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# Telephone Group Intervention for Older Stroke Caregivers

*Robert J. Hartke and Rosemarie B. King*

**Purpose:** This study evaluated the effectiveness of telephone groups for older, spousal caregivers of stroke survivors. **Method:** The 88 caregivers were mostly white females who were 70 years old on average and who had been providing care for an average of 3 years. Participants were randomized to treatment or control conditions, followed for 6 months, and assessed for depression, burden, loneliness, stress, and competence. Treatment participants engaged in an eight-session psychoeducational telephone group. **Results:** Treatment participants showed decreased stress over time but were not significantly different from control participants in the amount of change in stress. Control participants showed a significant increase in burden during the study; treatment participants showed a significant increase in competence. **Key words:** caregiver stress, depression, loneliness, stroke, telehealth, telephone

The stress of caregiving over time can result in emotional, physical, and social morbidities.<sup>1,2</sup> Increased mortality,<sup>3</sup> social isolation,<sup>4</sup> as well as a range of disruptive emotional states<sup>5,6</sup> have all been reported. Studies addressing the psychological consequences of caring for stroke survivors confirm significant levels of anxiety and depression in this population,<sup>7-11</sup> with rates of depression reported to be as high as 42%–52%, especially among spousal caregivers.<sup>10,12,13</sup>

Group interventions to alleviate caregiver stress have been viewed as clinically effective by their ability to provide respite; affiliation and emotional support; perspective on the universality of caregiver stress; and education about resources, coping strategies, and problem solving.<sup>14,15</sup> However, group interventions were most often praised anecdotally for their supportive effect and have shown disappointingly modest effect in moderating caregiver stress when submitted to empirical investigation.<sup>1,16-18</sup> Research on caregiver groups has been criticized for its lack of specificity. Studies have been complicated by sampling prob-

lems, poorly delineated treatment paradigms, and broad outcome measures that lacked a direct relationship to the focus of intervention.<sup>15-18</sup>

Research findings have suggested that elder spouses may be particularly vulnerable to caregiver stress. Spouses are the first choice in a predictable hierarchy of probable caregivers.<sup>6</sup> Pruchno and Potashnik<sup>19</sup> indicated that spouses provided the most extensive and comprehensive care, maintained the role of caregiver longer, and tolerated greater levels of disability. Their own advanced age and health problems make

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elder, spousal caregivers a high-risk group for morbidities due to the stress of providing care.

The stress of caregiving has been related to the nature of functional disability in the care receiver.<sup>20</sup> Physical care tasks present different challenges and have been considered less stressful than more unpredictable, poorly resolved cognitive and behavioral problems.<sup>6</sup> In the case of stroke, both physical and cognitive/behavioral disturbances may be intermingled, and this calls for a unique type of care. It also may take several months before deficits from a stroke are stabilized. MacNamara et al.<sup>8</sup> reported that anxiety may actually increase with time even in the case of "successful" stroke caregivers.

The increasing availability of telecommunications and information technology has provided a new route for provision of health care services. Telehealth provides alternative ways of delivering interventions when distance, cost, and inconvenience prohibit conventional face-to-face contact.<sup>21</sup> It has the potential to bring assistance to underserved groups, such as the homebound. Many caregivers are reluctant or unable to leave their disabled family member to travel distances and participate in face-to-face groups. Group treatment through telephone conference call is now feasible for delivery of support to caregivers. Liss et al.<sup>21</sup> reviewed the application of telehealth to persons with chronic disabilities and found preliminary evidence supporting its effectiveness, but they noted a particular need for evaluation of telephone-based counseling. Galinsky et al.<sup>22</sup> specifically reviewed literature on technology-based groups and surveyed practitioners on their knowledge, experience, and comfort level in this area. They cited

advantages to this format of accessibility, convenience and anonymity, and disadvantages of decreased interpersonal cues, technological problems, and limitations to group process, such as trust and cohesion. Galinsky et al.<sup>22</sup> recommended preliminary guidelines for conducting phone-based groups, such as use of co-facilitators who are more active in guiding group process. Limited research using this intervention paradigm has been conducted by Evans and his associates.<sup>23-28</sup> These studies have demonstrated the effectiveness of the intervention with older, blind, and otherwise severely disabled persons and have shown changes in loneliness, social involvement, and life satisfaction among other measures. Published studies of group interventions for caregivers provided by telephone conference call have just begun to appear in the literature. Brown et al.<sup>29</sup> compared the effectiveness of support groups delivered in person and by telephone for family caregivers of brain-injured adults, including stroke. Participants participated in 9 to 10 semi-structured group sessions either in person or on the phone, with group assignment depending upon the caregivers' distance from the sponsoring hospital. Rural caregivers were assigned to the telephone groups. Outcome measures were family functioning, burden, and mood disturbance. There were similar amounts of improvement found for both types of groups; participants showed significant reduction in mood disturbance regardless of mode of intervention. The study was complicated by group bias; rural caregivers (assigned to the telephone intervention) were less distressed across all assessment periods. Although both types of interventions were rated highly, the telephone

