

# Enhancing Caregiver Health: Findings from the Resources for Enhancing Alzheimer's Caregiver Health II Intervention

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**OBJECTIVES:** To examine the relationships between changes from baseline to post-Resources for Enhancing Alzheimer's Caregiver Health (REACH) intervention in caregiver (CG) self-reported health, burden, and bother.

**DESIGN:** Randomized, multisite clinical trial.

**SETTING:** CG and care recipient (CR) homes in five U.S. cities.

**PARTICIPANTS:** Four hundred ninety-five dementia CG and CR dyads (169 Hispanic, 160 white, and 166 African American) receiving intervention and their controls.

**INTERVENTION:** CGs were assigned to the REACH intervention or a no-treatment control group. Intervention subjects received individual risk profiles and the REACH intervention through nine in-home and three telephone sessions over 6 months. Control subjects received two brief "check-in" telephone calls during this 6-month period.

**MEASUREMENTS:** The primary outcome was change in CG health status from baseline to after the intervention. Secondary outcomes were CG burden and bother after the intervention.

**RESULTS:** After the intervention, CGs reported better self-rated health, sleep quality, physical health, and emotional health, which was related to less burden and bother with their caregiving role than for CGs not receiving the intervention. Changes in depression appeared to mediate these relationships. Several racial and ethnic group differences existed in physical and emotional health, as well as in total frustration with caregiving, emotional burden, and CG-rated bother with CR's activities of daily living and instrumental activities of daily living at baseline and at follow-up, although differences between baseline and posttest did not vary according to race.

**CONCLUSION:** A structured, multicomponent skills training intervention that targeted CG self-care behaviors as one of five target areas, improved self-reported health status, and decreased burden and bother in racially and ethnically diverse CGs of people with dementia. *J Am Geriatr Soc* 58:30–37, 2010.

**Key words:** dementia caregiving; physical health; mental health

Of the estimated 4.5 million individuals with Alzheimer's disease (AD), more than 70% live at home, where family and friends provide nearly 75% of their care.<sup>1</sup> The amount of time that primary caregivers (CGs) spend providing informal care to their loved ones with dementia ranges from 69 to 117 hours per week.<sup>2,3</sup> The stress and burden that accompanies caring for individuals experiencing the slow progressive deterioration of AD can have negative physical and emotional health effects on the CG.<sup>4</sup> Unfortunately, the amount of time CGs spend in the caregiving role often leaves little time or resources for them to attend to their own health-promoting practices and health-care needs.

The majority of previous research focusing on psychological outcomes of caregiving for persons with dementia has demonstrated higher rates of depression and anxiety in CGs than in non-CGs.<sup>5–8</sup> In addition, there are significant correlations between higher levels of CG depression and higher levels of burden and behavioral bother associated with the caregiving role, especially in spousal CGs.<sup>6–10</sup> Less attention has been paid to the effects of caregiving on CGs' physical health. Still, CGs have been found to report lower self-rated health scores; display fewer health-promoting behaviors; and have higher morbidity and mortality rates, more sleep problems, and higher numbers of illness-related symptoms.<sup>2,3,6,8,9,11–13</sup> Research has consistently shown that these deleterious effects of caregiving on physical and psychological health are intensified in CGs who report high levels of stress and whose care recipients (CRs) display

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greater numbers of behavioral disturbances and impairments in activities of daily living (ADLs) and instrumental activities of daily living (IADLs),<sup>3,6,10,13–16</sup> although previous studies have found that having a positive view of one's health is highly associated with engaging in healthful behaviors, quicker recovery from illness, promotion of physical and emotional well-being, and greater longevity.<sup>17</sup> CGs in good health, which may provide protection from the negative outcomes of caregiving, may better tolerate the resulting burden and bother of caregiving for persons with dementia.<sup>2</sup> Thus, it is necessary for CGs to attend to their own healthcare needs and engage in health-promoting behaviors.

Racial and ethnic differences in caregiving outcomes and CG characteristics are important to consider as well. One study found that African Americans' cultural beliefs helped explain CG health outcomes over 2 years; specifically, they found that higher levels of mastery were associated with poor health outcomes, a finding the authors attribute to African-American culture or socialization.<sup>18</sup> A meta-analysis of 116 family caregiving studies found that minority CGs reported worse physical health than white CGs.<sup>19</sup> They also found that African Americans reported lower levels of CG burden and depression than white CGs, whereas Hispanic CGs were more depressed than white CGs.<sup>19</sup> It is possible that different racial and ethnic factors may affect CG health, as well as CGs self-perceived level of burden and bother with the caregiving role.

