The Evaluation of a Telephone Caregiver Support Group Intervention[1]

Tamara L. Smith[2] and Ronald W. Toseland[3]

University at Albany, State University of New York

[1] This project was supported in part by a grant to the Senior Services of Albany, Inc. and the Institute of Gerontology, University at Albany, number 90-CG-2549, from the Administration on Aging, Department of Health and Human Services, Washington D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.

[2]Tamara L. Smith is a Ph.D. candidate, Department of Sociology, and Research Associate, 347 Draper Hall, 135 Western Avenue, Institute of Gerontology, University at Albany, State University of New York, Albany, NY 12222, tsmith@albany.edu.

[3]Ronald W. Toseland, Ph.D., is Professor and Director, Institute of Gerontology, School of Social Welfare, University at Albany, State University of New York.

Introduction

The needs of family caregivers of elderly persons have received increased attention in recent years. The majority of older persons needing assistance live either alone or with spouses or other family members, relying on their support. One method for supporting the needs of vulnerable caregivers is through telephone support groups. In recent years, technological advances have made it possible to facilitate support groups via the telephone, reaching out to caregivers who cannot attend face-to-face groups. This article focuses on the implementation and effectiveness of a telephone support group (TSG) intervention for spousal and child caregivers of frail elderly family members.

Although telephone groups have not been widely used or evaluated, reviews of the existing literature are very positive about their effectiveness (Schopler, Galinsky, & Abell, 1997; Schopler, Galinsky, & Abell, 1998; Colon, 1996; Toseland & Rivas, 2005). A comprehensive review of the literature for this article revealed 19 studies focused on the use of telephone support groups for people with many types of disability ranging from those with AIDS to those with visual impairments. Although there were few rigorously controlled studies, the results and conclusions of these studies indicated that telephone support groups are helpful for caregivers. Advantages of telephone support groups over traditional face-to-face support group models have been widely acknowledged.

Telephone support groups give to hard-to-reach caregivers. Telephone support provides a network for caregivers who are rural, those who are homebound because of their spouses' needs, those who cannot afford the transportation to attend face-to-face meetings, and those caregivers who are uncomfortable with in-person interaction (Galinsky, Schopler, & Abell 1997; Glueckauf & Loomis, 2003; Martindale-Adams,

Nichols, Burns & Malone, 2002; Rosswurm, Larrabee & Zangh, 2002). Telephone support allows caregivers from disperse geographical locations to interact (Kaslyn, 1999). These caregivers find telephone support groups more accessible and more convenient to attend than face-to-face groups because they do not have to leave their homes to attend.

The format of the telephone support group makes this mode of support more feasible for persons uncomfortable with the disclosure and interaction necessary within face-to-face groups. Telephone groups reduce stigma, increase confidentiality, and produce greater levels of self-disclosure, familiarity, and solidity than face-to-face groups. Because members' identities can be masked and because differences that are not salient to the group are less likely to interfere with interaction, members are more likely to share issues that are taboo in face-to-face groups (McKenna & Green, 2002; Galinsky, Schopler, & Abell, 1997; or Smokowski, Galinsky, & Harlow, 2001).

The third advantage to telephone groups is the ease of assembling such a group. Since the commitment to spend time on a telephone call is less intrusive than the time that it take to travel to and attend a group meeting, scheduling the group and finding members to participate is easier. Facility and transportation costs are eliminated with the telephone support group model.

Notwithstanding the advantages of telephone groups, there are limitations to these groups which make modifications necessary. Because group members cannot see each other, the leader must be sure that everyone can identify each speaker. The lack of visual cues can also change the group dynamics, necessitating the group leader to take an active role to ensure group cohesion (Lester, 1995; Martindale-Adams, et al., 2002; Nokes, Chew & Altman, 2003). Telephone conversations may be difficult for some

caregivers and attention must be paid to this when planning the duration of the group. Caregivers may have hearing difficulties, and may become fatigued from talking on the telephone for long periods of time (Stein, Rothman & Nakanishi, 1993; Weiner, Spencer, Davidson & Fair, 1993). Telephone support groups need to meet for a shorter duration than face-to-face groups. Other considerations for conducting telephone groups include the risks of being disconnected during the group session, the costs associated with telephone teleconferencing, and the lack of third-party reimbursement (Nokes, Chew & Altman, 2003; McCarty & Clancy, 2002; Rounds, Galinsky & Stevens, 1991).

