## Un essai sur le soutien téléphonique aux aidants de personnes souffrant de démence

Jennifer Martindale-Adams, Linda O. Nichols, Robert Burns, Marshall J. Graney, Jeffrey Zuber

La présente étude vise à déterminer si les groupes de soutien téléphonique pour les aidants de personnes souffrant de démence ont un effet sur les ennuis liés aux comportements des patients, l'accablement, la dépression et le bien-être général. L'essai clinique aléatoire a comporté la comparaison de groupes de soutien téléphonique (16 groupes composés de cinq ou six aidants) avec des groupes témoins (documents imprimés). Les groupes se sont réunis à 14 reprises au cours d'une année. Les séances d'une heure ont porté sur la formation, les habiletés d'adaptation et le soutien. Les données ont été recueillies au niveau de base puis après 6 mois et après 12 mois. L'échantillon a comporté 154 aidants et aidantes, 77 par bras, qui fournissent des soins à des vétérans souffrant de démence ou à un aidant vétéran. Il a été constaté que les ennuis variaient grandement au niveau de base. Il n'y avait pas de différences importantes dans l'effet thérapeutique entre les bras. Les participants et participantes ont dit avoir constaté une amélioration. Il a été conclu que les groupes de soutien téléphonique sont un moyen efficace d'interagir avec les aidants. D'autres études devraient toutefois examiner différents modèles de soins. Les interventions fréquentes ou portant sur des besoins particuliers pourraient être plus efficaces pour soutenir les aidants de personnes dont l'état s'aggrave.

Mots clés: groupe de soutien téléphonique, personne souffrant de démence, aidant, habiletés d'adaptation

# A Trial of Dementia Caregiver Telephone Support

Jennifer Martindale-Adams, Linda O. Nichols, Robert Burns, Marshall J. Graney, Jeffrey Zuber

The purpose of this study was to determine if telephone support groups for dementia caregivers have an effect on bother with patient behaviours, burden, depression, and general well-being. The randomized controlled trial compared telephone support groups (15 groups of 5 or 6 caregivers) with control groups (print materials). Groups met 14 times over 1 year. The 1-hour sessions included content on education, coping skills, and support. Data were collected at baseline and at 6 and 12 months. The sample comprised 154 caregivers, 77 per arm, providing care to veterans with dementia or a veteran caregiver. Bother was found to differ significantly at baseline. There were no significant treatment effect differences between study arms. Participants anecdotally reported improvement. It was concluded that telephone support groups are an efficient way to interact with caregivers. Further research should test different models of care. Interventions that are targeted to specific needs or occur frequently may provide better support for caregivers of individuals with a worsening condition.

Keywords: caregiving – informal, Alzheimer's disease, caregiver stress

Almost 11 million US caregivers provide 12.5 billion hours of care annually to Alzheimer's patients, at a value of almost \$144 billion (Alzheimer's Association, 2010). Caregiving can be all-encompassing. It includes assistance with personal care and activities of daily living, supervision, and monitoring (Schoenfelder, Swanson, Specht, Maas, & Johnson, 2000). Caregivers experience physical and psychological morbidity (e.g., depression, anxiety, sleep disturbance, increased hospitalization and mortality, increasing care recipient institutionalization) (Mahoney, Regan, Katona, & Livingston, 2005; Schulz & Beach, 1999). Dementia caregivers have more serious adverse events, such as morbidity and stress, than non-dementia caregivers (Schulz & Martire, 2004).

Caregiving interventions can ease the burden. One of the most successful interventions for a diverse caregiving population was the multisite National Institute on Aging/National Institute of Nursing Research randomized controlled trial Resources for Enhancing Alzheimer's Caregiver Health (REACH II). This intervention provided education, support, and skills-building through 12 individual sessions in-home and by telephone plus five support group sessions by telephone. It was targeted to risks

identified by a caregiver risk appraisal. Intervention caregivers showed significant improvement in terms of burden, depression, health and self-care, social support, and management of patient behaviours, and they gained 1 extra hour per day not spent on caregiving tasks (Belle et al., 2006; Nichols et al., 2008). There have been several adaptations of REACH II, including REACHVA (Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011), which was very similar to the original REACH II, REACH OUT (Burgio et al., 2009), and the Scott and White Family Caregiver Program (FCP) (Stevens, Smith, Trickett, & McGhee, 2012), both of which are shorter interventions.

Despite caregivers' need for education and assistance with tasks, caregiving is an obstacle to participation in interventions. To circumvent obstacles such as a dearth of local services, lack of access, and the need to travel (Salfi, Ploeg, & Black, 2005; Smith, Toseland, Rizzo, & Zinoman, 2004), non-face-to-face interventions have been developed and do show promise. In a Canadian study (Marziali & Garcia, 2011), both Webchat and video-based groups showed improvement in self-efficacy and a decline in distress related to caregiving tasks and the video group showed improvement in mental health.

We developed telephone support groups. With group leaders trained to manage a lack of verbal cues (Smith et al., 2004; Toseland, Naccarato, & Wray, 2007), telephone groups can have similar advantages to face-to-face groups. Participants can interact, obtain factual/current information (Toseland et al., 2007), share expertise and experiences, exchange social support, learn and practise skills, and seek assistance in addressing their own problems.

