

Design and Usability Testing of the Stroke Caregiver Support System: A Mobile-Friendly Website to Reduce Stroke Caregiver Burden

Michelle R. Caunca^{1,2,3}, BSc, Marialaura Simonetto², MD, MS, Gregory Hartley⁴, PT, DPT, Clinton B. Wright⁵, MD, MS & Sara J. Czaja⁶, PhD

Abstract

Purpose: The purpose of this study was to design a mobile-friendly, Internet-based website, modeled on previously described websites for Alzheimer caregivers, to equip stroke caregivers and potentially reduce caregiver burden.

Design: A mixed-methods study was performed to design and test the usability of the Stroke Caregiver Support System (SCSS).

Methods: An iterative, user-centered design approach was employed in three phases: (I) Focus Groups, (II) Structured Interviews, and (III) Usability Testing. Phase I and Phase II provided information for the development of the SCSS website, whereas Phase III helped in gathering data regarding the usability and efficacy of the newly implemented SCSS website.

Findings: Qualitative data on caregiving and the content and design of the SCSS were obtained from focus groups and interviews. In the usability test, the nine caregivers who completed Phase III (78% women, mean age = 46, *SD* = 17) exhibited a high level of burden and depressive symptoms (median [Q1, Q3] Zarit burden score = 18 [16, 23], Center of Epidemiologic Studies-Depression Scale = 15 [8, 17]). Caregivers conveyed the usability of the SCSS but also expressed several needed improvements.

Conclusions: Participants reported the value of the SCSS, but further refinements are needed to maximize its usability and potential efficacy.

Clinical Relevance: The SCSS has potential to reduce caregiver burden in stroke.

Keywords: Caregiver; stroke; technology.

INTRODUCTION

Stroke is the leading cause of adult disability in the United States (Benjamin et al., 2018), and consequently, the estimated prevalence of caregiver burden among informal stroke caregivers is high, ranging from 25% to 54% (Rigby,

Gubitz, & Phillips, 2009). The global estimated prevalence rates of depression and anxiety in stroke caregivers are 40.2% and 21.4%, respectively (Loh, Tan, Zhang, & Ho, 2017). Thus, burden among stroke caregivers remains an urgent public health problem.

Evidence suggests that the lack of adequate information is a major risk factor for burden in caregivers of stroke survivors (Camak, 2015; El Masry, Mullan, & Hackett, 2013). Educational interventions have employed face-to-face or telephone sessions led by healthcare professionals as methods of curricular delivery (Cameron et al., 2015; Fens et al., 2015; Forster et al., 2015; Pozet et al., 2016; Worrall et al., 2016). However, the American Heart Association recently recommended more research on technology-based interventions to better meet the rapidly changing needs of stroke caregivers (Bakas, McCarthy, & Miller, 2017). Technology-based interventions offer many advantages compared to traditional curricular delivery, including ease of implementation, increasing technological literacy, asynchronous communication, use of multimedia platforms, and potential to reduce disparities by increasing the reach of resources.

We aimed to design the Stroke Caregiver Support System (SCSS), a mobile-friendly website for stroke caregivers.

Correspondence: Michelle R. Caunca, BSc, University of Miami, 1120 NW 14th St., 1027, Miami, FL 33136. E-mail: m.caunca@med.miami.edu

¹ Division of Epidemiology and Population Health Sciences, Department of Public Health Sciences, Miller School of Medicine, University of Miami, Miami, FL, USA

² Department of Neurology, Miller School of Medicine, University of Miami, Miami, FL, USA

³ Evelyn F. McKnight Brain Institute, Miller School of Medicine, University of Miami, Miami, FL, USA

⁴ Department of Physical Therapy, Miller School of Medicine, University of Miami, Miami, FL, USA

⁵ National Institute of Neurological Diseases and Stroke, Bethesda, MD, USA

⁶ Division of Geriatrics and Palliative Medicine, Weill Cornell Medical College, New York, NY, USA.

Copyright © 2018 Association of Rehabilitation Nurses.

Cite this article as:

Caunca, M. R., Simonetto, M., Hartley, G., Wright, C. B., & Czaja, S. J. (2020). Design and usability testing of the stroke caregiver support system. *Rehabilitation Nursing, 45*(3), 166–177. doi: 10.1097/rnj.000000000000196

To maximize usability, we employed an iterative, user-centered approach based on protocols from the Center for Research and Education on Aging and Technology Enhancement (Czaja et al., 2006), which ensures that members of the target population contribute to the design of the intervention, increasing its usability and potential efficacy.

Methods

Rationale and Overview of Study Design

An iterative, user-centered approach was employed to develop the SCSS through focus groups, structured interviews, and a usability study (Figure 1). Research associates were trained based on protocols from the Personal Reminder and Information Management System for Seniors trial (Czaja et al., 2015). At each phase, feedback from caregivers was used to refine the intervention. All participants provided informed consent. This study was approved by the institutional review board at the University of Miami Miller School of Medicine. All quantitative data were captured using the RedCap Database at University of Miami Miller School of Medicine (Harris et al., 2009).

Recruitment and Eligibility Criteria

Recruitment was done through advertisements and referrals from the University of Miami Hospital and Clinics and stroke providers throughout Miami-Dade County. Eligibility criteria included (a) ≥ 18 years old, (b) self-identification as an informal (i.e., relative or friend who does not have a role as health care provider for the stroke survivor) caregiver to a stroke patient, (c) self-report of assisting the stroke patient with instrumental or basic activities of daily living, (d) stroke within the past year, and (e) access to the Internet and/or mobile device. Those who participated in one phase were ineligible for participation in a subsequent phase. Data gathered from Phase I and Phase II provided information for the SCSS website development and implementation, whereas data from Phase III provided insight on SCSS website usability and efficacy.