group participants were somewhat more satisfied with their experience. The investigators concluded that nothing essential was lost in conducting caregiver groups on the telephone when compared to traditional face-to-face participation.

The mechanism of change in caregiver stress intervention is often guided by a stress and coping model. Gatz et al.<sup>6</sup> provided a summary model of caregiving stress with the following critical features: onset of a disabling event prompting care as the *stressor*; *appraisal* of the experience of caring; the *mediators* or coping skills brought to bear; and the *outcome* of successful caring or abandonment of the role. According to this model, an intervention on the caregiver's appraisal of self and situation, as well as on mediators such as care skills, knowledge of disability, and outside supports, can positively influence coping and subjective distress.

Failure to demonstrate effectiveness of interventions in caregiver stress research has been attributed to problems in outcome measurement. One means of focusing measurement has been to combine more established global measures with those that are more specific to the caregiving situation. Zarit<sup>30</sup> recommended a multidimensional, multivariate, multimethod approach wherever possible. Evans et al.<sup>23,26,27</sup> and Jauregui and Evans<sup>28</sup> have consistently shown that group telephone treatment decreases loneliness. Depression is widely recognized as a specific morbidity in caregivers in need of treatment.<sup>1,6,10</sup> The high prevalence of depression among caregivers makes it a logical target of intervention. Depression among spousal stroke caregivers has been documented to be significantly higher than in the general older adult population.<sup>9,31</sup> Sense of competence or self-efficacy<sup>32,33</sup> has

been identified as a factor that mediates coping. Caregiver competence can buffer the experience of stress and has been shown to relate to depression.<sup>34,35</sup> The assessment of the stressfulness of individually identified problems of providing care has value as a monitor of the unique accumulation of stress in the caregiving situation.<sup>36</sup> Finally, reduction in sense of burden has been associated with successful caregiver stress interventions.<sup>6</sup> Higher subjective burden has affected caregiver decision making, such as nursing home placement.<sup>37</sup>

The present study attempted to further explore the feasibility and effectiveness of a structured caregiver intervention delivered by teleconference. The study addressed past criticism of poor specificity in caregiving research by targeting older, spousal, stroke carers with a focused intervention and outcome measurements. The intervention was tailored to the stress of providing care to a stroke survivor and concentrated on caregiver appraisals and mediating factors of skills and resources according to a stress and coping model. Specific outcomes of depression, burden, loneliness, stress, and competence were assessed for change. The following specific hypotheses were tested:

1. Participants in the treatment group will show significant improvement in depression, loneliness, burden, competence, and stress between entrance into the study and completion of the intervention and will maintain gains at 6-month follow-up ( $p < .05$ ).
2. Participants in the treatment group will show significant improvement in depression, loneliness, burden, competence, and stress in comparison to the control group at 6-month follow-up ( $p < .05$ ).

## Method

The current study utilized a randomized, treatment/control design to test the efficacy of a caregiver stress intervention. The intervention was designed according to a stress and coping model and was refined by input of a focus group of stroke caregivers. The newly designed intervention was compared to usual support provided to spousal, stroke caregivers.

## Sample

Participants were spouses of stroke survivors who received acute rehabilitation at a free-standing rehabilitation center or at a rehabilitation unit of a major suburban medical center. Participants were recruited from review of their spouses' admission records; various print, radio, and television media advertisements and news features; and targeted community outreach. Criteria for inclusion in the study were (a) 60 years of age or older, (b) married or spousal equivalent and living with the stroke survivor, (c) primary caregiver for a minimum of 1 month, (d) not currently in a caregiver support group, and (e) a telephone in the home and sufficient hearing to participate in telephone conference calls and individual assessment interviews. A primary caregiver was defined as someone who was providing emotional support in addition to participating in care in at least one of the following three areas: personal care, instrumental activities of daily living, decision making or informal case management. It was felt that participants had to be in their role as primary caregiver for a minimum of 1 month in order to benefit from the intervention.

