Published in final edited form as:

Rehabil Psychol. 2012 August ; 57(3): 196–206. doi:10.1037/a0029587.

Reducing Depression in Stroke Survivors and their Informal Caregivers: A Randomized Clinical Trial of a Web-Based Intervention

Gregory C. Smith, Nichole Egbert, Mary Dellman-Jenkins, Kevin Nanna, and Patrick A. Palmieri

Abstract

Purpose/Objectives—To develop and test the efficacy of a web-based intervention for alleviating depression in male stroke survivors (SSs) and their spousal caregivers (CGs) that blends both peer and professional support.

Design and Methods—The research consisted of an intervention protocol evaluated by a focus group of rehabilitation professionals, a “think aloud” session conducted with female stroke CGs, and a usability test of the intervention’s online features with 7 female stroke CGs. Efficacy of the final protocol was tested in a two-group randomized clinical trial with a sample of 32 CG-SS dyads. The CGs in the intervention condition received an online group intervention. Intervention components were based on the Stress Process Model. Those CGs in a control condition received minimal support with individualized access to relevant online information. Measures of depression, as well as the secondary outcomes of mastery, self-esteem, and social support, were obtained from SSs and CGs at pretest, post-test, and one-month later.

Results—At posttest and one month later, CGs in the intervention condition reported significantly lower depression than CGs in the control condition with baseline depression controlled. There was no significant effect on depression among SSs. Although no significant treatment effects for either SSs or CGs were found on the secondary outcomes, post-treatment changes on some constructs were significantly correlated with change in depression.

Conclusions/Implications—CGs benefit from web-based programs that help them better understand both their emotional needs and those of the SS.

Stroke is the major cause of long-term disability and rehabilitation in the United States (American Stroke Association, 2011). After hospitalization and rehabilitation, 80% of stroke survivors (SSs) return home with care largely provided by family caregivers (CGs; Eldred & Sykes, 2008). Many CGs are older wives with age-related infirmities that make being a CG more difficult (Hickenbottom et al., 2002). These wives often become isolated and overprotective of the disabled spouse (Michallet, Tetreault, & Le Dorze, 2003).

Both SSs and their informal CGs are at risk for depression. Recently, for instance, it was found that the amount of spouses with depressive symptoms ranged from 68 percent immediately after stroke onset to 50 percent at three years poststroke (Visser-Meiley et al., 2009). Depression is also the most common post-stroke psychiatric condition among SSs. In their systematic analysis of the world’s literature on post stroke depression, Robinson and Spalletta (2010) noted that prevalence rates for minor and major depression combined are about 23.0 percent in community settings and about 47.9 percent in outpatient settings (up to three years post stroke). However, few depressed SSs receive relevant treatment (Okan et al., 2004).

It has been shown repeatedly that the quality of informal care influences depressive onset in care recipients (Matire, Stephens, Druley, & Wojno, 2002; Newsom & Schulz, 1998; Williamson & Schaffer, 2001). Misguided support impedes rehabilitation for chronic illness and leads to excess disability (Cimarolli, Reinhardt, & Howowitz, 2006). Even actions meant as supportive are often viewed negatively by chronically ill persons (Matire et al., 2002). According to Newsom (1999), 33%-66% of care recipients (CRs) suffer from depression and unfavorable self-attributions due to poor informal care. In turn, Christie et al. (2009) argue that assessments of the quality of informal care must consider CG sensitivity to the CR's psychosocial needs for respect and pleasurable activities.

Many CGs of stroke patients, specifically, report feeling that they are not always understanding enough of the SS's needs (Hinojosa & Rittman, 2007). In turn, poor quality of spousal care (i.e., overprotection, patronization, and unnecessary care) predicts greater depression and less mastery in SSs (Palmer & Glass, 2003; Perrin, Heesacke, Hinojosa, Uthe & Rittman, 2009). Furthermore, CG depression predicts potentially harmful behaviors even when demographic variables, pre-illness CG-SS relationship quality, and illness severity are controlled (Williamson & Shaffer, 2001).

Risk for depression in both members of the CG-SS dyad suggests the need for interventions to improve psychological well-being of SS and CG alike (McCarthy, Powers, & Lyons, 2011). Matire and Schulz (2001) claim that such interventions should target CGs by alleviating burden and educating them to provide optimal supportive assistance. Similarly, Perrin et al. (2009) maintain that "because the functioning of individuals with stroke is intimately linked to the mental health of stroke caregivers, these interventions could improve the way that caregivers provide informal care and ultimately contribute to more effective rehabilitation of individuals with stroke" (p. 146). Nevertheless, intervention studies along these lines are scarce. Reviews of intervention research involving stroke CGs reveal that few randomized clinical trials (RCT) have been published where the intervention involved anything more than information and education (Brereton, Carroll & Barnston, 2007; Eldred & Sykes, 2008; Redfern, McKevitt, & Wolfe, 2006). Also, insufficient evidence exists to confirm the efficacy of interventions for stroke CGs. Extant studies vary greatly in approach, suffer methodological flaws, and are of low quality. Nevertheless, Eldred and Sykes (2008) concluded that psychosocial interventions for stroke CGs (especially if delivered by innovative technology) may offset the negative impact of informal caregiving and prevent decline in SSs' adjustment.

We describe the development and evaluation of a web-based psychoeducational intervention for CGs designed to reduce depression in both male SSs and their spouses. This particular dyadic configuration was selected due to the tendency of wives to isolate themselves and to demonstrate overprotection towards a disabled spouse (Michallet et al., 2003). The intervention, based on the prominent Stress Process Model (SPM; Pearlin, Aneshensel, Mullan, & Whitlatch, 1995), contained five interrelated components for countering depression within the CG-SS dyad (Table 1). A basic SPM principle is that the effect of stressors on psychological distress is mediated by the key psychosocial resources of mastery, self-esteem, and social support. Although originally designed for dementia care, the SPM's underpinnings in a stress and coping framework make it applicable to multiple chronic illnesses.

