Caring for Others: Internet Video-Conferencing Group Intervention for Family Caregivers of Older Adults With Neurodegenerative Disease

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Purpose: The aim of this pilot feasibility study was to evaluate the effects of an innovative, Internet-based psychosocial intervention for family caregivers of older adults with neurodegenerative disease. Design and Methods: After receiving signed informed consent from each participant, we randomly assigned 66 caregivers to an Internet-based intervention or to a no-intervention control group. The intervention group received computers and training in order to access a password-protected Web site with links to information, e-mail, and threaded discussion. Unique to the Web site was a video-conferencing link that supported caregivers’ participation in a 10-session, manual-guided psychosocial support group, followed by 12 additional online sessions facilitated by a group member. Participants completed health-status and stress-response measures at baseline and 6-month follow-up. Results: Content analysis of archived video sessions showed (a) reliable adherence to the manual-guided support-group intervention and (b) online group discussion themes similar to those in face-to-face caregiver support groups. Analyses of stress-response outcome data showed significant between-group differences, with the intervention group experiencing a decline in stress compared with an escalation in stress for the control group. Implications: Despite the limitations of this pilot study in terms of limited sample size and 54% dropout of control participants at 6-month follow-up, the results provide preliminary supportive evidence for a technology-based psychosocial intervention for family caregivers of individuals with neurodegenerative disease.

Key Words: Virtual psychosocial support groups, Caregivers, Neurodegenerative disease, Web-based intervention, Technology

Older adults with long-term disabilities rely on family members to meet their daily care needs. Family caregivers spend between 5 and 20 hours per day caring for the dependent family member, while simultaneously fulfilling numerous other role functions. Not surprisingly, they suffer from sleeplessness, fatigue, anxiety, depression, and impaired immunological responses. The median rate of depression in caregivers is 22%, compared with 11% for community-dwelling older adults (Vitaliano, Zhang, & Scanlan, 2003). When the health of the caregiver is in jeopardy, the care recipient’s health status is also compromised, frequently resulting in premature institutionalization.

Although community-based support services are available to urban-dwelling caregivers in the form of psychoeducational support groups, in-home instrumental support, and respite care, caregivers residing in rural and remote areas have few if any services available. Also, with progression of the disease, caregivers cannot leave the care recipient in order to access clinical programs such as educational or psychosocial support groups. In light of these service-access limitations, we designed a technology-supported intervention program available to caregivers regardless of location that could be accessed from their homes at times convenient to them. The study purpose was to provide preliminary evidence for the efficacy of an Internet-based psychosocial/educational intervention for family caregivers. The study was also timely given the fact that technological delivery of health care to individuals in their homes is increasingly feasible due to the expanding use of the Internet, which has approximately 606 million users worldwide (Nua Internet Surveys, 2002). This expansion means that isolated and
underserved populations can now receive health services in their homes, including health assessments, disease-management support, and mental health interventions (Burdick & Kwon, 2004).

**Background**

Meta-analyses of caregiver-intervention studies primarily focused on dementia caregivers show that various models of face-to-face interventions result in significant benefits with regard to caregiver distress, depression, satisfaction, and knowledge, and care receiver symptoms (Chu, Edwards, Levin, & Thompson, 2000; Kennet, Burgio, & Schulz, 2000; Sörensen, Pinquart, & Duberstein, 2002; Toseland & McCullion, 1997). Technology is increasingly being used to provide information and support services to family caregivers of individuals with chronic disabilities (Czaja & Rupert, 2002). Although there are numerous online support programs for caregivers, most have not been evaluated in terms of their effects on reducing caregiver stress and burden (Burdick & Kwon, 2004). We found only two published reports of randomized controlled trials of technology-based support interventions for caregivers of adults with dementia. ComputerLink, a computer support network evaluated in a randomized controlled trial with dementia caregivers (Bass, McClendon, Brennan, & McCarthy, 1998; Brennan, Moore, & Smyth, 1995), provided an online public bulletin board, private e-mail, and a question-and-answer segment facilitated by nurses. The participants benefited in the short term, but participation lagged in the long term. The National Institutes of Health developed REACH (Resources for Enhancing Alzheimer’s Caregiver Health; www.edc.gsp.pitt.edu/reach; Schulz et al., 2003), a comprehensive six-site research program, in order to study interventions designed to enhance dementia caregivers’ knowledge, skills, and self-care strategies. Of the six research sites, two used computerized telephone systems to deliver information and consultation to caregivers. All REACH programs showed benefits to caregivers in terms of reduced stress and higher skill acquisition.

