preparedness and showed improved posttest scores. Healthcare services use by the care recipient was assessed by one study, and the results indicated significant reduction in emergency department visits and hospital re-admissions. **Conclusions:** Despite various study designs and small sample sizes, available data suggest that an intervention that incorporates a theoretical-based model and is designed to target caregivers as early as possible is a promising strategy. Furthermore, there is a need to incorporate a cost-benefit analysis in future studies.

Key words: e-health, telecommunications, telehealth, telemedicine, teleneurology

Introduction

Stroke is a lingering clinical condition accountable for expanding healthcare costs in the elderly population. This medical condition is ranked as being the fourth highest cause for fatalities in the United States, causing about 130,000 deaths per year. For those who survive stroke, 40% experience functional impairments that need specialty care, and 10% end up in a nursing facility or other long-term rehabilitation centers.¹ Caring for stroke survivors can be depressing and burdening and can be related to survivors' and caregivers' health and environmental well-being.² A financial hardship from this clinical condition is defined as it relates to provider costs and ancillary or referral-based medical costs, as well as any productivity lost and costs generated from the recovery process.³ It has been estimated that total direct stroke costs are approximately \$34 billion annually in the United States.⁴ Essential caregiving for stroke survivors plays a key role in survivors' recovery process and in prevention of future strokes and other clinical events and in well-being; recent evidence has estimated that the cost of

day-to-day care for stroke victims more is than \$8,211.⁵ In looking to these estimates, more strategies are needed for empowering the caregiver's role to positively impact his or her well-being and, ultimately, the well-being of the survivor.

Many caregiving intervention programs have been developed to address this issue, ranging from in-person caregiver counseling sessions to telephone-based interventions up to rapidly emerging technology-based interventions.⁶

TECHNOLOGY-BASED INTERVENTION

A technology-based intervention is some form of telepractice that uses information and communication technologies⁷ to help eliminate distance barriers and to help with scheduling logistics, thus extending the scope for provision of quality healthcare. The majorities of these interventions are Internet-based and are likely to become increasingly practical, as information and communication technology becomes more user-friendly.

The Internet now has become increasingly affordable and accessible for many people. It is noteworthy that Internet use has increased even among older age groups. In 2013, the U.S. Census Bureau reported that 76% of the 45–64-year-old age group accessed the Internet and that 56.3% of those ≥65 years of age had used the Internet.⁸

Various innovative information and communication technology approaches have been developed for various chronic diseases, including Web-based interventions, smartphone applications, videoconferencing technology, and other tools.

WHY IT IS IMPORTANT TO DO THIS REVIEW

Given the increased use of technology with its wide application as a tool for delivering health interventions, along with the unprecedented figures for value of the healthcare that is given to stroke patients by their caregivers,⁹ this review was conducted to evaluate the evidence for technology-based interventions addressing stroke caregivers. Two reviews in the literature have discussed the effectiveness and the implication of technology-based intervention in the rehabilitation of stroke survivors.^{6,7} Furthermore, one evaluated the outcomes of non-pharmacological approaches that were focused on informal caregivers for stroke victims.⁶ However, the technology-based intervention addressed toward caregivers is not the main focus in any finding. The objective of this study was to assess the information and communication technology intervention's outcomes aimed at caregivers of stroke survivors.

TYPE OF PARTICIPANTS

Informal caregivers can be defined as any person who is involved in the unpaid daily care to the care recipient; they are usually family members, friends, or any neutral person.

