# Primary Care Interventions for Dementia Caregivers: 2-Year Outcomes From the REACH Study

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**Purpose:** This study developed and tested two 24-month primary care interventions to alleviate the psychological distress suffered by the caregivers of those with Alzheimer's disease. The interventions, using targeted educational materials, were patient behavior management only, and patient behavior management plus caregiver stress–coping management. We hypothesized that the addition of the stress–coping component would improve caregiver outcomes. **Design and Methods:** A randomized clinical trial of 167 caregiver–care recipient dyads was run, of whom 76 completed the study without bereavement or placement. **Results:** During 24 months, caregivers who received the patient behavior management component only, compared with those who also received the stress–coping component, had significantly worse outcomes for general well-being and a trend toward increased risk of depression (i.e., a score of >16 on the Center for Epidemiological Studies Depression scale). There was a studywide improvement for bother associated with care recipient behaviors (according to the Revised Memory and Behavior Problems Checklist). **Implications:** Our data suggest that brief primary care interventions may be effective in reducing caregiver distress and burden in the long-term management of the dementia patient. They further suggest that interventions that focus only on care recipient behavior, without addressing caregiving issues, may not be as adequate for reducing caregiver distress.

*Key Words:  Alzheimer's disease, Frail elders, Memory disorders*

Although primary care providers are usually the first contact with the health care system for patients with Alzheimer's disease and related dementias (ADRD), physician- or primary care-based interventions to assist patients and caregivers are rare. The goal of this research was to explore the effectiveness of brief, targeted interventions for ADRD caregivers in the primary care setting.

At least nine separate consensus statements and practice guidelines have emphasized the role of physicians in the treatment of ADRD patients (American Medical Association, 1999; Fillit, Knopman, Cummings, & Appel, 1999a, 1999b; Small et al., 1997; U.S. Department of Veterans' Affairs, 1997). Unfortunately, caregivers and physicians have different perspectives on what is important (Bogardus, Bradley, & Tinetti, 1998; Boise, Camicioli, Morgan, Rose, & Congelton, 1999; Levine & Zuckerman, 1999). Caregivers want concrete, practical advice from physicians and referrals or information on how to access community agencies (Boise et al., 1999; Cohen, 1991; Connell & Gallant, 1996; Haley, Clair, & Saulsberry, 1992; Levine & Zuckerman, 1999), as well as emotional support and attention (Brotman & Yaffe, 1994; Levine & Zuckerman, 1999).

Physicians are often frustrated with the expectations of families, the inadequacy of what the medical system has to offer patients, and their ability to manage dementia patients (Boise et al., 1999;

Miller, Glasser, & Rubin, 1992). Physicians have reported being uncomfortable giving advice about behavioral symptoms, perhaps reflecting the physician's lack of information on how to manage dementia (Boise et al., 1999; Miller et al., 1992) or lack of information about community resources (Fortinsky, 1998; Fortinsky, Leighton, & Wasson, 1995; Haley et al., 1992). With multiple medical problems to treat, physicians are less likely to spend time on cognitive problems, especially those that appear to be "untreatable" (Boise et al., 1999; Burns, Nichols, Martindale-Adams, & Graney, 2000). These issues may be exacerbated by the lack of reimbursement for family counseling (Brotman & Yaffe, 1994; Burns et al., 2000).

Despite these mismatched expectations around dementia (Miller et al., 1992), the primary care setting provides an excellent opportunity to advance interventions for long-term management of the dementia patient and the caregiver. Mittleman and her colleagues (Mittleman et al., 1995; Mittleman, Ferris, Shulman, Steinberg, & Levin, 1996) have shown that long-term behavioral interventions for caregivers are effective. Long-term primary care management has proved successful in maximizing and then maintaining the health status of frail older adults through ongoing reassessment and educational, therapeutic, and preventive measures (Burns et al., 2000). The long-term nature of dementia suggests that this type of primary care management model may be effective in assisting caregivers to manage the illness, if primary care physicians have the information and tools they need to provide care.