Even in the face of these limitations, this mode of support can be an invaluable tool for helping caregivers, and may be especially helpful for meeting the needs of vulnerable, hard to reach populations. Because the issues for adult children and spouse caregivers are somewhat distinct, this study stratified for relationship to care recipient, so that each telephone support group was composed of either adult children or spouses, rather than a combination of both. This also ensured that uncomfortable intergenerational family issues and pressing problems caregivers felt were not misinterpreted within the groups. Stratifying encouraged the development of mutual support and camaraderie among the members of the telephone groups, and allowed the group leaders to address caregiver issues in a more focused manner.

The TSG model is an adaptation of a face-to-face support group model that has been evaluated in a number of studies in the past decade (see, for example, Toseland, McCallion, Smith, Huck, Bourgeois, and Gartska 2001). This article advances the existing literature supporting telephone groups by providing a rigorous experimental design to assess the effectiveness of the TSG model. This model is tested separately for

both spouses and children. It is the first article that takes into consideration the varying effectiveness of telephone support for these two groups of family caregivers.

Methods

Hypotheses

It was hypothesized that, compared to caregivers receiving usual services (US), both types of caregivers in the TSG would experience short-term improvements in (a) social support, (b) pressing problems, (c) burden, (d) depression, (e) anxiety, and (f) knowledge and use of community services.

Participants

Participants were recruited from a sixteen-county area that included urban, suburban and rural areas. Recruitment strategies included newspaper advertisements, direct mailings, announcements to civic and religious organizations, radio announcements, and referrals from geriatric professionals. Caregivers who were interested in participating were instructed to call the Information and Referral line of a senior service center. Most referrals came from newspaper ads.

Those who expressed interest were screened for eligibility through a telephone interview using the Caregiver Strain Index (CSI). The 13-item CSI generates an overall caregiving strain score and has good internal consistency (r=.86) (Robinson 1986). Caregivers had to score a minimum of 7 or higher on the CSI to be eligible for the study.

ADL/IADL impairment of the care recipient was measured by the Activities of Daily Living (ADL) scale of the Older Americans Research and Services Center instrument (OARS). Caregivers had to perceive their care recipient to have at least two or more ADL/IADL impairments on the OARS to be eligible. The psychometric

properties of the OARS ADL scale have been extensively examined as part of the overall testing of the OARS instrument, and are well established (Fillenbaum 1978).

Over a one year period, 97 caregivers (sixty-one children and thirty-six spouses) agreed to participate, passed the eligibility screen, and signed a consent form. The dyads were randomly assigned to either receive the TSG or US. Volunteers were randomly assigned and groups were formed and conducted on an ongoing basis. A total of 53 caregivers (31 children and 22 spouses) were assigned to the TSG condition and 44 caregivers (30 children and 14 spouses) were assigned to US. The recruitment process resulted in twelve TSG groups (8 children-only groups; 4 spouse-only groups). Groups ranged in size from 5 members to 8 members.

As can be seen in Table 1, the typical spouse caregiver in the TSG groups was female, with a mean age of 66.2. The typical child caregiver was also female, with a mean age of 54.9. No significant differences were found between spousal or child participants in the TSG and US conditions on any of the demographic variables.

Study Design

A 2X2X2 randomized waitlist control group design was used to test the previously stated hypotheses. The design had two levels of intervention (TSG versus US), two times of measurement (one week prior to the start of the intervention program and twelve weeks after baseline), and two types of caregivers (spouses and adult children). Caregivers assigned to the control group were offered the opportunity to participate in a TSG group after the second time of measurement. Interviewers were kept blind to the participants' assigned condition and an intention to treat methodology was used in the analysis of the data (Applegate and Curb 1990; Pocock 1984).