Materials and Methods

Computerized literature searches for all English-language articles from 1970 to February 2015 were carried out using a key word search of the PubMed, PsycINFO, Scopus, and Cochrane databases. These searches were conducted using following medical subject heading (MeSH) terminology, along with variants: “telemedicine,” “telehealth,” “wireless,” “Internet,” “telecommunication,” “computers,” “telenursing,” “cell phones,” “telerehab*,” “technology,” “mobile,” “cell phones,” “telestroke,” “smart phones,” and “education.” These terms were also searched for MeSH words and exploded. In addition, two searches were conducted using the key words “stroke” or “cerebrovascular accident (CVA)” or “and caregiver” or “caregivers” or “carer” or “carers” and then crossed-matched using “AND.” The result again was cross-matched with the first search using “AND” to yield articles that used technology-based programs for stroke caregivers. The outcome yielded 633 articles, and to ensure the accuracy and notability, a librarian was consulted. The list of six systematic reviews and one meta-analysis was meticulously searched by hand, looking for any missing information.^{6,7,10–14} We also included one more relevant study through personal communication with the Principal Investigator at the Gainesville VA Health System, Gainesville, FL and the Co-Investigator at the Bruce W. Carter Department of Veterans Affairs Medical Center, Miami, FL.¹⁵

STUDY SELECTION

We chose studies to review for impact identification of recent technology and the impact on stroke caregivers. Studies were included using technology-based interventions aimed at adult informal caregivers (≥18 years old) of stroke survivors that reported impact on caregiver mental health, burden, health status, problem-solving ability, social support, preparedness, and quality of life. Exclusion criteria and excluded studies^{16–26} are illustrated in *Figure 1*.

Due to the heterogeneity, pool results were not made by a prior decision. Two authors (A.Y.A. and F.F.A.) independently reviewed the search strategies and results and then also looked through the directories of studies used for any other pertinent work. *Figure 1* outlines the written work searches and what was chosen for the study. This strategy yielded a final selection of five studies included in this review.

PRIMARY OUTCOME

Caregiver's mental health is the primary outcome of interest for this review, and it was measured by using the Center for Epidemiological Studies Depression (CES-D) scale, which is a Likert-type scale tool that assesses caregivers'

Fig. 1. Review process.

feeling regarding each item during the last week, with a cutoff value of ≥ 16 classifying individuals as having depressive symptoms.²⁷

SECONDARY OUTCOMES

1. *Caregiver's burden.* This was measured using the Short 12-item Zarit Burden Interview. This tool aims to assess subjective burden among caregivers and has a score range from 0 to 88, where a higher score indicates a higher burden.²⁸
2. *Problem-solving abilities.* This was measured using measures such as the Pearlin Mastery Scale Items and Scoring, a nine-item instrument with scores range be-

tween 9 to 30, that aims to measure level of efficacy that caregivers feel,²⁹ as well as the Social Problem-Solving Inventory tool, which measures five different components related to problem-solving ability.³⁰ For both scales, a higher score indicates a higher problem solving-ability.

3. *Caregiver's health status.* This was measured using the Health Status Questionnaire short form (SF-12)³¹ and its longer version (SF-36),³² both of which subjectively measure the well-being of participants. A higher score connotes a higher level of functioning.
4. *Social support.* This was measured using measures such as the Medical Outcomes Study (MOS) Social Support Survey, a 12-item scale that assesses affectionate, emotional, and informational support, with score range between 5 to 11,³³ as well as the Multidimensional Scale of Perceived Social Support, a scale that measures participants' comprehension of the availability of social support.³⁴ For both measures, a higher score represents greater support.
5. *Caregiver's preparedness.* This was measured using The Caregiver Preparedness Scale, a five-item measure that assesses participants' perception about their preparedness to take on caregiving responsibility. A higher average score represents a more prepared caregiver.³⁵
6. *Healthcare utilization.* This was measured by analyzing the number of provider visits, emergency department visits, hospital re-admissions, and nursing home placements.

DESCRIPTION OF INCLUDED STUDIES

Among the studies included, two studies were randomized controlled trials (RCTs),^{36,37} and three were pilot studies.^{15,38,39} One study also considered stroke survivors, along with caregivers, as targets of their intervention.³⁸ All of the retrieved studies assessed interventions that are Internet-based. In total, 299 caregivers and 32 stroke survivors were enrolled among the included studies. These studies are illustrated in Table 1.

In the RCT of Pierce et al.,³⁶ they compared the use of a Web-based intervention, as well as an e-mail forum to ask personal queries privately and a friendly, easy-to-read e-mail about possible depression and overall satisfaction with life.

