“Easing the Way” for Spouse Caregivers of Individuals with Dementia
A Pilot Feasibility Study of a Grief Intervention

Carol H. Ott, PhD, RN; Sheryl T. Kelber, MS; and Michele Blaylock, BS, RN

ABSTRACT
A multicomponent intervention targeting grief symptoms in spouse caregivers of individuals with dementia was pilot tested in this feasibility study. Twenty spouse caregivers completed the study within the 5-month protocol. The five-component intervention, deduced from Meuser, Marwit, and Sanders’ Dementia Caregiver Grief Model and tailored to participants’ grief, mental health, and learning needs, included supportive grief counseling, emotional support, education, skill building, and referral to community resources. Significant changes were found from baseline to intervention completion for the measures of grief, depression, anxiety, positive states of mind, and self-efficacy, resulting in a moderate effect size of –0.43 for grief to a large effect size of –2.40 for anxiety. Increases in quality of life and decreases in grief persisted at the 8-month follow up for caregivers who continued to provide care in the home. The Easing the Way intervention protocol is a promising caregiver program that warrants further testing in a randomized controlled study.

Caregivers of spouses with dementia have described their experience of loss as “triple grief”: grief due to changes in the relationship resulting from memory loss, grief at the time of admission to a long-term care facility, and finally grief after the spouse’s death (Prigerson, 2003). Grief originates from losses in the quality of the relationship, intimacy, memory, communication, social interaction, health status, and opportunities to resolve issues from the past (Loos & Bowd, 1997; Sanders & Corley, 2003). The person with dementia is physically present but psychologically absent, resulting in what some describe as an ambiguous loss (Boss, 1999). Spouse caregivers of individuals with dementia find themselves in an extremely difficult situation, providing care to someone who is unable to express appreciation for the care provided while at the same time grieving losses in the relationship (Prigerson, 2003). For spouse caregivers in particular, the grief experience is characterized by increased sadness and longing, worry...
and isolation, and personal sacrifice burden (Meuser & Marwit, 2001; Ott, Sanders, & Kelber, 2007). When spouse caregivers are unable to meet the complex needs of the care recipient with end-stage dementia, many make the difficult decision to place the person in a long-term care facility. This decision often results in an escalation of grief (Algase, 2007; Meuser & Marwit, 2001; Ott et al., 2007). The third grief experience for spouse caregivers occurs after the actual death of the spouse. The experience of the multiple losses faced by dementia caregivers has been described by family members as “the long goodbye” (Davis, 2004).

A multicomponent intervention, Easing the Way, was designed to address the grief experienced by spouse caregivers of individuals with moderate to severe dementia. The intervention, deduced from Meuser, Marwit, and Sanders’ (2004) Dementia Caregiver Grief Model, used responses to the subscales of heartfelt sadness and longing, worrying and felt isolation, and personal sacrifice burden to address pre-death grief. The pilot study reported in this article was designed to obtain preliminary data on the feasibility of testing the Easing the Way intervention in a larger randomized controlled study.

BACKGROUND

The stress of caring for a person with dementia has been shown to negatively affect mental and physical health (Pinquart & Sörensen, 2003; Vitaliano, Young, & Zhang, 2004). The disease develops most frequently in those who are of advanced age; consequently, the burden of caregiving usually falls on the spouse, who is often elderly as well with his or her own health problems. The duration of caregiving is long, with more than 30% of caregivers providing care for more than 5 years (Alzheimer’s Association, 2009), and the extent and type of care required is demanding and challenging, both physically and psychologically. Caregiving issues include managing behavioral and psychiatric symptoms such as physical and verbal aggression, paranoia and hallucinations; wandering; sleep disturbances; nutrition and swallowing problems; incontinence; skin problems; and others. Caregivers use a variety of emotion-focused, problem-focused, and dysfunctional coping strategies to address these challenges (Cooper, Katona, Orrell, & Livingstone, 2008).

