A Spiritually Based Caregiver Intervention With Telephone Delivery for Family Caregivers of Veterans With Dementia

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Caring for veterans with dementia is burdensome for family caregivers. This exploratory study tested the efficacy of an innovative, spiritually based mantram caregiver intervention delivered using teleconference calls. A prospective, within-subjects, mixed-methods, and 3-time repeated-measures design with 36-week follow-up telephone interviews was conducted. Sixteen caregivers (94% women, 94% Whites with mean age 69.2 years, SD = 10.35 years) completed the intervention. Significant effects for time and linear terms were found for decreasing caregiver burden, perceived stress, depression, and rumination and for increasing quality of life enjoyment and satisfaction, all with large effect sizes. Findings suggest that teleconference delivery of a spiritually based caregiver intervention is feasible.

Key words: caregivers, dementia, mantram, spiritual therapies, telemedicine

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he number of people with Alzheimer disease (AD) is growing. The estimated number of Americans with AD in 2008 was 5.2 million, and there are approximately 9.8 million caregivers in the United States. The Alzheimer's Association reports that "every 71 seconds, someone in America develops AD." As the baby boomer population ages, the number of people

with AD is likely to increase significantly, creating more burden on family caregivers. The majority of patients with AD live with their caregivers in the community rather than in institutions.

Caring for people with conditions such as AD is demanding, stressful, and often impairs health. Research has shown

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that there is an increase in depression, anxiety, and perceived stress as well as lower quality of life and increased mortality and morbidity in family caregivers. ^{2–5} Besides psychological distress, caregiving is shown to impair the immune system and overall caregiver health. ^{6–10} In the large 1994 Canadian Study of Health and Aging (N = 613), results indicated that high caregiver burden was associated with more depressive symptoms.

Another study has shown that caregivers living in the community have also reported higher caregiver burden and more depression. ¹¹ In a clinical trial comparing 41 caregivers with 41 noncaregivers, researchers found that AD caregivers with chronic stress had altered T-cell function and accelerated immune cell aging equivalent to adding an additional 4 to 8 years of aging to caregivers' lives when compared with the control participants. ¹²

An examination of the literature regarding caregiver interventions showed that of 40 studies, about two-thirds showed no improvements in any outcomes. Among interventions that did demonstrate improvements, social support or a combination of social support and cognitive skills was shown to be relatively effective. In a longitudinal study of AD family caregivers, Goode and colleagues found that benign appraisals of stressors, use of approach coping, and having social support were associated with more positive caregiver health outcomes. Limitations of these studies were small sample sizes and various methodological concerns. Recommendations were to carefully describe intervention components and design studies of sufficient size.

Marriott and colleagues evaluated the effects of a cognitive-behavioral intervention on reducing family caregivers' subjective burden of care. 15 A prospective, singleblind, randomized trial with 3-month follow-up was conducted. An experimental group (n = 11) received the family cognitive-behavioral intervention and was compared with 2 control groups (each with n = 9 caregivers). The 14-session intervention delivered in 2-week intervals consisted of caregiver education about AD and its manifestations and stress management skills including self-monitoring, relaxation, and cognitive-behavioral responses. Control groups did not receive any interventions. There were significant reductions in distress and depression in the caregivers in the experimental group when compared with those in the control groups at posttreatment and follow-up, and there were increased caregiver activities at 3 months. 15

These research results highlight the importance of caregivers learning to effectively manage disturbing patient behaviors and obtaining formal services to improve caregiver coping skills.¹¹ Studies have shown that care-

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givers who are better able to manage patients' symptoms and use of caregiver-related services have fewer physical health symptoms. 16 Despite the variety and effectiveness of caregiver support interventions, however, family caregivers often have difficulty utilizing them. Caregivers often have total responsibility for their loved ones. This can lead to isolation. They are frequently unable to obtain caregiver support services because of reluctance to leave care recipients alone 17 or because of the costs, time, and/or distance it takes to obtain services. Therefore, more convenient treatment options and services that are available to caregivers at home are needed. Using technology such as telecommunication or Internet connections to assist family caregivers may be one solution and is a growing area of study. Czala and colleagues, for example, demonstrated how a computer-integrated telephone system helped caregivers to meet care challenges and improve their quality of life. 18

