

The Value of Telephone Support Groups Among Ethnically Diverse Caregivers of Persons With Dementia

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Purpose: Dementia caregiving is a rapidly growing public health problem. Logistical problems prevent many caregivers from utilizing available interventions. This article provides a demonstration of the usefulness of technology for conducting telephone-based support groups in ethnically diverse dementia caregivers.

Design and Methods: Participants were 41 White American and Cuban American dementia caregivers participating at the Miami site of the Resources for Enhancing Alzheimer's Caregiver Health (known as REACH) program. Support groups were conducted over the telephone in English and Spanish as appropriate.

Results: Eighty-one percent of the participants found the group "valuable," largely because of the social and emotional support and useful information obtained from other group members. The majority of caregivers also reported that their participation had increased their knowledge and skills as caregivers. **Implications:** The findings demonstrate that telecommunications technology can overcome the often formidable logistical problems faced by both English- and Spanish-speaking

caregivers, and it can provide benefits similar to those obtained in face-to-face support groups.

Key Words: *Technology, Cuban American, Intervention, Support Group, Caregiving*

Dementia caregiving is rapidly becoming one of the most prominent public health issues in the United States. Of the estimated 4.5 million Americans who suffer from dementia of the Alzheimer's type, approximately 3 million live at home, and an estimated 75% are cared for by family members or friends. The burden on society will undoubtedly grow in the coming years, as the number of individuals with Alzheimer's and related dementias swells to as many as 16 million by 2050 (Hebert, Scherr, Bienias, Bennett, & Evans, 2003), and as caregiving duration increases as a function of (a) the greater life expectancy among Alzheimer's patients and (b) medical advances that delay institutionalization (Schulz & Martire, 2004). A burgeoning literature has found associations between caregiving and elevated levels of emotional distress, higher use of psychotropic medications, poorer immune function and physical health, and increased mortality (Kiecolt-Glaser & Glaser, 2001; Light, Niederehe, & Lebowitz, 1994; Schulz & Beach, 1999; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Shaw et al., 1997). Many caregivers also have limited access to the information and resources that exist in their communities, and they frequently report feelings of isolation and inadequate social support (Stoltz, Uden, & Willman, 2004).

Numerous caregiver intervention studies have been conducted to address the multiple negative outcomes experienced by caregivers, with generally modest degrees of success (Brodaty, Green, & Koschera, 2003; Sorensen, Pinquart, & Duberstein, 2002). Improvements have been demonstrated in caregiver burden, depressive symptoms, perceived caregiver satisfaction, and length of time delay to nursing home placement. Types of interventions have included psychoeducation, support,

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respite care or adult day care, psychotherapy, caregiver competence, and multicomponent approaches, delivered in individual, group, or mixed formats. Elements of the most successful interventions include involvement of the patient in addition to the caregiver in a structured program, longer length of intervention time, and complex, multicomponent approaches.

Despite the promise of the aforementioned findings, many caregivers are unable to utilize these varied interventions because of logistical problems. More specifically, caregivers often fail to attend community support or psychoeducational groups, individual psychotherapy, or skill training programs because of problems in arranging alternative help or supervision, inaccessible meeting places, or scheduling conflicts associated with multiple physician appointments and personal responsibilities (Wright, Lund, Pett, & Caserta, 1987). Thus, although modestly effective interventions for caregivers have been developed and refined, their lack of accessibility for many caregivers severely limits their value.

A small number of technology-based interventions have recently been developed to overcome the logistic problems faced by many dementia caregivers (Davis, Burgio, Buckwalter, & Weaver, 2004; Gallienne, Moore, & Brennan, 1993; Mahoney, Tarlow, & Jones, 2003; Martindale-Adams, Nichols, Burns, & Malone, 2002), with encouraging preliminary findings. These studies have demonstrated that caregivers of dementia patients can use computer- and telecommunications-based technology to access emotional support, gather information, and find some limited relief from symptoms of emotional distress. Unfortunately, the majority of these studies included very small numbers of ethnic minority participants, particularly Hispanic caregivers, thus limiting their generalizability. The paucity of research on these types of interventions in Hispanic dementia caregivers is alarming for a number of reasons. First, a projected 600% increase in cases of Alzheimer's and related dementia among Hispanic elders is anticipated by the year 2050 (Novak & Riggs, 2004), which undoubtedly will be accompanied by a corresponding increase in the number of Hispanic caregivers in need of psychosocial services. In addition, compared with White caregivers, Hispanic caregivers are more likely to delay institutionalization of their care recipients, resulting in longer time periods of caregiving and subsequent prolonged exposure to caregiver stress (Mausbach et al., 2004; Yaffe et al., 2002).