As a part of a large prospective multisite National Institutes of Health caregiver intervention study, Resources for Enhancing Alzheimer’s Caregiver Health (REACH), researchers followed caregivers during the year before and after the loved one’s death (Schulz, Boerner, Shear, Zhang, & Gitlin, 2006). During the last few months of the patient’s life, nearly 43% of the family caregivers had clinically significant levels of depression. After the death, 20% of the spouses experienced a long and complicated bereavement (Schulz et al., 2006). Although the REACH intervention did not target grief symptoms, caregivers in the intervention group reported lower levels of complicated grief and depression after the death compared with those in the control group. Similar results were reported from a randomized clinical trial of an enhanced caregiver support intervention (Haley et al., 2008). Recommendations from these prospective studies call for interventions to maximize the well-being of caregivers and an investment in resources for support at the end of life.

While it has been well documented that caregivers of individuals with dementia experience high levels of depression (Buckwalter et al., 1999; Crespo, López, & Zarit, 2005; Pinquart & Sörensen, 2003), the intense focus on depression has meant the concept of caregiver grief has only recently been explored (Meuser & Marwit, 2001; Ott et al., 2007; Ponder & Pomeroy, 1997). Prior to the intervention study described in this article, an initial descriptive study of 201 spouse and adult child caregivers of individuals with dementia was conducted to examine the intensity of pre-death grief and to identify the factors that contributed to higher levels of grief and personal growth (see Ott et al., 2007 and Sanders, Ott, Kelber, & Noonan, 2008). Results of the Ott et al. (2007) study indicated that high levels of pre-death grief were associated with decreased mental health; dysfunctional coping strategies were associated with increased grief; the majority of spouse caregivers experienced personal growth; and placement of the spouse with dementia in a long-term care facility was associated with increased grief and depression.

Using both results from the Ott et al. (2007) study and input from experts in the field of gerontology and grief studies, the Easing the Way intervention was developed. It includes the manual A Guide to Supporting Family Caregivers Through the Alzheimer’s Disease Trajectory: Grief and Personal Growth (Ott, Reynolds, Schlidi, & Noonan, 2006) to guide the intervention. The manual offers a description of pre-death grief in dementia caregivers; findings from the Ott et al. (2007) study; assessment of caregiver grief with interpretative statements; discussion of care recipient and caregiver needs in relation to the stage of dementia; and a compilation of community resources, information, and services to support caregivers. The Easing the Way manual can be downloaded free at http://www.ageandcommunity.org/products.html.
STUDY PURPOSE

This pilot study of caregivers of spouses with dementia was conducted to determine the feasibility of using the manual (Ott et al., 2006) as the basis for the Easing the Way intervention. A second goal of the pilot study was to estimate the effectiveness of the intervention by examining the changes in grief and mental health from baseline to completion of the intervention period and at the 8-month follow up. Key concepts from Meuser et al.’s (2004) Dementia Caregiver Grief Model used in this study were the causal pathways between the grief response, coping strategies, symptoms of the depression-stress-burden constellation, and emotional well-being.

METHOD

A single-group repeated measures design—baseline, end of intervention, and follow up at 8 months—was used to describe changes in grief and mental health in 20 spouse caregivers of individuals with dementia and to test the effectiveness of the Easing the Way pilot intervention.

Procedures

Institutional review board approval was obtained from the University prior to the initiation of the study. Between June and November 2007, informational pamphlets were distributed to eligible caregivers through community agencies, parish nurses, support groups sponsored by the Alzheimer’s Association, and adult care centers. After providing informed consent, caregivers received a packet of questionnaires to be completed within the next week. These data provided baseline information. Caregivers completed the same packet of questionnaires at the end of the intervention. To avoid caregiver fatigue and minimize participant withdrawal, an abbreviated packet of questionnaires was distributed at the 8-month follow up. Caregivers received $30 in gift certificates for their involvement in the study.