Following the SPM, we deduced that CG social support, self-esteem, and mastery would be enhanced by informational, emotional, and instrumental support from both a professional helper and peers. In turn, these positive changes in CG coping resources should reduce CG depression. Also, the information and skills imparted to the CGs would enable them to give care in ways that increase the perceived emotional support, autonomy, and self-esteem of the

SSs. Positive changes in these outcomes are then expected to diminish SS depression. Thus, this intervention is innovative in attempting to increase SSs' psychological well-being by encouraging CGs to provide optimal care.

Using web-base conferencing and video education is another innovation, given that few studies have evaluated the efficacy and utility of these modalities with family CGs (see, for review, Glueckauf & Noël, 2011). Only one study of an online support program for CGs of SSs has been reported to date (Pierce, Steiner, Khuder, Govoni, & Horn, 2009). That intervention encompassed four components delivered to CG: (1) linked Web sites about stroke and caregiving; (2) educational information or tips customized to CG needs; (3) an email forum to ask relevant professionals private questions; and (4) non-structured email discussions facilitated by a nurse. The intervention did not alter CGs' baseline depression and its impact on SSs' mental health was unexamined. To our knowledge, no study has investigated the efficacy of a web-based intervention on the well-being of CGs and SSs concurrently.

Within an RCT investigation, our goal was to reduce depression as the primary outcome in both members of the CG-SS dyad by encouraging CGs to better attend to their emotional needs, as well as to those of the SS. We hypothesized that outcomes for CGs and SSs receiving the intervention would be superior when compared to dyads assigned to an information only control condition. According to the SPM (Pearlin et al., 1995), we further hypothesized that increases in mastery, self-esteem, and social support would be associated with decreased depression for SSs and CGs alike. The conditions were also compared on measures of treatment credibility, effort, and perceived benefit.

Methods

Three steps for refining the intervention occurred before the RCT. First, a draft of the intervention protocol was reviewed and refined by a focus group of seven rehabilitation professionals. Second, two spouses of male SSs participated in think-aloud sessions to assess reactions to completing tasks within the draft protocol. Third, a usability study was conducted with seven CGs of male SSs.

Overview of the RCT

A two-group RCT was conducted where 38 CG-SS dyads were randomly assigned to either the intervention condition or to an information-only control condition. Both conditions occurred online in participants' homes over an 11 week period in a manner similar to that used in prior web-based intervention studies (see Pierce et al., 2009). The RCT was run in three waves (May to September, 2009). Participants were assessed via phone by doctoral level clinical psychologists at baseline (T1), posttest (T2), and one month follow-up (T3). Due to communication disorders, six SSs completed mailed questionnaires. Assessors were blind to condition.

Recruitment

Dyads were recruited nationally through notices on Web sites and listserv announcements of key organizations (e.g., National Stroke Association; Family Caregiver Alliance). Inclusion criteria were that the female CG provided care at home to a husband after stroke; either the SS or CG scored five or more on the PHQ-9 (at least mild depression); neither SS nor CG were medically unstable or terminally ill; and both were cognitively able to participate.

Procedures

Potential dyads for the RCT were screened via telephone. If CG and SS were both eligible, the dyad was randomly assigned to the intervention or control condition. The CG was asked if the household contained computer hardware and Internet access. If not, it was arranged for the CG to receive the required technology. Online and hard copy tutorials were developed to train the Web site users and made available to all CGs.

Randomization was conducted via computer by PP. Allocation involved a permuted block design with blocks of random length so that the final sample included 16 dyads per condition. Because a decision was later made to recruit further dyads, another block was randomly selected from all possible sequences of all possible lengths, resulting in the selection of a sequence of length 6. Ultimately, 38 dyads were randomized, initially yielding equal sample sizes for the two conditions. Recruitment and retention results are summarized in Figure 1.

Intervention Condition

The intervention consisted of five components designed to provide CGs with knowledge, resources, and skills to help them both reduce their personal distress and to provide optimal emotional care to the SS: Professional Guide, Educational Videos, Online Chat Sessions, E-mail and Message Board, and Resource Room. Descriptions of these components are in Table 1.

Summaries of weekly topics (and corresponding video), the goals of each weekly session, and the corresponding homework for the intervention condition are provided in Appendix A. Attempts were repeatedly made to acknowledge the positive and negative feelings of both members of the CG-SS dyad, as well as to illustrate how they were intertwined. Moreover, CGs were encouraged to interact with SSs in ways to enhance their mutual well-being.

Control Condition

Those CGs assigned to this condition had access to the Resource Room only. At the RCT outset, they were asked to watch an online video in which the same Professional Guide explained the features of the Resource Room and encouraged CGs to use it as a caregiving resource. There was no further exposure to the Professional Guide beyond that video. A weekly caregiving tip was also presented online, but none overlapped with content covered in the intervention condition. A toll free phone number was provided in case CGs encountered technological problems while accessing the Resource Room, or if a medical emergency occurred. Halfway through the RCT, an assistant phoned CGs to see if they encountered technical difficulties in accessing the Resource Room. Participants in both RCT conditions received identical computer resources for accessing web-based information and support. The critical difference was that the control condition had no exposure to the key intervention components.

Measures

Standard demographic data were collected on all participants. Identical outcome measures were administered to CGs and SSs following the theoretical perspective of the SPM. Cronbach's alphas are reported for T1 only.

Depression—The 20-item CESD (Radloff, 1977) measured the primary outcome of depression. Respondents rated each item from 0 (experienced rarely or none of the time) to 3 (experienced most or all of the time). Scores may range from 0 to 60, with higher scores

indicating more depressive symptoms; a score of >16 is widely seen as being at risk for clinical depression. Cronbach's alphas were .90 (SS) and .92 (CG).

The PHQ-9 was used to screen for depression in CGs and SSs (Kroenke, Spitzer, & Williams (2001). Respondents indicated how much over the past two weeks they had been bothered by each of nine symptoms from 0 (not at all) to 3 (nearly everyday). Scores from 5 to 9 indicate need for support and education; scores ≥ 10 indicate need for antidepressants or psychotherapy.

Mastery—This was assessed by 9 items from the Mastery Scale (Pearlin & Schooler, 1978). Respondents rated agreement with each item (e.g., “I can do just about anything I really set my mind to do”) from 1 (strongly disagree) to 4 (strongly agree). Scores may range from 9 to 36. Higher scores indicated greater perceived mastery. Cronbach's alphas were .62 (SS) and .71 (CG).