Over 500 people were solicited for participation. Of the 124 participants who were successfully recruited, 36 dropped out during the course of the study, resulting in a 29% dropout rate. Significantly more treatment participants ( $n = 25$ ) dropped out of the study than controls ( $n = 11$ ) ( $\chi^2 = 4.37$ ,  $p < .05$ ). The most frequent reason for dropping out of the control group was difficulty scheduling follow-up evaluations, whereas the most frequent reasons for dropping out of the treatment group were death of spouse or perception of a lack of need for the intervention. A total of 88 persons participated in the study to conclusion and were assessed at all time periods, with 43 cases in the treatment condition and 45 in the control condition. **Table 1** provides a description of the sample on relevant demographic factors. Treatment group participants had spouses who were more significantly impaired on the FIM<sup>TM</sup>\* motor scale, and the caregivers in this condition also significantly more often reported receiving help with their spouses' care.

## Measures

**Table 2** lists the means, medians, and standard deviations by group and time for the study outcome measures.

## Depression

The Center for Epidemiologic Studies–Depression Scale (CES-D) was a 20-item self-report scale<sup>38</sup> that measured the presence and severity of depressive symptomatology during the preceding week on a 3-point scale ranging from 0 for *rarely* to 3 for *all the time*.

\*FIM<sup>TM</sup> is a trademark of the Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, Inc.

**Table 1.** Sample characteristics

	Treatment ( <i>n</i> = 43)		Control ( <i>n</i> = 45)		Total sample ( <i>N</i> = 88)	
	Mean	( <i>SD</i> )	Mean	( <i>SD</i> )	Mean	( <i>SD</i> )
Age	69.74	(5.39)	69.69	(6.59)	69.72	(6.00)
Years caregiving	3.18	(4.91)	2.73	(2.77)	2.95	(3.95)
Years of education	13.77	(2.39)	14.11	(2.97)	13.94	(2.69)
Years married to current spouse	43.37	(9.88)	42.13	(12.38)	42.74	(11.18)
FIM <sup>TM</sup> scores of spouse						
Motor <sup>a</sup>	58.98	(21.56)	69.42	(17.60)	64.32	(20.22)
Cognition	27.23	(5.72)	28.20	(5.66)	27.73	(5.68)
	<i>n</i> (%)		<i>n</i> (%)		<i>n</i> (%)	
Gender						
Male	11	(26%)	10	(22%)	21	(24%)
Female	32	(74%)	35	(78%)	67	(76%)
Race						
White	34	(79%)	37	(82%)	71	(81%)
African American	7	(16%)	6	(13%)	13	(15%)
Other	2	(5%)	2	(5%)	4	(4%)
Receiving help with care <sup>b</sup>	34	(79%)	26	(58%)	60	(68%)
Source of help						
Family	15	(44%)	10	(38%)	25	(42%)
Other	19	(56%)	16	(62%)	35	(58%)

<sup>a</sup>*t* = -2.48, *p* < .05. <sup>b</sup> $\chi^2$  = 4.60, *p* < .05.

Scores ranged from 0–60, with higher scores representing greater symptom severity and a score of 16 being the usual cutoff to denote depression. The scale has been shown to be internally consistent with coefficients as high as .85 to .90<sup>38</sup> and .86 to .88 in a longitudinal study of stroke caregivers.<sup>39</sup> The scale has been shown to be a valid screening measure for depression in community samples,<sup>40</sup> medical patients (e.g., stroke patients<sup>41</sup>), and caregivers.<sup>9,19,42,43</sup> Internal consistency coefficients for the current study were .85 (Time 1) and .87 (Time 2).

### Loneliness

The UCLA Loneliness Scale was originally developed by Russell et al.<sup>44</sup> as a 20-item self-report scale and was revised by Russell et al.<sup>45</sup> to a 10-item version focused on the

psychological experience of loneliness. Respondents rated frequency of occurrence of symptoms of loneliness on a 4-point scale ranging from 1 for *never* to 4 for *often*, with higher scores reflecting greater loneliness. Russell et al.<sup>45</sup> reported the internal consistency of the revised measure to be high ( $\alpha$  = .94) for the longer version and also demonstrated a significant relationship between the scale and a self-labeling loneliness index and other social behaviors. Knight et al.<sup>46</sup> renormed the scale on a general adult population and reported internal consistency to be .83 to .86 for the short version with mean scores ranging from 17.4 to 17.9. The scale has been successfully utilized in the assessment of spousal caregivers.<sup>47</sup> Internal consistency coefficients for the current study were .80 (Time 1) and .79 (Time 2).