In this article we add to previous research by presenting findings on ethnically diverse dementia caregivers' experiences in telecommunications-based support groups. Conceptually, our technology-augmented intervention was developed to (a) provide caregivers with access to social support, information, and resources; (b) reduce isolation; and (c) overcome the multiple logistical barriers that prevent many caregivers from attending face-to-face support groups. These groups were one part of a multicomponent intervention at the Miami site of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program (Eisdorfer et al., 2003). REACH was a longitudinal, multisite program, sponsored by the National

Institute on Aging and the National Institute of Nursing Research, which evaluated the efficacy of multiple interventions targeting caregiver burden, physical and mental health, and quality of life in 1,222 family caregivers of persons with dementia. A detailed description of the REACH project design, interventions, and baseline characteristics is available elsewhere (see Eisdorfer et al.; also see Wisniewski et al., 2003)

In brief, the Miami site of the REACH program examined the efficacy of (a) a family-based psychotherapy intervention, the structural ecosystems therapy (SET), and (b) the SET intervention augmented by an innovative computer–telephone integrated system (SET + CTIS) in reducing depression and caregiver burden among family caregivers of persons with Alzheimer's disease. We examined the efficacy of these two interventions over time in both Cuban American and White American caregivers, in comparison with a telephone-administered minimal support control condition. Following initial assessment, we randomly assigned caregivers to one of the three intervention conditions, and we conducted follow-up assessments at 6, 12, and 18 months postrandomization. The caregivers assigned to the SET + CTIS condition had enhanced access to family, supportive resources outside of the home, and support groups by means of the computer–telephone technology. Our purpose in this present article is to provide a demonstration of the usefulness of the technology for conducting telephone-based support groups in an ethnically diverse sample of dementia caregivers. In addition, we present data on caregivers' experiences in the groups, and whether they benefited from their participation.

Methods

Participants

The sample for this study included 41 family caregivers of persons with dementia, who participated in the Miami REACH project. All participants were in the SET + CTIS condition. The mean age of the participants was 68.3 years ($SD = 11.2$), and their mean level of education was 10.7 years ($SD = 3.8$). The participants were predominantly female (76%). Nineteen caregivers (46%) were non-Hispanic White, and 22 (54%) were Cuban American. The relationships of the caregivers to the care recipients were as follows: 18 were wives, 10 were husbands, 11 were either daughters or daughters-in-law, and 2 were sisters or others. The mean length of time since participants began providing care was 3.7 years ($SD = 3.2$), and the mean number of hours per day spent caregiving was 13.7 ($SD = 6.7$). The mean age of the care recipients was 80.0 years ($SD = 7.6$).

Screen Phones

The CTIS system is an information network that relies on computer–telephone technology. The system utilizes screen phones, allowing both text and voice data to be sent and received during an interactive session. The computer–telephone system provides both Spanish and English text and voice messages. The system is

menu driven and customized for each caregiver. The system allowed users to place and receive calls, send and receive messages, leave reminders, access databases of local resources, and conference with several people simultaneously. This last feature allowed caregivers to participate in telephone-based support groups with other caregivers. A more detailed description of the CTIS system can be found in Czaja and Rubert (2002).

Support Group Questionnaire

We developed the Support Group Questionnaire to gather information about the caregivers' experiences in the telephone support groups and in using the CTIS system. The questionnaire consisted of 15 items, mostly in a Likert-scale format, which inquired about caregivers' likes, dislikes, preferences, attitudes, opinions, and benefits achieved by participating in the telephone support group. The questionnaire took approximately 10 to 15 min to administer. Our development of the questionnaire consisted of the following steps: (a) development of the items, many of which had yes-no responses; (b) review of the questionnaire by three experts in the area (coauthors S. Czaja, M. Rubert, and S. Argüelles), who provided feedback for minor modifications related to the content being assessed; (c) pilot testing of the questionnaire with five caregivers; (d) modification of the questionnaire on the basis of feedback from the pilot testing; and (e) conversion of the items into a Likert-type scale, and reassignment of the order of the questions.

Demographic and Outcome Variables

Demographic variables of interest included caregiver age, gender, ethnicity, education, and relationship to the care recipient.

Procedure

All participants received in-home family-therapy sessions during the first 12 months of the study. In addition, CTIS phones were placed in each participant's home to link the caregivers with both family members and supportive resources in the community. Installation of the system and training and practice in using the system were provided during the first three home visits by a family-therapy interventionist. The telephone support-group sessions were facilitated by study-certified therapists (who were not providing the family-therapy intervention) who held at least a master's degree in psychology or a related field. Each session was approximately 1 hr in length, and it included a maximum of six caregivers in addition to the group leader. Sessions were held bimonthly during the beginning of the intervention period, and monthly thereafter. Scheduled sessions ended at 18 months postrandomization, but several additional voluntary sessions were offered after the 18-month intervention period.