Caregivers can benefit from telephone support groups (Toseland & Rivas, 2005). Dementia caregivers have shown satisfaction and increased knowledge, skills, and support (Bank, Argüelles, Rubert, Eisdorfer, & Czaja, 2006; Martindale-Adams, Nichols, Burns, & Malone, 2002; Salfi et al., 2005). A telephone group for caregivers of frail older persons, compared to usual care, showed improvement with regard to burden, depression, social support, and pressing problems, and also increased knowledge and use of community services for adult children (Smith & Toseland, 2006).

The strategies of telephone support groups for reducing caregiving stress may best be understood through a stress/health process model. Caregivers experience stress if they perceive that the demands placed on them exceed their resources and their capacity to manage (Lazarus & Launier, 1978). Action-oriented management of environmental demands depends in part on information and skills directed towards diminishing, tolerating, or meeting the demands. The support groups focus on the

management of patient behaviours and activities of daily living/instrumental activities of daily living (ADLs/IADLs), a major demand placed on dementia caregivers.

Perceptions of demands and coping are individualized (Belle et al., 2006) and an individual's internal efforts to manage demands that cannot be changed are critically important (Folkman, Schaeffer, & Lazarus, 1979). While caregivers in this study were taught strategies for managing patient behaviours, they were also taught skills to reduce distress over behaviours and circumstances that are not amenable to change. Dementia caregivers who are provided with behavioural interventions alone, with no attention paid to intrapersonal coping, have poorer affective outcomes (Burns, Nichols, Martindale-Adams, Graney, & Lummus, 2003), which can lead to decreased quality of care or to institutionalization. Therefore, caregivers' internal responses were also targeted. Under this theoretical framework, the intervention had several components, including those shown to be successful in caregiving studies such as REACH II: education; support; and the building of practical skills, including problemsolving, communication, and stress reduction (Belle et al., 2006; Gottman, Gottman, & Atkins, 2011; Schulz et al., 2003).

The study was funded by the Department of Veterans Affairs (VA) and was focused on a VA medical centre. Although caregiving is a challenge for community health- and social-service agencies, in many ways the VA is at the leading edge in dealing with dementia. VA's patient population is reaching an all-time high in terms of advanced age, and veterans diagnosed with traumatic brain injury have more than twice the risk of developing dementia within 7 years of diagnosis (Spotswood, 2012). Also, caregivers of veterans show greater emotional stress, physical strain, financial hardship, and work stoppage/early retirement, although these results are not specific to dementia caregivers (National Alliance for Caregiving, 2010).

We hypothesized that caregivers in a telephone support group, compared to those in a control condition who received a packet of printed information, would show improved bother with patient behaviours, burden, depression, and general well-being.

#### Method

## Overview

CONNECT – Telephone Support for Dementia Caregivers was a 3-year randomized controlled trial, from October 2004 to September 2007, sponsored by VHA (Veterans Health Administration) Health Services Research and Development and the Veterans Affairs Medical Center in

Memphis, Tennessee (VAMC Memphis). CONNECT caregivers were family members reporting stress or difficulty with care, living with care recipient, providing 4 or more hours of supervision or care per day for at least 6 months. Care recipients had a dementia diagnosis or mini-mental state examination (MMSE) (Folstein, Folstein, & McHugh, 1975) score of 23 or less and at least one ADL or two IADL limitations (Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963; Lawton & Brody, 1969). One member of the dyad had to be a veteran receiving services at VAMC Memphis. Planned nursing home admission within 6 months was an exclusion criterion. Caregivers were recruited through brochures placed in the medical centre and mailed to VAMC patients receiving cognitive enhancers and through clinician referral.

The study was overseen by the VAMC Memphis Institutional Review Board. Informed consent was collected in-home before baseline data collection. Privacy and information security procedures included identification numbers on all analytic files, secure paper and electronic files with access limited to study personnel, and password-protected secure servers. Identifying information was kept separate from study data.

## Intervention

Content and structure of the intervention were based on the 6-month REACH II intervention of 12 individual in-home and telephone sessions and five telephone support group sessions (Belle et al., 2006). The CONNECT treatment arm comprised 15 support groups, each with five to six caregivers and a trained group leader. There were three group leaders, each with a caseload. The support groups met bi-weekly for 2 months and monthly thereafter for 1 year, for a total of 14 hour-long sessions. Each participant received a one-on-one introductory telephone call.

Training in group work and theory and motivational interviewing (Miller & Rollnick, 1991; Toseland & Rivas, 2005) as well as certification ensured consistency across the master's-prepared group leaders. Certification involved readings, videos, and practice sessions. During the certifying role play, each group leader led the first session and made two additional educational presentations. Study investigators evaluated behaviourally anchored ratings of specific procedural techniques (e.g., correct use of forms) and clinical skills (e.g., active listening).

Session materials consisted of a Caregiver Notebook and commercially available pamphlets. The Notebook, initially developed for a primary care intervention (Burns et al., 2003), comprised 29 behaviour—management chapters of five to eight pages each (e.g., bathing, repeated questions) and 17 caregiver stress/coping chapters (e.g., assertiveness,

communication, grief) based on research and practice, written in large print and at a fifth-grade reading level.