**Table 2.** Means, medians, and standard deviations for outcome measures by time and group

Measure	Time 1		Time 2			Time 3			
	Mean	(SD)	Mean	(SD)	Mean	(SD)			
Burden Interview <sup>a,*</sup>									
Treatment	31.58	13.78	30.77	13.29	31.04	15.39			
Control	25.11	10.84			29.78	12.09			
CES-Depression <sup>a,*</sup>									
Treatment	13.93	9.71	13.19	9.63	14.16	10.28			
Control	9.49	6.72			10.09	7.55			
UCLA-Loneliness <sup>a,*</sup>									
Treatment	19.15	6.54	18.21	5.74	18.44	5.74			
Control	16.36	4.22			16.67	4.71			
Pressing Problem Index <sup>a,*</sup>									
Treatment	6.18	1.55	5.48	1.64	5.39	1.52			
Control	5.52	1.32			5.12	1.50			
	Mean	(SD)	Median	Mean	(SD)	Median	Mean	(SD)	Median
Caregiver Competence <sup>b,**</sup>									
Treatment	13.74	2.02	14.00	14.35	2.23	15.00	14.07	2.16	15.00
Control	14.87	1.42	15.00				14.69	1.62	15.00

<sup>a</sup>t test. <sup>b</sup>Mann-Whitney U.\* $p < .05$  at Time 1; for depression also at Time 3. \*\* $p < .01$  at Time 1.

### Competence

The Caregiver Competence Scale was developed by Pearlin et al.<sup>32</sup> to measure the construct of competence in a stress and coping model of caregiving. It was a 4-item, 4-point self-rating scale ranging from 1 for *not at all* to 4 for *very much* in which the participants were asked to rate their sense of competence and confidence in their role as a caregiver. Total scores ranged from 4 to 16 with higher scores denoting greater competence. Pearlin et al.<sup>32</sup> indicated adequate internal consistency ( $\alpha = .74$ ). Internal consistency coefficients for the current study were .78 (Time 1) and .81 (Time 2).

### Burden

The Burden Interview (BI)<sup>48</sup> was a 22-item scale in which caregivers were asked

about feelings of stress, guilt, and resentment in their caring role. Responses were ratings of frequency on a 4-point scale ranging from 0 for *never* to 4 for *nearly always*. Item ratings were summed to achieve a total score that ranged from 0 to 88, with higher scores indicating a greater sense of burden. Evidence for concurrent validity<sup>48</sup> and internal consistency alphas ranging from .88 to .91<sup>49</sup> have been reported. Confirmatory factor analysis indicated the BI was comprised of two scales, personal strain and role strain.<sup>50</sup> Internal consistency coefficients for the current study were .85 (Time 1) and .88 (Time 2).

### Stress

The Pressing Problem Index (PPI)<sup>36</sup> was obtained from a semi-structured interview in which participants were



asked to appraise their caregiving situation by identifying current problems in providing care and assessing their severity. For each problem enumerated, the participant rated how stressful the problem is and how effectively the problem is managed. The scales were numbered from 1 to 5 (1 = *not stressful and effective*; 5 = *very stressful and effective*). A total index was derived by computing a composite score for each problem (the sum of the stress rating and the reverse scored effectiveness rating) and dividing by the total number of problems. A higher score indicated greater stress and less effective management. Toseland et al.<sup>36</sup> reported a significant decrease in the PPI among caregivers in peer and professionally led support groups compared with a respite-only group.

### ***Functional level***

The FIM™ was used to assess the functional status of the care receiver. Function was rated for 18 items on a 7-point response set from *maximum dependence* (1) to *independent without assistance* (7). Thirteen items and five items comprised motor and cognitive scales, respectively. The cognitive scale included language, social interaction, problem solving, and memory ratings. Higher scores indicated greater functional independence. Scores ranged from 18 to 125 for the total FIM. Intraclass correlations for scales have ranged from .89 (cognitive) to .94 (motor).<sup>51</sup> The scale has been shown to demonstrate adequate intra-rater reliability.<sup>52</sup> Internal consistency coefficients for the current study were .95 (motor) and .68 (cognitive).

### ***Demographic and caregiving information***

All participants were administered a questionnaire about basic demographic information and details of their caregiving situation, including amount of additional help received, therapies provided to spouse, and prior experience with support groups.

