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# Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease

Mary S. Mittelman, DrPH; William E. Haley, PhD; Olivio J. Clay, MA; and David L. Roth, PhD

**Abstract—Objective:** To determine the effectiveness of a counseling and support intervention for spouse caregivers in delaying time to nursing home placement of patients with Alzheimer disease (AD), and identify the mechanisms through which the intervention accomplished this goal. **Methods:** We conducted a randomized controlled trial of an enhanced counseling and support intervention compared to usual care. Participants were a referred volunteer sample of 406 spouse caregivers of community-dwelling patients who had enrolled in the study over a 9.5-year period. The intervention consisted of six sessions of individual and family counseling, support group participation, and continuous availability of ad hoc telephone counseling. Structured questionnaires were administered at baseline and at regular follow-up intervals, every 4 months for the first year and every 6 months thereafter. Cox proportional hazard models were used to test the effects of the intervention on the time to nursing home placement for the patients after controlling for multiple time-invariant and time-dependent predictors of placement. **Results:** Patients whose spouses received the intervention experienced a 28.3% reduction in the rate of nursing home placement compared with usual care controls (hazard ratio = 0.717 after covariate adjustment,  $p = 0.025$ ). The difference in model-predicted median time to placement was 557 days. Improvements in caregivers' satisfaction with social support, response to patient behavior problems, and symptoms of depression collectively accounted for 61.2% of the intervention's beneficial impact on placement. **Conclusion:** Greater access to effective programs of counseling and support could yield considerable benefits for caregivers, patients with Alzheimer disease, and society.

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Dementia increases the risk of nursing home placement (NHP) among the elderly more than fivefold.<sup>1</sup> Family caregivers help people with dementia remain at home, although they vary considerably in their ability to do so.<sup>2–4</sup> NHP reduces direct care obligations, but does not necessarily reduce caregivers' distress,<sup>5</sup> and is very costly to society.<sup>6,7</sup>

A randomized controlled trial of a counseling and support intervention for spouse caregivers of patients with Alzheimer disease (AD) began in 1987 at New York University (NYU). The median time from baseline to NHP of patients was 329 days longer in the treatment group than in the control group among the 206 subjects who enrolled between 1987 and 1991.<sup>8</sup>

An additional 200 spouse caregivers enrolled between 1991 and 1997, resulting in a final sample of 406 subjects. Caregivers have been followed longitudinally for up to 17 years, with documentation of the dates of NHP, death, and study termination. The NYU study, with its large sample size and extended length of follow-up, provides a unique opportunity to

gauge the potential long-term impact of psychosocial intervention.

Over the past two decades, efforts at cost containment have led to substantial decreases in utilization of nursing homes in the United States.<sup>9</sup> We hypothesized that despite this trend, the NYU counseling and support intervention would continue to demonstrate a significant effect on time to NHP over the entire time period examined (1987–2005), mediated by previously demonstrated improvements in spouse caregivers' social support, depressive symptoms, and tolerance of problem patient behaviors.<sup>10–12</sup>

**Methods. Overview.** Caregivers were assigned a family counselor when they enrolled in the study. Participants completed a comprehensive baseline assessment, consisting of structured self-report questionnaires, and then were randomized by lottery to an enhanced counseling and support intervention ( $n = 203$ ) or to usual care ( $n = 203$ ). Allocation was concealed from participants and counselors until after the baseline assessment, and was then revealed by the counselors opening a sealed envelope in the caregivers' presence showing randomization to treatment or usual care conditions. The assessment was repeated 4, 8, and 12 months after baseline, and every 6 months thereafter. Participation con-

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tinued until the caregiver became too ill to participate, died, or refused to continue in the study, or until 2 years after the death of the patient with AD. No adverse events were reported during the study.

**Participants.** Approximately half the caregivers who were recruited were spouses of subjects of our AD Center ( $n = 214$ , 53%); these patients had received a diagnosis of AD according to National Institute of Neurologic and Communicative Disorders and Stroke-AD and Related Disorders Association (NINCDS-ADRDA) criteria.<sup>13</sup> The rest of the sample of caregivers ( $n = 192$ , 47%) were spouses of patients who had received a diagnosis of AD and were recruited through referrals from the New York City chapter of the Alzheimer's Association, other community organizations, private physicians, or other study participants. To be eligible, caregivers were required to be living with the patient at baseline and they or the patient had to have at least one relative living in the metropolitan area. This study was approved by the Institutional Board of Review of the NYU School of Medicine. Informed consent was obtained from all participants.