Like REACH, the multi-component intervention targeted caregiving risks, including risks associated with emotional and physical well-being, safety, burden, social support, and patient behaviour management. To ensure that components of caregiving interventions shown to be successful (Belle et al., 2006; Gottman et al., 2011; Schulz et al., 2003) were addressed, the first six sessions were standardized to include an introduction, basic information about dementia and financial and legal issues, safety, caregiver health and well-being, communication, and problemsolving — all Caregiver Notebook chapters. The remaining eight topics were chosen by each group from the behavioural and stress topics in the Notebook, because interventions that are most effective are targeted to the specific needs of the dyad (Goy, Kansagara, & Freeman, 2010).

The sessions were semi-structured telephone calls with education, skills-building, and support. Each session began with a relaxation exercise, caregiver updates, review of strategies tried from the preceding session's topic, and the group leader's presentation on a behaviour management or stress and coping topic. The rest of the session included discussion and practice by the entire group on the session's topic, selection of individual strategies to try, selection of the next session's topic, and closure, including another signal breath relaxation exercise.

Control caregivers received pamphlets on dementia and safety as well as telephone numbers for local resources. At the end of the study they received the Caregiver Notebook and a workshop focusing on knowledge, safety, health, well-being, behaviour management, and stress.

## Data Collection

Measures used in REACH II (Belle et al., 2006) were collected in-home by trained research associates at baseline and at 6 and 12 months; each session lasted approximately 1.75 hours. Outcomes (patient behaviours, burden, depression, general well-being) and non-VHA health use and health costs were collected by telephone at 3 and 9 months, each call lasting approximately 20 minutes.

## Measures

Caregiver data. Demographic data included age, gender, race, work status, marital status, education, and income. Caregiving data included relationship, social support, number of years providing care, time on duty, and time providing care. Nineteen social support items measured received support and negative interactions (Krause, 1995), satisfaction (Krause, 1995; Krause & Markides, 1990), and social networks (Lubben, 1988).

The first three social support domains use a scale of 0 (never, not at all) to 3 (very often, very). Social network items use a scale of 0 (none) to 5 (9 or more). Social support items sum to 0 through 69; higher scores indicate more support. A US study with 1,103 older people yielded Cronbach's alphas of .84 for received support (Krause, 1997), .71 for support satisfaction (Krause & Shaw, 2002), and .83 for negative interactions (Krause, 1999). In a European validation study with 7,432 older people, social networks had a Cronbach's alpha of .83 (Lubben et al., 2006). Two Caregiver Vigilance questions (Mahoney et al., 2003) asked hours and minutes per day spent on duty and on care activities. Cronbach's alpha for the four-item scale is .66 (Mahoney et al., 2003).

Clinical data were health, self-care, burden, depression, general well-being, and number of and bother with care recipient behaviours. Health was assessed from 1 (poor) to 5 (excellent) with one question from the Medical Outcomes Study 36-item Short-Form Health Survey (SF-36) (Ware et al., 1995). Caregiver's self-care and preventive health measures (e.g., getting enough rest, keeping medical appointments) were assessed using four REACH II questions (Belle et al., 2006). All self-care items are scored 0 or 1 (no or yes), summed 0 to 4.

The 12-item Zarit Burden Interview (ZBI) (Bédard et al., 2001; Zarit, Reever, & Bach-Peterson, 1980) assessed caregiver burden. Scoring is 0 (never) to 4 (nearly always); a higher score indicates greater burden. Cronbach's alpha is .85 for a representative sample of 1,095 Canadian dementia caregivers (O'Rourke & Tuokko, 2003). The 10-item Center for Epidemiological Studies Depression Scale (CES-D) (Irwin, Artin, & Oxman, 1999; Radloff, 1977) assessed depressive symptoms within the past week. Scoring is 0 (rarely, none of the time) to 3 (most, almost all the time), for a score of 0 to 30; higher scores indicate greater symptoms. Cronbach's alpha is .92 (Irwin et al., 1999). The 22-item General Well-Being Scale (Brook et al., 1979) assessed well-being, anxiety, general health, vitality, depression, self-control, and mental health. Scoring is 1 (definitely true, all of the time) to 5 (definitely false, not at all) and summed; higher scores indicate greater well-being. Cronbach's alpha is .94 (Brook et al., 1979).

The 24-item Revised Memory and Behavior Problems Checklist (RMBPC), with a Cronbach's alpha of .78 (Teri et al., 1992), assessed frequency and bother of dementia behaviours. Each behaviour is rated 0 (not in past week) to 3 (daily or more often) and summed (0 to 72); higher scores indicate greater frequency. Bother is rated for each behaviour reported, from 0 (not at all) to 4 (extremely). Scoring is 0 to 96; higher scores indicate more bother.