Mantram repetition group intervention

A family caregiver support program was modeled after a spiritually based intervention using mantram or mantra,

The spiritually based caregiver program resulted in significant reductions in most measures of caregiver psychological distress and an improvement in quality of life satisfaction and enjoyment with time.

sometimes termed "holy name," repetition. Mantram repetition is defined as silently repeating a sacred word or phrase chosen by the participant to focus attention and calm the mind. ^{19,20} The intervention, delivered in face-to-face group meetings, includes education and skills training on slowing down and developing 1-pointed attention.

The mantram program has demonstrated benefits of reducing stress and anxiety while improving the quality of life and existential spiritual well-being in other groups of veterans²¹ and healthcare providers.^{22,23} In adults living with the human immunodeficiency virus (HIV), research has demonstrated that mantram participants, when compared with education controls, had significantly greater increases in positive appraisal coping,²⁴ increases in faith/assurance,²⁵ and reductions in traitanger.^{24,25} Findings also demonstrated lagged inverse relationships between faith/assurance and average salivary cortisol levels, suggesting a positive influence on immune function.²⁶

The family caregiver group intervention was originally provided as an 8-week (60 min/wk) group training on silently repeating a mantram for stress management. Caregivers were taught to choose and repeat a mantram silently whenever possible during spare moments every day and at night before sleep. When repeated during nonstressful moments, a mantram becomes associated with a subjective state of calmness. As a mental tool, a mantram can be repeated to redirect attention and interrupt negative, ruminating thoughts. Mantram repetition is practical, easy-to-learn, nontoxic, and inexpensive and requires normal (ie, nondelusional, nonschizoid) cognitive functioning, short-term memory, and a willingness to practice. It can be repeated at any time or place and requires no special equipment, thus making it portable, invisible, and convenient. It can be repeated during activities such as household chores or exercise or when still. To enhance caregiver patience, mantram repetition

was taught as a response to a loved one's forgetfulness, irritability, or demanding behaviors. By repeating a mantram to replace reactivity, caregivers could pause and more easily identify dysfunctional thoughts and interrupt the stress response.

Twenty family caregivers of veterans were enrolled in a pilot feasibility study of this face-to-face mantram caregiver program. Each course had 5 to 8 caregivers. The majority (85%) were spouses of veterans with AD (n=15), cancer (n=1), stroke (n=1), mental illness (n=1), or Parkinson disease (n=1). Sixteen (80%) were Whites, 3 (15%) were African American, and 1 (5%) was Hispanic. Average age was 71 years (SD = 7.09 years); average years of caregiving was 3.6 years (SD = 3.36 years; median = 5 years).

Results showed that perceived stress was reduced from a pretest mean of 19.9 (SD = 6.78) to posttest mean of 15.2 (SD = 4.63; t = 1.82, df = 14, P = 0.09). There were slight, nonsignificant increases in mindfulness attention awareness.

With time, however, it was discovered that many caregivers reported difficulty in attending classes due to travel and caregiver responsibilities. Because the face-to-face program was found feasible and useful with trends toward stress reduction, a teleconference-call method of delivering the program was created to reach more caregivers, especially those from a distance.

Teleconference-delivered caregiver intervention

The teleconference-delivered caregiver intervention consisted of the same 8-week program of mantram repetition as described previously but with 3 additional cognitive-behavioral skills of identifying and replacing dysfunctional thoughts, increasing caregiver self-care activities, and improving assertive listening. Education about patient placement and community resources (eg, Safe Return, adult day care, Alcoholics Anonymous, and Alzheimer's Association) was also included. Telephone headsets for "hands-free" listening were provided to caregivers who wanted them. The program was cofacilitated by a geriatric nurse practitioner and licensed clinical social worker. Caregivers met face-to-face in the first class and were provided course materials, the *Mantram Handbook*, ²⁷ reading assignments, and phone instructions for weekly conference calls.