Caregivers were called approximately 2 weeks after the initial session to schedule future meetings; most sessions had 3- to 4-week intervals between them. Spouse caregivers participated in the intervention over an average of 4.8 months (SD = 0.9). The intervention was delivered by the principal investigator (PI) (C.H.O.) in one-to-one sessions either in person or by telephone, and each session lasted 1 to 2 hours. The PI is a licensed professional counselor and an RN, certified as a thanatologist through the Association for Death Education and Counseling. She is also an End-of-Life Nursing Education Consortium instructor and regularly teaches palliative care graduate and undergraduate courses. She has a program of research in grief and loss and has conducted bereavement support groups in the community for more than 20 years. Because the intervention was tailored to each caregiver’s needs, the number of in-person sessions in the Easing the Way protocol varied from a minimum of 3 sessions to a maximum of 8 (mean = 4.9, SD = 1.7). In addition to the in-person sessions, telephone sessions were conducted with 8 caregivers (mean = 2.38, SD = 1.1). To ensure that appropriate interventions and referrals were made, cases were reviewed following each session by a medical social worker who is an expert in dementia and mental health. Nurse practitioner consultation was sought to address any identified physical needs of the care recipient.

Sample

Criteria for participation in the study included being a caregiver of a spouse with dementia, able to speak English, being older than age 18, and living with the care recipient. Caregivers were excluded if they had an illness that would prevent them from providing care.

A total of 23 spouse caregivers volunteered to participate in the intervention. Two of the 23 potential caregivers declined enrollment due to the time commitment, and one was excluded because of an anticipated hospitalization for major surgery scheduled during the study period. The 20 eligible volunteers agreed to meet with the PI either in their homes (n = 15) or at a local library (n = 5). All 20 caregivers completed the study. At the 8-month follow up, 8 care recipients no longer lived at home; 6 had been placed in nursing homes, 1 spouse-caregiver dyad had moved to a senior facility, and 1 had died.

The spouse caregivers ranged in age from 56 to 85 (mean age = 73.5, SD = 7.3 years), while the care recipients ranged in age from 63 to 88 (mean age = 77.7, SD = 7.8 years). Most of the caregivers were women (75%), the majority had completed high school or some college (80%), and all were Caucasian. Caregivers had been married between 13 and 63 years (mean = 45.1, SD = 13.8), 90% belonged to a major religious denomination, and approximately half (45%) indicated that their own health was poor.

The majority of caregivers indicated that since their spouse’s diagnosis of dementia, they had curtailed their social activities (65%), recreational activities (55%), volunteer activities (50%), and home maintenance (50%). In response to a question during the baseline interview about available services, caregivers indicated having used an adult care program (60%), a lawyer (55%), a physician (50%), a support group (35%), and resources from the Alzheimer’s Association (30%).
<table>
<thead>
<tr>
<th>Subscale</th>
<th>Description of Subscale</th>
<th>Examples of Interventions</th>
</tr>
</thead>
</table>
| Heartfelt sadness and longing    | “Traditional grief-related sadness and longing for what was in the past; a yearning for the old relationship from before the onset of dementia” (Sanders, Marwit, Meuser, & Harrington, 2007, p. 55) | Support the caregiver in telling the story of the care recipient's disease process (Sanders et al., 2007; emotion-focused coping).  
Assist in processing feelings of loss through one-on-one dialogue, group support, journaling, and creation of memory books (emotion-focused coping).  
Normalize feelings of sadness and longing (emotion-focused coping) while minimizing rumination (Nolen-Hoeksema, 2001; dysfunctional coping).  
Provide counseling on loss and grief and referral for complications in grief (Sanders et al., 2007; emotion-focused coping).  
Encourage coping strategies of reframing and moving toward acceptance of the situation (Ott, Sanders, & Kelber, 2007; emotion-focused coping).  
Educate on new ways to adjust the relationship while remaining connected to the care recipient through spiritual and religious practices, humor, celebrations, and life review from earlier life stages (Sanders et al., 2007; emotion-focused coping). |
| Worry and felt isolation         | Pertains to the depressive symptoms related to the loss of connections with and support from others (Sanders et al., 2007) | Challenge dysfunctional thinking, problematic emotions, and behavior patterns such as denial and substance use (dysfunctional coping).  
Encourage acceptance of the disease and future planning (problem-focused coping and emotion-focused coping). Examples include:  
• Educate about the progressive nature of dementia and help plan for changing needs.  
• Encourage maintenance of social connections via family and friends, social and recreational activities, support groups, and telephone support services.  
• Provide referral to community agencies for financial assistance (e.g., U.S. Department of Veterans Affairs for possible caregiver pension benefits).  
• Provide counseling or referral for depressive symptoms (Sanders et al., 2007). |
| Personal sacrifice burden        | “The caregiver’s sense of personal burden and loss from playing this role (e.g., what he/she had to give up in terms of family, career)” (Sanders et al., 2007, p. 55) | Challenge dysfunctional thinking, problematic emotions, and behavior patterns (dysfunctional coping).  
Examples include:  
• Use of reframing in one-on-one interactions and confronting self-blame and guilt.  
• “Brief therapy to assist with feelings of loss as a result of personal sacrifices” (Sanders et al., 2007, p. 55).  
• Mental health referral, if indicated  
Explore practical solutions (emotion-focused and problem-focused coping). Examples include:  
• Instructing in self-care and self-care strategies (Sanders et al., 2007).  
• Conducting a family meeting.  
• Increasing family involvement.  
• Educating about regular use of respite services.  
• Exploring long-term care options (e.g., home care, adult day health care, assisted living/nursing facility, hospice). |
Grief Intervention for Caregivers of Spouses with Dementia