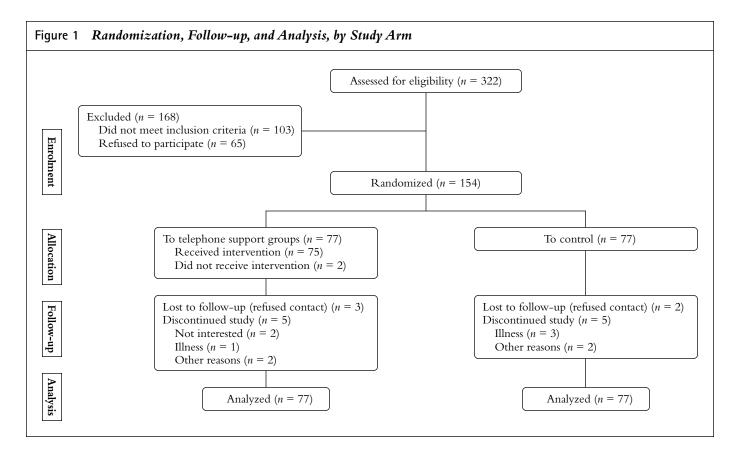
Care recipient data. All data except cognitive status were collected via caregiver report. Demographics included age, gender, and education. For clinical data, cognitive status was assessed using the MMSE, a 30-point scale determining orientation, short-term memory, visual construction, and language skills (Folstein et al., 1975). Higher scores indicate better cognitive functioning. Across multiple studies, Cronbach's alphas range from .54 to .96 (Tombaugh & McIntyre, 1992). Use, but not dosage, of cognitive enhancers was collected. Care recipient health was assessed using the same SF-36 question used for caregiver health (Ware et al., 1995). Care recipient function was assessed using the six-item Katz ADL Scale (Katz et al., 1963) and the eight-item Lawton and Brody IADL Scale (Lawton & Brody, 1969). Each item is scored 0 (no help needed) or 1 (help needed). ADL and IADL items are summed separately, with higher scores indicating greater impairment. Cronbach's alpha is .75 across three studies for ADL (Spector, Katz, Murphy, & Fulton, 1987) and averages .84 for IADL in a review of multiple studies (Sikkes, de Lange-de Klerk, Pijnenburg, Scheltens, & Uitdehaag, 2009).

## Project Evaluation

After final data collection, participants were asked by telephone about their satisfaction with the groups and components (e.g., format, length, information), any difficulties (e.g., talking to unseen members, distractions), and benefits (e.g., confidence, ability to provide care). Responses were scored from 1 (not at all) to 5 (extremely).

## Data Analysis

The data analysis strategy was intention to treat, with each outcome treated as independent. Baseline data were compared between intervention and control caregivers using chi-squared or independent-sample t tests. Randomized groups were compared using repeated-measures mixed linear models to estimate group by time interaction. Because this model accommodates missing data without subject loss, imputation was not necessary. P values of .05 or less were considered statistically significant, and those between .05 and .10 documented trends that approached statistical significance. The study was designed to provide statistical power of .80 to document a true population difference in intervention effect at least .25 SD of a primary outcome variable. For statistically significant comparisons, effect size of at least d 0.2 was considered clinically significant, consistent with the small-to-medium effect sizes for psychosocial interventions (Sorensen, Pinquart, & Duberstein, 2002). Interaction effect sizes were estimated as mean between-group gain score change relative to estimated population standard deviation (Cohen, 1988).



## Results

## Sample

Of the 322 caregivers screened, 154 were randomized, 77 to each arm (Figure 1). Fifteen caregivers (9.7%) were lost to follow-up or discontinued. Fifteen (9.7%) institutionalized the care recipient, and 18 were bereaved (11.7%), with no significant difference between arms. These caregivers generally remained in the telephone support groups.

There were 24 veteran caregivers. Caregivers were overwhelmingly female spouses approximately 66 years old and care recipients were approximately 16 years older (see Table 1). At baseline, intervention caregivers had a trend towards reporting fewer troubling dementia behaviours (p = .077) and less bother compared to control caregivers (p = .038). At baseline, care recipients were predominantly male and had severe dementia (Table 1). Intervention care recipients, compared to control, had greater use of cognitive enhancers (p = .032).

## Process

Of the 77 intervention caregivers, 47 (61%) had at least 75% of the 14 sessions and 59 (76.6%) completed at least half. Six caregivers (7.8%) had fewer than three sessions. On average, for each of the 15 groups, of the eight topics selected by group members, four were behaviour and four were stress and coping. Positive thinking was selected by 73% of groups, activities and holidays each by 60% of groups, and confusion, feelings, and getting help by 53% of groups.

During the year, intervention and control caregivers had contact with study personnel for data collection for approximately 6.75 hours. Data-collection time compared between control (M = 6.4 hours, SD = 1.9) and intervention (M = 5.7 hours, SD = 1.5) caregivers was not significantly different (p = .170).

#### Outcomes

There were no significant group by time interactions in caregiver outcomes (Table 2). Clinical significance, measured by effect size (*d*), ranged from .04 to .31. Controlling for baseline values made no substantive change to significant versus not-significant results.

Satisfaction scores for groups and components were all between *very* and *extremely satisfied*, with an overall group satisfaction score of 4.8 and average scores for logistics and components of 4.7 each. Difficulties were minimal. Benefit ratings were between *very much* and *extremely helpful* (M = 4.2). Participants valued the sharing of different perspectives and the support and interaction of others, with two thirds of comments mentioning these areas.