Self-Esteem—This was assessed by the 10-item Self-Esteem Scale (Rosenberg, 1965), a measure of beliefs in one's worth, competence, and capacity for success. Items were rated from 1 (strongly disagree) to 4 (strongly agree). Scores may range from 10 to 40. Higher scores indicated greater self-esteem. Cronbach's alphas were .86 (SS) and .90 (CG).

Social Support—This was assessed by 11 items from the MOS Social Support Survey (Sherbourne & Stewart, 1991), tapping emotional, informational, and affectionate support. Items were rated from 1 (none of the time) to 5 (all of the time). Scores may range from 11 to 55. Higher scores indicated greater support. Cronbach's alphas were .85 (SS) and .90 (CG).

Treatment Credibility, Reported Effort, and Perceived Benefit—These constructs were measured among CGs by items adapted from the Credibility/Expectancy Questionnaire (Deville & Borkovec, 2000). Three items, rated from 1 (not at all) to 9 (very much), measured credibility (e.g., “How logical was the treatment?”). Effort was measured by a single item (“How much effort did you devote to the program”) rated from 0 to 100. Benefit was assessed by two items rated from 0 to 100 (e.g., “How much benefit has there been for you as a result of the program?”).

Analyses and Results

Background Characteristics

Of 161 dyads screened, 40 were eligible. One dyad refused participation and another could no longer be reached, leaving 38 dyads randomized to the two conditions. Strict eligibility criteria, along with a national recruitment approach (e.g., use of national listservs), yielded many ineligible prospective participants. For example, many of the 161 dyads were not eligible, either because the relationship criterion was not met (i.e., not a wife caring for her husband), or because neither member of the dyad screened positively for depressive symptoms. Eligible dyads were from 16 states, encompassing urban, suburban, and rural areas.

Of 19 dyads allocated to the intervention condition, 15 received the intervention: two could not attend sessions due to scheduling conflicts, the SS in one dyad entered hospice prior to the intervention, and the SS in one dyad was found ineligible prior to the intervention. Of 19 dyads allocated to the comparison condition, 17 received this condition: one was eliminated because the SS was unable to be interviewed, and one dyad became unreachable (Figure 1).

Within both conditions, participating dyads ($n = 32$) had similar demographic characteristics regarding age, PHQ depression screening scores, education, employment status, family income, first time stroke for SS, and other SS medical problems (Table 2). More dyads in the intervention condition included a SS with language or cognitive impairment, reported other negative life events beyond the stroke within the past 5 months, and were using mental health treatment or psychotropic medications. By design, all dyads in both conditions had at least one member who scored five or above on the PHQ-9. The T1 scores on the outcome measures were similar for CGs and SSs in both conditions, with average CES-D scores exceeding the clinical cutoff of 16 (Table 2).

Data Analytic Plan

Of the 32 participating dyads, 3 were defined as “non compliers” (i.e., the CG was assigned to the intervention and attended fewer than 10 sessions). Data were thus analyzed separately in terms of both intent to treat ($n = 32$), including all dyads having at least initial exposure to their assigned condition during the RCT; and per protocol ($n = 29$), excluding non compliers originally assigned to the intervention (Ten Have et al., 2008). In five dyads, at least one member did not complete all measurements. An EM algorithm was used to impute missing data. Several approaches were used to conduct statistical analyses of the RCT data, including ANCOVAs on the depression and psychosocial resource variables, estimates of clinically meaningful change, analysis of dyadic level change on study outcomes, zero order correlations of change on study outcomes vis a vis the SPM, and an examination of perceived credibility, effort, and benefit among CGs. Where appropriate, analyses were conducted separately for SSs and CGs encompassing both intent-to-treat and per protocol. An alpha level of .05 was used for all statistical tests. All analyses were conducted with SPSS 18.0 software.

Change on Depression and Related Constructs—Although change in depression was the primary outcome for both members of the CG-SS dyad, change was also examined across theoretically related constructs of self-esteem, mastery, and social support. Separate 2 (condition) X 2 (time) repeated measures ANCOVAs were conducted for each outcome where condition was the between factor, time of measurement (i.e., T2 and T3) was the within subjects factor, and the T1 score was a covariate controlling for potential baseline differences.

As Table 3 reveals, CG depression was the only outcome for which statistically significant differences were found between conditions. At T2 and T3 alike, CGs in the intervention condition reported lower CES-D scores than did controls for both intent-to-treat ($F(1,29) 6.13, p < .01$; observed power = .67) and per protocol ($F(1,26) 5.80, p < .05$; observed power = .64) analyses. The standardized effect sizes associated with mean differences were large at T2 for CG (−.79 intent to treat; −.81 per protocol), but only medium at T3 (−.52 intent to treat; −.41 per protocol). Although no statistically significant differences existed for SSs, depression scores for those in the intervention condition were lower at T3 than for controls. Also, there was a non significant trend for lower levels of social support being reported at T3 by CGs receiving the intervention.

Clinically Meaningful Change—As reported in Table 4, we calculated the percent of CGs and SSs showing at least a 50 percent drop in T1 CES-D scores at T2 and T3. Higher percentages of CGs and SSs in the intervention condition showed these reductions versus those in the control condition. This pattern held in both intent-to-treat and per protocol analyses.

We also calculated the percent of individuals in remission at T2 and T3 as defined by dropping from a T1 CES-D clinical cut off score of ≥ 16 to a score < 16 at either T2 or T3 (Table 4). At T2, 33% (3/9) of CGs in the intervention condition with T1 CES-D scores ≥ 16 dropped below the clinical level, versus zero percent (0/9) in the control condition. Similar findings existed at T3 for CGs, where 50% (3/6) of CGs from the intervention condition who were compliant dropped below a T1 CES-D score of ≥ 16 at T3 versus 11.1% (1/9) in the control condition. Although comparable findings occurred for SSs, the between condition differences were not as large.