Intervention Conditions

Telephone Support Group Condition (TSG). The TSG intervention is an adaptation of a face-to-face support group model. The face-to-face intervention consisted of 8 weekly sessions that were each 2 hours in length. In order for the telephone format to be successful, the original face-to-face model was reformatted to be appropriate for a telephone support group. Sessions were shortened to 90 minutes, and the group met for a total of 12 weeks instead of 8 weeks. This was necessary because fatigue and disruptions could occur with longer phone calls.

TSG is a multi-component intervention for caregivers that includes problem-solving, education, coping strategies, and support. An agenda was set for each meeting, and the three components of TSG (emotion-focused coping, problem-solving coping, and support) were interwoven into each session. The first half of each weekly meeting began with a conference call hook-up. After this initial hook-up period, the group leader gave a brief overview of the previous meeting. This was followed by a "check-in" with group members regarding their progress between meetings. To help group members develop supportive relationships beyond the TSG program, group members were assigned a telephone buddy that they were encouraged to call in between group meetings to talk about their caregiving issues, discuss the skills they were learning, and to receive support as they worked on the goals they had identified to address their pressing problems. The group leader asked members about how their phone calls to each other. The remainder of each meeting focused on three components: emotion-focused coping, problem solving, and support.

The first component, emotion-focused coping, occurred during the first half of each weekly TSG meeting. Emotion-focused coping is based on the Stress Inoculation Training (SIT) developed by Meichenbaum and colleagues (Meichenbaum, 1977, 1985; Meichenbaum & Cameron, 1983). Emotion-focused coping utilizes strategies such as: didactic teaching, cognitive restructuring, perspective taking, relaxation training, self-monitoring and self-instruction. The social worker leading the group described the techniques, and encouraged members to practice them in each telephone support group meeting, and between meetings.

The second component, problem-focused coping, was introduced and practiced during a portion of each meeting. Problem-focused coping started by having members identify pressing problems that they would like to work on in the group. A six-step problem-solving model was used to help caregivers become effective in identifying and overcoming their problems.

The third component of the TSG model, support, was interwoven throughout each group meeting. The group leader helped members to (1) ventilate their feelings and concerns, (2) provide and receive empathetic understanding, (3) share different ways of coping with caregiving (i.e., peer helping), (4) feel hopeful about their situation, (5) play useful and meaningful roles by sharing their knowledge and experience with others in the group, and (6) provide peer models of how to effectively deal with stressful caregiving issues.

TSG sessions were monitored for treatment fidelity. All sessions were audiotaped. The tapes were listened to by a member of the research team, and scored with a rating form to verify that the leader conformed to the TSG intervention design. A

trained clinician on the research team provided weekly TSG supervision for the group leader.

Usual Services Condition (US). Caregivers in the control condition were offered the TSG after the initial 12-week period, after the pretest and posttest was completed. Caregivers in the US condition received the usual services offered by the senior services center. As per the Human Subjects agreement and consent form, participants were free to seek medical, psychological, social support, and social services available in the community at any point during the study.

Measurement and Measures

Telephone interviews were conducted with participants within two weeks prior to the intervention and again within two weeks of completing the intervention. Those caregivers initially assigned to UC were given a third interview if they chose to participate in a support group after the initial study period. Participants were interviewed by trained graduate assistants who were kept blind to condition assignment.

MOS Social Support Survey (MOS). The MOS Scale was used to assess how much tangible support, affectionate support, positive social interaction, and emotional/information support that caregivers received. For each area, respondents were asked: How often is each of the following kinds of support available to you if you need it: none of the time, a little of the time, some of the time, most of the time or all of the time? Higher scores indicate higher levels of support. The psychometric properties of the MOS have been well established.

Zarit Burden Interview (ZBI). The ZBI is a 22-item Likert-type scale that measures the total strain, role strain, and personal strain that caregivers experience as a

result of the impact of the patient's disabilities on their life. It was designed to assess the stresses experienced by family caregivers of elderly persons. For each item, caregivers are to indicate how often they have felt that way: never, rarely, sometimes, quite frequently, or nearly always. Higher scores indicate higher levels of burden. Internal reliability for the ZBI has been estimated with Chronbach's alpha at .88 (Hassinger 1985) and .91 (Gallagher, et al., 1985).