Table 1 Baseline Characteristics of Caregivers and Care Recipients (N = 154)					
Variable	Control $(n = 77)$ $M \pm SD \text{ or } \%$	Intervention $(n = 77)$ $M \pm SD$ or %	p value <sup>a</sup>		
CAREGIVER					
Demographics Age (years) Female Race White/Caucasian Black/African-American	65.0 ± 12.6 85.7 67.5 31.2	66.2 ± 12.3 81.8 72.7 27.3	.552 .512 .510		
Filipino/a Employed Married Education (years) Household income (\$)	$ \begin{array}{c} 1.3 \\ 22.1 \\ 83.1 \\ 12.9 \pm 1.9 \\ 34,946 \pm 22,310 \end{array} $	$ \begin{array}{c} 0 \\ 27.3 \\ 88.3 \\ 12.8 \pm 2.1 \\ 34,041 \pm 22,087 \end{array} $	.455 .357 .632 .803		
Caregiving Relationship to care recipient Spouse Child	71.4 22.1	72.7 23.4	.764		
Social support (0–69) Length of time caregiving (months) Caregiving hours on duty Caregiving time (hours)	$39.5 \pm 11.7$ $48.8 \pm 35.0$ $16.5 \pm 8.5$ $6.7 \pm 4.8$	$39.6 \pm 11.4$ $49.1 \pm 42.0$ $16.4 \pm 8.7$ $6.3 \pm 5.1$	.944 .957 .899 .631		
Clinical General health (1–5) Self-care (0–4) Burden (0–48) Depression (0–30) General well-being (22–110) Behaviours (0–72) Bother (0–96)	$2.8 \pm 1.1$ $2.9 \pm 1.1$ $17.7 \pm 9.1$ $10.4 \pm 6.8$ $67.4 \pm 16.3$ $24.0 \pm 11.2$ $26.4 \pm 18.0$	$2.9 \pm 1.0$ $2.9 \pm 1.0$ $16.4 \pm 8.3$ $10.8 \pm 6.2$ $69.0 \pm 16.5$ $21.1 \pm 9.0$ $21.0 \pm 13.7$	.750 > .999 .345 .709 .546 .077 .038		
CARE RECIPIENT					
Demographics Age (years) Male Education (years)	77.3 ± 7.7 88.3 11.2 ± 3.6	$77.5 \pm 7.2$ $87.0$ $11.2 \pm 4.0$	.899 .806 .916		
Clinical MMSE (0–30) Use of cognitive enhancers General health (1–5) ADL (0–6) IADL (0–8)	$15.6 \pm 7.3 \\ 51.9 \\ 2.3 \pm 1.2 \\ 3.1 \pm 2.1 \\ 7.5 \pm 0.9$	$15.2 \pm 7.7$ $68.8$ $2.2 \pm 0.9$ $2.8 \pm 2.1$ $7.5 \pm 1.0$	.785 .032 .821 .401 .871		
<sup>a</sup> <i>p</i> value from chi-square tests or <i>t</i> tests for independent samples, as appropriate.					

Table 2 Outcome Data for Intervention Caregivers (n = 77) and Control Caregivers (n = 77)							
Variable	Baseline M ± SD	3 Months $M \pm SD$	6 Months M ± SD	9 Months M ± SD	12 Months <i>M</i> ± <i>SD</i>	p value <sup>a</sup>	Intervention Effect Size
<b>Bother</b> (0–96)						.875	.07
Control	$26.4 \pm 18.0$	$22.4 \pm 16.2$	$22.6 \pm 17.2$	$19.0 \pm 13.3$	$21.7 \pm 16.5$		
Intervention	$21.0 \pm 13.7$	$17.7 \pm 12.0$	$17.0 \pm 12.4$	$15.1 \pm 10.7$	$18.6 \pm 14.1$		
<b>Burden</b> (0–48)						.708	.07
Control	17.7 ± 9.1	_	$15.6 \pm 9.3$	_	$15.3 \pm 9.1$		
Intervention	$16.4 \pm 8.3$	_	$15.6 \pm 7.9$	_	$14.5 \pm 6.6$		
Depression (0-30)						.802	.04
Control	$10.4 \pm 6.8$	_	$10.2 \pm 7.1$	_	$9.4 \pm 6.6$		
Intervention	$10.8 \pm 6.2$	_	$10.0 \pm 6.5$	_	$9.4 \pm 5.7$		
General well-being							
(22–110)						.385	.31
Control	$67.4 \pm 16.3$	$68.2 \pm 16.9$	$68.9 \pm 16.2$	$70.3 \pm 15.3$	$70.9 \pm 16.9$		
Intervention	69.0 ± 16.5	$67.0 \pm 15.7$	$67.9 \pm 15.1$	$68.4 \pm 14.9$	$67.4 \pm 13.3$		

*Note:* Values were not collected at 3 and 9 months for burden and depression.

 $<sup>^{\</sup>mathrm{a}}$  Group by time p values from repeated measures mixed linear model analyses.

## Discussion

This study with dementia caregivers found no significant difference in change over time between intervention and control caregivers. There can be multiple reasons for this, including factors related to outcomes, intervention, study design, or participants. There is no obvious reason for the lack of significant difference between the two groups. Because they were providing care for veterans, there was a high proportion of spouses, since more older men are married than older women. In their levels of burden, depression, and general health, our participants were similar to other populations of dementia caregivers (Belle et al., 2006). A qualitative analysis of control participants showed that 82% reported benefits from study participation (Nichols et al., 2012). Judging from the responses of control caregivers, the standardized questions of the assessment battery and the time spent interviewing the caregiver appear to be possible mechanisms of benefit.