The intent of this study, part of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) project, was to develop and test simple, standardized, and systematic approaches for physicians or their staffs to guide their interactions with caregivers and patients. The interventions would provide the information that Alzheimer's caregivers seek from their physicians—techniques to manage patient behaviors and strategies to alleviate caregiving stress. This paper examines groups randomized at Memphis primary care sites to address our hypothesis that the management of patient behavior alone is not sufficient to alleviate caregiver distress and burden.

Given the primary care time constraints, both interventions were brief. One intervention focused only on education about patient behavior management; the other added education about caregiver well-being and coping to patient behavior management, although both were based on primary care and were parallel in structure and format. The addition of caregiver coping to the primary care setting changes the focus of the physician's care from patient to patient–caregiver dyad. Reflecting the long-term nature of primary care, we hypothesized that, over 24 months, the stress of psychological distress, as measured by depression, general well-being, and the amount of bother caregivers experi- ence when dealing with care recipient behaviors, would decrease with the addition of the caregiver well-being component.

## Methods

REACH was a unique 6-year multisite research program sponsored by the National Institute on Aging (NIA) and the National Institute of Nursing Research (NINR). Its purpose was to carry out social and behavioral research on interventions designed to enhance family caregiving for ADRD. Six research sites and a coordinating center focused on characterizing and testing the most promising home and community-based interventions for maintaining and improving the health and quality of life of caregivers of dementia patients. Psychological distress was the primary outcome of interest, measured at Memphis by the variables of general well-being, depression, and response to behaviors.

### Intervention

*Intervention Overview.*—This paper compares two structured, parallel interventions, Behavior Care and Enhanced Care, from the Memphis REACH study, a 24-month randomized clinical trial. The Memphis study was approved and monitored by the University of Tennessee and VA Medical Center Institutional Review Boards. Behavior Care interventions focused only on improving the caregiver's management of the care recipient's behavioral problems (e.g., repeated questions or wandering), using 25 pamphlets addressing particular behaviors. Enhanced Care interventions focused on these same problem behaviors but also on improving the caregiver's own well-being in response to those problems (e.g., guilt or grief). For these stress-reduction issues, the interventionist used an additional 12 pamphlets specifically geared toward caregiver well-being.

Thus, both interventions had a Behavior Care component, but Enhanced Care interventions had additional content geared toward caregiver well-being and were longer in duration. Otherwise, the two types of contact were carried out in the same manner. All were conducted during scheduled primary care office visits for the care recipients. As there are no established guidelines for how frequently dementia patients should be clinically reevaluated, the interventions were scheduled every 3 months, based on four primary care visits per year for a relatively healthy, but demented, patient. This schedule was designed in consultation with local geriatricians. If an office visit was canceled, the intervention visit was rescheduled, whether or not the primary care office visit was also rescheduled.

In the office setting, a master's-prepared health educator–interventionist met with the caregiver to discuss his or her problems and the appropriate

pamphlets or strategies for addressing them, while a research specialist sat with the care recipient. In keeping with the primary care-based nature of these interventions, the face-to-face portion of each was designed to be short. Each Behavior Care intervention was designed to be no more than 30 min, and each Enhanced Care intervention no more than 60 min.

Between office visits, telephone contacts lasting 10 min or less were scheduled with each caregiver to monitor the success of any strategies proposed in the office visits and to modify those strategies if needed. During the first 6 months, caregivers received telephone calls twice a month; thereafter, they received one call per month.

*Education Materials.*—Comprehensive pamphlets for managing dementia problems or addressing stress and coping were written at a fifth-grade reading level and with large print, using best practices from nursing and psychology theory and practice; the work of dementia-focused groups and organizations, such as the national ADRD Association; and the Office of Geriatrics and Extended Care, Veterans Health Administration, Department of Veterans Affairs. Each five- to six-page pamphlet provided information on possible triggers for and strategies for coping with specific behaviors or issues. Strategies primarily focused on simple environmental modification (e.g., removing distractions) and task breakdown. Each pamphlet also included references ranging from easily accessible materials for family caregivers, such as *The 36-Hour Day* (Mace & Rabins, 1991), to tapes and materials designed primarily for institutional caregivers (Teri, 1994; Teri et al., 1992) and scholarly articles that may be of interest to clinicians and some caregivers (Strumpf, 1994).