Previous work in this area has been largely cross-sectional in design, with few studies examining changes in the physical health status of CGs over time. The few existing longitudinal studies have found that current CGs had a higher occurrence of illness than former CGs<sup>15</sup> and that spousal CGs made more emergency department visits and were more likely to seek treatment for anxiety, falls, rheumatological disease, and diabetes mellitus than comparison spouses.<sup>5</sup> Few intervention studies have included treatment components promoting CG physical health. One study evaluated a behavioral intervention addressing disturbed sleep in CGs.<sup>20</sup> Results showed better sleep quality and sleep efficiency in CGs receiving the intervention, although this single-component intervention did not improve CG mood or burden. Racial and ethnic differences were not a focus in these studies.

The Resources for Enhancing Alzheimer's Caregiver Health (REACH) II trial is the only multiethnic, multisite, randomized clinical trial of an intervention to reduce stress and burden in CGs of people with AD funded by the National Institutes of Health. It is a multicomponent intervention package with one component addressing CG self-care and health behaviors.<sup>21</sup> CGs received educational materials on self-care and preventative health practices and a "health passport" that provided reminder information regarding health maintenance activities and a place to track pertinent health information. CGs were also referred to the healthy living feature of a computerized telephone support system. The main outcomes article reported that the intervention's effects were similar in each racial and ethnic group in the study, whereas significant improvements in quality of life (measured according to depression, burden, social support, self-care, and CR problem behaviors) were more likely to be found in Hispanic and whites than African-American

CGs.<sup>21</sup> (Results were significant for African-American spousal CGs.) Like all REACH II treatment components, teaching self-care involved interventionists' "active engagement" with the CG. Active engagement involved written prescriptions regarding CG health behaviors, reviewing progress toward health-related goals, and feedback from the interventionist regarding necessary modification of the prescriptions.

The purpose of the present study was to examine the relationship between changes from baseline to after the intervention in REACH II CGs' self-reported health status (e.g., questions regarding self-rated physical and emotional health, distinct from their health-maintenance practices) and self-reports of burden and bother in the caregiving role. It was hypothesized that CGs receiving the intervention would report better self-rated health and lower levels of perceived burden and bother. The role of potential mediators (CG depression and CR problem behaviors) in this relationship were also explored. This study fills a gap in the current literature in that it specifically evaluated changes in CGs' self-perceived health status after completing an intervention in which health promotion was a main component and investigates how changes in CG perception of health affects CGs' perceptions of burden and bother.

## METHODS

### Study Design and Data Collection

This study included family CGs, including close friends, who were enrolled in the REACH II trial. Recruitment procedures, eligibility criteria, and baseline data for CGs and CRs participating in REACH II are described in detail elsewhere.<sup>21</sup> Briefly, 642 CGs and their CRs with dementia who qualified for the study were randomly assigned to the control or intervention. Participants were recruited through five sites across the country (Birmingham, AL; Memphis, TN; Miami, FL; Palo Alto, CA; and Philadelphia, PA) and enrolled beginning in June 2002, with follow-up ending in August 2004. For the purposes of the present study, only participants who completed the 6-month follow-up and for whom data regarding their health status and burden and bother measures were available were included in the analyses, leaving a total of 495. CGs completing the intervention had higher levels of education than those who dropped out ( $F = 41.26, P < .001$ ), and their CRs had higher Mini-Mental State Examination scores than those of CGs who dropped out ( $F = 18.47, P < .001$ ). The most common reasons for CG discontinuation were that the CG withdrew consent or could not be located. CGs self-identified themselves as black or African American ( $n = 166$ ), Hispanic or Latino ( $n = 169$ ), or white or Caucasian ( $n = 160$ ). Demographic data for these participants are displayed in Table 1. This study followed the tenets of the Declaration of Helsinki, and institutional review boards at all five sites and at the Coordinating Center in Pittsburgh, Pennsylvania, approved the study. All participants provided informed or proxy consent before participation.