Dyadic Change—Dyadic level change for each outcome measure was calculated by (a) subtracting T1 values from the T2 and T3 values for CG and SS separately, and (b) taking the average of the SS and CG change at each time point. Multivariate ANOVAs were then conducted to compare experimental conditions. Although none of the omnibus multivariate F-tests were significant, the univariate F-tests for depression in the intent-to-treat analysis revealed that dyads in the intervention condition had significantly greater averaged reductions at T3 ($F(1, 29) 4.50; p < .05; ES = .75$) than those in the control condition. However, statistical significance was not reached at T2 ($F(1, 29) 2.93; p < .10$), despite an ES of .60. A nearly identical pattern of dyadic change in depression was observed in the per protocol analysis. Although differences between the conditions fell short of statistical significance, the effect sizes for depression (T2 = .57; T3 = .54) were medium.

Intercorrelations of Change on Outcomes—To examine if changes in study outcomes were consistent with the SPM, raw difference scores were calculated for each variable by subtracting its T2 and T3 scores, respectively, from its T1 score. Zero-order correlations between the respective change scores were then computed for CGs and SSs separately. Reduced depression in SSs at T2 was significantly related to increased mastery ($r = -.58; p < .005$) and self-esteem ($r = -.45; p < .01$). At T3, reduced depression in SSs was significantly related to increased mastery ($r = -.49; p < .005$) and social support ($r = -.37; p < .05$). For CGs, the only statistically significant relationship was that reduced depression at T3 was associated with increased mastery ($r = -.30; p < .05$).

Perceived Credibility, Effort, and Benefit—At T2, CGs in both conditions were queried regarding (a) how credible their condition seemed to them, (b) the amount of effort they had devoted to the program, and (c) the benefit to themselves and to the SSs as a result of their participation. For credibility, there was no significant group difference regarding how logical the program appeared to be. However, CGs receiving the intervention reported that the program was significantly more useful ($t = 2.26; p < .05$) and they felt more confident in recommending it to others ($t = 3.33; p < .004$) than did controls. There were no significant differences between the conditions concerning either effort devoted to the program or perceived benefit to themselves. However, CGs receiving the intervention perceived significantly greater benefit to the SS than did those in the control condition ($t = 2.42; p < .03$).

Discussion

We developed and tested an intervention using web-based technology to conduct professionally led psychoeducational support groups with the spouses of male SSs. The goal was to reduce depression in both members of the CG-SS dyad by encouraging CGs to better attend to their emotional needs, as well as to those of the SS. We hypothesized that outcomes for CGs and SSs receiving the intervention would be superior when compared to dyads assigned to an information only control condition. According to the SPM (Pearlin et al., 1995), we further hypothesized that increases in mastery, self-esteem, and social support

would be associated with decreased depression for SSs and CGs alike. The conditions were also compared on measures of treatment credibility, effort, and perceived benefit.

Our findings suggest that the intervention reduced the primary outcome of depression for CGs at levels reflecting statistical and clinical significance. The practical impact of the intervention was demonstrated on several levels. First, it is noteworthy that about 40 percent of CGs receiving the intervention demonstrated a 50 percent decrease from CESD baseline scores, given that this type of change is widely used as the critical end point for defining improvement in depression treatment studies (Keller, 2003). We also looked at the proportion of participants who dropped from baseline scores exceeding the CESD clinical cut off of 16 to scores less than 16 at posttest, which is another recommended approach for judging the clinical impact of treatment studies (Frank et al., 1991). Not only did the intervention condition favor this type of change at posttest, a similar pattern was found at the one month follow-up as well. These patterns were true in both the intent-to-treat and per protocol analyses.

The clinical impact of the intervention in reducing CG depression is further suggested by the standardized ES ($-.79$ for intent-to treat and $-.81$ per protocol) associated with posttest mean differences on the CESD. This is especially evident when the effect sizes observed across other caregiver intervention studies are considered. For instance, in a meta-analysis of interventions for improving the mental health of CGs of SSs (as measured by change on the Short Form Health Survey; SF-36), Lee, Soeken, and Picot (2007) reported that four high quality studies yielded varied effects with an overall mean weighted ES of 0.28. Pinquart and Sörensen (2006), in their meta-analysis of psychosocial interventions for CGs of dementia patients, concluded that ESs in the range of $-.70$ to be large and meaningful with respect to improving CG mental health outcomes. Although there is not full agreement on what magnitude of effect is necessary to establish practical significance, it has been advised that the most informative interpretation occurs when the effect size is compared to other effects involving the same or similar variables within related contexts (Ferguson, 2009).

Although depression was not similarly reduced for SSs at clinically and statistically significant levels (as it was for the CGs), the overall pattern of change was in the predicted direction. However, reduced depression for SSs did not appear until one month after treatment, as evident in both the intervention and control. Thus, although the efficacy of the intervention for reducing depression in SSs was in the expected direction, it was not convincingly supported.

One possible explanation for lower intervention efficacy with SSs is that they were not directly involved with the intervention (apart from interacting with the CG on the homework assignments meant to benefit both dyad members). In turn, it could be that either CGs poorly implemented these assignments, or put insufficient effort into completing them. Similarly, CGs receiving the intervention may have ineffectively showed increased respect and concern for SSs' emotional well-being as targeted by the intervention. In retrospect, quality assurance checks regarding homework completion and skill implementation seem advisable. Attempts to involve SSs more directly with the intervention might also be needed. For example, even SSs with significant communication impairments could participate more fully in the future by receiving reminders on a Smart Phone device to use relaxation techniques or to engage in pleasant activities. Such control enhancing techniques yield higher mastery and reduced depression (Landreville, Desrosiers, Vincent, Verreault, & Boudreault, 2009).

Although our intervention did not produce significant change in outcomes other than depression for SSs or CGs, the pattern of zero-order correlations across the change scores

for study measures lend modest support to the conceptual framework of the SPM (Pearlin et al., 1995). This was mostly true for SSs where decreased depression was associated with increased mastery, self-esteem, and social support. Moreover, these correlations were large in magnitude. Although scholars have applied the SPM in studies of the well-being of family CGs of chronically ill adults (see, for example, Paoli, 2010), the present study is unique in demonstrating its relevance to CRs.