### ***Treatment evaluation***

All participants in the experimental condition responded to questions to evaluate the treatment subjectively, including assessment of specific features of the group, what they liked most and least, and what they would change. At the final 6-month follow-up, participants in the experimental condition were asked about subsequent use of written materials and frequency and nature of ongoing contact with other support group members. Control participants were asked about their use and evaluation of the reading materials that were provided to them.

### ***Procedure***

Recruitment was carried out over a 4-year period. Participants reviewed and signed an Institutional Review Board–approved consent form when agreeing to join the study. They were assessed with measures of depression, loneliness, competence, burden, and stress (PPI). Questionnaires were administered to gather demographic and caregiving facts. Participants were then randomly assigned to a usual care or the telephone support group intervention condition and were followed for 6 months to test the enduring effects of the intervention. Participants in the experimental condition were assessed when entering the study

(Time 1), immediately after support group participation (Time 2), and 6 months after entering the study (Time 3). Participants in the usual care condition were assessed when entering the study (Time 1) and after 6 months (Time 3) only. At Time 2, participants in the experimental condition also gave subjective feedback about their experience in the group; at Time 3, they were asked about further contact with group members and use of reading materials provided to them. At Time 3, participants in the usual care condition were asked about any counseling sought during the interim period and their use of reading materials provided to them. All assessments were conducted by members of the research staff via individual telephone interviews.

The telephone support group met for eight 1-hour sessions and followed a structured, psychoeducational format. A group manual that outlined the eight topics of discussion was mailed to each participant. These included:

- a session to introduce participants to one another and the group philosophy,
- facts about stroke and caregiving,
- communicating with your spouse,
- dealing with your spouse's problematic feelings and behavior,
- your stress as a caregiver,
- taking care of yourself as a caregiver,
- resources for you in the community as a caregiver, and
- a concluding session for review, future goal-setting, and termination.

The manual included an audiotape of a relaxation procedure and a publication on stress management. Each participant was given a list of the stressful problems in caregiving that they had identified during the initial assessment. Sixteen groups were

conducted through the course of the study, with the size of each group varying from three to six members. Most groups had two group facilitators who were clinicians in the areas of psychology, social work, or nursing. The original protocol called for in-person luncheons for the first and last meetings of each group. However, these in-person meetings became too difficult to schedule. Consequently, almost all groups were conducted exclusively by telephone conference call initiated by the group facilitators over a period of approximately 8 weeks.

Guidelines were developed and communicated to the participants during the introduction of each group in order to address the special features of telephone conference calls and to emphasize the peer support component of the intervention. Confidentiality was stressed by asking participants to keep private the personal reactions of others in the group. When possible, participants were asked to disable the call waiting feature on their phone to reduce intrusions. They were also encouraged to find a private space in their home during the sessions (away from the care receiver) so that they could speak freely. The need for consistent attendance was emphasized because the presence of each participant was valued for his or her contributions in the sessions. Participants were asked to identify themselves when they spoke during the initial sessions until voice recognition could be established. Pictures of the group facilitators were included in the treatment manual. Finally, to augment the supportive nature of the intervention, participants were encouraged to have contacts with one another outside of the group meetings; with the group's permission, a list of their names, addresses, and phone numbers



was mailed to each of them.

Participants in the control condition received the same stress management publication included in the treatment manual as well as a brief written description of caregiver stress and stroke. All participants in both conditions were given small mementos (e.g., specially designed mugs and cards) of their participation in the study to help them positively identify with their role as caregiver and express gratitude for their time and effort.

## Analysis

### *Objective evaluations*

Descriptive statistics and frequencies were calculated for important sample characteristics, and groups were tested for equivalence using independent *t* and chi-square tests as appropriate. The treatment and control groups were tested at Time 1 for equivalence on the dependent variables using independent *t* tests for depression, burden, loneliness, and stress. A Mann-Whitney U statistic was used to test for equivalence for competence as this measure did not meet the assumption of normal distribution.

*Hypothesis 1.* Within-group comparisons for the treatment condition were tested with repeated-measures analyses of variance (ANOVAs) over the three time intervals separately for depression, burden, loneliness, and stress (as measured by the PPI). The competence scores were not normally distributed, thus a Friedman's ANOVA was performed to test differences in this variable within the treatment group over time.