In summary, both face-to-face and technology-based support programs for family caregivers have shown that caregivers benefit from supportive intervention programs regardless of the platform from which they are delivered. Although our program replicated many of the features of the technology-based programs, it differed significantly by adding a face-to-face support-group intervention in an Internet video-conferencing environment. The challenge was to demonstrate that our program was supported by a valid theoretical framework, could be reliably replicated, and yielded evidence of its efficacy for reducing caregiver stress and burden.

**Caring for Others Intervention Program**

With the exception of using technology for its delivery, the Caring for Others intervention program shared the same program goals of other caregiver intervention programs: education, psychosocial support, and problem-solving skills (Hebert et al., 2003; Schulz, 2000; Schulz et al., 2003). Caring for Others provided a password-protected Web site with links to (a) disease-specific information, (b) private e-mail, (c) a question-and-answer forum, and (d) a video-conferencing link for the support-group intervention. The Web site, a computer training manual, and an intervention training manual had been developed during pilot studies predating the current study (Marziali, in press).

**Theoretical Framework**

We based Caring for Others on a psychosocial, lifespan perspective for understanding variations in behavioral expression in adult caregivers. The aim was to understand how caregiver characteristics have historically contributed to adaptive or maladaptive responses to life stressors. In particular, we postulated that personality traits shape the ways in which emotions are regulated and information is cognitively processed (Brandtstädter & Renner, 1990; Gross, 1998; Ryff, Kwan, & Singer, 2001). This theoretical framework aligned with Skinner’s (1995) view that coping with stress includes both volitional and automatic (trait-based) responses that focus on basic human needs for competence, autonomy, and relatedness. The framework also supported the view of Vitaliano and colleagues (2003) that caregiver health outcomes result from the interaction between individual caregiver characteristics and environmental factors, such as psychiatric history, personality, ethnicity, comorbidities, social support, and socioeconomic status.

**Caring for Others Video-Conferencing Support Group**

A group therapist met with six caregivers using the Caring for Others video-conferencing link for 1 hour weekly for 10 weeks. The aim was to provide therapeutic support by focusing on helping group members understand how personal styles for regulating emotions and processing information either advanced or thwarted caregiving role functions. The therapist initially focused on building rapport and mutual trust by encouraging group members to tell their caregiving stories in an unstructured format. The therapist empathically reflected on the caregivers’ anxiety, sadness, and sense of helplessness, emotions typically experienced by family caregivers when they realize that their lives have been changed forever. Group members responded by readily empathizing with one another as...
they disclosed some of the painful realities of caregiving; as one caregiver put it: “I’ve come to realize that I shouldn’t get frustrated or angry when he needs things repeated over and over—knowing what other people are going through makes it easier.” The therapist encouraged the members to reflect on personal cognitive style and strategies used to manage disturbing emotions. The aim was to help caregivers tolerate and manage the anxiety associated with being in a continual state of uncertainty due to having no control over the progression of the care recipients’ disease. In summary, the role of the group therapist was to integrate strategies for encouraging the caregivers to mutually identify with one another’s caregiving responses with strategies that supported self-reflection on how personality style merges with environment factors in ways that either facilitate or detract from adaptive problem solving. Following the 10 therapist-led sessions, a group member assumed the task of guiding group discussion weekly for an additional 12 weeks.

Methods

Study Design and Sample

We implemented a randomized controlled pilot study in order to assess the feasibility, reliability, and effects of an Internet-based psychosocial intervention for family caregivers of older adults with neurodegenerative disease. The sampling strategy focused on identifying 66 caregivers of relatives with moderate-level disability distributed across three forms of neurodegenerative disease: Alzheimer’s, stroke-related dementia, and Parkinson’s (22 participants per disease group). Geriatricians at two participating hospitals located in two remote areas in Canada (the project sites) used their own clinical judgments of moderate-level disability at time of referral. However, time constraints imposed by the funding agencies truncated the recruitment phase, resulting in the need to accept referrals regardless of disability level. Despite this limitation, level of disability, care recipient age and gender, and duration of caregiving were similarly distributed within and across groups.

After receiving signed informed consent from each participant, we randomly assigned individuals from each disease-specific cohort of 22 caregivers to either the Internet-based intervention group or to a no-intervention control group. Subsequently, we divided the intervention group caregivers into disease-specific caregiver groups, each with 4 to 6 members. We added individual usernames and passwords to the Caring for Others Web site and programmed them to link each participant only to members in his or her group and to educational materials relevant to his or her relative’s disease.