For CGs in our sample, diminished depression was correlated solely with increased mastery. Although this finding alone is not highly supportive of the SPM, it is consistent with prior research where perceived mastery mediated the relationship between stressors and CGs' psychological well-being for chronic illnesses beyond stroke (Gaugler et al., 2009; Shirai, Koerner, & Kenyony, 2009). Thus, perhaps the main goal of psychoeducational programs should be to increase feelings of mastery in route to improving the overall well-being of the primary CG. However, the exact causal relationships between self-esteem, mastery, social support, and well-being remain an active area of investigation within family caregiving research. Consistent with our results, Shirai et al. (2009) found the impact of social support on CGs' well-being to be mediated by perceived mastery in a non-intervention study with CGs of dependent older adults.

It is important to consider why our intervention did not yield significant changes on outcomes beyond depression. Because both CGs and SSs scored high on the other measures at baseline, there may have been insufficient opportunity for improvement to occur in a short 11 week period. In contrast, dyads were screened for elevated depression permitting a greater opportunity for change on this outcome. In addition, although prominent global measures of mastery, self-esteem, and social support were used (given their well-known reliability and validity), situation specific measures may have shown greater sensitivity to change (Paoli, 2010).

Our findings also provide initial evidence that stroke families can benefit from a web-based intervention and that they are willing to use it. Even though CGs in our intervention condition found the program to be more useful than did controls, and were more confident in recommending it to others, there were no significant differences by condition in amount of reported effort devoted to the online programs.

Given the paucity of online intervention studies with stroke families, it is worth considering why the present findings are dissimilar from those of Pierce et al. (2009), whose intervention did not reduce CG depression. One possibility is that there was little room for change on this outcome in their sample where there was no initial screening for elevated depression. The two interventions also were based on different conceptual underpinnings, with Pierce et al. relying on Friedemann's (1995) framework of systemic organization. In turn, the primary outcome intended for SSs in their study was reduced use of services without corresponding attention given to quality of emotional care and its relationship to psychological well-being within the CG-SS dyad. Pierce et al. (2009) also did not include enacted video support groups and real life chat sessions in their intervention. Thus, they did not provide the potentially therapeutic exposure to other CGs that was present in our intervention. Future research is needed to compare different varieties of online programs with stroke families and to identify specific therapeutic components that are most beneficial to psychological well-being.

Our findings should be interpreted cautiously in view of the exploratory and developmental nature of this project where the primary aim was to examine initial feasibility and efficacy of the intervention. Subsequent research is required to refine this intervention further, as well as more rigorously test its efficacy (ability to positively affect clinical outcomes) and

effectiveness (applicability on a wide scale basis; Wells, 1999). A comparison of the efficacy of our web-based intervention to a more traditional in-person format is also an important next step.

Our RCT involved only a small number of dyads that were almost entirely Caucasian. Thus, statistical power was compromised, potential moderators of treatment change (e.g., comorbidity, stroke severity, caregiving duration) could not be considered, mediational analyses based on the SPM were limited to zero-order correlations, differential treatment affects across racial and ethnic groups went unexplored, and characteristics of SSs (e.g., level of functional impairment) and CGs (e.g., amount or duration of care) that might influence treatment efficacy could not be meaningfully considered as covariates.

Given the very strict eligibility associated with the RCT, generalization of these findings across a wider spectrum of stroke care dyads is unknown. Furthermore, a limited timeline did not permit conducting long-term follow-ups. This limitation, coupled with the small sample size, restricted a fuller examination of collateral treatment changes at the dyadic level over time as predicted by the SPM. Our exclusive use of self-report measures points to the need to include more objective outcome indices in the future.

The major limitation, however, involves the specific control condition used. As Schulz et al. (2009) pointed out, “The most appropriate control condition for this type of intervention... is under considerable debate. Options include treatment as usual, minimal support, or attention control” (p. 13). In turn, we reasoned that our control condition involved elements of both “treatment as usual” and “minimal support,” given that it provided access to large amounts of relevant information. Nevertheless, CGs receiving the intervention interacted both with each other and the Professional Guide, whereas those in the control condition did not. Therefore, in the absence of an attention control condition, we cannot conclude if the observed treatment differences were the result of anything beyond interacting with and gaining attention from others. Our control condition did not exclude the possibility that the opportunity to express feelings in a supportive atmosphere was the underlying therapeutic agent in the intervention condition.

Despite these limitations, we successfully developed and tested a theoretically derived web-based psychoeducational program that shows promise for enhancing the psychological well-being of SSs and CGs alike. Our findings also suggest that CGs perceived the intervention as credible and were willing to devote considerable effort to it. Because telehealth interventions for caregiving families are in their infancy, developmental initiatives like this are important and timely. As Glueckauf and Noel (2011) pointed out, web-based videoconferencing is likely to become the preferred medium for obtaining CGs’ information and support as the technology-savvy baby boomers become increasingly involved in family care. The Internet provides economic advantages in providing education and support to family CGs as compared to standard face-to-face treatment, which is meaningful in the context of health care finance reform initiatives.

Acknowledgments

This research was funded by grant number R21NR010189-02 to Drs. Gregory C. Smith (PI); Nichole Egbert (Co-PI; and Mary Dellman-Jenkins (Co-PI)

References

- American Stroke Association. Facts. 2011. Retrieved from <http://www.strokeassociation.org>
- Brereton L, Carroll C, Barnston S. Interventions for adult family carers of people who have had a stroke: A systematic review. *Clinical Rehabilitation*. 2007; 21:867–884. [PubMed: 17981846]