CGs assigned to the intervention group received an individualized intervention based on a risk appraisal completed during baseline interviews. All of the components of the intervention are described in detail elsewhere.<sup>21</sup> Certified interventionists delivered the intervention over 6

**Table 1. Sample Demographics**

Demographic Variable	Control Group n = 238	Intervention Group (n = 257)
Age at enrollment, mean $\pm$ SD		
Caregiver	60.2 $\pm$ 12.9	62.3 $\pm$ 12.1
Care recipient	79.0 $\pm$ 9.6	78.6 $\pm$ 9.4
Care recipient Mini-Mental State Examination score, mean $\pm$ SD*	12.7 (7.4)	13.4 (7.1)
Education, median		
Caregiver	Median = 13 (equivalent to post-high school training)	Median = 14 (equivalent to 2 years of college)
Care recipient	Median = 10 (equivalent to 10 <sup>th</sup> grade)	Median = 11 (equivalent to 11 <sup>th</sup> grade)
Caregiver race, %		
Hispanic	34.9	33.5
White	30.2	34.2
Black	34.9	32.3
Sex, %		
Caregiver		
Male	14.2	18.2
Female	85.8	81.8
Care recipient		
Male	43.9	44.7
Female	56.1	55.3
Relationship between caregiver and care recipient, %		
Nonspouse	60.0	56.0
Spouse	40.0	44.0

\* A score of  $\leq 23$  indicates cognitive impairment. SD = standard deviation.

months through 12 sessions (9 in home and 3 telephone sessions) and five structured telephone support group sessions. Certified interviewers administered standardized survey instruments and questionnaires. Participants in the control group were mailed a packet of educational materials and given two brief “check-in” telephone calls 3 and 5 months after randomization. Demographic data and data regarding CGs’ self-perceived health status, burden, and bother were collected at baseline and at the 6-month follow-up period.

### Measures of Self-Rated CG Physical and Emotional Health

CGs’ physical and emotional health in the present study were measured by including four items from REACH II measures.

Items addressing CGs’ physical health were

- “Compared to 6 months ago, how would you rate your health in general now?” Responses ranged from 0 (much better now) to 4 (much worse now).
- “During the past month, how would you rate your sleep quality overall?” Responses ranged from 0 (very bad) to 3 (very good).
- “During the past month, how often have you had trouble staying awake while driving, eating meals, or en-

gaging in social activity?” Responses ranged from 0 (never) to 3 (three or more times per week). (These two sleep questions were combined using a pre-existing REACH II algorithm to produce a total score indicating sleep quality, with scores ranging from 0 to 6, where higher scores indicate better sleep quality).

- “In the past 6 months, do you feel your physical health has improved?” Responses included 0 (no) and 1 (yes).

Emotional health was measured through the question: “In the past 6 months, do you feel that your mood or emotional well-being has improved?” Responses included 0 (no) and 1 (yes).

These items were chosen to represent CG health because self-reported health status is a robust predictor of morbidity and mortality, and sleep quality has been shown to be related to physical and emotional health in CGs of people with dementia.<sup>22–25</sup> The relationship between these four items was examined and found to be moderately correlated (correlation coefficient ( $r$ ) range = 0.11–0.47;  $P < .02$ ).

### Measures of CG Burden and Bother

CGs’ burden and bother were measured using five questionnaires: the brief 12-item version of the Zarit Subjective Burden Inventory,<sup>26</sup> the frustrations of caregiving subscale from the REACH II Quality of Care measure,<sup>21</sup> the Caregiver Assessment of Functional Dependence and Caregiver Upset measure (CAFU),<sup>21</sup> the Revised Memory and Behavior Problem Checklist (RMPBC),<sup>27,28</sup> and the Center for Epidemiologic Studies Depression Scale (CES-D).<sup>29</sup>

#### Zarit Subjective Burden Interview

The 12-item modified Zarit Subjective Burden Inventory measured CGs’ responses to questions regarding physical and emotional strain on a 5-point scale ranging from 0 (never) to 4 (nearly always). Scores range from 0 to 44, with higher total scores indicating greater levels of CG burden. This shorter version is highly correlated with the full measure ( $r$  range = 0.92–0.97) and has good internal consistency (Cronbach  $\alpha$  = 0.88).<sup>26</sup>

#### Frustrations of Caregiving

This scale asked CGs whether they “felt like” engaging in eight different behaviors indicative of CG frustration when encountering a problem in caregiving such as resistance to care. CGs’ responses to questions such as: “How often in the past 6 months have you felt like screaming or yelling at [the CR] because of the way he/she behaved?” were rated on a 4-point scale from 0 (never) to 3 (always). Total scores range from 0 to 24, with higher scores indicating greater frustration. This scale has good predictive validity.<sup>30</sup>