The pamphlets were used to guide the interactions of the caregiver and interventionist. Each pamphlet had suggestions categorized and numbered. This documentation enabled the interventionist to determine which suggestions caregivers tried, which were most helpful, and which did not work for certain problems and certain care recipients.

*Behavior Care.*—The Behavior Care intervention provided education sessions on behavior management of the patient. Using the 25 patient behavior modification pamphlets, the intervention focused on dementia behaviors ranging from bathing, combativeness, confusion, and hallucinations to medications, nutrition, sexuality, and wandering. Using a structured interviewing protocol adapted from the Bayer Institute on Health Care Communication (Keller & Carroll, 1994), the interventionist and caregiver assessed the caregiver's current knowledge and identified areas of concern about the patient's functioning. The protocol focused on shared de-

cision making and used structured comments and process to engage the subject, empathize, educate, and enlist cooperation in addressing issues and concerns. After problem identification, using the appropriate pamphlet, the interventionist and caregiver (a) discussed possible causes of the problems and actions that could be taken, (b) arrived at the most feasible solutions, and (c) discussed implementation of behavior management strategies.

*Enhanced Care.*—The structure of the Enhanced Care intervention was the same as that of the Behavior Care intervention, with a component on stress–behavior management for the caregiver added to the care recipient behavior management component. Using the 12 caregiver-focused pamphlets, the additional component addressed the caregiver's stress–coping concerns, such as anger management, grief, and communication. The specific nature of the cognitive–behavioral skills training included relaxation training and strategies to help cope with negative thoughts and feelings or emotional distress in situations in which the course of events could not be changed. The intervention was structured like the Behavior Care intervention, with at least one patient behavioral issue and one caregiving issue discussed each visit, with caregivers receiving the appropriate educational materials for the problems identified.

*Participants.*—Memphis caregivers and care recipients (patients) were recruited from their physicians' offices. The 14 practice sites included all areas of the city and county and 19 physicians. Study physicians represented multiple specialties, including geriatricians, internists, family practitioners, psychiatrists, and neurologists. After referral from the physician's office, subjects were telephone screened for eligibility by a trained data collector. Caregivers were eligible for study participation if they were over the age of 21, lived with a relative with ADRD, and provided a minimum of 4 hr of supervision or direct care per day for at least the past 6 months. Caregivers were excluded if they were involved in another caregiver study or if they or their care recipients had a terminal or severe illness or disability that would prohibit them from participating in the study.

Care recipients had to have a medical diagnosis of probable ADRD or score <24 on the Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975). In addition, they had to have at least one limitation in basic activities of daily living (ADLs; Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) or two dependencies in their instrumental activities of daily living (IADLs; Lawton & Brody, 1969) as reported by the caregiver. (See Data, Patient Data section for descriptions of these measures.) These participation criteria were designed to ensure that caregivers were involved in daily tasks that were

potentially burdensome. To ensure comparability of intervention groups, caregivers were randomized according to a blocked randomization scheme, within practice site, using race and gender. Randomization occurred immediately after data collection.

## Data

*Data Collection.*—REACH data collected by all study sites included both caregiver and patient data, although only MMSE data were collected directly from the patient. Informed consent was obtained from each participating caregiver prior to the administration of the REACH interview. The caregiver granted permission to allow the MMSE to be administered to the patient. All data were collected at the physician's office during a visit by the patient, before the intervention, for those visits when interventions occurred, and before the physician's visit. Data were collected at baseline and at 6-month intervals for the 2-year duration of the active intervention by master's-prepared research specialists who were masked to intervention assignment.

*Caregiver Demographic Data.*—Caregiver demographic data included age, sex, race, education, income, duration of caregiving, and relationship. A four-question Health Status scale (Archbold, Stewart, Harvath, & Lucas, 1986) was used to assess caregivers' perceived physical health and anticipated changes in health. All four questions are scored on a 5-point scale, producing a composite score ranging from 4 (poor) to 20 (excellent).

*Caregiver Outcome Data.*—The modified General Well-Being scale (Applegate et al., 1991; Brook et al., 1979; Burns et al., 2000), a global measure of caregiver well-being, was one of the three main outcome measures and the only site-specific measure not part of the multisite REACH battery. This 22-item scale has two main domains of General Health and Mental Health and assesses positive well-being, anxiety, general health, vitality, depression, self-control, and mental health. Items are scored from 1 to 5 and summed, with higher scores indicating greater well-being.