To assess the functional ability of the spouse with dementia, the Functional Assessment Staging Tool (Sclan & Reisberg, 1992) was administered. Caregivers were asked to respond to specific questions describing the care recipient's ability to perform certain tasks. The majority of the care recipients were in the moderate to moderately severe stage of dementia. More than half of the care recipients (55%) required assistance with bathing and dressing, and nearly half (40%) required assistance with toileting. The majority of caregivers had assumed sole responsibility for instrumental activities of daily living (Stone, 2006), including overseeing finances (95%), cooking (85%), nonfood shopping (80%), and food shopping (70%). Caregivers indicated that they provided between 4 and 13 hours of care per day (mean = 5.3, SD = 3.7), and they had been providing this kind of care between 1 and 15 years (mean = 5.3, SD = 4.0).

**Intervention**

An assessment of the status and needs of both the caregiver and care recipient was obtained in the initial session through an interview and an analysis of responses to a set of questionnaires. The interpretation of these data served as the basis for the next session.

After the researcher shared and explained participant responses from the questionnaires, the caregivers received a copy of the manual *A Guide to Supporting Family Caregivers Through the Alzheimer's Disease Trajectory: Grief and Personal Growth* (Ott et al., 2006) and reviewed it with the PI. The manual was used as a basis for a discussion of the caregiver's (a) heartfelt sadness and longing, (b) worry and felt isolation, and (c) personal sacrifice burden, which are subscales of Marwit and Meuser's (2005) Caregiver Grief Inventory Short Form (MMCGI-SF). These subscales were explained and plotted on a personal grief profile contained in the manual. As suggested by Marwit and Meuser (2002), grief subscales were explored in the context of their "larger life situation" (p. 764). The stages of the disease process with suggestions for caregiver coping behaviors, and interventions were explored. Caregivers were encouraged to engage in some positive tasks that were specific to their situation (e.g., visiting a friend, attending church).

General principles for working with grief in dementia caregivers outlined by Marwit and Meuser (2002) were used in this intervention. These include:

- Realizing that grief is a unique experience for each person.
- Using an individualized approach while considering the caregiver's grief response and coping resources.
- Considering that men may express less of an emotional response while needing similar levels of support as women.
- Listening more than talking while also addressing emotions such as anger and guilt.
- Proceeding at a comfortable pace corresponding to the caregiver's openness and coping abilities.

**Table 1** contains a description of the MMCGI-SF (Marwit & Meuser, 2005) subscales and examples of typical interventions.

The magnitude, intensity, type, and duration of the intervention was tailored to the caregiver's needs. The interventions included supportive grief counseling (Marwit & Meuser, 2002; Worden, 2002), family problem solving (Mittelman, Epstein, & Pierzchala, 2003), emotional support, education, skill building, and referral to community resources. The intent of the intervention was to decrease the level of grief by reducing the use of dysfunctional coping mechanisms and strengthening the use of problem-focused and emotional coping strategies (**Table 1**).
Demographic variables were collected based on an adaptation of The Caregiver Questionnaire (Mittelman et al., 2003). Grief and mental health were the principal outcome variables.