**Treatment.** The intervention consisted of two individual and four family counseling sessions tailored to each caregiver's specific situation, encouragement of weekly support group participation, and availability of ad hoc telephone counseling. Individual and family counseling sessions occurred within 4 months of enrollment. The content of the counseling sessions depended on the needs of each spouse caregiver and family (e.g., learning techniques for managing troublesome behaviors, promoting better communication between concerned family members). The family counseling sessions included relatives suggested by the caregiver; the person with AD was not included. Caregivers in the intervention group agreed at baseline that they would join a support group that met weekly after the 4-month follow-up for ongoing emotional support and education. There are many support groups in the New York metropolitan area, and caregivers were encouraged to join groups in their own neighborhoods. Ad hoc telephone counseling was available to caregivers and their families, making it possible for them to determine the amount of contact they had with counselors beyond the scheduled individual and family counseling sessions and helping them deal with crises and with the changing nature of the patient's symptoms over the course of the disease. Counselors also provided resource information and referrals for auxiliary help, financial planning, and management of patient behavior problems. Each caregiver in the intervention group had access to all the interventions, and was provided with support for an unlimited time. A published counseling manual describes the intervention in detail.<sup>14</sup>

Caregivers assigned to the usual care group received services routinely provided to patients and their families in the NYU-ADRC, such as resource information and help upon request, but they did not participate in formal counseling sessions, and these caregivers' family members did not generally have any contact with the counselors. Although the nature of the study made it impossible for caregivers or counselors to remain blind to group assignment, caregivers in the usual care group were free to join support groups and could call the same counselors as those in the intervention group. Thus usual care participants undoubtedly received more information and support than is generally provided in typical medical or community treatment settings.

While agreement to participate in a support group was a criterion for inclusion, and no one refused at the outset to do so, not all participants in the treatment condition ultimately joined support groups, and many subjects in the usual care condition joined support groups on their own; 42% of the caregivers in the control condition joined support groups within 12 months of enrollment, compared to 58% of those in the treatment condition ( $\chi^2 = 10.13$ ,  $p = 0.0015$ ). All caregivers were permitted to continue in the study, and remained in the condition to which they were originally assigned regardless of whether they joined support groups.

**Measures.** Demographic information, including patient and caregiver age, caregiver gender, and caregiver reports of patient income, was obtained at the baseline assessment. A number of self-report instruments were completed by caregivers at baseline and at each follow-up assessment to determine the extent of patient impairment, the psychological status of the caregiver, and the physical health of the patient and caregiver. Dates of permanent nursing home placement and of death were monitored throughout the project during regular follow-up interviews and

telephone contacts with caregivers and family members. Dates of death were subsequently confirmed by use of the Social Security Death Index.<sup>15</sup>

Patient functioning was assessed by the counselor, using the Global Deterioration Scale (GDS; Cronbach's  $\alpha = 0.83$ ),<sup>16</sup> a semi-structured rating based on an interview with the caregiver. Patients with dementia have scores ranging from 4 to 7 on this scale. Caregivers also reported on the frequency of 30 memory and behavior problems using the Memory and Behavior Problems Checklist (MBPC,  $\alpha = 0.80$ ).<sup>17</sup>

We included several self-report scales to assess the psychological status of the caregiver. The Geriatric Depression Scale ( $\alpha = 0.94$ )<sup>18</sup> is a 30-item, yes/no depression scale specifically designed for older adults. Caregivers reported on the degree to which they found each of the memory and behavior problems in the MBPC upsetting; this has been used in previous research as an indicator of caregiver appraisal or burden.<sup>11,12,19</sup> The Burden Scale ( $\alpha = 0.88$ )<sup>17</sup> consists of 22 questions to measure the perceived burden experienced by caregivers of patients with dementia.

Caregiver satisfaction with social support was assessed by averaging three questions from the Stokes Social Network Questionnaire ( $\alpha = 0.92$ )<sup>20</sup> about the caregiver's satisfaction with general support, assistance, and emotional support from family and friends, each ranging from 1 (very dissatisfied) to 6 (very satisfied). Caregiver and patient physical health were estimated for these analyses with the subjective rating of overall health (excellent/good/fair/poor) from the OARS Physical Health Form (ICC = 0.83).<sup>21</sup> Caregivers provided ratings for themselves and their spouses with AD.