Table 1. Characteristics of Included Studies

	REFERENCE				
	PIERCE ET AL. ³⁶ (2009)	SMITH ET AL. ³⁷ (2012)	UPHOLD ET AL. ¹⁵ (2015)	STONE ³⁸ (2013)	MARZIALI AND DONAHUE ³⁹ (2006)
Sample	103 CGs: I=51, C=52 73 completed the study (I=36, C=37) Mean age: 54.55 years Female: 69% I, 81% C White, non-Hispanic: 86% I, 84% C	32 dyads: I=15, C=17 29 completed the study: I=12, C=17 CG mean age: 55.3–54.9 years	72 CGs Female: 95.8% White: 68.1% Mean age: 62.46 years	70 CGs completed the predischARGE preparedness tool. 30 returned both tools postdischarge. Female: 82% Age: 18–34 years, 20%; 25–44 years, 20%; 45–54 years, 25.7%; 55–64 years, 20%; ≥ 65 years, 14.3%	66 CGs (22 are SS CGs): I=33 (11 stroke CGs), C=33 (11 stroke CGs)
Design	RCT	RCT	Pilot study	Preliminary study	Randomized controlled pilot study
Eligibility criteria	Adult CGs (≥18 years) for person with first-time stroke English proficiency TV and telephone necessary	Female CGs of husbands after stroke Either the SS or CG has least at least mild depression (≥5 on the PHQ-9) Cognitively able to participate and not terminally ill	CGs of veterans who have a primary diagnosis of stroke for less than 12 months (according to ICD-9 codes for stroke diagnosis)	Adult CGs (18 years) for SSs with diagnoses of the following: stroke, brain injury, amputation, joint surgeries, multiple trauma, and debility, who were admitted during the data collection at a regional inpatient rehabilitation center Exception of non-English-speaking caregivers Results are not organized by disease subgroups.	Family CGs of patients with moderate-level disability across three forms of neurodegenerative disease: Alzheimer's, stroke-related dementia, and Parkinson's Results are not organized by disease subgroups.
Intervention	I: 1: Caring-Web provides easy and quick access to Web-based education and support in home settings for CGs of SSs. 2: e-mail forum to ask a nurse specialist and a rehabilitation team any questions in private. 3: nonstructured e-mail discussion among all participants facilitated by the nurse C: non-Web users	I: 1: professional guide 2: educational videos 3: online chat sessions 4: e-mail 5: message board 6: resource room C: had access to the Resource Room only	I: 1: VA RESCUE stroke CG Web site 2: problem-solving ability guide mailed to all participants 3: 4 telephone sessions with nurse	1: Web-based resources to enhance the preparedness and satisfaction of stroke CGs 2: e-mail access to a rehabilitation nurse practitioner	I: 1: Internet-based intervention to access Web site with links to information 2: E-mail 3: threaded discussion as 4: videoconferencing link that supported caregivers' participation in 10 sessions of manual-guided psychosocial support group, followed by 12 additional online sessions facilitated by a group member C: face-to-face group Support sessions
Study length and measurement intervals	1-year intervention. Trained telephone interviewers surveyed caregivers about their well-being every 3 months and about the use of healthcare services every 2 weeks	11-week intervention; measurement three times: T1, pretest; T2, posttest; and T3, 1 month later (at Week 15)	2-month intervention; pretest (baseline) and posttest assessments (2–4 weeks postintervention)	2-week intervention. Preparedness for caregiving was assessed before utilization of the Web site and within 2 weeks after discharge. Satisfaction was assessed within 2 weeks after discharge	6-month intervention; evaluation at baseline and 6-month follow-up
Outcomes					
Depression	No significant difference in CES-D scores at baseline (12) and 12 months (12.3) ($p=0.478$)	The I group reported significantly lower depression than CGs in the C group. Participants' scores on the CES-D scale at T1 were I=21.7, C=17.7; at T2, I=12.8, C=18.8 ($p>0.01$); and at T3, I=13.3, C=15.7 ($p>0.05$).	Statistically significant decreases in caregiver depressive symptoms ($t=-2.84$, $df=71$, $p=0.006$) and burden (-3.026 , $df=70$, $p=0.003$)		There were no significant differences between groups at baseline and follow-up.