Grief. To test the hypothesis that pre-death grief might be decreased by the Easing the Way intervention, grief was measured with the MMCGI-SF (Marwit & Meuser, 2005). The MMCGI-SF is an empirically derived instrument based on spouse and adult child caregiver statements obtained from focus groups. Validity of the grief construct was assessed against measures including grief, depression, caregiver strain, well-being, and perceived family support. The factor analysis of the 18-item instrument identified three subscales: heartfelt sadness and longing, worry and felt isolation, and personal sacrifice burden. Examples of subscale items include: “I long for what was, what we had and shared in the past,” “I spend a lot of time worrying about the bad things to come,” and “I’m stuck in this caregiving world, and there’s nothing I can do about it.” Items are rated on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree), with higher scores indicating more grief. The authors indicated that caregivers scoring higher than a standard deviation of 1 above the mean may be at risk for grief complications. For this study, the Cronbach’s alpha coefficient for the total scale was 0.91; the Cronbach’s alpha coefficients for heartfelt sadness and longing, worry and felt isolation, and personal sacrifice burden were 0.79, 0.86, and 0.83 respectively.

Depression and Anxiety. Two standard measures were administered to measure mental health status: the 20-item Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977) and the 20-item State-Trait Anxiety Inventory (STAI) (Spielberger, 1983). Depression was assessed with the CES-D (Radloff, 1977). The CES-D measures a range of cognitive, affective, motivational, and somatic symptoms of depression. Scores are computed by summing the frequency of each symptom occurring during the previous week. Scores range from 0 to 60, with higher values indicating more depressive symptoms. In the baseline assessment, 60% of the sample scored above 16, the cut off for depression (Radloff, 1977). The Cronbach’s alpha coefficient for the CES-D in this study was 0.95. Anxiety was assessed with the STAI, which measures perceived feelings of apprehension, tension, nervousness, and worry. Scores range from 20 to 80, with higher scores indicating more anxiety. For this sample, the scores ranged from 25 to 74 (median = 61). The Cronbach’s alpha coefficient for the STAI in this study was 0.95.

Positive States of Mind. In a previous study of spouse caregivers (Ott et al., 2007), as Positive States of Mind (Horowitz, Adler, & Kegeles, 1988) scores increased, grief decreased. The instrument assesses the extent to which the caregiver was able to achieve each of six positive states in the previous 7 days: focused attention, productivity, responsible caregiving, restful repose, sensuous nonsexual pleasure, and sharing. Responses range from 0 (unable to achieve the state) to 3 (easily achieve the state). The Cronbach’s alpha coefficient in this study was 0.88.

Self-Efficacy. The General Self-Efficacy Scale (Schwartz & Jerusalem, 1995) assesses general confidence in one’s ability to adjust to daily challenges (e.g., “I can always...”)

### Table 3

<table>
<thead>
<tr>
<th>Measure</th>
<th>Care Recipient Living at Home (n = 12)</th>
<th>Care Recipient Not Living at Home (n = 8)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Month 5</td>
</tr>
<tr>
<td>Grief</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Grief</td>
<td>51.8 (10.26)</td>
<td>47.7 (10.18)</td>
</tr>
<tr>
<td>Depression</td>
<td>16.9 (13.63)</td>
<td>11.5 (8.62)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>60.5 (9.32)</td>
<td>28.49 (5.96)</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>2.9 (0.33)</td>
<td>3.2 (0.41)</td>
</tr>
<tr>
<td>Positive state of mind</td>
<td>1.8 (0.73)</td>
<td>2.2 (0.60)</td>
</tr>
</tbody>
</table>

* Partial eta squared.
** *p < 0.05; ** *p < 0.01.
manage to solve difficult problems if I try hard enough."). Responses on the 10-item scale range from 1 (not at all true) to 4 (exactly true). The Cronbach's alpha coefficient in this study was 0.89.