Caregiver affect was assessed in two ways using the Center for Epidemiological Studies Depression scale (CES-D; Radloff, 1977): a CES-D score and a probable depression score. The CES-D is a 20-item measure that assesses the frequency with which respondents have experienced depressive symptoms within the past week. Items are scored from 0 (rarely or none of the time) to 3 (most or almost all of the time). Items are summed for an overall score of 0 to 60, with higher scores indicating greater depressive symptoms. A CES-D score of 16 or over has been clinically associated with a greater risk of depression

(Radloff & Teri, 1986). Therefore, we used this CES-D $\geq$ 16 cutoff point to examine the proportion of individuals in each group at greater risk of depression.

For an outcome assessment of how the dementia was manifested for the patient and affected the caregiver, information was collected by using the 24-item Revised Memory and Behavior Problems Checklist (RMBPC; Teri et al., 1992). For each patient behavior reported, caregivers respond in terms of how much they are bothered on a 5-point scale, from 0 (not at all) to 4 (extremely bothered). Scores range from 0 to 96, with higher scores indicating greater bother. For REACH, average RMBPC scores were calculated among all behaviors, assigning "no upset" to behaviors that were not manifested.

*Patient Data.*—All patient data were part of the larger REACH battery. Demographic data included age, sex, race, and education. The patient's cognitive status was assessed at entry into the study using the MMSE, a 30-point scale used to assess orientation, short-term memory, visual construction, and language skills (Folstein et al., 1975); higher MMSE scores indicate better cognitive functioning. Care recipient functional status was assessed by 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 was scored 0 (no help needed) or 1 (help needed). ADL and IADL scores were created by summing scores across the items, with higher scores indicating greater functional impairment.

*Data Analysis.*—The distributional characteristics of study variables were reviewed, and none were sufficiently skewed to justify data transformation. An analysis was undertaken on those caregiver–patient dyads that completed 24 months of data collection without bereavement or placement (completers). Baseline demographic and clinical characteristics of REACH caregivers and patients were compared between completers and noncompleters, that is, those who did not finish 24 months of intervention, using chi-square tests for contingency tables or independent-samples $t$ tests, as appropriate. Baseline characteristics were compared in the same fashion between the completer intervention groups. In accordance with the original a priori research hypothesis, outcome variables were analyzed to test for differences between the Behavior Care and Enhanced Care interventions. Analyses of outcome variables of general well-being (GWB), CES-D, increased risk of depression as defined by CES-D $\geq$ 16, and RMBPC were accomplished by using repeated measures analyses of variance (ANOVA) of baseline, 6-, 12-, 18-, and 24-month data, controlling for baseline scores as a covariate. Analyses of study
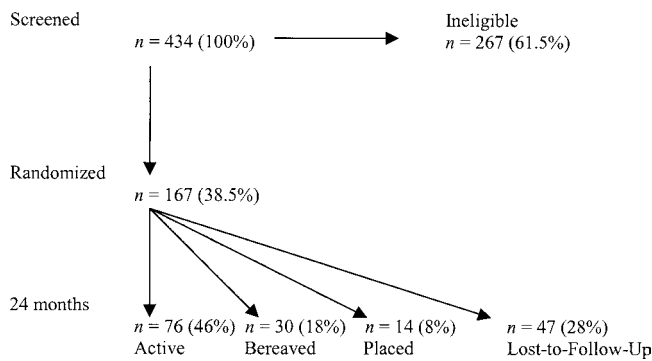
Figure 1. Recruitment results and study attrition over 24 months.

data using earlier endpoints than 24 months, and using last value carried forward to 24 months, provided equivalent findings to those based on active dyads at 24 months (which are presented in the Results); *p* values less than or equal to .05 were considered statistically significant, and those between .05 and .10 were considered to document trends that approached, but did not attain, statistical significance. The study was designed to provide a statistical power of 0.80 to document as statistically significant a true population difference in intervention effects equal to at least 0.25 *SD* of a primary outcome variable.