continued→

Table 1. Characteristics of Included Studies *continued*

	REFERENCE				
	PIERCE ET AL. ³⁶ (2009)	SMITH ET AL. ³⁷ (2012)	UPHOLD ET AL. ¹⁵ (2015)	STONE ³⁸ (2013)	MARZIALI AND DONAHUE ³⁹ (2006)
Burden			Not statistically significant		
Health status			Not statistically significant		There were no significant differences between groups at baseline and follow-up.
Problem-solving abilities		There were no significant differences.	Not statistically significant		
Social support		There were no significant differences			There were no significant differences between groups at baseline and follow-up.
Preparedness				Average scale scores for preparedness were 19.26 on the pretest and 22.34 posttest, revealing improved preparedness.	
Healthcare utilization	There were significant decreases in ED visits ($p=0.001$) and hospital re-admission ($p=0.0005$) related to health of survivors.				

BI, Brief Burden Interview; C, control condition; CES-D, Center of Epidemiologic Studies Depression Scale; CG, caregiver; *df*, degrees of freedom; ED, emergency department; I, intervention condition; ICD-9, International Classification of Disease, 9th Revision; PHQ-9, Patient Health Questionnaire; RCT, randomized controlled trial; SS, stroke survivor.

The RCT of Smith et al.³⁷ applied an online group intervention, with its components being derived from the Stress Process Model. It recruited male patients who had had a stroke and were receiving care from spouses as subjects for the intervention. Caregiver and survivor depression were the primary evaluated outcomes.

In the pilot study of Stone,³⁸ he tested the use of Web-based resources, along with e-mail access to a rehabilitation nurse, for enhancing the preparedness and satisfaction among caregivers following survivors' discharge to home. The framework of this project relied on the Transitional Care Model.

In the pilot study of Marziali and Donahue,³⁹ they compared the effect of Web-based resources and online sessions using two-way videoconferencing against face-to-face group intervention.

In the pilot study by Uphold et al.,¹⁵ which was aimed at caregivers of veterans, they evaluated the implementation of the VA RESCUE stroke caregiver Web site (the Web site has access to information and other caregiver resources), along with a mailed problem-solving guide and telephone sessions with a nurse on problem solving.

SAMPLE CHARACTERISTICS

Sample sizes ranged from 14 to 103 participants, with three studies having 70 or more participants.^{15,36,38} Most subjects included in these studies were in the 50s to 70s years age range; one study also included younger age groups.³⁸ Female participants dominated the samples, with one study only including female caregivers.³⁷

Results

There were two RCTs and two pilot studies that assessed caregiver depression.^{15,36,37,39} Two studies reported a statistically significant decrease in caregivers' depressive symptoms.^{15,37} The results of the RCT of Smith et al.³⁷ demonstrated significant lower depressive symptoms; it included subjects with at least mild depression at the baseline. On the other hand, the RCT of Pierce et al.³⁶ did not report a significant difference related to depression. It is noteworthy to point out that their subjects were not depressed at baseline. The pilot study of Marziali and Donahue³⁹ showed no significant differences between study groups. All studies used the CES-D to measure this outcome.

CAREGIVER'S BURDEN

There was one study¹⁵ that measured caregiver's burden using the Burden Interview tool and reported no statistically significant differences.

PROBLEM-SOLVING ABILITIES

Two studies reported outcomes for problem-solving abilities.^{15,37} The RCT of Smith et al.³⁷ measured this outcome through the Pearlin Mastery Scale, whereas the pilot study of Uphold et al.¹⁵ used the Social Problem-Solving Inventory tool. Both studies reported no significant differences post-intervention.

CAREGIVER'S HEALTH STATUS

Two studies reported outcomes related to caregiver's health status^{15,39} using the SF-12 and the SF-36. Neither of the studies reported statistically significant results.