Coping Strategies. The BriefCOPE (BC) (Carver, 1997), a 28-item questionnaire, was administered to examine types of coping strategies, specifically emotion-focused (e.g., "getting comfort or understanding from someone"), problem-focused (e.g., "trying to come up with a strategy about what to do"), and dysfunctional-focused (e.g., "blaming myself for things that have happened") strategies. The BC with these three subscales has been used in other dementia caregiver studies (Cooper et al., 2008; Crespo et al., 2005). The relevant items were combined to create mean scores of each type of coping. Cronbach's alpha coefficients for these three subscales were 0.76, 0.83, and 0.72 respectively.

Program Acceptability. To assess program acceptability, caregivers were interviewed on what things they liked about the Easing the Way protocol, what things should be changed with a future study, and whether they would recommend the program to other caregivers. Responses were audio recorded, transcribed verbatim, summarized, and categorized according to the five components of the intervention.

Data Analysis
Analyses included descriptive statistics of means, standard deviations, frequencies, and percentages. Paired t tests and repeated-measures analyses of variance (ANOVA) were computed. Bivariate relationships were examined by computing Pearson's product moment correlations. Effect sizes were computed using Cohen's d (mean change from baseline to completion of the intervention, divided by the standard deviation of the change scores).

RESULTS
Significant changes were found from baseline to the completion of the intervention for the measures of grief, depression, anxiety, positive states of mind, and self-efficacy, resulting in a moderate effect size of –0.43 for grief to a large effect size of –2.40 for anxiety (Table 2).

Paired t tests were used to compare the measures of grief, depression, anxiety, self-efficacy, and positive states of mind from baseline to the completion of the intervention. Self-efficacy and positive states of mind increased from baseline to the completion of the intervention, while grief, depression, and anxiety decreased, indicating a positive change.

Although living at home with the care recipient was a criterion for entrance into the study, 3 months after the intervention, 8 of the 20 caregivers were no longer residing with their spouse at home. On the basis of results from a previous study indicating that grief increased for spouse caregivers after placement in a long-term care facility (Ott et al., 2007), the analysis for the 8-month follow up were stratified by place of residence, resulting in two groups. Repeated-measures ANOVAs were computed for grief, depression, anxiety, positive states of mind, and self-efficacy stratifying by place of residence. Although some of the measures lacked power to find statistical significance due to the small group sizes, the trends and effect sizes are noteworthy. For the 12 caregivers who were still providing care in the home at the 3-month follow up, grief and depression scores remained stable. For the 8 caregivers whose spouses were living in a care facility or who had died, grief scores returned to baseline levels, while depression scores increased (Table 3 and Figure).

The caregivers used a variety of strategies for coping. At baseline, the most frequently used coping style was problem focused, followed by emotional focused and lastly dysfunc-
tional coping. Baseline dysfunctional coping was significantly correlated to grief ($r = 0.62, p = 0.004$), depression ($r = 0.63, p = 0.003$), anxiety ($r = 0.62, p = 0.004$), and positive states of mind ($r = -0.57, p = 0.008$). As dysfunctional coping increased, grief, depression, and anxiety increased, while positive states of mind decreased. Paired $t$ tests were used to compare coping strategies at baseline and at completion of the intervention. All three coping strategies changed significantly from baseline to the completion of the study. Dysfunctional coping strategies decreased while emotion-focused and problem-focused coping increased (Table 4).

There was no correlation between the dose of the intervention delivered on any of the outcome variables: grief, depression, anxiety, positive states of mind, or self-efficacy. In addition, no significant differences were found in the magnitude of change between those who received only in-person sessions compared with those who received both in-person and telephone sessions.

**Caregiver Satisfaction with the Intervention**

Caregiver comments about what they liked about the Easing the Way intervention are grouped according to the five components of the intervention.

**Supportive Grief Counseling.** Supportive grief counseling was both problem focused and emotion focused. One participant noted, “The findings from your study in the manual was very helpful to me to hear that caregivers can actually grieve…. [I’m] realizing that part of my grief is due to the loss of my spouse’s loss of personhood.”

**Emotional Support.** Counseling provided a forum that enabled the caregivers to express themselves in a productive manner rather than venting and blaming themselves. Caregiver comments included:

- “It was just so good that I could get it off my chest because I was having quite a bit of health problems and that was causing anxiety, and I was kind of a mess…. I feel much more at ease and confident.”
- “I liked being complimented on the fact that I’m doing a good job. That helps me go on the way I am.”
- “You represent the outside world and the fact that someone has an interest in this situation is a comfort. I need to have adult people to talk with me. I appreciated having the nurse come over and take a look at my wife to make sure that nothing was going on physically.”
- “Just having someone to talk with that understands and doesn’t judge me was helpful.”