#### Caregiver Assessment of Functional Dependence and Caregiver Upset

The CAFU assesses CGs’ appraisals of CRs’ level of physical dependence in 15 daily activities and their reaction to or upset with providing assistance with each area. CGs were then asked to indicate how bothered they felt about providing help with each assisted activity. Responses were rated on a 5-point scale from 0 (not at all) to 4 (extremely). Total bother scores were calculated by averaging the CGs’ bother level over the number of items they reported they

assisted with. Higher total scores indicated greater levels of bother. This measure has been shown to have high internal consistency (Cronbach  $\alpha = 0.80\text{--}0.91$ ) and discriminant validity.<sup>31</sup>

### Revised Memory and Behavior Problem Checklist

The RMBPC asks CGs about the occurrence of 24 problem behaviors displayed by persons with dementia. If the CG indicated that a particular problem had occurred in the preceding week, they were asked to rate how much the problem “bothered or upset” them on a 5-point scale from 0 (not at all) to 4 (extremely). Scores range from 0 to 96, with higher total scores indicating greater behavioral bother. As with the CAFU, total behavioral bother scores were calculated by averaging the CGs’ bother level over the number of behaviors the CR exhibited. This scale is well validated and highly reliable (Cronbach’s  $\alpha = 0.90$ ).<sup>27,28</sup>

### Center for Epidemiologic Studies Depression Scale

The 10-item version of the CES-D scale was used to assess depression. For each item statement, participants were asked how often they had felt that way during the past week. Responses were rated using a scale ranging from 0 (rarely or none of the time) to 3 (most or all of the time). Total scores were calculated by summing individual item scores (after reverse coding responses where necessary), with higher scores indicating greater presence of depressive symptoms. This short form has been found to have reliability statistics comparable with those of the original CES-D and to have good sensitivity, specificity, and positive predictive value.<sup>32,33</sup>

### Statistical Methods

The present study examined 495 CGs and their CRs who participated in the REACH II study, including those in the intervention and control conditions.

Descriptive statistics were first computed for important demographic variables to provide a basic understanding of the sample characteristics. A two (treatment condition: intervention vs control, manipulated between subjects) by two (time, pretest vs posttest, manipulated within subjects) mixed factorial analysis of variance (ANOVA) was then performed on each CG health measure to determine whether the treatment had a significant effect on CG health. In each case, a significant treatment condition by time interaction showing that those in the treatment condition have a greater improvement in health than those in the control condition is expected. Bivariate correlations were next used to determine whether there were significant relationships between CG health variables and CG outcome variables, including burden, bother, and depression. A multifactor ANOVA was used to compare racial and ethnic group differences on baseline and postintervention measures of CG health and CG outcome variables.

The primary hypothesis was that CG depression would mediate the observed changes in CG health variables and CG burden and bother variables. It has been demonstrated that the strength of the mediated effect can be estimated by multiplying the estimate of the relationship between the independent variable (IV) and the mediator by the estimate of the relationship between the mediator and the dependent variable (DV) after controlling for the IV,<sup>34</sup>

although the current study examined whether *changes* in the mediator could explain the relationship between *changes* in the IV and *changes* in the DV. The mediated effects were therefore calculated by multiplying the estimate of the relationship between the IV and the mediator at Time 2 after controlling for the effects of the IV, mediator, and DV at Time 1 by the estimate of the relationship between the mediator and the DV at Time 2 after controlling for the effects of the IV at Time 2, as well as the effects of the IV, mediator, and DV at Time 1. (The same results were obtained using this method as by directly testing the mediation between Time 2 and Time 1 difference scores, but it was decided to present the results from this method because of the superiority of controlling for Time 1 scores over directly examining difference scores in regression.)

## RESULTS

### Sample Demographics

Summaries of the distributions of important demographic variables are presented in Table 1. CGs were on average aged 60 and older, and CRs were nearly 80 years old. On average, CRs had moderate cognitive impairments. The majority of CGs had postsecondary education, whereas the majority of CRs did not graduate from high school. Because of purposeful sampling procedures, the sample had strong representation from each race, and there were no general Time 1 differences between intervention and control groups. The CGs were primarily female, but the CRs were more evenly divided. The sample included substantial numbers of spousal and nonspousal CGs.