- Christie J, Smith G, Williamson G, Lance C, Shovali T, Silva L. Quality of informal care is multidimensional. *Rehabilitation Psychology*. 2009; 54:173–181. [PubMed: 19469607]
- Cimarolli AR, Reinhardt JP, Howowitz A. Perceived overprotection: Support gone bad? *Journal of Gerontology*. 2006:S18–S23.
- Devilly GJ, Borkovec TD. Psychometric properties of the credibility/expectancy questionnaire. *Journal of Behavior Therapy and Experimental Psychiatry*. 2000; 31:73–86. [PubMed: 11132119]
- Eldred C, Sykes C. Psychosocial interventions for caregivers of survivors of stroke: A systematic review. *British Journal of Health Psychology*. 2008; 13:563–581. [PubMed: 17708832]
- Ferguson CJ. An effect size primer: A guide for clinicians and researchers. *Professional Psychology: Research and Practice*. 2009; 40:532–538.
- Frank E, Prien RF, Jarrett RB, Keller MB, Kupfer DJ, Lavori PW, Rush AJ, Weissman MM. Conceptualization and rationale for consensus definitions in terms of major depressive disorder: Remission, recovery, relapse, and recurrence. *Archives of General Psychiatry*. 1991; 48:851–855. [PubMed: 1929776]
- Friedemann, M. The framework of systemic organization: A conceptual approach to families and nursing. Thousand Oaks, CA: Sage; 1995.
- Gaugler JE, Linder J, Given CW, Kataria R, Tucker G, Regine WF. Family cancer caregiving and negative outcomes: The direct and mediational effects of psychosocial resources. *Journal of Family Nursing*. 2009; 15:417–444. [PubMed: 19776210]
- Glueckauf, RL.; Noël, LT. Telehealth and family caregiving: Developments in research, education, policy, and practice. In: Toseland, RW.; Haigler, DH.; Monahan, DJ., editors. Education and support programs for caregivers: Research, practice, and policy. New York, NY: Springer; 2011. p. 85-105.
- Hickenbottom SL, Fendraick JM, Kutcher JS, Kabeto MU, Katz SJ, Langa KM. A national study of the quantity and cost of informal caregiving for the elderly with a stroke. *Neurology*. 2002; 58:1754–1759. [PubMed: 12084872]
- Hinojosa MS, Rittman MR. Stroke caregiver information needs: Comparison of Mainland and Puerto Rican caregivers. *Journal of Rehabilitation Research & Development*. 2007; 44:649–658. [PubMed: 17943676]
- Keller MB. Past, present, and future directions for defining optimal treatment outcome in depression. *Journal of the American Medical Association*. 2003; 289:3152–3160. [PubMed: 12813121]
- Kroenke K, Spitzer &, Williams JB. The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*. 2011; 16:606–613. [PubMed: 11556941]
- Landreville P, Desrosiers J, Vincent C, Verreault R, Boudreault V. The role of activity restriction in poststroke depressive symptoms. *Rehabilitation Psychology*. 2009; 54:315–322. [PubMed: 19702430]
- Lee I, Soeken K, Picot S. A meta-analysis of interventions for informal stroke caregivers. *Western Journal of Nursing Research*. 2007; 29:344–356. [PubMed: 17420524]
- Matire, LM.; Schulz, R. Informal caregiving to older adults: Health effects of providing and receiving care. In: Baum, A.; Revenson, T.; Singer, J., editors. Handbook of health psychology. Mahwah, NJ: Erlbaum; 2001. p. 477-493.
- Matire LM, Stephens MAP, Druley JA, Wojno WC. Negative reactions to received spousal care: Predictors and consequences of miscarried support. *Health Psychology*. 2002; 21:167–176. [PubMed: 11950107]
- McCarthy MJ, Powers LE, Lyons K. Poststroke depression: Social workers' role in addressing an unrecognized problem for couples who have experienced stroke. *Health and Social Work*. 2011; 36:139–148. [PubMed: 21661303]
- Michallet B, Tetreault S, Le Dorze G. The consequences of severe aphasia on the spouses of aphasic people: A description of the adaptation process. *Aphasiology*. 2003; 17:835–859.
- Newsom JT. Another side to caregiving: Negative reactions to being helped. *Current Directions in Psychological Science*. 1999; 8:183–187.
- Newsom JT, Schulz R. Caregiving from the recipient's perspective: Negative reactions to being helped. *Health Psychology*. 1998; 17:172–181. [PubMed: 9548708]

- Okan NJ, Fitzpatrick KC, Betts-Lion C, Cole A, Allen M, Felberg RA. Barriers to therapy in post-stroke depression. *Stroke*. 2004; 35(1):288.
- Palmer S, Glass TA. Family function and stroke recovery: A review. *Rehabilitation Psychology*. 2003; 48:255–265.
- Paoli MF. Global and caregiving mastery as moderators in the caregiving stress process. *Aging & Mental Health*. 2010; 14:603–612. [PubMed: 20480415]
- Pearlin, LI.; Aneshensel, CS.; Mullan, JT.; Whitlatch, CJ. Caregiving and its social support. In: Binstock, RH.; George, LK., editors. *Handbook of aging and the social sciences*. 4. San Diego, CA: Academic Press; 1995. p. 283-302.
- Pearlin LI, Schooler C. The structure of coping. *Journal of Health & Social Behavior*. 1978; 19:2–21. [PubMed: 649936]
- Perrin PB, Heesacker M, Hinojosa MS, Uthe CE, Rittman MR. Identifying at-risk, ethnically diverse stroke caregivers for counseling: A longitudinal study of mental health. *Rehabilitation Psychology*. 2009; 54:138–149. [PubMed: 19469603]
- Pierce L, Steiner V, Khuder S, Govoni A, Horn LJ. The effect of a web-based stroke intervention on carers' well-being and survivors' use of healthcare services. *Disability and Rehabilitation*. 2009; 31:1676–1684. [PubMed: 19479528]
- Pinquart M, Sörensen S. Helping caregivers of persons with dementia: Which interventions work and how large are their effects? *International Psychogeriatrics*. 2006; 18:577–595. [PubMed: 16686964]
- Radloff LS. The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*. 1977; 1:385–401.
- Redfern J, McKevitt C, Wolfe CD. Development of complex interventions in stroke care: a systematic review. *Stroke*. 2006; 37:2410–2419. [PubMed: 16902171]
- Robinson RG, Spalletta G. Poststroke depression: A review. *The Canadian Journal of Psychiatry*. 2010; 55:341–349.
- Rosenberg, M. *Society and the adolescent self-image*. Princeton, NJ: Princeton University Press; 1965.
- Schulz R, Czaja SJ, Lustig A, Zdaniuk B, Martire LM, Perdomo D. Improving the quality of life of caregivers of persons with spinal cord injury: A randomized controlled trial. *Rehabilitation Psychology*. 2009; 54:1–15. [PubMed: 19618698]
- Sherbourne CD, Stewart AL. The MOS Social Support Survey. *Social Science & Medicine*. 1991; 32:705–714. [PubMed: 2035047]
- Shirai Y, Koerner SS, Kenyony DB. Reaping caregiver feelings of gain: The roles of socio-emotional support and mastery. *Aging & Mental Health*. 2009; 13:106–117. [PubMed: 19197696]
- Ten Have TR, Normand ST, Marcus SM, Brown CH, Lavori P, Duan N. Intent-to-treat vs. non-intent-to-treat analyses under treatment non-adherence in mental health randomized trials. *Psychiatric Annals*. 2008; 38:772–783. [PubMed: 20717484]
- Visser-Meily A, Post M, van de Port I, Maas C, Forstberg-Warleby G, Lindeman E. Psychosocial functioning of spouses with patients with stroke from initial rehabilitation to 3 years post-stroke: Course and relations with coping strategies. *Stroke*. 2009; 40:1399–1404. [PubMed: 19095973]
- Wells KB. Treatment research at the crossroads: The scientific interface of clinical trials and effectiveness research. *American Journal of Psychiatry*. 1999; 156:5–10. [PubMed: 9892291]
- Williamson GM, Shaffer DR. The family relationship in late life project. *Psychology of Aging*. 2001; 16:217–226.