**Referral to Community Resources.** Several caregivers commented on the importance of referral to support groups and other community resources, noting “Going to the Alzheimer’s meetings that you put me in touch with has helped a lot. I feel so much better,” and “I didn’t think that my wife was as far along as she is, and I got on the list for services through [the] County.”

**Education.** Education, an example of a problem-focused strategy, was appropriate for all of the caregivers. One participant shared the following: “I learned how I wanted to conduct a family meeting with my children… and I learned how to access my long-term care insurance.” The same caregiver also noted: “I contacted the Alzheimer’s society, and they sent me a lot of good material. I love to solve problems because I’ve learned something. So, I would like more education right away when you find out the diagnosis.”

**Skill Building.** Skill building, another example of a problem-focused strategy, was appreciated by a number of caregivers. Comments included: “You helped me to learn how to be more patient with my wife and to learn more about what to expect in the future,” and “I got an education. I learned that I had a very high stress level…and I now have an idea of what to do.”

---

**TABLE 4**

<table>
<thead>
<tr>
<th>COPING STYLE</th>
<th>BASELINE MEAN (SD)</th>
<th>INTERVENTION MEAN (SD)</th>
<th>T</th>
<th>P VALUE</th>
<th>EFFECT SIZE</th>
</tr>
</thead>
<tbody>
<tr>
<td>EMOTIONAL FOCUSED</td>
<td>2.46 (0.50)</td>
<td>2.67 (0.51)</td>
<td>3.81</td>
<td>0.001</td>
<td>0.42</td>
</tr>
<tr>
<td>PROBLEM FOCUSED</td>
<td>2.68 (0.62)</td>
<td>3.00 (0.67)</td>
<td>2.90</td>
<td>0.005</td>
<td>0.49</td>
</tr>
<tr>
<td>DYSFUNCTIONAL</td>
<td>1.58 (0.36)</td>
<td>1.45 (0.34)</td>
<td>2.00</td>
<td>0.035</td>
<td>-0.37</td>
</tr>
</tbody>
</table>

* Degree of freedom = 19.
Two caregivers offered suggestions when asked what could be changed with a future intervention. One person suggested that a family meeting should be a part of any future intervention study, and the other suggested having a more flexible schedule for completing the questionnaires. All caregivers stated that they would recommend the program to other caregivers.

DISCUSSION

This pilot study was designed to test the feasibility of using the manual A Guide to Supporting Family Caregivers Through the Alzheimer’s Disease Trajectory: Grief and Personal Growth (Ott et al., 2006) as the basis for the Easing the Way intervention and to evaluate the effectiveness of the intervention in decreasing grief and improving mental health. This is the first pilot study that examined a multiple component, tailored intervention targeting pre-death grief in spouse caregivers of individuals with dementia. These data lend support for the Easing the Way intervention as a model for a future clinical trial. From baseline to the completion of the intervention, grief and depression decreased, while well-being increased. Effect sizes ranged from moderate for grief reduction and changes in coping strategies to large for decreasing anxiety. Coping strategies influenced the grief response, which in turn influenced emotional well-being and symptoms of the depression-stress-burden constellation. These findings are consistent with Meuser et al.’s (2004) causal pathway model.

Coping strategies that are unique to the individual and affect grief and the depression-stress-burden constellation were assessed at baseline. These coping strategies, once identified, lent themselves to intervention. Dysfunctional coping (i.e., self-blame, behavioral disengagement, venting, denial, alcohol and other drug use) was associated with increased grief and depression. Cooper et al. (2008) recommended that caregiver intervention studies should emphasize decreasing dysfunctional coping strategies and increasing emotion-focused coping. By challenging dysfunctional thought patterns through the use of reframing techniques and encouragement of self-care activities, grief, depression, and anxiety decreased (Table 1).