Initial Design of SCSS

The template for the SCSS was the “Caring for the Caregiver Network” (Czaja, Loewenstein, Schulz, Nair, & Perdomo,

2013), a technology-based intervention for dementia caregivers. Consultation from stroke specialists (G. H. and C. B. W.), publicly available resources from the American Stroke Association and National Stroke Association, and existing literature on stroke caregiving were used to guide the initial prototype. The online teaching platform Moodle (<https://moodle.org/>) was used to build the SCSS.

Phase I: Focus Groups

The objectives of Phase I were to identify the concerns of stroke caregivers and to gather preliminary qualitative feedback on an initial prototype of the SCSS. The focus group guiding script is presented in Table 1. Focus groups were conducted in the preferred language of the caregiver (English or Spanish). A sociodemographic questionnaire and the 12-Item Zarit Burden Interview (Bédard et al., 2001) were administered prior to the focus group. The facilitator inquired about challenging domains of caregiving and technology use by asking participants to raise their hand if they agreed/disagreed with a statement. The number of participants who agreed/disagreed was recorded. Participants were then asked about their personal experiences and resources that would have benefited them. Finally, participants were presented with the SCSS prototype via PowerPoint presentation and asked about the design and content of the prototype. Sessions were audio-recorded and annotated. Data from these focus groups were used to refine the SCSS for Phase II.

Phase II: Structured Interviews

The purpose of the structured interviews was to gather detailed feedback regarding the design and potential usability of SCSS. Structured interviews were conducted in the preferred language of the caregiver (English or Spanish). Participants completed the sociodemographic and 12-Item Zarit Burden Interview (Bédard et al., 2001) questionnaires before the interview. A research associate asked the participants about the modules, design (color scheme, font, legibility, etc.), and potential value of the SCSS. Feedback from the structured interviews was used to further refine the SCSS for Phase III. The final version of the SCSS contained modules with an introductory video custom-made by the research team and resources from the American Heart Association and the National Stroke Association, organized by topic area (Figure 2).

Phase III: Usability Testing

The objectives of the usability test were (a) to test usability of the mobile-friendly website, (b) gather more feedback for intervention refinement, and (c) collect preliminary data

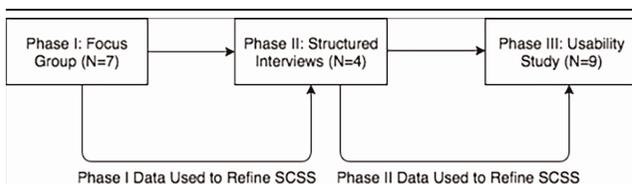


Figure 1. Overview of study design.

Table 1 Guiding script for focus group

Caregiving Questions
<ol style="list-style-type: none"> 1. What types of challenges do caregivers of stroke patients confront? <ol style="list-style-type: none"> a. How many of you think "physical"? b. How many of you think "emotional"? c. How many of you think "cognitive"? d. How many of you think "behavioral"? e. How many of you think "communication"? f. How many of you think "financial and/or legal"? g. How many of you think "resources in the community"? h. How many of you think "stress management"? 2. What do you think are the main concerns about being a caregiver to a relative who has had a stroke? 3. What type of barriers do you think stroke caregivers confront in terms of accessing needed care and support? 4. Do you feel stroke caregivers have problems getting needed informal care and needed social and emotional support? <ol style="list-style-type: none"> a. How many of you think "YES"? b. How many of you think "NO"? 5. What were some positive aspects of caring for your loved one after their stroke?
Curriculum Video and Design Questions
<ol style="list-style-type: none"> 1. How many of you use other applications on your smartphones? <p>What types of smartphone applications do you currently use</p> <ol style="list-style-type: none"> a. Social media (Facebook, Twitter, etc.) b. Resources (recipes, maps, etc.) c. Entertainment (online games, entertainment news, etc.) d. Shopping (Amazon, HauteLook, etc.) 2. Please take a moment to look at the prototype for our smartphone application. What are your initial thoughts? <ol style="list-style-type: none"> a. Do the menu options/icons make sense? Do they flow logically? b. Would you rather have the options/icons at the top of the screen? On the right/left side? c. Is the font legible? d. Is the color scheme easy to look at? e. What are some areas of improvement? 3. Please take a moment to look at the prototype for our website. What are your initial thoughts? <ol style="list-style-type: none"> a. Do the menu options/icons make sense? Do they flow logically? b. Would you rather have the options/icons at the top of the screen? On the right/left side? c. Is the font legible? d. Is the color scheme easy to look at? e. What are some areas of improvement? 4. Please take a moment to watch this curriculum video. What are your initial thoughts? <ol style="list-style-type: none"> a. Is the information relevant? b. Is the information presented clearly? c. What are some areas of improvement? 5. Do you think that stroke caregivers would find this useful? <ol style="list-style-type: none"> a. If not, how can we make it more user-friendly/useable?

on the main outcome measures of interest. Participants were asked to attend initial and follow-up in-person assessments and utilize the SCSS for approximately 2 months. During the initial assessment, participants completed the sociodemographic questionnaire (Czaja et al., 2006) and a battery

based on the "Caring for the Caregiving Network" protocol (Czaja et al., 2013), which include the 12-Item Zarit Burden Interview (Bédard et al., 2001), Activities of Daily Living (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963), Instrumental Activities of Daily Living (Lawton & Brody, 1969), 10-Item Center for Epidemiologic Studies-Depression Scale (Radloff, 1977), Social Support (Barrera, Sandler, & Ramsay, 1981; Krause, 1995; Krause & Markides, 1990), Preparedness (Archbold, Stewart, Greenlick, & Harvath, 1990), and Caregiving Self-Efficacy (Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002). Research associates introduced participants to the intervention on a laptop or desktop computer and mobile device. Participants were assigned a username and password and access to the first three modules (Table 2). Research associates instructed the participants to watch the introduction video for each module, then peruse and utilize the resources best suited for their situation. Two modules were released biweekly per the module schedule (Table 2). Participants were e-mailed weekly reminders and asked to complete a brief survey about each module. During the follow-up assessment, participants completed the above assessments and a program evaluation, data from which will be used to improve the intervention for future studies.