CONNECT was based on REACH II (Belle et al., 2003), which has since been successfully translated into the VA (Nichols et al., 2011) and the Scott and White health-care system (Stevens et al., 2012). The CONNECT and REACH interventions both were multi-component with education, skills-building, and support and based on a stress-health process model. Both were risk-based to include safety, caregiver self-care/health and emotional well-being, social support, and patient problem behaviours/caregiver skills, all of which have been shown to be important for caregivers (Belle et al., 2006; Gottman et al., 2011; Schulz et al., 2003). Both were also targeted to the specific needs of the dyads who participated.

However, there were differences. REACH participants had 12 face-to-face or telephone individual sessions plus five telephone support group sessions over 6 months, whereas CONNECT participants had one individual telephone session and 14 telephone support group sessions over 12 months. Although telephone support groups have shown positive results for dementia caregivers (Bank et al., 2006; Martindale-Adams et al., 2002; Salfi et al., 2005), less one-on-one interaction may have decreased caregivers' response to the intervention.

Although the risk appraisal for the two interventions was the same and the intervention was targeted to meet the caregiving of the dyads — and has been shown to be effective (Goy et al., 2010) — there were differences in targeting. REACH was targeted to the concerns of one dyad, whereas CONNECT was targeted to the concerns of the five or six caregivers in a group. With these changes, our intervention may not have been able to elicit the effectiveness of REACH.

Although the cost-effectiveness of the REACH II intervention has been demonstrated (Nichols et al., 2008), in-home and/or individual visits are not feasible for many community agencies (Goy et al., 2010). For the CONNECT study, the telephone groups provided all components of the intervention using a low-cost, low-staffing modality. Each caregiver received 14 hours of intervention over the year in a group setting with four or five other caregivers. The groups had low technological demands, flexible meeting schedules, increased accessibility for those in rural areas and with frail care recipients, and no need for transportation.

One intervention limitation cited by participants was too little time spent in the groups. Some participants providing care for a person in the early stages of disease were frightened by the problems experienced by those caring for individuals with severe disease and felt that the discussions of associated problems were not germane to their situation. They might have benefited more from groups homogeneous as to severity level. Another possible limitation, which is a factor for telephone support groups in general, was lack of face-to-face interaction. One new trend in telephone and online support groups for dementia caregiving is interactive screen telephones or Web cameras so that participants can see each other, although these are not feasible for all agencies or all participants.

Although our study had ambiguous findings, it has clinical and research implications. Comparing CONNECT to REACH II, it appears that interventions targeted to specific needs or held more frequently than once a month may provide better support for caregivers who are caring for someone with a worsening condition. A shorter duration (6 months vs. 1 year) may represent a less daunting time commitment for participants. Based on participant comments, a support group that allows more time for members to discuss their concerns and more homogeneous groups based on severity may lead to better outcomes. In other work, we have focused on specific commitment action plans from each participant in a support group. These commitments may help participants personalize and take ownership of the information presented. In future research and practice, all of these avenues can be explored.

Two reviews have concluded that multicomponent, individualized treatments targeting specific caregiver-identified problems while offering individual and group interaction produce meaningful change in caregiver mood and coping (Brodaty, Green, & Koschera, 2003; Goy et al., 2010). However, while REACH II has been demonstrated to be cost-effective (Nichols et al., 2008), extensive in-home and individualized interventions may be too resource-intensive for organizations (Goy et al., 2010). A short, focused REACH VA intervention, delivered by telephone or in person and maximizing the efficiency of caregiver and interventionist

time together, is being implemented in VA. Another face-to-face or telephone model that should be tested is an individualized intervention in a group setting, where caregivers can work on individual concerns but exchange support and problem-solving. These low-cost, low-staffing modalities meet caregiver needs yet feature low technological demands, flexible meeting schedules, increased accessibility for those in rural areas and with frail care recipients, and no need for travel.

## References

- Alzheimer's Association. (2010). *Alzheimer's disease facts and figures*. Chicago and Washington: Author. Retrieved April 15, 2010, from http://www.alz.org/documents\_custom/report\_alzfactsfigures2010.pdf.
- Bank, A. L., Argüelles, S., Rubert, M., Eisdorfer, C., & Czaja, S. J. (2006). The value of telephone support groups among ethnically diverse caregivers of persons with dementia. *Gerontologist*, 46(1), 134–138.
- Bédard, M., Molloy, D., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *Gerontologist*, 41(5), 652–657.
- Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., . . . Zhang, S. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial. *Annals of Internal Medicine*, 145(10), 727–738.
- Brodaty, H., Green, A., & Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*, 51(5), 657–664.
- Brook, R. H., Ware, J. E., Davies-Avery, A., Stewart, A. L., Donald, C. A., Rogers, W. H., ... Johnston, S. A. (1979). Overview of adult health measures fielded in Rand's health insurance study. *Medical Care*, 17(Suppl 7), 1–131.
- Burgio, L. D., Collins, I. B., Schmid, B., Wharton, T., McCallum, D., & DeCoster, J. (2009). Translating the REACH caregiver intervention for use by area agency on aging personnel: The REACH OUT program. *Gerontologist*, 49(1), 103–116.
- Burns, R., Nichols, L. O., Martindale-Adams, J., Graney, M. J., & Lummus, A. (2003). Primary care interventions for dementia caregivers: 2-year outcomes from the REACH study. *Gerontologist*, 43(4), 547–555.
- Cohen, J. (1988). Statistical power analysis for the behavioral sciences (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum.
- Folkman, S., Schaeffer, C., & Lazarus, R. (1979). Cognitive processes as mediators of stress and coping. In V. Hamilton & D. Warburton (Eds.), *Human stress and cognition* (pp. 265–298). Chichester: John Wiley.
- Folstein, M. F., Folstein S. E., & McHugh, P. R. (1975). Mini-mental state: A practical method for grading the cognitive state of patients by the clinician. *Journal of Psychiatric Research*, 12(3), 189–198.