The number of sessions attended by the participants ranged from 1 to 23. The caregivers chose the topics

discussed in each group session. Topics included respite care, medication management, behavioral interventions to deal with problem behaviors, instrumental support, and emotional support. Each session began with a brief review of what was covered in the previous session, as well as an overview of the current session's topic. This was followed by discussion of the topic among group members, brief psychoeducation, and, as the session concluded, referral to relevant resources for additional follow-up. During each session, participants were encouraged to share their caregiving knowledge or experience with others, and emotional support was provided by both group members and the group leader. The support groups and the CTIS were both manualized.

The caregivers participated in one of six concurrently run telephone support groups. Non-Hispanic White caregivers participated in one of three English-language groups, and Hispanic caregivers (except for one or two who preferred the English language) participated in one of three Spanish-language groups. Caregivers completed the aforementioned Support Group Questionnaire at the conclusion of the REACH project (e.g., at 18 months postrandomization).

Results

There were a total of six discussion telephone groups (three English language, three Spanish language). Fifty-one caregivers participated in the support groups (75% female, 51% Cuban American), and complete data was available for 41 participants. Reasons for attrition included substantial cognitive decline, institutionalization, or death (4); refusal to complete the questionnaires (4); and loss to follow-up (2). We performed attrition analyses to determine if the results were biased as a result of differential sample loss; we used *t* tests and chi-squares to determine if there were any differences in certain baseline characteristics (age, education, gender, ethnicity, marital status, caregiver relationship to the care recipient, caregiver employment status, years spent caregiving, hours per day spent caregiving, and care recipient age) and number of group sessions attended between those caregivers who completed the questionnaires ($n = 41$) and those who did not ($n = 10$). We found no significant group differences, suggesting that the results were not biased by differential attrition related to these variables. Lastly, we found no significant difference in the frequency of support group attendance between caregivers who did have complete questionnaire data and those who did not. We restricted the remaining analyses to the 41 caregivers who completed the support group questionnaires.

Most of the support group participants (58%) reported that they attended the groups very often or always; 33% attended once in a while (no more than six times per year), and 10% attended rarely (only once or twice). The mean number of group sessions attended was 7.10 ($SD = 5.00$; range = 1–23); 54% of participants attended 7 or more sessions. Eighty-one percent of the participants found the group "valuable." Individuals who attended a high frequency of support group sessions (i.e., 7 or more sessions) were more likely to

indicate that they found the group to be valuable, compared with those who attended fewer sessions (i.e., 6 or fewer sessions), $\chi^2(1, N = 41) = 6.77, p < .01$. There was no statistically significant difference between White caregivers and Cuban American caregivers with regard to whether they found the group to be of value to them. Those participants who found the group to be valuable ($n = 33$) indicated that the following aspects of the group were of value to them: the group allowed them to obtain emotional support from others (88%); they obtained useful information from others (85%); the group provided an opportunity to meet new people (64%); the group provided opportunities for social interaction (61%); and the group gave them a break from caregiving responsibilities (36%).

Seventy-three percent of participants indicated that they did not attend support groups in the community. Reasons provided by these participants ($n = 30$) for not attending community support groups included the following: the meeting schedules were not convenient (67%); they did not have anyone to watch the care recipient while they attended the group (53%); they lacked transportation to attend these groups (17%); they had physical limitations that prevented them from attending (13%); they had other reasons (17%). For those caregivers who attended both a community support group and who participated in the REACH support group ($n = 11$), complete data was available for 10 of the 11 caregivers: 30% preferred the community support group, 30% preferred the telephone support group, and 40% preferred both.

Fifty-nine percent of participants reported that they had made new friendships with members of their support groups; 43% reported that they thought the telephone support group should meet more often; and 38% reported that they talked with other members of their telephone support group outside of the regularly scheduled group sessions. Relatively few problems were reported by participants who attended the groups: 13% reported that the CTIS system was not reliable; 13% reported some "other" problem; 10% stated that the CTIS system was too slow; 8% reported that they had difficulty hearing other group participants during the sessions; and 2.5% reported that there were too many people in the group.

Seventy-three percent of the individuals either agreed or strongly agreed that their participation had increased their knowledge and skills as caregivers; 70% either agreed or strongly agreed that their participation had increased their knowledge about memory disorders like Alzheimer's disease; 68% either agreed or strongly agreed that their participation had increased their knowledge about community resources for caregivers and persons with memory problems; 68% agreed or strongly agreed that their participation in the telephone support group had helped them to care for their family members with a memory problem; 62% either agreed or strongly agreed that their participation had improved their relationships with members of their family; and 51% agreed or strongly agreed that their participation in the telephone support group had made them more willing to attend a support group in the community.