Center for Epidemiological Studies Depression Scale (CES-D). Depression was measured by the Center for Epidemiologic Studies Depression Scale (CES-D). Respondents were asked to determine how frequently twenty different events were experienced in the last seven days. These events were indicative of depression. Each event had a score of 0 (happened rarely or not at all) to 3 (most or all of the time). Higher scores indicated more depression. The CES-D was selected because normative data for both community and psychiatric patients are available. The CES-D has good reliability and validity, and correlates strongly with other standardized measures of depression (Radloff 1977).

State Trait Anxiety Inventory (STAI). This scale measures anxiety for caregivers. Twenty statements that people have used to describe themselves are given. Caregivers are asked the extent to which they agree (4) or disagree (1) with the statement. The final score is a summary of the answers to these 20 questions. Higher scores indicate more anxiety. The STAI has been used extensively in research and practice. The STAI has been shown to have excellent psychometric properties for the assessment of anxiety in elderly persons (Patterson et al. 1980).

Pressing Problems Index (PPI). The 18-item Pressing Problems Index was developed to assess the extent to which participants' health and social service problems were addressed. The PPI contains a listing of problems that caregivers encounter while caring for a family member with a chronic illness. For each problem, the caregiver is asked how stressful the problem was from (0) not at all to (4) extremely; how much their stress has changed from (-3) much worse to (3) completely better; how effective they have been in dealing with this problem from (0) not at all effective to (4) extremely effective; and how much their effectiveness has changed from (-3) much worse to (3) completely better. Variations on the PPI have been used by Toseland and colleagues in previous research (Toseland, et al. 1989; Toseland, et al. 1995), and have increasingly been recommended in the literature (McCallion, Diehl, & Toseland, 1994). The PPI has been described as a sensitive outcome indicator in several published papers and Chronbach's alphas reported in previous studies have ranged from .82 to .96 (Toseland, et al. 1989).

Use of Community Services (UCS). This scale was used to determine the extent to which participants' community and social services needs were addressed. Caregivers were asked three questions regarding twenty-one services: Did the caregiver know about the service? Did the caregiver know how to access the service? Did the caregiver use the service in the last year? The answers were scored 1 for yes, and 0 for no. The final three subscales were given a summary score of 0-21. A higher score represents more knowledge about what community services offer, how to access these services, and use of community services. This scale was originally developed for a previous study of

caregiver support groups (Toseland et al., 1989) and has been modified and used in several studies since that time (see, e.g., Toseland et al., 1995, 2001).

Data Analyses

Baseline demographic variables were compared using independent sample *t*-tests and χ^2 tests. Because of its ability to include cases with missing data, and other analytic advantages, random effects regression models (RERMs) was the primary analytic method. Outcome measures given at baseline and again at posttest were analyzed using RERMs in order to test for the effects of condition, time, and condition X time interaction. RERMs offer several advantages over more traditional repeated measures designs or nonparametric tests for analyzing data from randomized field trials with data collected over time (Gibbons, Hedeker, & Elkin, 1993; Hedeker, 1995). The RERMs included adjustments for first order autoregressive error terms, which indicate whether data collected during the crossover assessment period were correlated with data collected during the previous time periods. Data used in the randomized effects regression models were normally distributed.

Results

Data analyses were conducted on the entire sample of caregivers, and spouses and adult children separated. Tables in this analysis are based on the adult children. Some effects on the outcome measures were present for the entire sample; however, most of the effects were driven by the adult children rather than by the spouses. Analyses revealed that spouses receiving TSG had no significant differences on outcome measures from spouses receiving US.

Table 3 indicates that there were significant condition by time effects for two subscales of the MOS Social Support Survey. These children reported increases in positive social interaction and emotional/informational support over time. In comparison, children receiving US reported decreases in these two measures of social support. There were no significant differences between children in TSG and US for tangible support or affectionate support, the two other subscales of the MOS social support survey.