**Data analysis.** The predictors of nursing home placement were primarily examined using Cox proportional hazards models.<sup>22,23</sup> The time, measured in days, from date of enrollment and randomization into the project until date of nursing home placement, served as the primary outcome variable. Two patients entered Alzheimer's units in assisted living facilities and were included in the analyses as nursing home placements. For patients who died without ever being placed, date of death was used as a right-censoring event (except in supplemental cumulative incidence analyses described below, in which date of death was considered a competing risk event). For patients who dropped out of the study, the date of the last follow-up interview was used as the censoring date. Caregivers who were continually active in the study and were still caring for their family member in the community were censored at the date August 30, 2005, for these analyses.

Treatment group and gender were included as indicator variables (enhanced counseling = 1, usual care = 0 and female = 1, male = 0). Information on patient income, which was obtained in seven categories and coded at the midpoint of each category interval, was transformed by taking  $\log_{10}(1 + \text{income})$ , to reduce the effects of extreme values. The Global Deterioration Scale was recoded into a set of three dichotomous (0,1) variables representing moderate dementia (GDS 5), severe dementia (GDS 6), and very severe dementia (GDS 7), with the mild stage of dementia (GDS 4) serving as the reference group for the other GDS levels. Other variables were entered without transformation.

Predictors were categorized as either time-invariant (do not change over time) or time-dependent (variation assessed over time). The primary time-invariant predictor was treatment group, but we also examined other potentially important time-invariant predictors including caregiver and patient age, caregiver gender, patient income, and year of study entry. Time-dependent predictors were classified as to whether they were likely to be influenced by the enhanced support intervention. Time-dependent risk factors for placement that were likely to be affected by psychosocial intervention included caregiver burden,<sup>24-26</sup> caregiver depression,<sup>27,28</sup> caregiver social support,<sup>4</sup> and appraisal of patient behaviors as stressful.<sup>11,29</sup> While unlikely to respond to our intervention, we also considered other time-dependent risk factors, GDS stage, caregiver and patient physical health, and frequency of memory and behavior problems.

In the Cox proportional hazards models, we first examined the predictive effects of each variable individually. Next, in a multivariable model, we examined the effect of the intervention after taking into account the effects of time-invariant predictors and the baseline (pre-intervention) observations of the time-dependent predictors. Baseline covariates were included primarily to esti-

mate their own effects on time to placement, and also to account for these effects before estimating the incremental effect due to the intervention. Including baseline variables as covariates to adjust for small and random baseline imbalances is a common and well-accepted strategy that yields an estimate of the intervention effect that is both adjusted for and stratified by the covariate influences.<sup>30-32</sup>

Mediation analysis is increasingly being used in intervention research to identify the likely underlying mechanisms of successful psychosocial interventions and the factors that should be targeted to maximize intervention effectiveness.<sup>33</sup> Changes in the time-dependent covariates, including caregiver satisfaction with social support, reaction to patient memory and behavior problems, burden, and number of depressive symptoms, were subsequently added to the multivariable model to test our hypotheses that these changes would mediate or explain a significant portion of the intervention's effect on nursing home placement rates.

In order to demonstrate statistical mediation according to accepted guidelines,<sup>33-35</sup> the intervention must lead to significant change in the potential mediator (e.g., caregiver depression), and this intervention-induced change must also explain a significant proportion of variance in the primary outcome, time to nursing home placement. The structure of our mediation analysis models is summarized below:

$\log h(t) = a(t) + b_1X_1 + b_2X_2 + \dots + b_jX_j$  (time-invariant and baseline covariates)  
+  $b_{j+1}(M(t) - M(0))$  (change from baseline in hypothesized mediator)  
+  $b_{j+2}(\text{group})$  (direct (unmediated) intervention effect)

In these models,  $t$  represents the time, in days, of each observation up to placement (or censoring),  $j$  indicates the number of individual time-invariant and baseline covariates, and  $M$  represents the hypothesized mediating variable. Consequently,  $M(t) - M(0)$  is a time-dependent predictor that quantifies the change observed on the mediator over time from baseline.

By examining the predictive influence of time-dependent changes in each potential mediator separately, we were able to determine that mediator's total mediation effect. The proportion of the intervention effect that can be attributed to the mediator is the difference in magnitude between the intervention effect in the baseline covariate-adjusted model and the intervention effect in the mediation model that also includes the change score for that time-dependent predictor. We determined the percentage of the intervention effect that could be attributed to changes in the mediator as follows:

$$\% \text{ mediated} = 100 \times ((\ln(HR_B) - \ln(HR_M)) / \ln(HR_B))$$

where  $HR_B$  = the hazard ratio for the intervention effect from the baseline covariate-adjusted model and  $HR_M$  = the hazard ratio for the intervention effect from the mediation model.