Lastly, we examined the relationship between frequency of group participation and several demographic variables, including age, education, gender, ethnicity, and caregiver relationship to the care recipient (spouse vs nonspouse), using *t* tests and correlational analyses as appropriate. We found no statistically significant relationships between frequency of participation and any of the aforementioned demographic variables.

Discussion

The present study provides a demonstration of the use of technology to conduct telephone-based support groups in an ethnically diverse sample of dementia caregivers. The data indicate that most of the participants found the support groups to be valuable, primarily because of the emotional support obtained, the useful information from others, and the social aspects of the group. A smaller number of caregivers expressed appreciation for the break that the group gave them from caregiving responsibilities. These findings are consistent with results from in-person support group studies (e.g., Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Morano & Bravo, 2002) and a small, brief-duration (6 weeks) pilot study of telephone support groups (Martindale-Adams et al., 2002). The findings are particularly important because they demonstrate that telecommunication technology can be used to overcome the often formidable logistical problems faced by many caregivers, and it can provide benefits similar to those obtained in face-to-face support groups. The barriers that prevented many caregivers in this sample (73%) from attending community support groups (e.g., inconvenient meeting schedules, not having someone to supervise the care recipient) are unlikely to lessen in the future, making technology-augmented interventions an increasingly attractive part of multicomponent caregiver treatments. Furthermore, this study demonstrates that these benefits can be delivered not only to English-speaking non-Hispanic White caregivers but also to the rapidly growing populations of Spanish-speaking Hispanic caregivers.

It is also important note that the technology was generally well accepted by this diverse sample of caregivers, with relatively few problems reported. Some of the technology-related problems identified by caregivers can be addressed by modifying the technology itself, for example, by examining ways to increase the speed and reliability of the system. More specifically, future studies should consider using a high-speed connection with high bandwidth (e.g., DSL or cable) to improve the speed and reliability of the teleconferencing technology. The use of these more advanced technologies would potentially allow the incorporation of videoconferencing into the support groups, and they would more closely simulate a face-to-face group. Other more user-related problems might be addressed by modifying the technology according to the caregivers' individual sensory deficits; possible adaptations include amplification of the speech signal, slowing the

rate of the speech messages, or incorporating speech recognition for those caregivers with motor limitations.

Frequency of group participation was unrelated to a number of demographic variables, suggesting that caregivers of varying ages and educational levels, males and females, Hispanics and non-Hispanics, and spouses and nonspouses were equally interested and able to attend the telephone support groups. More than half of the participants attended seven support group sessions or more, demonstrating that the intervention was well accepted over a substantial period of time. In addition, the majority of caregivers reported important benefits from their participation, including increased knowledge and skills as caregivers, increased knowledge about memory disorders and community resources, and improvements in family relationships.

There are a number of limitations to the current study. First, the small sample size was relatively small, which limited the power to detect significant relationships between frequency of group participation and demographic variables. In addition, as a result of the design of the study, the effects of the telephone support group by itself (as well as the effects of other individual aspects of the CTIS system) on psychosocial outcomes could not be examined, given that all components of the CTIS system were delivered to all participants in the SET + CTIS condition. At the same time, this study is one of the first to demonstrate the feasibility, usability, and value of technology-augmented, telephone-based support groups for Spanish- and English-speaking caregivers of persons with dementia. Telephone support groups for caregivers of persons with dementia have already been implemented in real-world clinical practice (e.g., in New York, Iowa, and Pennsylvania), and further research that replicates and expands on our findings, using larger ethnically diverse samples, is clearly needed.

Another potential shortcoming of the current study is the absence of more objective, non-self-report data to verify some of the benefits reported by caregivers. For example, although many caregivers reported increased knowledge about memory disorders and community resources after participating in the groups, no data on knowledge of memory disorders or local community resources were collected. Likewise, although many caregivers reported improvements in family relationships, no data from other family members to corroborate this were obtained. Lastly, no cost-effectiveness data for the telephone support groups were collected. Evaluation of the differences in costs and outcomes between face-to-face groups and telephone-based groups will be important before these groups are implemented on a broader basis.

In spite of these limitations, our results demonstrate the value of technology-augmented telephone support groups in ethnically diverse caregivers of persons with dementia, and they provide evidence that this method can overcome the logistic problems presented by face-to-face support groups. The need for expansion and refinement of this model by use of more recent advances in technology (such as videoconferencing) will grow in importance as both the number and diversity of dementia caregivers mushroom.

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