## Results

Four hundred and thirty-three caregivers were telephone screened for the study. The main reasons why caregivers were not eligible included the following: caregiving less than 4 hr a day care; caregiving less than 6 months; planned, imminent nursing home placement; or caregiver not living with the patient. The main reasons patients were not eligible were too many hospitalizations or too few ADL–IADL dependencies. One hundred sixty-seven caregivers–patient dyads were randomized into Behavior Care (*n* = 85) and Enhanced Care (*n* = 82). At 2 years, 76 of the original 167 active caregiver–patient dyads remained for analysis. Of the original 167 caregivers, 18% were later bereaved, 8% placed the patient but remained in the study, and 28% were lost to follow-up. The only significant difference between completers and noncompleters in baseline characteristics for either caregivers or patients was that completer caregivers had been caregivers for a shorter time (3.4 ± 2.8 vs. 4.6 ± 4.5 years; *p* = .048; see Figure 1).

Of the original 167 caregiver–patient dyads, 66 were Black–African American, 99 were White–Caucasian, and 2 were "other race." In all dyads, caregiver and care recipient race was the same. Baseline data showed that caregivers were predominantly older women and were likely to be spouses or children. They had been caregivers for an average of

Table 1. Behavior Care and Enhanced Care Caregiver Baseline Characteristics

| Characteristic | Behavior Care | Enhanced Care | *p* Value |
|---|---|---|---|
| Age (years) | 64.5 (13.0) | 65.1 (12.6) | .834 |
| Sex (% female) | 78.4 | 84.6 | .483 |
| Race (% Black) | 37.8 | 46.2 | .467 |
| Marital Status (% married) | 73.0 | 61.5 | .338 |
| Income ($K) | 25.0 (15) | 17.5 (15) | .081 |
| Education (0–17 years) | 13.1 (1.8) | 12.7 (2.7) | .492 |
| Relationship (%) | | | .831 |
| Spouse | 51.4 | 48.7 | |
| Child | 35.1 | 41.0 | |
| Other | 13.5 | 10.3 | |
| Caregiving (years) | 3.7 (3.2) | 3.2 (2.5) | .451 |
| GWB (22–110) | 70.3 (16.2) | 75.7 (15.5) | .141 |
| CES-D (0–60) | 14.7 (11.6) | 11.5 (9.7) | .201 |
| RMBPC (0–96) | 19.6 (11.6) | 11.8 (12.7) | .007 |

*Notes*: Subject characteristics are *M* (*SD*) or percent. GWB = General Well-Being scale; CES-D = Center for Epidemiological Studies Depression scale; RMBPC = Revised Memory and Behavior Problems Checklist. Behavior Care, *n* = 37; Enhanced Care, *n* = 39.

approximately 4 years. Average income for all caregivers was $22,000, and average education level was approximately 1 year past high school. The prevalence of probable depression, as measured by CES-D scores ≥ 16 was 30.2%. Although also predominantly female, the patients were, on average, 16 years older than the caregivers, with education levels of approximately 1 year less than high school completion. On average, care recipients were severely demented, as measured by mean MMSE scores of approximately 11, with functional deficits in IADLs and ADLs.

At baseline, the RMBPC was significantly different between completer caregivers in the two intervention groups, with Enhanced Care caregivers exhibiting less bother. There was a trend toward lower income for Enhanced Care caregivers, as shown in Table 1. Enhanced Care group completer patients showed a trend toward less education than Behavior Care patients at baseline, as shown in Table 2. Baseline values for all variables were controlled for in subsequent analyses.

The intervention contact time was shorter than planned for both groups. During the 24-month period, Behavior Care caregivers received, on average, approximately 3 hr of intervention; Enhanced Care caregivers received approximately 4 hr of face-to-face and telephone contact. Although our Enhanced intervention was targeted to be 60 min in person and 10 min by telephone, for a total of 730 min, on average, telephone contacts were approximately 5 min, or half the intended time, and face-to-face interventions were approximately 20 min, or one third of the intended time.