- Gottman, J. M., Gottman, J. S., & Atkins, C. L. (2011). The Comprehensive Soldier Fitness Program: Family Skills component. *American Psychologist*, 66(1), 52–57.
- Goy, E., Kansagara, D., & Freeman, M. A. (2010). A systematic evidence review of interventions for non-professional caregivers of individuals with dementia. Washington: Evidence-Based Synthesis Program Center, Portland VA Medical Center, Department of Veterans Affairs. Retrieved November 1, 2010, from http://www.hsrd.research.va.gov/publications/esp/Dementia Caregivers.pdf.
- Irwin, M., Artin, K. H., & Oxman, M. N. (1999). Screening for depression in the older adult: Criterion validity of the 10-item Center for Epidemiological Studies Depression Scale (CES-D). *Archives of Internal Medicine*, 159(15), 1701–1704.
- Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffee, M. W. (1963). The index of ADL: A standardized measure of biological and psychosocial function. *Journal of the American Medical Association*, 185, 914–919.
- Krause, N. (1995). Negative interaction and satisfaction with social support among older adults. *Journals of Gerontology, Series B, Psychological Sciences and Social Sciences*, 50(2), 59–73.
- Krause, N. (1997). Anticipated support, received support, and economic stress among older adults. *Journals of Gerontology, Series B, Psychological Sciences and Social Sciences*, 52B(6), 284–293.
- Krause, N. (1999). Assessing change in social support during late life. *Research on Aging*, 21(4), 539–569.
- Krause, N., & Markides, K. (1990). Measuring social support among older adults. *International Journal of Aging and Human Development, 30*(1), 37–53.
- Krause, N., & Shaw, B. A. (2002). Welfare participation and social support in late life. *Psychology and Aging*, 17(2), 260–270.
- Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *Gerontologist*, 9(3), 179–186.
- Lazarus, E. B., & Launier, R. (1978). Stress-related transactions between persons and environment. In L. Pervin & M. Lewis (Eds.), *Perspectives in international* psychology (pp. 287–325). New York: Plenum.
- Lubben, J. E. (1988). Assessing social networks among elderly populations. Family and Community Health: Journal of Health Promotion and Maintenance, 11(3), 42–52.
- Lubben, J., Blozik, E., Gillmann, G., Iliffe, S., von Renteln Kruse, W., Beck, J. C., & Stuck, A. E. (2006). Performance of an abbreviated version of the Lubben Social Network Scale among three European community-dwelling older adult populations. *Gerontologist*, 46(4), 503–513.
- Mahoney, D., Jones, R., Coon, D., Mendelsohn, A., Gitlin, L., & Ory, M. (2003). Caregiver vigilance instrumentation and use with Alzheimer's family caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, 18(1), 39–48.

- Mahoney, R., Regan, C., Katona, C., & Livingston, G. (2005). Anxiety and depression in family caregivers of people with Alzheimer's disease: The LASER-AD study. *Journal of the American Geriatrics Society*, 13(9), 795–801.
- Martindale-Adams, J., Nichols, L. O., Burns, R., & Malone, C. (2002). Telephone support groups: A lifeline for isolated Alzheimer's disease caregivers. *Alzheimer's Care Quarterly*, 3(2), 181–189.
- Marziali, E., & Garcia, L. J., (2011). Dementia caregivers' responses to 2 Internet-based intervention programs. *American Journal of Alzheimer's Disease and Other Dementias*, 26(1), 36–43.
- Miller, W. R., & Rollnick, S. (1991). *Motivational interviewing: Preparing people for change*. New York: Pacific Press.
- National Alliance for Caregiving. (2010). Caregivers of veterans Serving on the homefront: Report of study findings. Bethesda, MD: Author. Retrieved December 16, 2010, from http://www.caregiving.org/data/2010\_Caregivers\_of\_Veterans\_FULLREPORT\_WEB\_FINAL.pdf.
- Nichols, L. O., Chang, C., Lummus, A., Burns, R., Martindale-Adams, J., Graney, M. J., . . . Czaja, S. (2008). The cost-effectiveness of a behavior intervention with caregivers of Alzheimer's patients. *Journal of the American Geriatrics Society*, 56(3), 413–420.
- Nichols, L. O., Martindale-Adams, J., Burns, R., Graney, M. J., & Zuber, J. (2011). Translation of a dementia caregiver support program in a health care system: REACHVA. *Archives of Internal Medicine*, 171(4), 353–359.
- Nichols, L. O., Martindale-Adams, J., Burns, R., Graney, M. J., Zuber, J., & Kennedy, S. E. (2012). Potential explanations for control group benefit. *Clinical Trials*, *9*(5), 588–595.
- O'Rourke, N., & Tuokko, H. A. (2003). Psychometric properties of an abridged version of the Zarit Burden Interview with a representative Canadian caregiver sample. *Gerontologist*, 43(1), 121–127.
- Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measures*, 1(3), 385–401.
- Salfi, J., Ploeg, J., & Black, M. E. (2005). Seeking to understand telephone support for dementia caregivers. Western Journal of Nursing Research, 27(6), 701–721.
- Schoenfelder, D., Swanson, E., Specht, J., Maas, M., & Johnson, M. (2000). Outcome indicators for direct and indirect caregiving. *Clinical Nursing Research*, 9(1), 47–69.
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association*, 282(23), 2215–2219.
- Schulz, R., Burgio, L., Burns, R., Eisdorfer, C., Gallagher-Thompson, D., Gitlin, L. N., & Mahoney, D. F. (2003). Resources for enhancing Alzheimer's caregiver health (REACH): Overview, site-specific outcomes, and future directions. *Gerontologist*, *43*, 514–520.
- Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry*, 12(3), 240–249.