*Hypothesis 2.* Despite randomization, the treatment and control groups were not equivalent on the outcome measures at

Time 1 (see **Table 2**). Therefore, difference scores were calculated on the five dependent variables between Time 1 and Time 3. Between-group comparisons were performed using the difference scores with independent *t* tests for depression, burden, loneliness, and stress. Because the competence change scores were not normally distributed, a Mann-Whitney U statistic was used to test group difference on this dependent variable. A repeated-measures ANOVA was also performed on the stress measure for all participants having both Time 1 and Time 3 completed assessments with group as the independent variable.

### *Subjective evaluations*

Frequencies were tabulated for specific questions, and content analysis was completed for open-ended questions.

## Results

### *Objective evaluation*

As shown in **Table 1**, the majority of the sample was white and female with an average age of nearly 70 years and more than a high-school education. The participants were mostly in longstanding marriages with the stroke survivor and, on average, had been providing care for nearly 3 years. However, 25% of the sample had been in the caregiver role for less than 6 months. The majority were receiving some help from outside of the family. The participants were caring for spouses who needed minimal assistance to supervision overall. The treatment and control groups were equivalent on most of these characteristics, except that the caregivers in the treatment group

**Table 3.** Treatment group means on outcome variables by time ( $N = 43$ )

Variable	Time			Statistic
	T1	T2	T3	F ratio
Depression	13.93	13.19	14.16	.30
Burden	31.58	30.77	31.04	.15
Loneliness	19.12	18.21	18.44	.92
Stress	6.08	5.44	5.40	5.34** <sup>a</sup>
Competence	13.74	14.35	14.07	4.92 <sup>b</sup>

<sup>a</sup> $n = 38$ . <sup>b</sup>Friedman's ANOVA with chi-square statistic.

\*\* $p < .01$ .

had spouses who were more motorically impaired, and they were more frequently receiving assistance in providing care.

Despite random assignment, the treatment group was more distressed overall at the Time 1 assessment with significantly higher levels of depression, burden, loneliness, and stress and lower sense of competence (see **Table 2**). **Table 3** shows the within-group change over time for the treatment group (Hypothesis 1). There were no significant changes in depression, burden, loneliness, or competence from entry into the study (Time 1) to the 6-month follow-up (Time 3). However, there was a significant reduction in stress, as measured by the PPI, over time [ $F(2, 74) = 5.34, p < .01$ ]. Post hoc analysis showed the change to be significant from Time 1 to Time 2 [ $t(37) = 2.71, p < .01$ ] and from Time 1 to Time 3 [ $t(37) = 2.68, p < .05$ ]. Between-group comparisons were made on the basis of change scores, given the lack of group equivalence at Time 1. As shown in **Table 4**, there were no significant differences in the degree of change between treatment and control groups for depression, loneliness, or stress. The group differences in change scores were significant for burden and competence [ $t(86) = -2.40, p < .05$ , for burden;  $U = -2.15$ ,

$p < .05$ , for competence]. Compared to the treatment group, the control participants showed significantly greater change in burden between Time 1 and Time 3. The treatment participants showed a significant gain in their sense of competence from Time 1 to Time 3. For the repeated-measures ANOVA comparing the two groups on stress over time, there was a significant effect overall for time [ $F(1, 80) = 12.47, p < .01$ ] but no significant interaction between group and time.

#### Subjective support group evaluation and 6-month follow-up

Results of specific questions are summarized in **Table 5**. In general, participants expressed a high level of satisfaction with various aspects of the group and, similarly, felt that most of the characteristics of the group identified in **Table 5** were important. Only 20% of the participants indicated a willingness to meet in person. When questioned about contact with one another outside of the group, 27% indicated that they had spoken with at least one other group member one or more times while the support group was in process; at 6-month follow-up, 35% had spoken with another

**Table 4.** Change score (T1-T3) comparison between treatment and control groups

Variable	Mean change		<i>t</i> statistic
	Treatment	Control	
Depression	.23	.60	-.22
Burden	-.54	4.17	-2.40*
Loneliness	-.67	.31	-1.04
Stress	-.74	-.40	-1.10
Competence	.33	-.18	-2.15* <sup>a</sup>

<sup>a</sup>Mann-Whitney U; *z* score shown.

\**p* < .05.