The total mediation effect for each mediator includes the unique contribution of that mediator as well as the effect it might share with other mediators, since intervention-induced changes in these mediators are not necessarily independent from each other. Indeed, we have previously shown that intervention-induced changes in depression and reaction to patient behavior problems after 1 year of intervention were correlated both with each other and with changes in satisfaction with the social support network.<sup>36</sup> This suggests that these mediators would share explanatory power in the present analyses, accounting for a significant portion of the intervention's impact on nursing home placement. Therefore, additional multivariate mediation models were estimated in which multiple time-dependent changes were entered simultaneously. These models allowed us to quantify the proportion of the total intervention effect on nursing home placement rates that could be attributed to changes on the potential mediators collectively.

Because patient death was a common right-censoring event, we conducted a supplemental analysis to estimate the effect of treatment, using Kaplan-Meier cumulative incidence analysis methods,<sup>37,38</sup> in which patient death was an informative competing risk event rather than a non-informative right-censoring event. The magnitude of the treatment effect was compared to similar findings from the right-censored proportional hazards models to examine whether simple treatment group differences might be an artifact of an informative censoring process. There is little information available on the use of cumulative incidence for competing

risks analyses in multivariate models, particularly those with time-dependent predictors, so these methods were not used for the multivariate and mediation model analyses that were central to our primary research questions.

**Results.** *Baseline characteristics of subjects, subject accrual, and follow-up.* Salient baseline characteristics of caregivers and patients are presented in table 1. We used  $t$ -tests to compare the treatment and control groups on continuous variables, and  $\chi^2$  tests for caregiver gender and GDS. In spite of randomization, imbalances ( $p < 0.05$ ) were found between the treatment groups on four of the baseline variables—gender, GDS, MBPC, and depressive symptoms. These variables were included, along with the other baseline variables, in our analytic models as potential prognostic predictors of nursing home placement. Effects for intervention and for other variables are also adjusted for these imbalances between treatment groups by including the relevant baseline variables in the models as covariates.

At least one follow-up interview was obtained from 396 of the 406 caregivers, and information on the primary endpoint for this analysis was available for all 406 subjects. There were 210 nursing home placements and 196 censored cases as of August 30, 2005 (figure 1).

*Univariate effects on nursing home placement.* The results of the univariate proportional hazard models, including hazard ratios and 95% CIs, are presented in table 2. This analysis, unadjusted for covariates, showed that caregivers in the intervention group were able to keep their spouses at home longer than caregivers in the usual care control group (hazard ratio = 0.714,  $\chi^2 = 5.88$ ,  $p = 0.015$ ). The difference in the model-predicted median time from baseline to nursing home placement for the two groups in this univariate analysis was 585 days; the estimated median time for the usual care group was 1,181 days compared to 1,766 days for the enhanced counseling and support group.

Slightly stronger group differences were found in supplemental analyses using Kaplan-Meier cumulative incidence methods that treated patient death as a competing risk event. Cumulative incidence rates in analyses that account for competing events are generally lower than those that treat such events as censoring events.<sup>37</sup> In this context, a median (i.e., 0.50) cumulative incidence rate from the censored analysis corresponded to a cumulative incidence adjusted for competing risk (CICR) of 0.40 for the intervention group, and the two groups differed by 697 days at this CICR point (intervention = 1,766 days, usual care = 1,069 days). Thus, the right-censored proportional hazards estimate of the intervention effect was lower than the similar estimate from the CICR approach, suggesting that the censored approach was not leading to a spuriously inflated estimate of the intervention effect.

Among the demographic variables we considered, the proportional hazards models summarized in table 2 indicated that neither caregiver gender nor age were significant predictors of placement. An effect that approached conventional levels of statistical significance was found for patient age. Patient income was a significant predictor, with people of higher income being less likely to place. Year of study entry also had a significant impact, with those who entered more recently being less likely to place their relatives than those who entered in the earlier years.