Data Analysis

Qualitative Data Analysis

For Phases I and II, qualitative data were recorded by a trained research associate and summarized using matrix analysis methods with a rapid assessment approach (Miles, Huberman, & Sandaña, 2014), which is designed for interventions that require faster assessment due to continuously developing technologies or emerging public health problems. Matrices allow for the analysis of responses by domains of caregiving and/or design feature.

Quantitative Data Analysis

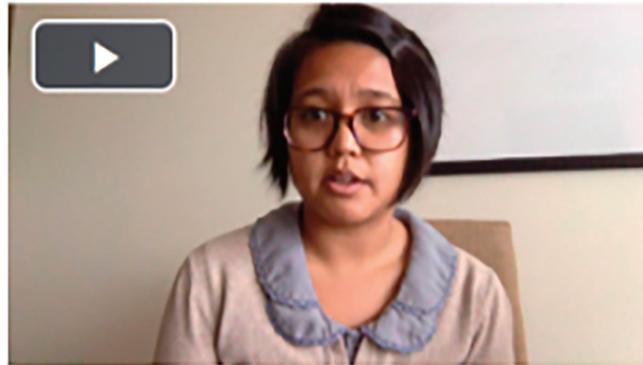
Questionnaire responses were summarized with frequencies and percents (for categorical data) or means (standard deviations) or medians (25th percentile, 75th percentile; for continuous data). Medians were presented for nonnormal data. Because of the small sample size of this study, data are presented per participant. Data management and analysis was conducted in SAS 9.4 (SAS Institute, Cary, NC), and plots were generated in R using the ggplot2 package (Wickham, 2009).

Results

Phase I

A total of seven stroke caregivers ($n = 3$ English-speaking, $n = 4$ Spanish-speaking) participated in two focus groups

Welcome to An Introduction to Caregiving



We know that becoming a caregiver to a stroke survivor can be overwhelming. We hope this page will provide you with resources that will help guide you through your journey as a caregiver.

Latest Updates

Click here for some of the latest updates to this page.

Stroke Family Warmline

Call 1-888-4-STROKE (1-888-478-7653) to reach the Warmline team and speak to an American Stroke Association team member who can provide more information about stroke.

Source: American Stroke Association

What is Caregiving?

This section will help you understand what caregiving is.

iHOPE: Creating a Caregiving Support System

This webinar is given by Sara Palmer, PhD, and provides information on the caregiving role, social support, and self-care.

Source: National Stroke Association

Caregiver Poem

This poem, by a fellow stroke caregiver, summarizes common feelings that are experienced when caregiving.

Source: American Stroke Association

Figure 2. Screenshot of standard module format.

(Table 3). All the caregivers were women and ranged in age from 49 to 72 years (mean [SD] = 60 [9]). Of the seven caregivers, four identified as the spouse of the stroke survivor,

five reported greater than a high school education, and six identified as Hispanic/Latino. The median Caregiver Burden Score for these seven caregivers was 18 (Q1, Q3: 12, 20;

Table 2 Phase III: Schedule of module release

Time	Name of Module
First Assessment	Introduction to the Stroke Caregiver Support System What Is Stroke? Introduction to Caregiving
Week 2	Stress Management Behavioral and Emotional Aspects of Stroke Caregiving
Week 4	Cognitive Aspects of Stroke Caregiving Physical Aspects of Stroke Caregiving
Week 6	Financial and Legal Issues
Week 8	Communication With Stroke Survivors Communication With Healthcare Providers

maximum possible score = 44), suggesting elevated caregiver burden in our sample.

Stroke caregivers reported many challenges across all domains of caregiving (Table 4). In particular, caregivers reported concerns regarding the physical aspects of caregiving, especially ambulating and fall risk. Also, caregivers reported difficulties with time constraints, concerns with the lack of trained professional caregivers, and financial difficulties. Emotional challenges reported included acceptance of caregiving situation, depressive symptoms, and stress management. Behavioral and cognitive issues experienced by the stroke survivors were also of concern to the caregivers, especially memory problems and resistance to accept help. Caregivers reported a lack of information regarding caregiving from their physicians, with a desire for more information upon hospital discharge. Caregivers also reported positive aspects of caregiving, including the ability to help their family and improvement of the stroke survivor's function.

Almost all caregivers reported regular, current use of smartphones. Feedback for the prototype of the intervention included addition of a chat forum, integration of videos with resources and demonstrations, improvement of design, and information regarding accessibility and cost of resources (Table 4).

Given these data, we added a module on Financial and Legal resources and a chat forum and redesigned the videos to address resources available in each module.

Phase II

A total of four caregivers participated in one-on-one, structured interviews to provide detailed feedback regarding the intervention, which was refined upon based on Phase I data. All four caregivers were women, with a mean (*SD*) age of 57 (3) years and reported greater than a high school education. Of the four caregivers, two were English-speaking, three were children of the stroke survivor, and two identified as Hispanic/Latino. This sample exhibited a median

Burden score of 7 (Q1, Q3: 6.5, 9.3, maximum score possible = 44), which indicates a relatively low level of burden in this sample (Table 3).