### Effect of Treatment on CG Health

Table 2 provides the mean score and standard deviation for each CG health variable broken down according to treatment group and time of assessment. The results of two (treatment condition) by two (time) mixed factorial ANOVAs conducted on each CG health measure are presented in Table 3. These results show that, in three of the four cases, there was a significant time by treatment interaction, such

**Table 2. Caregiver Health Variable Scores According to Treatment Group and Time**

Caregiver Health Variable	Mean Score $\pm$ Standard Deviation	
	Time 1	Time 2
<b>Control</b>		
Self-rated health	2.20 $\pm$ 0.81	2.07 $\pm$ 0.77
Caregiver sleep	4.01 $\pm$ 1.40	4.12 $\pm$ 1.40
Mood improvement	0.27 $\pm$ 0.45	0.32 $\pm$ 0.47
Physical improvement	0.18 $\pm$ 0.39	0.21 $\pm$ 0.41
<b>Intervention</b>		
Self-rated health	2.08 $\pm$ 0.82	1.81 $\pm$ 0.95
Caregiver sleep	3.98 $\pm$ 1.46	4.38 $\pm$ 1.31
Mood improvement	0.28 $\pm$ 0.45	0.49 $\pm$ 0.50
Physical improvement	0.21 $\pm$ 0.41	0.32 $\pm$ 0.47

See Methods for explanation of scores.

**Table 3. Effects of Time and Treatment Condition on Caregiver Health Variables**

Analysis of Variance Test	Caregiver Health Variable			
	Self-Rated Health	Caregiver Sleep	Mood Improvement	Physical Improvement
Time, $F$ (numerator $df$ , denominator $df$ )	12.70 (1, 492) <sup>  </sup>	18.79 (1, 493) <sup>  </sup>	19.30 (1, 489) <sup>  </sup>	4.76 (1, 491) <sup>‡</sup>
Treatment, $F$ (numerator $df$ , denominator $df$ )	7.08 (1, 492) <sup>§</sup>	1.67 (1, 493)	5.21 (1, 489) <sup>‡</sup>	3.96 (1, 491) <sup>‡</sup>
Time by treatment, $F$ (numerator $df$ , denominator $df$ )	4.71 (1, 492) <sup>‡</sup>	3.66 (1, 493)	12.67 (1, 489) <sup>  </sup>	3.98 (1, 491) <sup>‡</sup>
Contrasts exploring time by treatment, mean difference (standard error)*				
Control <sub>2</sub> – control <sub>1</sub>	0.06 (0.06)	– 0.16 (0.09)	– 0.02 (0.04)	– 0.00 (0.03)
Intervention <sub>2</sub> – intervention <sub>1</sub>	0.26 (0.06) <sup>  </sup>	– 0.40 (0.09) <sup>  </sup>	– 0.20 (0.04) <sup>  </sup>	– 0.09 (0.03) <sup>§</sup>

\* Bonferroni post hoc tests.  $P \leq$  <sup>‡</sup>.05, <sup>§</sup>.01, <sup>||</sup>.001.  
 $df$  = degrees of freedom.

that there was significant improvement in the intervention condition but not in the control condition. This same pattern was found for the remaining variable (CG sleep), but the interaction effect was not significant. Thus, it appears that the REACH II intervention significantly improved CG health variables.

#### Relationship Between CG Health, Burden, Bother, and Depression

The correlations between CG health and the various CG outcome variables are presented in Table 4. From this it can be seen that the CG health variables are each significantly related to most of the CG burden variables and that most of these relationships are small to medium-sized effects.

#### Depression as a Mediator

Previously reported analyses of the REACH II intervention found that CGs assigned to the intervention group reported lower levels of depression after treatment (12.6% vs 22.7%;  $P < .001$ ).<sup>21</sup> Thus, the role of depression as a mediator of the relationships between each CG health variable and each CG burden or bother variable was investigated. The results indicate that, in each case, depression mediates the relationship between CG health and CG burden (all Sobel test  $Z > 2.6$ , all  $P < .01$ ). In each case, better CG health led to less CG depression, which in turn led to lower CG burden. Although it would have been possible to create a single composite for the health variables and a single composite for the burden variables, it was felt that this would misrepresent what seem to be truly multidimensional

constructs. Using structural equation modeling would similarly reduce the dimensionality to a single health construct and a single burden construct. The uniformity of the results supports the proposition that CG depression mediates the relationship between CG health and CG burden.