Procedures

Technicians at each site installed equipment in the participants’ homes and provided two computer training sessions using the Caring for Others computer training manual. Research assistants (not blind to group) administered questionnaires to caregiver participants in their homes at baseline and 6-month follow-up. Questionnaires included (a) the Health Status Questionnaire 12 (Pettit et al., 2001), an abbreviated version of the validated Medical Outcomes Study 36 (Ware & Sherbourne, 1992); (b) the Center for Epidemiologic Studies–Depression scale (Radloff, 1977), a short self-report of depressive affect and behavior that is used extensively in medical and mental health studies; (c) a measure (Finch, 1995) that required the caregiver to endorse the presence or absence of activities of daily living (ADLs) and instrumental ADLs (IADLs) performed on behalf of the care recipient (in the current study, for each endorsed ADL and IADL, we asked participants to rate the degree of stress experienced on a 3-point severity scale); (d) the Revised Memory and Behavior Problems Checklist (Teri et al., 1992), which asks the caregiver to rate levels of distress experienced in relation to managing the patient’s difficult and/or disruptive behaviors; and (e) the Multidimensional Scale of Perceived Social Support (Zimit, Dahlem, Zimit, & Farley, 1988), a 12-item scale that measures the respondent’s perceptions of the availability of social support. All measures are those typically used in studies of dementia caregiver responses to intervention programs (Hebert et al., 2003; Schulz et al., 2003).

Group Therapist Training

We used the Caring for Others intervention training manual to train two clinicians (a social worker and a nurse) to carry out the intervention reliably. Tele-video conferencing facilities at each of the participating sites were used for weekly meetings in order to train and subsequently supervise the therapists for the duration of the 10-session, psychosocial group intervention.

Data Analyses

We archived all Internet-based video-conferencing group sessions. We analyzed the archived sessions in order to determine reliable adherence to the treatment strategies, and we also conducted qualitative analyses of group-discussion themes. We computed analyses of variance for each outcome variable (general health; depression; stress response to ADLs, IADLs, and difficult behaviors; and social support) in order to determine differences between the intervention and no-intervention groups, controlling for baseline status on each measure.
Results

Participant Characteristics

The average age of the caregivers was 67.8 years, and 76% were women. The majority had completed some high school or community college training, and more than half had annual incomes less than $40,000. The caregivers had been providing care for an average of 3.5 years. There were no between-group (caregiver/disease) differences for any dimension.

Reliability of Adherence to Intervention Strategies

We trained two research assistants to independently analyze the sessions using a coding system that identified intervention strategies specified in the intervention training manual. Inter-rater agreement on application of the coding system on six randomly selected sessions ranged from 85% to 90%. Subsequently, each research assistant independently coded half of the sessions randomly selected from the six online intervention groups. A frequency count of categories of intervention strategies used by each therapist across all groups showed that more than 90% of strategies used were faithful to the treatment model.

Qualitative Analyses: Group-Discussion Themes

We used an open-coding system in order to conduct qualitative analyses of discussion themes across groups using early, middle, and late phases of each group for the analyses. We identified key constructs and subsequently recorded theme categories. The analyses yielded four salient themes, each supported by dialogue extracted from the session analyses (Creswell, 1998). The themes and sample dialogue follow.

Empathic Communication and Understanding Among Group Members.—“I’m finding a lot of frustrations, and, like Mary said, there are good days and bad days.” “That’s what makes these sessions meaningful... We’re not alone and we share some of the same experiences and challenges.”

Insights Into Personal Characteristics That Function as Barriers to Managing Emotions and Cognitive Processes.—“When I’m tired and stressed, I don’t want to communicate. I want to hibernate.” “It’s my temperament; I’m not as patient with people as I should be.” “I’m the sort of person who needs to think about things when they happen, then I deal with it... I don’t know if that’s the right way, but it works better for me.”

Insights Into the Meanings of the Changing Relationship With the Dependent Relative.—“As Robert has said in earlier conversations, the person that we love is not the same person that she was before.” “I was used to my mother doing things for herself, and now suddenly I have to take over... I feel resentful and, I guess, angry, frustrated.” And (referring to a spouse): “I was used to a big strong man for 50 years, and then you see him suddenly collapsing because of his memory... Maybe I expect too much.”

Recognition of Emotional Reactions Associated With Decision Making Regarding Transfer of the Care Recipient to Institutional Care.—“When the time comes that I can’t physically or mentally look after her [mother], then I’ll think about it... I can’t allow myself to go into a total burnout situation.” “It’s going to be a very hard thing to do when the time comes.” “With my wife there will be no problem [with an admission to a facility], but myself, I know I will miss her very dearly.”