The overall aim of this study was to evaluate the feasibility and efficacy of this innovative, teleconference-delivered, spiritually based family caregiver intervention on psychological distress and quality of life in a sample of family caregivers of veterans with dementia. The conceptual framework supporting the study is shown in Figure 1.

Caregiver burden & psychological distress Caregiver intervention Mantram repetition for relaxation and cognitive-behavioral skills training Caregiver burden & psychological distress Caregiver intervention Mantram repetition for relaxation and cognitive-behavioral skills training

AIM: To assess feasibility and efficacy of a teleconference-delivered, spiritually based, cognitive-behavioral family caregiver intervention on caregiver burden and psychological distress.

Hypothesis 1: Caregivers in the teleconference-delivered, spiritually based, cognitive-behavioral family caregiver intervention will report lower caregiver burden and psychological distress across study time points.

Hypothesis 2: Caregivers in the teleconference-delivered, spiritually based, cognitive-behavioral family caregiver intervention will report significantly greater quality of life and mindful attention awareness across study time points.

METHODS

Setting

The study was conducted at a Veterans Affairs (VA) hospital on an outpatient geriatric psychiatry unit serving elderly veterans with dementia or other psychiatric conditions or both with comorbid medical illnesses located in southern California. Human subjects' protections approvals were obtained from university and VA committees.

Inclusion and exclusion criteria

The study population consisted of family caregivers of veterans who received care for dementia, AD, Parkinson disease, brain injury, or other cognitive impairment from April 2006 to 2007. Inclusion criteria were caring for a veteran and having the ability to speak, read, and comprehend English. Exclusion criteria were difficulty hearing or inability to maintain confidentiality.

Participant recruitment

Caregivers, recruited from provider referrals and flyers, called the researcher with their interest to participate and

were assessed for eligibility. They attended a group meeting where the study was described and the researcher obtained written informed consent from them. Caregivers were enrolled in groups (3 to 5 caregivers per group) and were told that the study would include information related to both Western and Eastern religions or spiritual traditions or both.

Procedure

The intervention was delivered in 8 weekly classes: face-to-face meetings in weeks 1 and 8, teleconference calls in weeks 2 through 7. Cofacilitators conducted individual phone calls in weeks 10, 12, and 14 to assess adherence to, and encourage practice of, mantram repetition and cognitive-behavioral skills. A face-to-face meeting was held at week 16 for follow-up assessments. A final telephone interview was conducted at week 36 by a blinded interviewer who also assessed adherence to intervention skills.

Materials

Caregivers completed self-report demographics of age, gender, race/ethnicity length of time caregiving, relationship to care recipient, and recipient's diagnosis. Primary measures included Zarit Caregiver Burden Scale, ²⁸ Perceived Stress Scale, ^{29,30} Clinical Epidemiology Study for Depression (CESD)–Short Form, ^{31,32} Rumination, ³³ Spielberger Trait-Anger subscale, ³⁴ Quality of Life Enjoyment and Satisfaction Questionnaire Short Form, ³⁵ Mindfulness Attention Awareness Scale, ³⁶ and Client Satisfaction Questionnaire. ³⁷ All measures have previously reported acceptable validity and reliability. Caregivers completed questionnaires at preintervention (week 1), postintervention (week 8), and the 16-week follow-up. Structured telephone interviews using "yes" or "no" questions regarding mantram and cognitive-behavioral skills use were

conducted by cofacilitators at weeks 10, 12, and 14. The same questions were asked at 36 weeks postintervention.

Data analysis

Descriptive statistics were run on all study variables. The study had a completely within-subjects design with time = 3 repeated measures. Outcomes were first analyzed using the omnibus F test for significance (using α level of .05). If outcomes were found to be significant, then, up to time-1 polynomials were tested for any nonlinear trajectories. In this case, the maximum term to be tested for this trend analysis was quadratic. The partial eta squared (η^2) was the reported effect size with small/medium/large being .01/.059/.138 per Cohen, 38 although it was kept in mind that determination of effect size was context dependent.