#### Racial and Ethnic Group Differences in CG Health and Outcomes at Baseline and After the Intervention

The mean scores and standard deviations for the CG health and outcome variables are presented in Table 5 according to racial or ethnic group. Separate multifactor ANOVAs were performed examining racial and ethnic group differences on each CG health variable (self-rated health, CG sleep, mood improvement, and physical improvement) and each CG burden and bother variable (frustrations of caregiving, emotional burden, role burden, RMBPC bother, IADL bother, ADL bother, and CES-D). The results indicate that there were significant baseline group differences in mood improvement ( $F[2, 491] = 8.50, P < .001$ ), physical improvement ( $F[2, 490] = 5.47, P = .004$ ), frustrations of caregiving ( $F[2, 492] = 9.76, P < .001$ ), emotional burden ( $F[2, 492] = 5.31, P = .005$ ), IADL bother ( $F[2, 486] = 3.83, P = .02$ ), and ADL bother ( $F[2, 418] = 5.23, P = .01$ ). There were significant postintervention group differences in mood improvement ( $F[2, 489] = 4.35, P = .01$ ), physical improvement ( $F[2, 492] = 3.33, P = .04$ ), frustrations of caregiving ( $F[2, 488] = 9.04, P < .001$ ), emotional burden ( $F[2, 489] = 7.00, P = .001$ ), IADL bother ( $F[2, 476] = 3.72, P = .03$ ), and ADL bother ( $F[2, 411] = 3.37, P = .04$ ).

**Table 4. Correlations Between Caregiver Health Variables, Burden, Bother, and Depression at Follow-Up**

Measures of Burden, Bother, and Depression	Self-Rated Health	Caregiver Sleep	Mood Improvement	Physical Improvement
Frustrations of caregiving	0.10*	– 0.11*	– 0.09*	– 0.07
Emotional burden	0.26 <sup>‡</sup>	– 0.23 <sup>‡</sup>	– 0.17 <sup>‡</sup>	– 0.18 <sup>‡</sup>
Role burden	0.11*	– 0.18 <sup>‡</sup>	0.01	– 0.02
Revised Memory and Behavior Problem Checklist bother	0.12 <sup>‡</sup>	– 0.16 <sup>‡</sup>	– 0.14 <sup>‡</sup>	– 0.08
Instrumental activity of daily living bother	0.13 <sup>‡</sup>	– 0.15 <sup>‡</sup>	– 0.09*	– 0.07
Activity of daily living bother	0.14 <sup>‡</sup>	– 0.06	– 0.14 <sup>‡</sup>	– 0.13*
Center for Epidemiological Studies Depression Scale	0.36 <sup>‡</sup>	– 0.31 <sup>‡</sup>	– 0.24 <sup>‡</sup>	– 0.19 <sup>‡</sup>

$P \leq$  \* .05, <sup>‡</sup> .01, <sup>‡</sup> .001.

**Table 5. Scores According to Racial or Ethnic Group at Baseline and After the Intervention for Caregiver Health and Outcome Variables**

Variable	Mean Score ± Standard Deviation					
	Baseline			Postintervention		
	Hispanic	White	Black	Hispanic	White	Black
<b>Caregiver health</b>						
Self-rated health	2.2 ± 0.9	2.1 ± 0.7	2.0 ± 0.9	1.9 ± 1.0	2.0 ± 0.8	1.9 ± 0.9
Caregiver sleep	3.8 ± 1.5	4.0 ± 1.4	4.0 ± 1.5	4.3 ± 1.4	4.3 ± 1.3	4.2 ± 1.4
Mood improvement	0.3 ± 0.5	0.2 ± 0.4	0.4 ± 0.5	0.4 ± 0.5	0.3 ± 0.5	0.5 ± 0.5
Physical improvement	0.3 ± 0.4	0.1 ± 0.3	0.2 ± 0.4	0.3 ± 0.4	0.2 ± 0.4	0.3 ± 0.5
<b>Caregiver burden and bother</b>						
Frustrations of caregiving	3.1 ± 2.7	4.4 ± 2.7	4.0 ± 2.9	2.8 ± 2.7	4.0 ± 2.6	3.6 ± 2.7
Emotional burden	14.0 ± 9.2	15.5 ± 7.8	12.6 ± 7.5	12.7 ± 9.0	14.7 ± 7.8	11.5 ± 7.2
Role burden	4.6 ± 3.2	4.6 ± 3.0	4.2 ± 2.8	3.9 ± 3.3	4.2 ± 3.1	3.5 ± 2.5
Revised Memory and Behavior Problem Checklist bother	12.0 ± 4.3	11.4 ± 3.7	11.1 ± 4.2	9.9 ± 4.4	10.4 ± 3.9	9.9 ± 4.5
Instrumental activity of daily living bother	0.5 ± 0.8	0.8 ± 0.8	0.7 ± 0.8	0.4 ± 0.6	0.6 ± 0.7	0.5 ± 0.6
Activity of daily living bother	0.7 ± 0.9	1.1 ± 1.1	1.0 ± 1.0	0.6 ± 0.9	0.8 ± 0.8	0.9 ± 1.0
Center for Epidemiological Studies Depression Scale	10.6 ± 7.2	9.9 ± 5.9	9.2 ± 6.1	8.9 ± 7.0	8.3 ± 5.6	7.7 ± 5.9

See Methods for explanation of scores.