These caregivers provided feedback regarding the design of the intervention (Table 5). One caregiver reported the font was too small in some modules. Low volume of the videos was a common criticism of the interface. Most caregivers preferred accessing the website through their smartphone browser rather than their computer (Table 5).

Caregivers also provided detailed feedback regarding each module of the intervention (Table 6). Generally, most modules were considered well-organized, complete, and necessary, with helpful information and adequate resources. The discussion of different stroke types in the "What Is Stroke" module was appreciated by most participants. One participant warned about terms that may be "too scientific" for the audience. Caregivers also expressed that caregiver burnout and mental health should be emphasized more in the "Introduction to Caregiving" module. Two out of the four caregivers found the "Stress Management and Self-Care" module helpful and necessary. The "Physical Aspects of Stroke Caregiving" module seemed particularly important to caregivers who expressed a need for this information and confusion about where to find it. The modules concerning behavioral and emotional issues, cognitive issues, and communication modules were appreciated by the caregivers.

Given these data, we increased the font size of the SCSS, edited and re-recorded videos if needed to address low volume issues, and revisited each module to address complexity of language.

Table 3 Participant Characteristics for Each Study Phase

	Phase I (N = 7)	Phase II (N = 4)	Phase III (N = 9)
	Frequency (%)		
Female	7 (100)	4 (100)	7 (78)
English-speaking	3 (43)	2 (50)	7 (78)
Spanish-speaking	4 (57)	2 (50)	2 (22)
Relationship to care recipient			
Spouse	4 (57)	0 (0)	1 (11)
Child	3 (43)	3 (75)	6 (67)
Parent	—	—	2 (22)
Greater than high school education	5 (71)	4 (100)	7 (78)
Identifies as Hispanic/Latino	6 (86)	2 (50)	6 (67)
	Mean (<i>SD</i>), Range		
Age (years)	60 (9), 49–72	57 (3), 53–59	46 (17), 25–68
Caregiver Burden Scale ^a (median [Q1, Q3])	18 (12, 20), 2–27	7 (6.5, 9.3), 5–16	19 (16, 23), 8–38

^aMaximum possible score = 44.

Table 4 Phase I: Rapid assessment matrix analysis of focus group data

	Challenges in Stroke Caregiving						Technology-Related Questions		
	Physical	Emotional	Behavioral	Cognitive	Communication	Resources	Positive Aspects of Caregiving	Smartphone and Internet Use	Feedback for Preliminary Website
Focus Group 1 (English) N = 3	3/3 reported difficulties Problems with walking after stroke	2/3 reported "acceptance of the situation" was a challenge	2/3 reported difficulties Stroke survivor had issues with talking	2/3 reported difficulties Memory affected months after stroke	2/3 reported difficulties Doctor asked them for the "plan" to care for stroke survivor, and she did not know how to respond	3/3 reported difficulties with time constraints 3/3 reported a concern with the lack of trained professional caregivers	Helping family Improvement of stroke survivor Acceptance of situation Ability to help others	3/3 use smartphones in their personal life	Resources need to be more connected to videos Need information about cost, access, and availability of resources Actor examples and demonstrations should be provided Overall design needs to be more professional Log-in form for caregivers requested
Focus Group 2 (Spanish) N = 4	2/4 reported difficulties Worried about falls	3/4 reported difficulties Reported depression, blame on the caregiver	1/4 reported difficulties Reported that stroke survivor can be resistant to being helped	4/4 reported difficulties	Reported that not enough information was provided after leaving the hospital	Reported economical issues as an obstacle for helping their stroke survivor	N/A	3/4 use smartphones in their personal life	Add chat forum Typical patient presentations should guide curriculum about disability discounts and out-of-the-house activities for both patient and caregiver Wanted information on stroke prevention

Table 5 Phase II: Rapid assessment matrix analysis of style and design of the Stroke Caregiver Support System

	General Features	Video Quality	Phone Version
General comments	Font size and color adequate well-organized, feedback survey had appropriate questions. All approved of the forum.	—	—
Participant 1 (English)	—	Low volume on intro video	Prefer phone over laptop “looks even better” on the phone
Participant 2 (Spanish)	Thought that font was too small in some modules	Low volume Content informative Adequate size and image quality	Prefer phone over laptop
Participant 3 (English)	—	—	Prefer laptop over phone
Participant 4 (Spanish)	—	Low volume Content informative Adequate size and image quality	Prefer phone over laptop

Phase III

Baseline characteristics for the participants in this phase are presented in Table 3. Most caregivers were women, English-speaking, children of the care recipient, had a greater than high school education, and identified as Hispanic/Latino. The mean (*SD*) age of our sample was 46 (17) years.

Figure 3 displays the baseline measures in the outcomes of interest for each caregiver. The median (Q1, Q3) Zarit Burden Score was 18 (16, 23; maximum score = 44), indicating a relatively high level of burden in our sample. Caregivers exhibited a high number of depressive symptoms (median [Q1, Q3] = 15 [8, 17], maximum score = 30), with about half of the caregivers in our sample exhibiting elevated depressive symptoms (Center for Epidemiologic Studies-Depression Scale score ≥ 15). Caregivers helped their care recipients with more Instrumental Activities of Daily Living (median [Q1, Q3] = 7 [7, 8], maximum score = 8) than Activities of Daily Living (median [Q1, Q3] = 3 [1, 6], maximum score = 7). Caregivers reported adequate social support (median [Q1, Q3] = 36 [33, 39], maximum score = 53) and preparedness (median [Q1, Q3] = 2 [1.25, 2.13], maximum score = 4). Finally, caregivers reported a relatively high level of self-efficacy (median [Q1, Q3] = 196 [180, 208], maximum score = 12).