**Table 2. Behavior Care and Enhanced Care Patient (Care Recipient) Baseline Characteristics**

| Characteristic | Behavior Care | Enhanced Care | p Value |
|---|---|---|---|
| Age (years) | 80.8 (7.9) | 78.6 (7.3) | .207 |
| Sex (% female) | 59.5 | 51.3 | .474 |
| Race (% Black) | 37.8 | 46.2 | .467 |
| Education (0–17 years) | 11.6 (3.1) | 10.1 (9.7) | .070 |
| ADL (0–6) | 2.8 (2.0) | 3.2 (2.0) | .457 |
| IADL (0–8) | 7.5 (0.8) | 7.5 (0.7) | .874 |
| MMSE (0–30) | 13.2 (6.4) | 11.4 (7.8) | .276 |

*Notes*: Subject characteristics are *M* (*SD*) or percent. ADL and IADL = activities of daily living and instrumental ADL; MMSE = Mini-Mental State Exam. Behavior Care, *n* = 37; Enhanced Care, *n* = 39.

## Outcome Variables

*Outcome: GWB Scale.*—Over a period of 2 years, there were significant changes in the GWB over time ($p = .004$), with significant GWB group by time interaction ($p = .045$), documenting the benefit from Enhanced Care, as shown in Table 3.

*Outcome: CES-D Scale.*—There were significant changes in the CES-D over time ($p = .007$) and a trend toward group difference, with Behavior Care caregivers reporting worse CES-D scores ($p = .072$), but no significant intervention group by time interaction ($p = .311$).

*Outcome: Risk of Depression.*—There was a trend toward a time effect in the proportion of caregivers with scores of CES-D $\geq$ 16, indicating increased risk of depression ($p = .052$), as shown in Table 3. Documenting a likely benefit from Enhanced Care,

there was a trend toward an intervention group by time interaction in the proportions of individuals with increased risk of depression, as indicated by scores of CES-D $\geq$ 16 ($p = .096$).

*Outcome: RMPBC.*—There was a significant decrease in RMBPC scores over time ($p = .010$), but no significant group or group by time interaction for RMBPC, as shown in Table 3.

## Discussion

Most patients with ADRD and their caregivers enter the health care system through their primary care provider and remain with their provider throughout the long-term course of the illness. Previous research has found that most caregivers want information from their physician about managing the disease and their own responses to caregiving (Boise et al., 1999; Cohen, 1991; Connell & Gallant, 1996; Haley et al., 1992; Levine & Zuckerman, 1999). Therefore, the first objective of this study was the development, delivery, and test of brief psychoeducational primary care interventions for caregivers. Although primary care cannot offer complete assistance as the first and often only health care setting that caregivers access and as the continuing site for long-term management, primary care is a critical component of dementia care.

Our interventions, based on Lazarus and Launier's (1978) action-oriented, individual-environment model of stress and coping, were problem focused, appropriate for the caregivers' needs, and well suited to the time-sensitive primary care setting. The two interventions were identical in structure and format, differing only in content. Both the Behavior Care and

**Table 3. Repeated Measures Analyses of Variance Outcome Measures**

| Variable | n | Time of Measurement | | | | | p Value | | |
|---|---|---|---|---|---|---|---|---|---|
| | | Baseline | 6 month | 12 month | 18 month | 24 month | Group Diff. | Time Change | Interact. Effect |
| GWB | | | | | | | | | |
| Behavior | 34 | 71.6 (16.3) | 71.5 (14.3) | 69.7 (15.9) | 65.5 (12.9) | 67.5 (12.9) | .202 | .004 | .045 |
| Enhanced | 36 | 77.2 (15.3) | 75.5 (14.7) | 75.0 (13.7) | 71.5 (13.4) | 76.5 (13.4) | | | |
| CES-D | | | | | | | | | |
| Behavior | 37 | 14.7 (11.6) | 14.9 (10.2) | 15.6 (11.4) | 14.6 (10.3) | 16.1 (12.2) | .072 | .007 | .311 |
| Enhanced | 38 | 11.5 (9.8) | 10.6 (8.0) | 10.9 (8.0) | 10.3 (8.8) | 11.6 (9.6) | | | |
| CES-D $\geq$ 16 | | | | | | | | | |
| Behavior | 37 | 0.35 (0.48) | 0.39 (0.49) | 0.41 (0.50) | 0.43 (0.50) | 0.43 (0.50) | .642 | .052 | .096 |
| Enhanced | 39 | 0.32 (0.47) | 0.29 (0.46) | 0.24 (0.46) | 0.24 (0.43) | 0.29 (0.46) | | | |
| RMBPC | | | | | | | | | |
| Behavior | 37 | 19.6 (11.6) | 19.6 (11.6) | 16.0 (11.5) | 15.9 (12.5) | 14.8 (10.2) | .920 | .010 | .976 |
| Enhanced | 38 | 11.8 (12.7) | 12.0 (12.8) | 11.4 (12.4) | 10.7 (15.9) | 9.2 (12.8) | | | |