- Sikkes, S. A., de Lange-de Klerk, E. S., Pijnenburg, Y. A., Scheltens, P., & Uitdehaag, B. M. (2009). A systematic review of Instrumental Activities of Daily Living scales in dementia: Room for improvement. *Journal of Neurology, Neurosurgery and Psychiatry, 80*(1), 7–12.
- Smith, T. L., & Toseland, R. W. (2006). The effectiveness of a telephone support program for caregivers of frail older adults. *Gerontologist*, 46(5), 620–629.
- Smith, T. L., Toseland, R. W., Rizzo, V. M., & Zinoman, M. A. (2004). Telephone caregiver support groups. *Journal of Gerontological Social Work*, 44(1–2), 151– 172.
- Sorensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist*, 42(3), 356–372.
- Spector, W. D., Katz, S., Murphy, J. B., & Fulton, J. P. (1987). The hierarchical relationship between activities of daily living and instrumental activities of daily living. *Journal of Chronic Disease*, 40(6), 481–489.
- Spotswood, S. (2012). To plan for future care VA must assume TBI-dementia link. *US Medicine*, 2012 Compendium of Federal Medicine. Retrieved December 11, 2012, from http://www.usmedicine.com/compendium/to-plan-for-future-care-va-must-assume-tbi-dementia-link-.html.
- Stevens, A. B., Smith, E. R., Trickett, L. R., & McGhee, R. (2012). Implementing an evidence-based caregiver intervention within an integrated healthcare system. *Translational Behavioral Medicine*, 2(2), 218–227.
- Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1992). Assessment of behavioral problems in dementia: The Revised Memory and Behavior Problems Checklist. *Psychology and Aging*, 7(4), 622–631.
- Tombaugh, T. N., & McIntyre, N. J. (1992). The mini-mental state examination: A comprehensive review. *Journal of American Geriatrics Society*, 40(9), 922–935.
- Toseland, R. W., Naccarato, T., & Wray, L. O. (2007). Telephone groups for older persons and family caregivers: Key implementation and process issues. *Clinical Gerontologist*, *31*, 59–76.
- Toseland, R., & Rivas, R. (2005). An introduction to group work practice (5th ed.). Needham Heights, MA: Allyn & Bacon.
- Ware, J. E., Kosinski, M., Bayliss, M. S., McHorney, C. A., Rogers, W. H., & Raczek, A. (1995). Comparison of methods for the scoring and statistical analysis of SF-36 health profile and summary measures: Summary of results from the Medical Outcomes Study. *Medical Care*, 33(4 Suppl), 264–279.
- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist*, 20(6), 649–655.

## Acknowledgements

This work was supported by the Veterans Health Administration, Health Services Research and Development Service (IIR-03-287-1), US Department of Veterans Affairs, with additional support from the Memphis Veterans Affairs Medical Center. The contents are solely the responsibility of the authors and do not represent the views of the

Department of Veterans Affairs or the United States government. Clinical Trials Identifier: NCT00119561.

We would like to thank the CONNECT intervention and data-collection staff: Celeste Bursi, MSSW; Barbara Higgins, MA; Juliana Lindenberg, MDiv; and Patricia Miller, MA. Invaluable comments on the manuscript were provided by Jordan Fields, MS; Katherine Bracken-Minor, MS; and Francisco Salgado-Garcia, MA. We also thank our caregivers for finding the time to participate in the study while providing excellent care to their family members.

Jennifer Martindale-Adams, EdD, is Assistant Professor, Department of Preventive Medicine, University of Tennessee Health Science Center, and Co-Director, Caregiver Center, Veterans Affairs Medical Center, Memphis, United States. Linda O. Nichols, PhD, is Co-Director, Caregiver Center, Veterans Affairs Medical Center, and Professor, Departments of Preventive Medicine and Internal Medicine, University of Tennessee Health Science Center. Robert Burns, MD, is Principal, Geriatrics Group of Memphis, and Professor, Departments of Preventive Medicine and Internal Medicine, University of Tennessee Health Science Center. Marshall J. Graney, PhD, is Researcher, Veterans Affairs Medical Center, and Professor Emeritus, Department of Preventive Medicine, University of Tennessee Health Science Center. Jeffrey Zuber, MA, is Research Specialist, Department of Preventive Medicine, University of Tennessee Health Science Center, and Veterans Affairs Medical Center.