RESULTS

Twenty-one caregivers enrolled, and 16 (76%) completed the study in small groups of 3 to 5 per group. Those who dropped out (23%) were "too busy" (n=4) or were not burdened enough (n=1) and did not differ in demographics from those who completed the study. Caregivers were 94% women, 94% Whites, 3% Hispanic/Latino, and 3% Asian with mean age of 69.2 years (SD = 10.35 years). Three-quarters were spouses with an average of 4.0 years (SD = 2.92 years) of caregiving. The majority (81%) of care recipients had AD.

Change in outcomes was determined by first using the omnibus F test, and if established and significant at P < 0.05, a test for linear trend was performed for each measure. Caregiver burden scores in this sample were considered "high" at baseline with a mean of $23.2~(\mathrm{SD} = 9.58)$; and they decreased significantly, showing a linear trend at weeks $8~(M = 17.94, \mathrm{SD} = 7.74)$ and $16~(M = 16.75, \mathrm{SD} = 7.99)$. Similarly, there were significant effects for time and linear terms for perceived stress, depression, and rumination, but little change was observed in trait-anger (see Table 1). There was also a significant effect for time and linear terms for quality of life but not for mindfulness attention awareness.

The intervention content that was evaluated at 8-week follow-up interviews indicated that 14 (88%) caregivers found that the cognitive behavioral action skills "were helpful." All 16 caregivers (100%) reported that mantram repetition skills "were helpful," and all stated that they would recommend the program to others. Other aspects of the

TABLE 1.

		M (SD)				Partialb	
Outcomes ^a (possible range)	Preintervention	Postintervention	8-week follow-up	F	Ь	η2	Post hoc ^c
Zarit caregiver burden (0–40)	23.19 (9.58)	17.94 (7.74)	16.75 (7.99)	5.78	0.02	.28	Tl vs T3
Perceived stress (0-40)	21.06 (5.35)	15.25 (6.23)	16.25 (5.31)	8.81	0.001	.37	TI vs T2 & T3
Depression (CES-D-SF) (0-10)	4.56 (1.21)	3.31 (2.33)	2.94 (2.35)	5.00	0.02	.25	TI vs T3
Rumination (10–40)	20.67 (3.65)	19.42 (2.64)	17.17 (3.38)	6.82	0.005	.38	TI vs T3
Trait-anger (10–40)	13.81 (2.46)	14.25 (4.48)	14.25 (4.06)	0.29	0.68	.02	A Z
Quality of life Q-LES-Q-SF (14-70)	45.83 (6.87)	46.37 (9.86)	50.14 (7.44)	4.65	0.04	.24	T3 vs Tl & T2
Mindful attention awareness (15–90)	67.16 (9.82)	67.25 (8.71)	67.31 (11.06)	.003	0.99	.0002	AZ.

Abbreviations: CES-D-SF, Center for Epidemiological Studies Depression Scale Short Form; Q-LES-Q-SF, Quality of Life Enjoyment and Satisfaction Short Form.

Higher scores mean more of the variable.

^bPartial $\eta^2 =$ effect sizes: small (.01), medium (.059), and large (.138). Post hoc testing conducted via Sidak Test (reported significant pairwise differences only if the omnibus F had P < 0.05)

TABLE 2.

Number and Percentage of Caregivers (n = 16) Reporting Use of Mantram and Cognitive-Behavioral Skills at Weeks 10, 12, 14, and 36 Postintervention^a