Impact

- This paper adds to the literature by demonstrating that mental health can be enhanced by means of a psychoeducational intervention that emphasizes caregivers' vulnerability to depression and the psychological sequelae and prognosis of stroke in the care recipient.
- Brief Innovative telehealth interventions for informal caregivers of stroke survivors can be delivered effectively via the Internet.
- Further consideration of how to involve both members of the informal stroke care dyad in psychoeducational interventions for caregiving families is needed.

Figure 1.
Recruitment and retention flow diagram

Table 1

Summary of Components included in the Intervention Condition

Component	Description	Role in Intervention
Professional Guide	PhD student in Nursing with experience as a cardiovascular nurse manager. Trained in active listening, group facilitation, and computer skills	<p>Oversee and blend all intervention components, including</p> <ul style="list-style-type: none"> a. Introduce, summarize, and facilitate weekly topics featured in the Video Educational Modules and the Chat Room b. Use e-mail messages to provide individually-tailored support to participants by providing emotional support, answering questions related to caregiving, and directing CGs to requested information c. Encourage participants to become better CGs, especially at attending to the CR's emotional needs
Educational Videos	<p>11 educational videos developed specifically for the intervention that depicted a support group of women discussing (and illustrating) topics relevant to stroke caregiving. Each video (average length = 17 minutes) included:</p> <ul style="list-style-type: none"> a. A brief introduction by the Professional Guide b. An enacted support group c. A summary from the Professional Guide discussing the main points. 	<ul style="list-style-type: none"> a. To impart key information to study participants b. Foster identification with the CGs in the videos c. Serve as stimuli for the online chat sessions
Online Chat Sessions	<p>Two online chat sessions weekly were led by the PG for a total of 17 sessions. Chats were held using Adobe Connect in groups of 4–5 CGs each, with group membership held constant. The software permitted participants to be able to talk over the Internet, so they were provided USB headsets and microphones.</p> <p>The format consisted of:</p> <ul style="list-style-type: none"> a. Announcement by Professional Guide of the weekly video b. CGs watched weekly video at their convenience c. First scheduled chat discussed the topic of the video d. Professional Guide summarized the main ideas and provided at-home application e. Second scheduled chat discussed the at-home application 	<ul style="list-style-type: none"> a. Allow the PG to acknowledge the positive and negative feelings of both the CGs and the SSs with regard to the topics (see Table 1 for a summary of the topics for each week) b. Encourage CGs to interact with SSs in ways to enhance their mutual well-being.
E-mail and Message Board	Private E-mail and message board located within the intervention website	<ul style="list-style-type: none"> a. Allow Professional Guide to tailor the intervention to the individual CG-SS b. Facilitate communication between participants c. CGs can use the message board to report on their at-home applications
Resource Room	Virtual online library containing information on the following content areas: stroke causes, consequences, and prevention; managing SSs' behaviors and emotions; providing physical and instrumental care to SSs; accessing services at the local, state and national levels; and dealing with the CGs' physical, emotional, and social reactions to caregiving.	Provide participants with a wealth of online information relevant to all aspects of stroke and caregiving, with all content screened to meet seven criteria for assessing the quality of Internet health information ¹ .

Component	Description	Role in Intervention
	Informational sources included links to other Web sites, quizzes and self-assessment instruments, instructional videos, and other .pdf files. A search engine was available for key word searches.	

Table 2

Baseline Scores and Key Background Characteristics for Caregivers and Stroke Survivors by Intervention (n=15) and Control (n=17) condition.

	Caregivers (CG)		Stroke Survivors (SS)	
	Intervention	Control	Intervention	Control
BACKGROUND CHARACTERISTICS				
Age M (SD)	55.3 (6.9)	54.9 (12.9)	59.9 (8.2)	59.1 (13.6)
PHQ Score N (%)				
0–4 Minimal	3 (20.0)	4 (23.5)	2 (13.3)	1 (5.9)
5–9 Mild	6 (40.0)	7 (41.2)	6 (40.0)	4 (23.5)
10–14 Moderate	2 (13.3)	4 (23.5)	2 (13.3)	8 (47.0)
15–19 Moderately Severe	3 (20.0)	1 (5.9)	5 (33.3)	2 (11.8)
20 Severe	1 (6.6)	1 (5.9)	0 (0)	2 (11.8)
Education N (%)				
High School or Less	6 (40.0)	4 (23.5)	9 (60.0)	9 (52.9)
High School or More	9 (60.0)	13 (76.5)	8 (40.0)	8 (47.1)
Employment N (%)				
Employed	3 (20.0)	8 (47.1)	1 (6.7)	2 (11.8)
Homemaker	1 (6.7)	0 (0)	0 (0)	0 (0)
Retired	3 (20.0)	6 (35.3)	8 (53.3)	9 (52.9)
Not Working	8 (53.3)	3 (17.6)	6 (40.0)	6 (35.3)
Family Income ^a				
20,000	4 (28.6)	3 (18.8)		
21,000 – 35,999	6 (42.8)	8 (50.0)		
36,000 – 50,999	0 (0)	3 (18.8)		
60,000	4 (28.6)	2 (12.5)		
First Stroke for SS N (%)			14 (93.3)	14 (82.4)
SS had Language/Cognitive Impairment N (%)			6 (35.3)	2 (13.3)
SS had Other Medical Problems N (%)			8 (61.5)	12 (75.0)
Other Negative Life Events: CG or SS N (%) ^b	11 (76.6)	7 (46.7)		
Mental Health Care Use: CG or SS N(%) ^b	6 (42.9)	3 (20.0)		
Psychotropic Medication Use: CG or SS N (%)	9 (64.3)	6 (40.0)		
BASE LINE SCORES on RCT OUTCOMES ^c				
Depression M (SD)	21.7 (13.2)	17.7 (11.7)	21.3 (12.9)	19.3 (13.4)
Mastery M (SD)	23.0 (3.3)	23.9 (4.0)	22.5 (3.2)	23.5 (4.1)
Self-Esteem M (SD)	28.8 (6.0)	32.6 (5.0)	27.8 (6.1)	28.8 (6.6)
Social Support M (SD)	35.9 (6.4)	31.9 (8.3)	39.1 (5.6)	40.9 (8.4)