**Table 5.** Summary of subjective evaluation of telephone support group (*N* = 41)

Item	%
1. Satisfaction with...	<u>good-excellent</u>
number of sessions	83%
length of each session (1 hr.)	76%
relevance of topics discussed	93%
telephone vs. in-person meetings	85%
facilitator helpfulness	98%
overall experience	93%
2. Importance of...	<u>important-very important</u>
group discussion	90%
convenience of phone meetings	85%
group manual	90%
relaxation tape <sup>a</sup>	40%
contact with other caregivers	88%
group leader knowledge	98%
3. Would have participated in person?	20%
4. One or more contacts with group participants outside of the group sessions	
during group meetings	27%
at 6-month follow up <sup>b</sup>	35%
5. Had used written materials one or more times	
at 6-month follow-up <sup>c</sup>	68%

<sup>a</sup>*n* = 35. <sup>b</sup>*n* = 43. <sup>c</sup>*n* = 28.

group member. The majority of these con-

tacts (81%–82%) were by telephone. Finally, when questioned at the 6-month follow-up, 68% of the participants had referred to the treatment manual and associated materials at least once.

Treatment condition participants were questioned about their barriers to in-person attendance. The vast majority of their comments focused on their inability to obtain coverage for their spouses' care needs in their absence and their inability or unwillingness to travel a distance for in-person meetings. When questioned about what they liked most about the group experience, the participants most frequently identified various interpersonal benefits, especially peer contact. They appreciated the honest, empathic communication that allowed for emotional ventilation, comparison with one another, and the experience of the commonality of caregiver problems. Relating to other participants often brought a downward comparison in which they experienced someone else as having a more difficult situation. Secondly, participants liked the content of the intervention, especially the written materials provided, resources mentioned during sessions, solutions to specific care problems, and the expertise of the group facilitators.

The most frequent criticisms of the group

focused on technical problems associated with phone use, such as not being able to hear all of the participants, as well as the loss of intimacy due to the absence of in-person contact. Other most frequent criticisms centered on the intervention as a whole or individual session time being too short and specific complaints about a disruptive group member. When asked what they would like to see changed about the intervention, participants indicated a desire to meet in-person while simultaneously acknowledging the difficulties for them in doing so. Of equal frequency, participants commented that they would have liked the intervention to have been extended, either by having more meetings or longer sessions.

At 6-month follow-up, 98% of the participants in the control condition ( $n = 43$ ) had reviewed the reading material sent to them and 85% ( $n = 39$ ) rated it as good to excellent. However, when asked about how useful the information was to them, only 36% ( $n = 36$ ) could mention at least one coping strategy drawn from the reading, while 64% had minimal or nonspecific comments. Only 19% ( $n = 32$ ) had any comments about how the information could have been made more useful to them.

## Discussion

The current study provides limited evidence of the effectiveness of the telephone conference group format as a means of intervention for caregivers. The study hypotheses were partially supported. The treatment group showed a decrease in stress related to their caregiving problems. However, when compared to the control group over time, the magnitude of the change was not significantly different. While the treatment group

remained largely unchanged in the experience of burden, burden significantly increased in the control group over time. Treatment participants also showed significant gain in caregiver competence in comparison to control participants who remained relatively unchanged throughout the study on this outcome variable. The groups were positively rated by the participants in most ways, and the study demonstrated the feasibility of conducting this type of structured group treatment entirely over the phone.

The PPI was the most targeted outcome measure in the study. The items assessed came directly from the spouses' caregiving experiences, and the participants in the treatment condition were given their personal list of problems to which they could refer during the group sessions. This level of specificity could have made the stress measure more sensitive to change. Because of the open-ended discussion involved in the measurement, however, the process of identifying and rating the problems may have been therapeutic in itself. Thus, the control participants may have experienced a beneficial effect from the initial administration of the measure and subsequent rating of the same problems. The pattern of change in burden between the treatment and control groups suggests that the intervention may have prevented rather than reduced the accumulation of strain over time. Only the control participants increased in burden scores over the study, while the treatment participants remained relatively stable. The emotional outlet and comparison with others provided by the group may have helped achieve this effect. In their open-ended comments, participants noted that they felt free to express themselves and spoke "from the heart" and that

others often had worse problems. The increase in the sense of competence in the caregiving role among treatment participants may have also been a result of the content and process of the intervention. Participants in the groups were able to share their knowledge and strategies with one another and obtain affirmation of their contribution to their spouses' recovery. Participants noted that they learned from each other, were allowed to contribute to the group, and felt they were among equals.

The lack of significant change in depression and loneliness among the treatment participants and between the two study conditions may be due to the lack of consistent, specific focus on these issues in the intervention. It was surprising, however, that the treatment participants did not show a significant decline in loneliness given the results of prior studies with telephone group support for the homebound.<sup>23,27</sup> Further, lack of social involvement was one of the most frequently mentioned types of problems on the PPI.<sup>4</sup> It is possible that the time-limited phone contact may have been insufficient to substantially reverse the participants' sense of isolation. Even though the group members were encouraged to have informal contact with one another outside of group meetings, only a minority did so. Also, the disruption of the marital relationship due to the stroke with the resulting loss of personal and social companionship may have been too large a void to be adequately filled through this type of peer contact.