With respect to Pressing Problems, there were significant interaction effects for adult children for all four subscales of the PPI. Table 3 indicates that children in TSG reported a significant decrease in how stressful they felt their pressing problems were over time. In addition, the children in TSG had positive reductions in their stress. Adult children in TSG had higher levels of effectiveness after receiving TSG. Their change in effectiveness also increased over time. In comparison, although the adult children in US started with less stress than the TSG group, they did not decrease their stress levels as extensively as the TSG group did. Adult children in US had a negative change in stress over time (they felt more stress), and their effectiveness decreased. Their change in effectiveness was minimal over time.

With regard to the USC, the data presented in Table 3 indicate that there were significant interaction effects for knowledge of services, knowledge about how to access services, and use of services in the last year. The means in Table 3 reveal that adult children receiving TSG had increased knowledge of services, knowledge of how to access services, and use of services over time, whereas adult children in US had decreases all three of these subscales.

Table 3 reveals significant interaction effects for the three subscales of the Burden Interview. Adult children in the TSG had significant decreases in total strain over time. Their role strain and personal strain were both significantly reduced over time. In comparison, adult children in US had increases in their total strain, role strain, and personal strain from baseline to 12 weeks.

Depression rates, as measured through the CESD, revealed significant interaction effects. The means in table 3 reveal that depression decreased for adult child caregivers in both arms of the study. However, the depression scores of TSG participants decreased significantly more than scores of US participants.

No significant differences were found among adult child caregivers in the two arms of the study for the STAI. Table 3 indicates that TSG participants had a slight decrease in anxiety over time. US participants had slight increases in anxiety over time. These differences were not large enough to be statistically significant.

Discussion

Results indicate that the TSG intervention had strong positive effects on adult children. Adult children had increases in positive social interaction and emotional/informational support, higher levels of effectiveness after receiving TSG, increased knowledge of services, knowledge of how to access services, and use of services over time. The adult children in the TSG had decreases in how stressful they felt their pressing problems were over time, reductions in their stress, decreases in total strain, role strain and personal strain, and depression rates.

These same effects were not found for adult spouses. Because of the smaller sample of spouses, we investigated effect sizes and power sizes. Retrospective power

effect analyses revealed that even with larger numbers, these effects would not be significant. Ceiling and floor effects were examined for spouses. There were no differences for spouses and children at pretest. The differences were not a measurement issue. Finally, each session adhered to the protocol of TSG. Group sessions were monitored for treatment fidelity, and the group leader was provided with weekly TSG supervision. The differences were not due to the groups being run differently. Therefore, the TSG was more effective for children than spouses.

There are several plausible alternative explanations for this disparity between the effectiveness of TSG for adult children versus spouses. The first explanation is that spouses prefer face-to-face groups. Qualitative comments made by TSG participants indicated that spouses were more frustrated with the dynamics of the telephone group meeting, and particularly regretted not being able to see who they were talking to. Spouses expressed a desire to meet face-to-face with group participants after the cessation of TSG. Comparatively, adult children indicated that face-to-face groups would have been burdensome on their schedules, and appreciated the ease with which the TSG could accommodate their lives. The telephone format may address the particular time needs of adult children more effectively, while neglecting to meet the social needs of spouses.

A second explanation is that adult children may benefit more from support groups in general than spouses do because caregiving is an “off-time” event for adult children. As such, adult children may need more resources to help them. The TSG provides a framework through which to address pressing problems associated with caregiving. Adult children may be less equipped to deal with their problems upon going into TSG.

They are less likely than older spouses to have provided care in the past. Adult children's relationship with the care recipient may be qualitatively different than that of spouses, and their secondary role strains including work and family pressures exert strain for adult children. The TSG is particularly effective at providing information, tools to deal with stress and pressing problems, and introducing caregivers to others who are in similar situations. These dynamics may be more effective for children than for spouses.

Previous research has alluded to differences in the overall effectiveness of support groups between adult children and spouses. This study analyzed these differences directly by examining the effectiveness of TSG on both adult children and spouses. Results indicated that TSG is an effective means of supporting adult children, but spouses did not benefit from the same model. Future investigators must address ways to support spouses providing care.