*Notes*: Behavior Care and Enhanced Care are shown as *M* (*SD*); *p* values are repeated measures analyses of variance of baseline, 6-, 12-, 18-, and 24-month data, with the baseline score of the outcome variable as a covariate controlled for. GWB = general well-being; CES-D = Center for Epidemiological Studies Depression scale; RMBPC = Revised Memory and Behavior Problems Checklist.

Enhanced Care interventions addressed the patient's behavioral management. Increasing caregiver ability to manage problem behaviors has been shown to increase competency and confidence and thereby decrease depression (Dunkin & Anderson-Hanley, 1998; Graham, Ballard, & Sham, 1997; Schulz, O'Brien, Bookwala, & Fleissner, 1995). Teri and colleagues (Teri, Logsdon, & Yesavage, 1997) also reported that caregivers who learned to manage behavior problems had significant decreases in depressive symptoms.

In addition to behavior management skills, caregivers also want more emotional support and attention than physicians have routinely offered (Brotman & Yaffe, 1994), including recognition of their anxiety (Levine & Zuckerman, 1999). Because Enhanced Care caregivers were also given the opportunity to focus on their own stress and coping, we hypothesized that the Enhanced Care intervention would be more beneficial than the Behavior Care intervention in decreasing psychological distress, as measured by caregiver appraisals of their GWB, affect, and response to the behavioral manifestations of the disease.

During 2 years, the Behavior Care group had approximately 3 hr and the Enhanced Care group had approximately 4 hr of intervention, both face to face and by telephone. The Enhanced Care intervention averaged 20 min, less than planned, although time appropriate for primary care. This shorter than planned intervention time may be due to scheduling interventions during primary care visits, which could be lengthy, especially on those occasions when data were also collected. However, treatment implementation data collected from the intervention sessions, which were taped, indicated that interventions were being delivered and received as planned, except for shorter duration.

During 24 months, Behavior Care caregivers, who only received information about managing the care recipient's behavioral problems, compared with Enhanced Care caregivers, who had information both about managing the care recipient's behavioral problems and about their own coping, had significantly greater distress when assessed with the GWB. These results appear to be clinically significant. According to Kazdin (1999) and Kendall (1999), clinical significance refers to the practical implications or importance of the impact of an intervention, or the extent to which it makes a "real" difference in the everyday life of the client. The GWB is a recognized quality of life instrument that includes measurement of both psychological and somatic well-being, and both of these domains are clinically relevant.

In addition, although the Behavior Care group CES-D score averaged 16 at 24 months, which is associated with increased risk of depression, the Enhanced Care group had relatively stable CES-D scores of approximately 12. The results of the CES-D $\geq$ 16 group by time interaction also appear

clinically significant, given the chronic, progressive nature of dementia, although our sample sizes did not provide sufficient power to document statistical significance. The RMBPC scores, which focused on care recipient behaviors and the caregiver's response, for Behavior Care and Enhanced Care caregivers combined, showed a significant decrease during 24 months.

There may be several reasons for our findings, but we believe the differences were primarily due to the content of the interventions. The RMBPC improvement over time may reflect the large behavioral component in both interventions, which targeted patient behaviors and caregivers' handling of these behaviors. Although caregivers in both groups addressed the management of problem behaviors, caregivers in the Enhanced Care group also focused on managing their own coping issues, such as improving communication or telling friends and family about the disease, and caring for themselves, including such techniques as relaxation training and cognitive retraining and reappraisal. Our GWB and CES-D results both suggest that it is important to address the caregiver's own issues as well as to provide skills to manage disease-related behaviors.