These differences, found at baseline, persisted at follow-up, although there were no significant race by before or after interactions for any of the CG health, burden, or bother variables.

## DISCUSSION

In this multicenter, randomized controlled trial designed to target several problem areas, including CG self-care, the intervention package led to better self-rated health and subsequent reductions in CG burden and bother at 6-month follow-up. This relationship was mediated through decreases in CG depression levels. The finding that this intervention improved CG health in four domains of health (general self-rated health, sleep, mood improvement, and physical improvement) is a contribution to the caregiving literature because few studies have specifically examined CG health,<sup>15</sup> with this trial being the only study to the authors' knowledge to specifically address the global concept area of CG health through a longitudinal intervention. One other study employing a health-related longitudinal intervention in dementia CGs (although targeting only one area of health: sleep)<sup>20</sup> found that CGs' sleep quality improved as a result of the intervention, although there was no improvement in CGs' depression or burden levels.

In older adults in general, the presence of disease and disability negatively affects self-perceptions of health and emotional well-being.<sup>17</sup> Also, previous studies have shown that having a positive view of one's health is highly associated with engaging in healthful behaviors, quicker recovery from illness, promotion of physical and emotional well-being, and greater longevity.<sup>17</sup> Typically, CGs of persons with dementia have been found to report lower self-rated health scores, engage in fewer health-promoting behaviors, have worse illness-related symptoms and sleep problems, and have higher mortality than non-CG older adults.<sup>2,3,6-9,11,12,16</sup> The stress of the caregiving role is often

associated with this decline in CG health, such that, as perceived burden increases, CGs self-rated health declines, and the number of somatic symptoms increases.<sup>7,15,35</sup> Previous cross-sectional studies have found that CGs who reported lower perceived burden with the caregiving role practiced more health-promoting behaviors than those reporting higher burden.<sup>36</sup> This is similar to the results of the present study in that, upon follow-up, CGs who reported better health also reported lower perceived burden and bother with the caregiving role.

Although not a main focus of this study, racial and ethnic variations in the before and after measures of CG health, depression, burden and bother were examined. Hispanics and whites were more likely to report improvements in these domains than African Americans, although all racial and ethnic groups benefited from the intervention.<sup>21</sup> Additionally, the results confirm that CGs from each ethnic or racial group who reported better health after receiving the intervention reported reductions in their burden and bother. That African Americans were the least likely to benefit from the intervention's effects is similar to a previous study in which researchers reported that none of the CG stressors measured (e.g., CRs' ADL and cognitive status, CGs' role strain) were significant predictors of CG psychosocial health at follow-up. Only CG comorbidity was reported to be a significant predictor of CG physical health at follow-up.<sup>18</sup> The findings of the current study suggest that Hispanics were less likely to report role strain (total frustrations of caregiving, ADL, and IADL bother), whereas whites were more likely to report higher emotional burden with the caregiving role.

CGs have not uniformly been found to be more disadvantaged with regard to their health than non-CG older adults. A previous study found that, over a 3-year period, spouses of persons with dementia appeared to be healthier than comparison spouses, having fewer chronic conditions and lower comorbidity indices, even though their levels of

health service utilization were equivalent to comparison spouses.<sup>5</sup> This study may have obtained different results because spouses were not specifically identified as primary CGs. Two additional cross-sectional studies found that CGs did not report poorer health practices or engage in more health-risk behaviors than non-CGs and that CGs who reported higher levels of caregiving stress engaged in more self-care behaviors.<sup>6,37</sup> The authors explained this finding by asserting that CGs performed more self-care behaviors when they were faced with greater illness symptoms. Although the present study did not specifically compare CGs with non-CGs, it remains pertinent that CGs in the intervention group were able to effect a change in their self-perceived health status that led to lower levels of depression and resultant decreases in burden and bother.

Additionally, previous studies examining CG health have found lower self-perceptions of health to be a powerful predictor of higher levels of depression.<sup>7,38</sup> CGs' depressive symptoms have been found to have stronger associations with physical health than did objective stressors.<sup>16</sup> Similarly, in the present study, depression was strongly correlated with each measure of CG health.