	Week 10	Week 12	Week 14	Week 36
Total who responded, n	16	16	13	15
Have you used mantram? "Yes" responses	14 (88)	15 (94)	10 (77)	15 (100)
Have you used mantram for (the emotion listed)? "Yes"	responses for th	ne following with	actual quotes from	week 36:
1. Anger—"when I get so angry"	12 (75)	8 (50)	8 (62)	9 (60)
2. Anxious/worried—"when driving/on freeway"	12 (75)	13 (81)	10 (77)	10 (67)
3. When inpatient—"getting inpatient; having to wait"	8 (50)	10 (63)	6 (46)	11 (73)
4. Frustrated/irritated—"when irritated with husband's behavior" or "to find misplaced objects"	9 (56)	8 (50)	10 (77)	11 (73)
5. Depressed/hopeless—"feeling little depressed"	6 (38)	6 (38)	4 (31)	7 (50)
 Sad/grieving—"when husband doesn't hear me" or "I know he is not the same man" 	7 (44)	6 (38)	4 (31)	6 (43)
 Insomnia/cannot sleep—"to go to sleep; when waking up at night" or "to go back to sleep" 	10 (63)	12 (75)	10 (77)	11 (73)
8. Bored/tired—"in day when tired"	7 (44)	6 (38)	6 (46)	5 (33)
9. Excited/overly happy	1 (6)	1 (6)	0 (0)	2 (13)
Have you used cognitive-behavioral skills for (listed below)	"Yes" respons	es		
1. Identified and replaced dysfunctional thoughts	11 (69)	8 (50)	11 (85)	11 (73)
2. Planned pleasurable activity	11 (69)	12 (75)	11 (85)	14 (93)
3. Used assertive listening skills	10 (63)	11 (69)	11 (85)	9 (60)

aValues are expressed as n (%) unless otherwise indicated.

teleconference-delivery method that were evaluated positively included the length of calls, ease of calling in, and feeling supported. Most caregivers, however, did not like the hands-free telephone headsets and returned them before the end of the study.

Satisfaction of the program was evaluated by using the Client Satisfaction Questionnaire. Results of the Wilcoxin signed ranks test at 8 weeks postintervention showed significance (Z=-2.0, P=0.046), suggesting that the majority of caregivers were satisfied. Satisfaction from week 8 to week 16 was evaluated using the McNemar test, which ignores the rank-ordered nature of categories, and was found to be nonsignificant, suggesting satisfaction levels not significantly changing with time. At week 8, 81% rated satisfaction as "high" and 19% as "moderate." At week 16, 56% rated satisfaction as "high" and 44% as "moderate."

Results of individual phone calls assessing adherence to mantram and cognitive-behavioral skills in weeks 10, 12, 14, and 36 are shown in Table 2. Various ways that caregivers utilized mantram repetition are provided. At 36-week follow-up, caregivers also reported needing support longer than the 16 weeks of the study. They preferred

group phone calls every 2 weeks and suggested caregiver interventions be provided for longer periods.

DISCUSSION

The spiritually based caregiver program resulted in significant reductions in most measures of caregiver psychological distress and an improvement in quality of life satisfaction and enjoyment with time. The teleconference delivery of the program was feasible and appeared to improve access and participation such as for 1 caregiver who lived 160 miles away. All caregivers reported moderate to high satisfaction with the intervention, both at weeks 8 and 16.

It is noteworthy that the majority of caregivers found the behavioral/action skills "helpful" and all found mantram repetition "helpful." The mantram practice was still being used at 36-week follow-up, indicating its practicality and sustainability. Mantram was used for a variety of stressful or frustrating situations, not all directly related to caregiving.

There are limitations to this study, however, and the lack of a control group suggests caution in the interpretation of its benefits. Larger samples and randomized trials are needed to determine whether these therapeutic outcomes are associated with either mantram practice or cognitive-behavioral skills, beyond the social support provided by the group. Findings of this study may not be generalizable to other nonveteran caregiver groups, and there were no measures of the care recipients' symptom severity. Findings may have differed if care recipients were more debilitated.

Cost of the program for provider time was no different from the cost of face-to-face group meetings, but some administrative support was needed to set up the conference call bridge for the weekly calls. Other costs included materials and textbooks.

Nevertheless, because of constraints on family caregivers' time and energy, more innovative, teleconference-delivered programs are needed to reach more caregivers and potentially reduce caregiver burden in a larger number. This method of caregiver support may be especially useful in rural settings. Spiritually based interventions may offer a unique component of support, and more study of such programs is needed. Maintaining caregivers' psychological health may improve quality of life and assist them in caring for veterans. The expected benefit to veterans is a greater likelihood of maintaining access to and receiving VA healthcare via their caregivers.

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