^a there was one case of missing data for each condition;

^b There was missing data for 1 Intervention and 2 Control dyads;

^c There were no statistically significant mean differences by condition for either CGs or SSs

Table 3

Repeated Measures ANCOVAs for Treatment Outcomes by Experimental Condition

Outcomes ES ^b	Intent to Treat (n=32)						Per Protocol Only (n = 29)									
	T2			T3			T2					T3				
	Intervention (n=15)			Control (n=17)			Intervention (n=12)					Control (n=17)				
	X	SE		X	SE		X	SE		X	SE	X	SE		X	SE
CG only																
Depression .18	13.9	2.0		19.7	1.8	-.79	13.4	1.6	16.6	1.5	-.52	12.8	2.1	18.8	1.8	-.81
Mastery .03	24.2	0.7		23.6	0.6	.23	24.1	0.5	24.4	0.5	-.15	25.1	0.7	23.8	0.6	.53
Self Esteem .06	31.6	0.6		31.9	0.6	-.12	31.1	0.7	32.6	0.7	-.53	30.9	0.7	31.9	0.6	-.41
Social Support .01	37.0	1.7		37.0	1.6	.00	33.8	1.6	36.3	1.5	-.40	37.0	2.1	37.0	1.7	.00
SS only																
Depression .01	19.5	2.2		20.4	2.1	-.10	14.0	2.1	17.9	1.9	-.49	20.1	2.5	20.3	2.1	-.02
Mastery 01	21.6	1.2		22.8	1.2	-.25	24.6	1.1	24.4	1.1	.05	21.7	1.1	22.5	0.9	-.21
Self Esteem .01	26.7	1.0		27.7	0.9	-.26	28.5	1.2	27.2	1.2	.27	27.3	1.0	27.3	0.9	.00
Social Support .00	41.5	1.7		41.0	1.6	.08	43.2	1.2	44.0	1.2	-.17	41.1	2.0	40.8	1.7	.04

Note. Estimated marginal means adjusted for T1 scores are reported..

Univariate F-tests for between subjects effects are reported

*
p < .05;
**
p < .01; NS = not statistically significant
^aES = standardized effect size for mean difference between intervention and control condition
^bES = effect size for multivariate F-test reported as partial eta squared

NIH-PA Author Manuscript

NIH-PA Author Manuscript

APPENDIX A

Summary of Topics, Goals, and Homework Activities within the Intervention Condition

Weekly Topic	Goals	Homework
1 Intervention Overview	<ul style="list-style-type: none"> Describe intervention Introduce participants Explore intervention components 	<ul style="list-style-type: none"> Identify Pressing Problems Complete Needs and Concerns Checklist
2 Getting in Touch with Your Feelings as a Caregiver	<ul style="list-style-type: none"> View CG feelings as a normal reaction to stress Explain links between CG feelings and behaviors Differentiate positive and negative CG feelings Encourage self-exploration of own feelings 	<ul style="list-style-type: none"> Learn “feeling” vocabulary Identify and record daily emotions
3 Understanding What It’s Like to be a Care Receiver	<ul style="list-style-type: none"> Develop understanding of CR feelings Explore possible negative reactions to receiving help Differentiate instrumental and emotional support Explain why overprotective care can occur 	<ul style="list-style-type: none"> Review Do’s and Don’ts Read letter on overprotection written by a CG
4 Being a Good Listener	<ul style="list-style-type: none"> Learn basic attending and listening skills Understand the meaning and importance of empathy 	<ul style="list-style-type: none"> Practice listening skills
5 Non-Verbal Behavior	<ul style="list-style-type: none"> Recognize main categories of non-verbal behavior Develop awareness of own non-verbal behavior Develop awareness of CR non-verbal behavior 	<ul style="list-style-type: none"> Review attending skills handout Observe & record CR nonverbal behavior
6 Choice, Control, & Predictability	<ul style="list-style-type: none"> Recognize importance of personal control for CR Understand link between overprotection and control Discuss strategies for increasing CR personal control 	<ul style="list-style-type: none"> CR identifies strengths CG identifies strengths CG- CR jointly discuss their strengths
7 Relaxation and Positive Imagery to Control Stress	<ul style="list-style-type: none"> Experience a relaxation with positive imagery technique Understand links between relaxation, coping, & control Encourage CG and CR use of relaxation & positive-imagery 	<ul style="list-style-type: none"> CG and CR record mood before and after relaxation Consider other ways to relax
8 Pleasant Activities	<ul style="list-style-type: none"> Understand link between pleasant activity and mood Discover usefulness of Pleasant Activities List 	<ul style="list-style-type: none"> CG do activities CR do activities CR and CG attempt to do joint activities

Weekly Topic	Goals	Homework
9 Saying Goodbye	<ul style="list-style-type: none">Understand how stroke may derail pleasant activitiesProvide closure to interventionIdentify and reinforce treatment gains	<ul style="list-style-type: none">CG and CR log moodNone