Results from the project evaluation generally reflected potential for the SCSS to aid in caregiver preparation and alleviate caregiver burden. Overall, participants reported that they benefited from participating in the study (mean [*SD*] = 1.5 [0.84], maximum possible score = 2). Participants reported that the website was easy to use (mean [*SD*] = 1.7 [0.52]) and that the information provided by the website was easy to understand (mean [*SD*] = 1.7, [0.52]). Six participants used the SCSS once a month, three participants reported weekly use, and half of the participants used the SCSS on their mobile device. Overall, caregivers appreciated the “easily accessible and organized”

resources and the specific resources on stress management. Caregivers also noted that the website was “useful because [it was] accessible anytime” and that the “information was well-organized.” One caregiver noted that, “the resources were very useful to explain stroke and they helped me handle stress and anxiety.”

Results from the project evaluation also highlighted several important points for improvement. Caregivers reported that the SCSS improved the stroke survivor’s life only “some” (mean [*SD*] = 1 [0.63]). The modules that were least useful were “What Is Stroke?” (mean [*SD*] = 1.2 [0.98]) and “Behavioral and Emotional Challenges of Stroke Caregiving” (mean [*SD*] = 1.2 [0.75]). Also, caregivers reported that the module videos were only somewhat useful (mean [*SD*] = 1 [0.89]). Overall, caregivers found the “website layout not engaging,” “first two modules too generic,” and the information in the videos “not specific.” Caregivers also reported that they would prefer if all modules were provided at the beginning “as stroke is sudden and all patients have a different journey.” Finally, caregivers would like videos “with real-life experiences of other caregivers” and “with more practical information.”

Discussion

The present study describes the development of a mobile-friendly, web-based curricular intervention targeting stroke caregiver burden. An iterative, user-centered approach was employed to maximize the usability and potential efficacy. Results indicate that informal caregivers experience emotional stress attributable to caregiving. Caregivers also expressed the potential usability of the SCSS, but further refinements are needed. Examples of these refinements include making all modules immediately available for the caregiver and greater individualization of modules to meet the specific needs of the caregiver.

These findings support the American Stroke Association recommendations to explore technology-based interventions

Table 6 Phase II: Rapid assessment matrix analysis modules in the Stroke Caregiver Support System

General comments	Intro	Stroke	Caregiving	Self-Care	Behavioral & Emotional	Cognitive	Physical	Financial & Legal	Communication: Stroke Survivor	Communication: Healthcare Providers
			Well-organized Complete Necessary Content is interesting and appropriate	Necessary Well organized Size of content is adequate	Information is complete, very good Helpful	Content size appropriate	All considered that the length of this module is appropriate because it is very important	Very important module, with information that is often neglected; content is appropriate	Content is appropriate and adequate	Well organized and complete
Participant 1 (English)		Good that types of stroke are explained	Suggested adding "something that said a caregiver should always try to be happy"	"It is very important to know how to control the stress"	"It has everything, I can't wait to read about it"	"Size of content is perfect, because I think that more than that would be too much" Relates to their case		"The Obamacare section should be removed now"	"It is great that you have options for people with communication problems"	"The caregiver is the person that knows the most about the patient"
Participant 2 (Spanish)		"Ataque cerebrovascular" might be too scientific a term							Change "afasia" for "dificultad para hablar"	
Participant 3 (English)		Good that types of stroke are explained" Likes that stroke prevention is discussed	Suggested expanding the "preventing burnout" section, considers it the most important part of the module			Asked about the "Stroke Help-Line" Relates to their case	"All this information would've been very helpful to me, because I had nowhere to read this. I tried looking online but there were too many websites and it was confusing"	"This is very important, I hadn't thought about it"	"I can't understand my mom sometimes, I would love to know how to deal with it"	
Participant 4 (Spanish)	Wanted more written information besides the videos	Good that types of stroke are explained		"I think this would be very helpful"	"It would be good to have information on how to prevent the patient from becoming very sensitive about everything"	Wants tips on how to exercise your memory	Wanted to know more about how to help the patient recover from fatigue and about more occupational therapy tasks to do at home			Needs this to be able to communicate with doctors