SOCIAL SUPPORT

Two studies aimed to address the impact of their interventions on caregiver's social support.^{37,39} Of these, one study³⁸ used the MOS Social Support Survey, whereas the other study³⁷ used the Multidimensional Scale. Neither study reported statistically significant results.

PREPAREDNESS

The study of Stone³⁸ was the only study that assessed the Web-based effect of intervention utilization on caregivers' readiness. Posttest average scores reveal improved preparedness.

HEALTHCARE UTILIZATION

One study examined the impact of using of Web-based intervention by caregivers on the implementation of medical treatments by care recipients.³⁶ The results show significant decrease in emergency department visits and hospital re-admission related to stroke survivors.

Discussion

Despite the high burden in terms of caregiver time and cost to society, we found only five studies that met the criteria and thus were eligible for this review. There is a growing literature about technology-based interventions developed and tested for stroke caregivers. Overall, diverse technology-based interventions have been identified, but the literature is insufficient to conclusively determine the effects of these interventions on caregivers.

There is evidence that some technology interventions that target depression can be effective. Among the four

studies that targeted depression, the RCT of Smith et al.³⁷ and the pilot study of Uphold et al.¹⁵ reported statistically significant lower depressive symptoms postintervention. On the other hand, results of the RCT of Pierce et al.³⁶ showed no significant difference related to depression. Furthermore, the study of Pierce et al.³⁶ did not specifically enroll caregivers with reported low levels of mental health well-being, unlike the RCT of Smith et al.,³⁷ which required their participants to have at least mild depression for eligibility. This raises the issue of inherent selection bias. The pilot study of Marziali and Donahue³⁹ reported no significant difference for depression between intervention and control conditions, although it did not represent the results per disease-specific subgroups. The pilot study of Stone³⁸ did not measure caregiver depression. In addition, the participants included in the studies were heterogeneous regarding depression baseline upon entrance into the study, which might have resulted in the variability of outcomes among the included studies.

The results for burden, problem-solving abilities, health status, stress, and social support were not significant.

There was only one study that measured healthcare utilization, over 1 year after applying their intervention.³⁶ The results show significant drop in emergency department visits and hospital re-admission related to stroke survivors, whereas other studies did not provide any data regarding costs and benefits that would be expected to result from the introduction of technology-based intervention into the routine rehabilitation process. In addition, none of the included studies provided cost-benefit analysis.

Three studies did report the theoretical bases of their designs; all of them reported statistically significant results for their primary outcomes. The RCT of Smith et al.³⁷ and the pilot project of Uphold et al.¹⁵ both targeted caregiver's depression using the Stress Process model and the COPE model, respectively. The third study³⁸ used the Transitional Care Model model and showed improved preparedness of caregivers. Of note is that of the two intervention studies that showed a positive effect on caregiver depression, both had a theoretical basis for their intervention design—the Stress Process model³⁷ and the COPE model¹⁵—versus the studies of Pierce et al.³⁶ and Marziali and Donahue,³⁹ which, unlike the two aforementioned studies, did not report a conceptual basis for their design. This evidence could favor use of these theoretical models in designing future technology-based caregiver interventions.

In addition, one study that we did not include²⁰ because it did not assess any impact on outcomes and was only a feasibility study reported that 90% of the caregivers in the study

indicated that an initial contact with a care coordinator would have benefited them when they first returned home from the hospital, emphasizing the need of early timing for intervention, as soon as caregivers start new responsibilities. This tip was applied in the preliminary study of Stone³⁸ through measurement of the preparedness level while at the rehabilitation center before utilization of the Web site and within 2 weeks of stroke survivor discharge. Study results revealed improved preparedness postintervention, and the timing of the intervention may be an important factor in the design of future interventions because the emphasis should be on preparing caregivers for a new role before their loved one gets transferred from a medical or rehabilitation centers to the home or other types of settings.

Therefore, despite various study designs and small sample sizes, the available data suggest that an intervention that incorporates a theoretical-based model and is designed to target caregivers as early as possible is a promising strategy.