The Easing the Way protocol resulted in clinically significant decreases in anxiety that were maintained at the 8-month follow up. It is possible that by increasing knowledge about the progression of the disease and the inevitability of death, caregiver anxiety decreased as they felt more prepared for the future. Hebert, Dang, and Schulz (2006) reported that despite providing in-depth care over many years, some bereaved caregivers perceive themselves as being unprepared for the care recipient’s death. Previous research has demonstrated an association between being unprepared for the death and higher levels of grief and depression in bereavement (Barry, Kasl, & Prigerson, 2002).

As would be expected with a chronic, progressive illness, care recipients experienced a decline in health, resulting in placement in long-term care facilities. At the 8-month follow up, 40% of the care recipients had either been placed in a long-term care facility or had died. Placement in extended care facilities resulted in significant increases in caregiver grief and decreased mental health. For these caregivers, mental health gains realized at the completion of the intervention were not maintained. Continued support is necessary to maintain the effects of the intervention. Placement in a nursing home triggers further losses, exacerbating the grief experience (Prigerson, 2003). With the care recipient being physically absent, the caregiver no longer has control of the caregiving role and is faced with increased heartfelt sadness and longing and worry and isolation. Caregivers face the second part of the “triple grief” phenomenon.

The theoretical basis for post-death grief interventions have been identified in recent years and include the Dual Process Theory (Stroebe & Schut, 2001), the Meaning Reconstruction Theory (Niemeyer, 2001), the Attachment Theory (Bowlby, 1982), and the Grief Work Theory (Freud, 1917/1957). None of these theories has been established for pre-death grief. This pilot intervention was guided by Meuser et al.’s (2004) pre-death dementia caregiver grief model using responses to the subscales of heartfelt sadness and longing, worry and felt isolation, and personal sacrifice burden to address pre-death grief. Because this grief intervention had never been pilot tested, it was necessary to see if and how the intervention worked prior to conducting a randomized clinical trial.

LIMITATIONS

We believe the data from this pilot study suggest that the intervention has demonstrated positive results and warrants further investigation; however, there are limitations in this pilot study that merit discussion. The absence of a control group is an important limitation. The possibility of a self-selection bias is also present; in addition, the intervention was carried out by the PI, which could also introduce a bias. Another limitation is the lack of an ethnically diverse group of spouse caregivers. Previous research has found differences in the caregiver experience from ethnically diverse groups (Haley et al., 2004). This pilot study...
included a small sample, and results should not be generalized beyond this group of spouse caregivers.

A threat to internal validity in this study was maturation effect. Forty percent of the care recipients experienced a change in their place of residence. We addressed this issue through an examination of differences between caregivers who maintained their caregiving role compared with those caregivers who were no longer providing direct care. This analysis revealed that the two groups were different at baseline: The continuing caregivers had less grief and depression. At the 8-month follow up, positive gains were maintained for caregivers who were still providing care in the home, while the group that was no longer providing care experienced a resurgence of grief back to baseline scores and depression that exceeded baseline scores.

FUTURE RESEARCH AND CONCLUSION

In a comprehensive review of the impact of caregiver research on bereavement outcomes, Schulz, Boerner, and Hebert (2008) pointed out that researchers have generally not tested preventive interventions delivered prior to the care recipient’s death. These authors noted that what is missing from the literature are “data showing how anticipatory grief affects bereavement adaptation” (p. 281). Several prospective studies that targeted pre-death caregiver depression have demonstrated a decrease in complicated grief after the care recipient’s death (Haley et al., 2008; Schulz et al., 2006). Future controlled studies are needed to determine whether pre-death caregiver grief interventions decrease complications of grief in bereavement.

Future research should be adequately powered, include an ethnically diverse population with participants randomized into treatment and control groups, and contain a booster component after the initial phase of the study. Health care practitioners who would be qualified to deliver the intervention would include psychiatric and palliative care nurses and social workers who are knowledgeable about grief, dementia, and community resources.

Results from this study seem to indicate that spouse caregivers who place their spouse in a long-term care facility may need continued support and education through the transition period. For now, the Easing the Way intervention protocol is a promising caregiver program that warrants further testing in a randomized controlled study.

REFERENCES