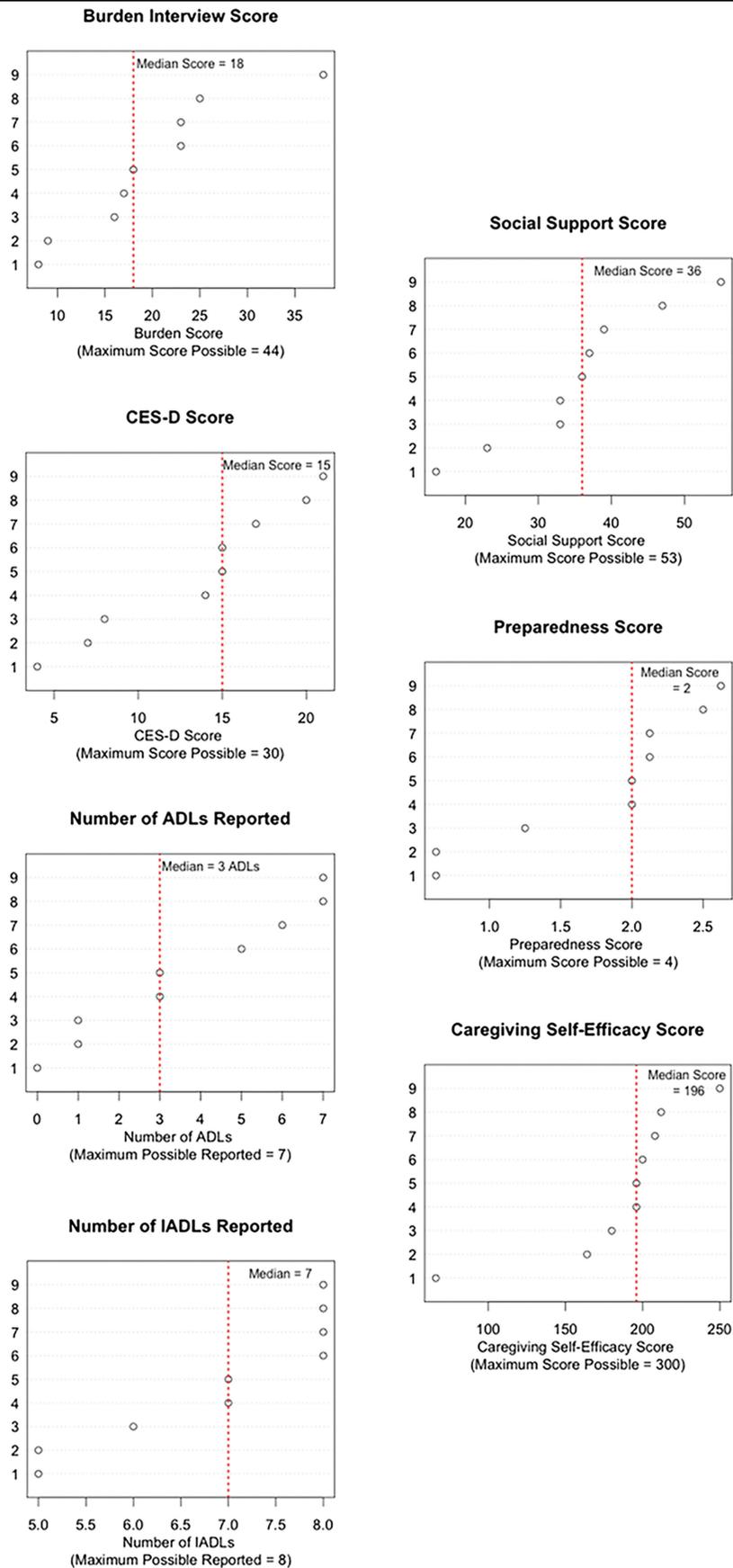


Figure 3. Baseline measures for usability test (N = 9). CES-D = Center for Epidemiologic Studies-Depression Scale; ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living.

for stroke caregiver burden (Bakas et al., 2017). The acute and heterogeneous nature of stroke necessitates a tailored and flexible intervention, which could be addressed with a technology-based intervention. Given the caregivers' preference for the mobile version of the website, leveraging mobile technologies could increase the reach of the SCSS. A mobile-friendly, web-based intervention has been tested in a multinational European study (Barbabella et al., 2016), but because caregivers for many different diseases were studied, further work is needed to tailor interventions specifically for stroke caregiving. Pierce et al. investigated the role of an e-rehabilitation team in responding to caregivers' concerns by e-mail as part of the Caring ~ Web web-based intervention. This study showed how the Caring ~ Web intervention helped the caregivers deal with their new caregiving role and with caregiving burden by providing information through e-mails on community services, medication management, and physical well-being of the stroke survivors (Pierce, Steiner, Khuder, Govoni, & Horn, 2009). Our study extends this work through a standardized set of modules based on existing resources that can be accessed by the stroke caregivers both through mobile phone or personal computers. Unlike Caring ~ Web, we did not provide a one-to-one e-mail service nor did we have specific resource modules, which should be improved in future studies.

Indirect evidence supports the use of mobile technology for stroke caregiver burden. Telephone interventions have been used to improve skill building (Pfeiffer et al., 2014) and reduce task difficulty (Bakas et al., 2009). In addition, a recent proof-of-concept trial tested an e-Health intervention to improve stroke patient outcomes through caregiver-mediated mobility exercises facilitated by tele-rehabilitation services and showed reduced strain and improved self-efficacy in caregivers (van den Berg et al., 2016). Though promising, this intervention did not include targeted curricula on stress management or non-physical consequences of stroke. Other interventions similarly target specific deficits in stroke, such as aphasia or depression, and are not comprehensive (Woodford, Farrand, Watkins, Richards, & Llewellyn, 2014; Worrall et al., 2016). The comprehensive nature of the SCSS can help fill this gap in the literature. The SCSS also must incorporate a more tailored curriculum that is individualized to the needs of the stroke caregiver, including the status of the stroke survivor recovery similar to other interventions that maximize caregiver support during particular phases in poststroke recovery (Cameron et al., 2014). Future enhancements of the SCSS will increase the usability and the potential efficacy to reduce caregiver burden.

Limitations of this study should be noted. The small sample size limits the generalizability of the findings. Usability can still be reliably assessed in a small sample (Lewis,

1994), but data on outcome measures should be interpreted with caution. History effects and the lack of a control group are also potential sources of bias. Most of our participants were women; two participants of Phase III were men. African Americans were underrepresented in our sample, which is a limitation of this study given the high risk of stroke in this racial group (Benjamin et al., 2018). Future studies should include a larger, diverse sample to enhance generalizability. This study also has several strengths. First, our sample included Hispanic/Latino participants, an ethnic group at higher risk of stroke compared to non-Hispanic Whites (Benjamin et al., 2018). Second, we employed an iterative, user-centered design, which maximizes potential usability and involves the target population in each stage of development. Finally, the SCSS was based on evidence-based caregiver interventions in older adults (Czaja et al., 2013).