Our review included one recently published manuscript¹⁵ in which the data have been presented in an abstract. We are certain that we included all pertinent studies in this growing field. However, it is possible that we missed studies. We were not able to assess the quality of evidence due to the limited number of RCTs.

We also examined six systematic reviews^{6,7,10,12-14} and one meta-analysis¹¹ that evaluated caregivers' interventions effectiveness and technology-based approaches as they related to the stroke rehabilitation process.

One systematic review by Legg et al.⁶ evaluated 14 RCTs. The main outcomes in their review were caregiver stress and strain, with measures of anxiety, depression, satisfaction, and mortality assessed as secondary outcomes. It examined various nonpharmacological models of delivery of intervention, including the Internet. Furthermore, interventions were described into three broad intervention categories (support and information, vocational education, and psychoeducational), and the review concluded that the studies with a preparation focus for a caregiver to help their loved one before hospital discharge (vocational education) appear to be the most hopeful. This review overlaps most with our review; however, it did not include technology interventions alone. It did include one of our included studies (Pierce et al.³⁶), in which depression was the only outcome that is related to our review and was targeted using a technology-based intervention. Data were extracted to pool results with other studies that measured depression using interventions other than technology-based ones. However, discussions about the intervention design that it is based upon and the best available tools to measure depression

were not the main focus in their review. Three additional technology-based stroke caregiver interventions (one additional RCT³⁷ and two preliminary studies^{15,38}), which came out since the review of Legg et al.,⁶ are examined in the present article.

The systematic review of Laver et al.⁷ compared the use of technology-based intervention against in-person rehabilitation in improving the ability to perform daily activities among stroke survivors; however, it did not include interventions toward caregivers.

The review of Rubin et al.¹⁴ examined the literature of telemedicine to ponder the care given after a stroke, as it related to mobility, ease of use, available tools, and considering other ideas. Communicating via audio and video components was a consideration for this review. Most of their included reports included focus on stroke survivors, with only three studies involving caregivers. Of the three caregivers' studies, one study³⁹ overlapped with this review, whereas the other two^{18,19} were excluded in our review because they were feasibility studies. Three additional systematic reviews^{10,12,13} and one meta-analysis¹¹ were excluded, as they did not include any technology-based interventions.

FUTURE DIRECTIONS FOR RESEARCH

The best way to help is not entirely evident due to the various types of measured outcomes, measurement tools, and variability of interventions from study to study, nor is it clear whether such interventions would have a beneficial impact on the patient or caregiver outcomes. However, having established guidelines for describing the interventions and participants, as well as measuring outcomes, would make it easier to collect future evidence and to allow pooling of the evidence from various studies to assess for impact and for strength and direction. For instance, it is apparent that depression and burden are recognized as among the most prominent poor outcomes that result from caregiving. For depression, we recommend that future studies use the CES-D as it was used to measure depression in every study included in this review and is a validated tool in this population. Regarding caregiver burden, we suggest the short version of Zarit Burden Interview as it has been widely used and is pertinent among different caregivers' populations, along with the short version of the Health Status Questionnaire (SF-12). The Bakas Caregiving Outcomes Scale, although not commonly used, is a good option to determine life quality and changes that result from caregiving.⁴⁰ Other choices of scales for other outcomes depend on what each study is trying to target.

More RCTs comparing various methods of delivery are most needed to determine impact on outcomes, efficacy, and sustainability. The information is insufficient and not completely clear regarding the impact of these telehealth interventions on the use of healthcare services by stroke survivors, which can be considered as a reflection of benefits and skills acquired by caregivers from these interventions. Also, future studies providing cost-benefit analysis are needed in order to impact policy regarding funding projects with these types of innovative interventions. Most of the interventions were multipronged, and a greater understanding of what works in a multipronged model is necessary in order to design future successful interventions. Furthermore, there is a need for future projects to explain the conceptual bases for their designs in order to determine the most appropriate model for each segment of the population, as well as possibly to innovate an integration of different theoretical constructs or conceptual models. There is a need to innovate and design models rapidly in this important field, which has scarce data at this time.

Disclosure Statement

No competing financial interests exist.

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