Follow-Up Reactions to Using Internet Video-Conferencing for Group Meetings

Approximately half of the caregivers in the intervention group had never used computers and stated that the training provided was sufficient. About 78% indicated that the Web site was easy to use, and 95% felt that using computers to meet in the online group was very positive or moderately positive. For example, one caregiver said, “I think it’s great... It seemed much easier to get to know them than in person. In reality, I wouldn’t have talked as much.” Regarding the video-conferencing, 61% of the caregivers felt that sharing their experiences with the support group via video-conference was as helpful as meeting people face to face. One caregiver noted, “In a way it was even more helpful... Not only that, but I could do it in my home.” Another 30% indicated that the video-conferences were almost as helpful as meeting people face to face.

Quantitative Analyses: Group Differences

There were no follow-up data on 28 participants, with the majority (n = 18) of dropouts being in the control group (possibly due to the fact that they were not receiving needed support). Baseline comparisons between intervention and control groups on all five measures showed no significant differences. Similarly, there were no differences between intervention and control groups at follow-up on any measures. Examination of total sample responses on all measures showed considerable variation. For example, at baseline more than half of the total sample reported having no ADL/IADL-related stress or stress associated with managing difficult care recipient behaviors. Therefore, we decided to examine between-group differences, if any, in
increments of experienced stress between baseline and 6-month follow-up. For each participant we combined the responses to the two stress measures (ADL/IADL and managing difficult behaviors) and computed stress change scores by subtracting the baseline combined stress-response score from the 6 month combined stress-response score. A lower or negative score would reflect a decrease in stress between the two time points. A one-way analysis of variance of the baseline-to-follow-up change scores showed a statistically significant effect for the intervention condition: $M$ stress change score $2.519$ ($n = 15$) for control group; $M$ stress change score $-1.326$ ($n = 23$) for intervention group; $F(1, 37) = 9.68, p < .004$.

**Discussion**

The analyses of the Caring for Others online group model of intervention for caregivers of older adults with neurodegenerative disease showed that the intervention was reliably delivered and that the extracted group-discussion themes appear to address the key issues of importance to family caregivers of individuals with neurodegenerative disease. According to participant feedback, their experience with the Caring for Others online group intervention program paralleled experience with face-to-face, clinic-based support group programs. Caring for Others shows promise as an effective way of providing educational and supportive interventions to family caregivers, especially those who live in remote areas with little or no access to services.

The analyses of session themes showed that, despite meeting in an Internet-based videoconferencing format, group members developed empathic understanding of one another and were able to offer mutual support and understanding. The process analyses lend some support for our theoretical framework, showing that the caregivers used self-reflective strategies for understanding person-specific barriers to emotion regulation, information processing, and action taking. The between-group analyses of stress change scores that showed greater outcome benefits for the intervention group support the cumulative evidence; that is, most caregiver intervention programs yield small to moderate outcomes in terms of reduction in experienced stress and burden (Hebert et al., 2003; Schulz et al., 2003). Furthermore, we were able to demonstrate that the facilitators delivered the intervention reliably, providing some preliminary support for an evidence-based model of intervention for the caregiver groups recruited for this project.

Despite the fact that sample-selection criteria specified the recruitment of caregivers of individuals with a neurodegenerative disease at a moderate level of disability regardless of type of disease (Alzheimer’s, vascular dementia, Parkinson’s), we were unsuccessful in controlling for level of disability due to recruitment time limitations imposed by the funding agency. This may explain the considerable variation in caregiver questionnaire responses at the two measurement points.

In order to replicate the Caring for Others intervention program, researchers must address a number of issues. In particular, there needs to be a focus on ensuring that any Web-based intervention meets the same ethical and professional standards that apply in face-to-face delivery of clinical programs. There is little in the literature that specifies minimum professional practice standards or privacy protection standards for Web-based health interventions (Marziali, Serafini, & Mc Cleary, 2005).

We summarize here the methods used in order to ensure that we met professional practice and privacy standards for the delivery of the Caring for Others Internet-based intervention. In terms of professional practice standards, therapist strategies specified in the intervention training manual reflected the theoretical framework, and session analyses demonstrated faithful adherence to the model of intervention. In addition, the qualitative and quantitative data analyses provide preliminary evidence for the efficacy of the Caring for Others program.

In terms of protecting client privacy, our Web site was password protected. Within the Web site there were three levels of security; the site administrator had access to all links and groups, whereas the professional therapists had access only to the caregivers in their intervention groups. We have removed all e-mail messages and video-conference sessions from the Web site, encrypted them, and stored them on the server. Subsequently, we copied all information onto CDs and stored them in locked cabinets for analyses. The CDs will eventually be destroyed.

**References**


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