Overall, the SCSS has the potential to alleviate stroke caregiver burden and can be an extremely useful tool in stroke rehabilitation nursing. Reducing caregivers' stress and burden will ultimately benefit stroke survivors' health, well-being, and recovery poststroke. Feasibility studies are warranted to determine potential usability and gather data on a broader sample.

Conflict of Interest

The authors declare no conflict of interest.

References

- Archbold, P. G., Stewart, B. J., Greenlick, M. R., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health, 13*(6), 375–384.
- Bakas, T., Farran, C. J., Austin, J. K., Given, B. A., Johnson, E. A., & Williams, L. S. (2009). Stroke caregiver outcomes from the Telephone Assessment and Skill-Building Kit (TASK). *Topics in Stroke Rehabilitation, 16*(2), 105–121. doi:10.1310/tsr1602-105
- Bakas, T., McCarthy, M., & Miller, E. T. (2017). Update on the state of the evidence for stroke family caregiver and dyad interventions. *Stroke, 48*(5), e122–e125. doi:10.1161/strokeaha.117.016052
- Barbabella, F., Poli, A., Andréasson, F., Salzmann, B., Papa, R., Hanson, E., ... Lamura, G. (2016). A web-based psychosocial intervention for family caregivers of older people: results from a mixed-methods study in three European countries. *JMIR Research Protocols, 5*(4), e196. doi:10.2196/resprot.5847
- Barrera, M., Sandler, I., & Ramsay, T. B. (1981). Preliminary development of a scale of social support: Studies on college students. *American Journal of Community Psychology, 9*(4), 435–447.
- Bédard, M., Molloy, D. W., Squire, L., Dubois, S., & Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: a new short version and screening version. *Gerontologist, 41*(5), 652–657.
- Benjamin, E. J., Virani, S. S., Callaway, C. W., Chamberlain, A. M., Chang, A. R., Cheng, S.; American Heart Association Council on Epidemiology and Prevention Statistics Committee and Stroke Statistics Subcommittee. (2018). Heart disease and stroke statistics-2018 update: A report from the American Heart Association. *Circulation, 137*(12), e67–e492. doi: 10.1161/CIR.0000000000000558
- Camak, D. J. (2015). Addressing the burden of stroke caregivers: a literature review. *Journal of Clinical Nursing, 24*(17–18), 2376–82. doi:10.1111/jocn.12884