As both clinicians and researchers are aware, the physical and emotional toll of caregiving on caregivers is significant. Caregivers provide care for an individual with a progressive disease that ultimately ends in death. Furthermore, the care recipient exhibits not only loss of functional ability, which requires physical assistance from the caregiver, but also personality changes and behavioral disturbances. Studies of dementia caregivers have found that depressive symptomatology is virtually universal (Schulz et al., 1995). It may be naïve to think that interventions will eliminate or markedly decrease caregiver stress or depression over the course of the illness. Instead, a reasonable clinical goal may be to stabilize symptoms of stress, depression, and distress for some and to improve emotional coping skills in others. Thus, no change in the level of depression or quality of life during a period of 1 to 2 years in the face of cognitive and physical loss by the care recipient may be evidence of an effective intervention. This pattern was found by Mittleman and her colleagues (Mittleman et al., 1995, 1996), who showed that, after 1 year, depression levels for the control group increased while those of the intervention group remained stable.

A significant question relates to the translation of this research into clinical practice. As the population ages, and if the number of geriatricians trained to work with dementia patients and caregivers does not increase at a commensurate rate, internists and family practitioners will provide the majority of long-term dementia medical care. This study demonstrates that potentially beneficial interventions for caregivers can be administered in a primary care setting.

The unfortunate reality of hectic physician practices, coupled with low reimbursement for the primary care provider, may make this a daunting task. However, this research may form a basis for dementia primary care interventions that emulate current standard clinical practice. Education for disorders such as diabetes, hypertension, or heart failure is routinely provided in primary care. Although physicians may provide this education, frequently other office staff deliver the educational information. Our intervention could fit easily into this office practice model. Physicians did not deliver our interventions; instead, the interventions were designed to allow delivery by other health care providers, including nurses. The intervention protocol we developed is straightforward for both educators and caregivers. The written materials, which have concrete, practical, suggestions written at a fifth-grade reading level, are designed to lead the interventionist and caregiver through problem solving and identification of solutions, without extensive interventionist training. The constraints of the primary care practice setting dictated that the time spent in the interventions was short—approximately 20 min per face-to-face contact. Therefore, there is a precedent for this type of patient education model and it makes clinical and economic sense to have a nonphysician deliver the caregiver interventions.

There were several limitations to our research. It was conducted in a single city by trained interventionists, so further study in different areas of the country and with a variety of interventionists is needed to examine the generalizability of our findings. We also had a 28% lost-to-follow-up rate. Documented reasons for discontinuation included caregiver time constraints, death of the caregiver, change of the caregiver, difficulty with travel, and severity of illness of the care recipient. The stress of the caregiver and a perceived lack of benefit from study participation may also have been factors. In an article comparing home versus clinic assessments of cognitively impaired individuals (Bédard et al., 1995), 8 of 24 clinic patients versus 4 of 22 home patients withdrew, leading the authors to conclude that travel put a burden on participants.

Because we wanted to examine individuals who were receiving active intervention with the caregiver–patient dyad intact, as would occur in a physician's office with the patient and caregiver, 26% of caregivers who were bereaved or had placed the patient were excluded from analysis, although the caregivers were available for data collection. These figures are not dramatically different from other long-term studies. Other studies of dementia caregivers have reported death rates of 7.5% and institutionalization rates of 32.3% over 1 year (Baumgarten et al., 1994) and death rates of 18% and institutionalization rates of 22.7% over 2 years (Schulz & Williamson, 1991). However, without those lost to follow-up, bereaved, and placed, the small number of dyads remaining in the study limits our generalizability. Finally, our lack of a true control group may have diminished our ability to identify stronger intervention effects.

The integration of family caregiving into primary care is an important clinical and policy issue. The medical care system serves as the portal of entry into other formal and informal systems, and primary care is the continuing access and management point for patient and family. However, in addition to these societal and system issues, the expansion of the physician's role and focus to include the caregiver is much desired by families. On a national Internet dementia caregiving site, the caregiver feedback to health care professionals is explicit: "Your job description may only include the patient, but a major part of helping the patient is helping the caregiver" (Tad Publishing, 2001). The results of this study demonstrate that caregiver-focused interventions can be delivered in a primary care setting and may improve quality of life for the caregiver.

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