The relationship between the caregiving role and CG depression has been well documented, finding depression levels ranging from 28% to 55% for CGs of persons with dementia, compared with 15% in community surveys of older adults.<sup>7,8,10,39,40</sup> There is a significant correlation between higher levels of CG depression and higher levels of burden and behavioral bother associated with the caregiving role, especially in spousal CGs.<sup>6–10</sup> Although studies have shown that interventions targeting CG mental health (e.g., depression and anxiety) have been moderately successful in reducing the burden and behavioral bother CGs associate with their role,<sup>8,10,41,42</sup> no previous interventional studies have targeted CGs' physical health and its relationship to caregiving outcomes. In the present study, depression was expected to have a role in any relationship physical health may have with caregiving outcomes; this hypothesis was tested through mediation analyses after finding correlations between physical health and caregiving outcomes. As expected, depression was a potent mediator of this relationship for all CG health and CG outcome variables. This is similar to the findings of a meta-analysis of caregiving studies (although not specific to dementia CGs), in which greater CG burden and more-severe depressive symptoms were related to worse physical health of CGs.<sup>16</sup> Additionally, a cross-sectional investigation found that CGs who reported higher levels of caregiving stress had poorer self-rated health and physical functioning, larger number of illness symptoms, and higher levels of depressed mood; these variables also mediated the relationship between caregiving stress and self-care behaviors, with depression being a particularly potent mediator.<sup>6</sup> The results of the present study suggest that this relationship also holds in the reverse, in that targeting improvement of CG health may result in lower levels of depression and CG burden and bother.

There are several limitations to the present study. It is possible that CGs' subjective health mediates the relationship between depression and CG outcomes, because previous research has shown subjective health to mediate the effects of disease and disability on depression in older adults,<sup>17</sup> but CGs of persons with dementia are a specific

subgroup of the older adult population in which previous research has demonstrated that declines in CG health have been shown to be correlated with increased levels of depression and that greater levels of depression are correlated with higher perceived CG burden and behavioral bother, making depression the most logical choice for the mediator in the relationships between CG health, burden, and bother.

Although it would be interesting to explore racial and ethnic variation in the strength of depression as a mediator for reported relations (e.g., between CG health and bother), this would entail six separate mediational analyses. However, conducting these analyses would increase experiment-wise Type 1 error markedly, thus invalidating the results.

Additionally, other factors not available in this secondary data analysis of REACH II might partially explain the relationships between CG self-reported health and burden and between CG self-reported health and bother. For example, investigators have found CG and CR depression to be highly correlated,<sup>43</sup> although additional variables that were plausibly related to outcomes (e.g., CG comorbidity, CR physical functioning and problem behaviors) were explored, and none were found to be related to the outcomes in this study.

The CGs enrolled in the present study may also be a select subgroup of the older adult population, because previous researchers have posited that older adults taking on the caregiving role would need to be in a state of physical and mental health in which they were able to take on this role.<sup>7,11</sup> This could mean that these CGs were in a superior state of physical and mental health when they assumed the caregiving role, although more than 40% of the CGs in the present study were spousal CGs who had been CGs for an average of 4.5 years, making their health status at the onset of caregiving less important to the present findings. Previous research has shown that, after several years of caregiving, informal CGs have more physical complaints than the general population according to age and sex<sup>15</sup> and that spousal CGs rate health more poorly than adult children CGs.<sup>7</sup> Thus, it is likely that the CGs in the present sample would no longer be in a better state of physical or mental health than when they began the CG role and than non-CGs.

The novelty of the present study is that it addresses the question of CG health in a longitudinal time-frame, showing that, when CGs receive knowledge and skills training in health and health behaviors, they are able to incorporate these practices into their daily routine. This not only improves their health, but also decreases their levels of depression and lessens the burden and bother they associate with the caregiving role. This study provides support for the assertion that negative health effects associated with the caregiving role can be ameliorated through this type of intervention. These findings suggest that clinicians should consider exploring CG risk factors (e.g., depression, burden, and bother) in practice and should target appropriate resources if these factors are present. A previous study recommended that clinicians use the Caregiver Assessment Tool developed by the American Medical Association to identify CGs at risk for adverse health outcomes.<sup>8</sup> Because depression is one of several powerful contributors to CG burden, bother, and health outcomes, future research investigating CG health effects on CG outcomes should also examine other factors that have been found to mediate the

relationship between CG stress and depression, including the quality of the CG–CR relationship, CG self-esteem, and social support.<sup>2</sup>

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