- Cameron, J. I., Naglie, G., Gignac, M. A., Bayley, M., Warner, G., Green, T., ... Cheung, A. M. (2014). Randomized clinical trial of the timing it right stroke family support program: research protocol. *BMC Health Services Research*, *14*, 18.
- Cameron, J. I., Naglie, G., Green, T. L., Gignac, M. A., Bayley, M., Huijbregts, M., ... Czerwonka, A. (2015). A feasibility and pilot randomized controlled trial of the "Timing It Right Stroke Family Support Program." *Clinical Rehabilitation*, *29*(11), 1129–1140. doi:10.1177/0269215514564897
- Czaja, S. J., Boot, W. R., Charness, N., A Rogers, W., Fisk, A. D., Sharit, J., ... Nair, S. N. (2015). The personalized reminder information and social management system (PRISM) trial: Rationale, methods and baseline characteristics. *Contemporary Clinical Trials*, *40*, 35–46. doi:10.1016/j.cct.2014.11.004
- Czaja, S. J., Charness, N., Fisk, A. D., Hertzog, C., Nair, S. N., Rogers, W. A., ... Sharit, J. (2006). Factors predicting the use of technology: Findings from the Center for Research and Education on Aging and Technology Enhancement (CREATE). *Psychology and Aging*, *21*(2), 333–352.
- Czaja, S. J., Loewenstein, D., Schulz, R., Nair, S. N., ... Perdomo, D. (2013). A videophone psychosocial intervention for dementia caregivers. *American Association for Geriatric Psychiatry*, *21*(11), 1071–1081. doi:10.1016/j.jagp.2013.02.019
- El Masry, Y., Mullan, B., & Hackett, M. (2013). Psychosocial experiences and needs of Australian caregivers of people with stroke: Prognosis messages, caregiver resilience, and relationships. *Topics in Stroke Rehabilitation*, *20*(4), 356–368.
- Fens, M., Beusmans, G., Limburg, M., van Hoef, L., Haastregt, J., Metsemakers, J., & van Heugten, C. (2015). A process evaluation of a stroke-specific follow-up care model for stroke patients and caregivers; a longitudinal study. *BMC Nursing*, *14*(1), 3. doi:10.1186/s12912-014-0052-8
- Forster, A., Dickerson, J., Melbourn, A., Steadman, J., Wittink, M., ... Young, J.; TRACS Trial Collaboration (2015). The development and implementation of the structured training programme for caregivers of inpatients after stroke (TRACS) intervention: The London Stroke Carers Training Course. *Clinical Rehabilitation*, *29*(3), 211–220. doi:10.1177/0269215514543334
- Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics*, *42*(2), 377–381. doi:10.1016/j.jbi.2008.08.010
- Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., ... Jaffe, M. W. (1963). Studies of illness in the aged: The index of ADL: A standardized measure of biological and psychosocial function. *JAMA*, *185*, 914–919. doi:10.1001/jama.1963.03060120024016
- Krause, N. (1995). Negative interaction and satisfaction with social support among older adults. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, *50*(2), P59–73
- Krause, N., & Markides, K. (1990). Measuring social support among older adults. *International Journal of Aging & Human Development*, *30*(1), 37–53. doi:10.2190/CY26-XCKW-WY1V-VGK3
- Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*, *9*(3), 179–186.
- Lewis, J. R. (1994). Sample sizes for usability studies: Additional considerations. *Human Factors: The Journal of the Human Factors and Ergonomics Society*, *36*(2), 368–378. doi:10.1177/001872089403600215
- Loh, A. Z., Tan, J. S., Zhang, M. W., & Ho, R. C. (2017). The global prevalence of anxiety and depressive symptoms among caregivers of stroke survivors. *Journal of the American Medical Directors Association*, *18*(2), 111–116. doi:10.1016/j.jamda.2016.08.014
- Miles, M. B., Huberman, A. M., & Sandaño, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd ed., pp. 107–120). Thousand Oaks, CA: SAGE Publications.
- Pfeiffer, K., Beische, D., Hautzinger, M., Berry, J. W., Wengert, J., Hoffrichter, R., ... Elliott, T. R. (2014). Telephone-based problem-solving intervention for family caregivers of stroke survivors: A randomized controlled trial. *Journal of Consulting and Clinical Psychology*, *82*(4), 628–643. doi:10.1037/a0036987
- Pierce, L. L., Steiner, V. L., Khuder, S. A., Govoni, A. L., & Horn, L. J. (2009). The effect of a Web-based stroke intervention on carers' well-being and survivors' use of healthcare services. *Disability and Rehabilitation*, *31*(20), 1676–1684. doi:10.1080/09638280902751972
- Pozet, A., Lejeune, C., Bonnet, M., Dabakuyo, S., Dion, M., Fagnoni, P., ... Bonnetain, F. (2016). Evaluation of efficacy and efficiency of a pragmatic intervention by a social worker to support informal caregivers of elderly patients (The ICE Study): Study protocol for a randomized controlled trial. *Trials*, *17*(1), 531. doi:10.1186/s13063-016-1622-8
- Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, *1*, 385–401.
- Rigby, H., Gubitz, G., & Phillips, S. (2009). A systematic review of caregiver burden following stroke. *International Journal of Stroke*, *4*, 285–292.
- Steffen, A. M., McKibbin, C., Zeiss, A. M., Gallagher-Thompson, D., & Bandura, A. (2002). The revised scale for caregiving self-efficacy: Reliability and validity studies. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, *57*(1), 74–86.
- van de Berg, M., Crotty, M. Prof, Liu, E., Killington, M., Kwakkel, G. Prof, & van Wegen, E. (2016). Early supported discharge by caregiver-mediated exercises and e-Health support after stroke: A proof-of-concept trial. *Stroke*, *47*(7), 1885–1892. doi:10.1161/strokeaha.116.013431
- Wickham, H. (2009). *ggplot2: Elegant graphics for data analysis*. New York, NY: Springer-Verlag.
- Woodford, J., Farrand, P., Watkins, E. R., Richards, D. A., & Llewellyn, D. J. (2014). Supported cognitive-behavioural self-help versus treatment-as-usual for depressed informal carers of stroke survivors (CEDaRS): Study protocol for a feasibility randomized controlled trial. *Trials*, *15*, 157. doi:10.1186/1745-6215-15-157
- Worrall, L., Ryan, B., Hudson, K., Kneebone, I., Simmons-Mackie, N., Khan, A., ... Rose, M. (2016). Reducing the psychosocial impact of aphasia on mood and quality of life in people with aphasia and the impact of caregiving in family members through the Aphasia Action Success Knowledge (Aphasia ASK) program: Study protocol for a randomized controlled trial. *Trials*, *17*, 153. doi:10.1186/s13063-016-1257-9

For more than 14 additional continuing education articles related to technology, go to
www.NursingCenter.com.

Instructions:

- Read the article. The test for this CE activity can be taken online at www.NursingCenter.com. Find the test under the article title. Tests can no longer be mailed or faxed.
- You will need to create a username and password and login to your personal CE Planner account before taking online tests. Your planner will keep track of all your Lippincott Professional Development online CE activities for you.
- There is only one correct answer for each question. A passing score for this test is 7 correct answers. If you pass, you can print your certificate of earned contact hours and access the answer key. If you fail, you have the option of taking the test again at no additional cost.
- For questions, contact Lippincott Professional Development: 1-800-787-8985.

Registration Deadline: June 3, 2022

Disclosure Statement:

The authors and planners have disclosed that they have no financial relationships related to this article.

Provider Accreditation:

Lippincott Professional Development will award 1.0 contact hour for this continuing nursing education activity.

Lippincott Professional Development is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

This activity is also provider approved by the California Board of Registered Nursing, Provider Number CEP 11749 for 1.0 contact hour. Lippincott Professional Development is also an approved provider of continuing nursing education by the District of Columbia, Georgia, and Florida, CE Broker #50-1223.

Payment:

- The registration fee for this test is free for members through July 31, 2020 and \$10.00 after July 31, and \$12.50 for nonmembers.
 1. ARN members can access the discount by logging into the secure "Members Only" area of <http://www.rehabnurse.org>.
 2. Select the Education tab on the navigation menu.
 3. Select Continuing Education.
 4. Select the Rehabilitation Nursing Journal article of your choice.
 5. You will appear at nursing.CEConnection.com.
 6. Log in using your Association of Rehabilitation Nursing username and password. The first time you log in, you will have to complete your user profile.
 7. Confirm the title of the CE activity you would like to purchase.
 8. Click start to view the article or select take test (if you have previously read the article.)
 9. After passing the posttest, select +Cart to add the CE activity to your cart.
 10. Select check out and pay for your CE activity. A copy of the receipt will be emailed.