### **Evaluation by group participants**

Similar to the findings of Brown et al.,<sup>29</sup> the subjective comments of the treatment

group participants generally reflect a high rate of satisfaction with the telephone format and endorsement of the importance of the program. Within the context of this broad approval rating, the participants frequently stated a desire for an extended intervention and were ambivalent about meeting over the telephone. They complained of difficulty hearing others and wished they could have met in person, although 80% stated they could not do so. The fact that the study was conducted in a large metropolitan area could have contributed to this ambivalence. Participants were generally not as widely dispersed as might be the case in a rural setting. In-person contact was generally possible but was not very convenient. In the participants' open-ended comments, the interpersonal aspects of the group were most frequently cited as beneficial and the content of the intervention was less frequently mentioned. However, while only a minority of group participants had additional contact with one another, a majority continued to refer to the treatment manual. These contradictory reactions may reflect the limits of the structure and length of the group. A psychoeducational, time-limited, group format over the telephone may not move beyond initial positive group cohesion to a more emotionally intimate experience.<sup>22</sup> Similarly, the time limit may preclude sufficient integration of the information to achieve an enduring impact on coping. Notably, none of the participants commented on the advantage of anonymity provided by only telephone contact.<sup>22</sup> It may be that caregivers (generally not a stigmatized group) do not wish for anonymity but appreciate being known, especially by others in a similar situation.

Limited comments from the control group suggest that they reviewed and appreciated the written information sent to them, but without ongoing contact, they may not have integrated the content into their role as caregiver in a useful way.

### **Clinical implications**

The study results indicate both the feasibility and limitations of applying this format to caregivers in the clinical setting. The appeal of teleconference intervention lies in the convenience it can offer caregivers who may feel too constrained by time and distance to engage in face-to-face contact. However, the current study suggests limits to the impact one can achieve when using this form of intervention exclusively. Combinations of in-person and telephone sessions to foster relationship building and to reinforce effects over time may be a reasonable, more powerful alternative. Continuing technological advances that include visual input (such as video conferencing) will add other options to combine with traditional in-person gatherings. In the telephone group format, it appears that structured sessions and associated written material and use of group leaders comfortable with the format all contribute to a successful subjective experience for the participants.

Further, some of the caregivers in this study had been in their role for many years and had also provided care to their parents in the past. As caregivers, their coping patterns had stabilized and they were difficult to modify. This observation suggests that early intervention when caregivers are establishing their role behavior may have a greater impact

### **Study limitations and future research needs**

There are several limitations that should be considered in interpreting the results of this study. The sample of caregivers had spouses who, on average, were not experiencing severe impairments from their stroke and the majority were receiving additional, outside assistance. In addition, caregivers were not selected on the basis of their level of distress. These characteristics may have diminished the impact of certain aspects of the intervention. Sampling was also restricted to older spouses who have been found to benefit less from interventions than adult children.<sup>17</sup> The intervention design and choice of assessments may have been too general despite efforts at increasing specificity. The treatment program was ambitious in its scope considering the limited number of sessions. As confirmation of the latter limitation, the group participants expressed a desire for more contact in their evaluative comments. A more exclusive focus (such as coaching of a particular skill or management of mood) may have been a more realistic approach for a successful impact in a short time frame. Finally, the attention and materials provided to the control group may have been sufficient to lessen the difference between the two conditions and the resulting outcomes.

Future research will be important in further developing this form of intervention to address the needs of stroke caregivers. Evaluation of combinations of formats and greater specification in both interventions and assessment are necessary. Innovative approaches to respite care are needed to free caregivers to obtain help for themselves. The identification of characteristics that differentiate those caregivers who might be more



receptive to teleconference versus in-person contact would also be useful to encourage caregivers to access help. For example, the stressed caregiver who is reluctant to accept help might be persuaded to join a telephone group because of its convenience and anonymity. After having a positive experience in this format, they might be encouraged to access in-person support. Finally, the problems of the study illustrate the ongoing need to refine design and measurement in caregiver stress research in order to determine how to best assist and sustain the growing number of family caregivers who are an

essential, but fragile and often neglected, component of long-term care after stroke.

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