**Table 1** Key demographic and predictive characteristics at baseline by treatment

	Treatment, n = 203	Control, n = 203	Total, n = 406
Female caregiver, n (%)	111 (54.68)	133 (65.52)	244 (60.10)
Caregiver age, y, mean (SD)	71.52 (8.61)	71.15 (9.31)	71.33 (8.96)
Patient age, y, mean (SD)	73.80 (8.46)	74.81 (8.30)	74.31 (8.38)
Patient income,* mean (SD)	3.54 (1.45)	3.70 (1.26)	3.62 (1.36)
Global Deterioration Scale (GDS), n (%)†			
4	72 (35.47)	64 (31.53)	136 (33.50)
5	91 (44.83)	77 (37.93)	168 (41.38)
6 or 7	40 (19.70)	62 (30.54)	102 (25.12)
Caregiver physical health, mean (SD)	2.15 (0.64)	2.07 (0.63)	2.11 (0.64)
Patient physical health, mean (SD)	2.20 (0.72)	2.17 (0.73)	2.18 (0.72)
Satisfaction with social support, mean (SD)	4.52 (1.32)	4.41 (1.41)	4.47 (1.37)
Frequency of memory and behavioral problems, mean (SD)	41.15 (18.29)	46.55 (19.49)	43.85 (19.07)
Reaction to memory and behavioral problems, mean (SD)	22.31 (13.77)	24.77 (16.99)	23.54 (15.50)
Depressive symptoms, mean (SD)	8.92 (5.74)	10.58 (7.21)	9.75 (6.56)
Caregiver burden, mean (SD)	34.46 (14.01)	37.13 (16.25)	35.80 (15.21)

\* Patient income was log transformed.

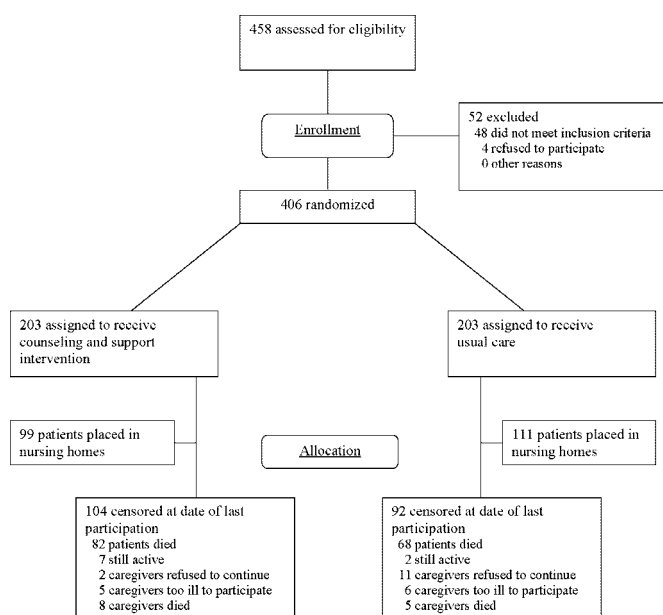
† Only one patient had a GDS of 7 at baseline, so this case was combined with those who had a GDS = 6 for the baseline covariate analyses only.

Among the time-dependent predictors, increased severity of dementia, poorer caregiver physical health, poorer patient physical health, lower satisfaction with social support, greater frequency of memory and behavior problems, greater reaction to memory and behavior problems, more symptoms of depression, and higher caregiver burden were all significant predictors of higher nursing home placement rates ( $p < 0.020$ , see table 2).

*Effect of the intervention on time to nursing home placement after adjusting for the effects of baseline covariates.*

The time-invariant covariates and the baseline (pretreatment) values of the time-dependent predictors were entered simultaneously along with treatment group in our baseline covariate-adjusted model of the effect of the intervention condition. The hazard ratios and 95% CIs from this model are displayed in table 3. The primary effect of interest from this table is the one for treatment group (hazard ratio = 0.717,  $\chi^2 = 5.05$ ,  $p = 0.025$ ), indicating that, after considering the influence of all other covariates in table 3, including those with significant imbalances at baseline between the intervention and usual care groups, the patients who were cared for by spouses in the enhanced counseling and support group were placed at slightly less than 72% of the rate observed for those whose spouses were in the usual care group. The difference in the model-predicted median time from baseline to nursing home placement for the two groups from this model was 557 days (usual care = 1,209 days, enhanced counseling and support group = 1,766 days). The intervention effect, adjusted for baseline covariates, is displayed graphically in figure 2, where 11-year survival curves show the significant difference between the two groups. In addition, significant covariate effects were found for patient income, year of study entry, GDS, and depressive symptoms.

*Mediators of the intervention effect on nursing home placement.* The results of the mediation analyses are presented in table 4. The hazard ratio of 0.717 for treatment group from the baseline covariate-adjusted model (table 3) represents the intervention effect before considering the impact of any time-dependent changes in potential intervention mediators. Each row of table 4 reports the results when changes on that time-dependent predictor only are added to the model summarized in table 3. The hazard ratio for the intervention effect will move closer to the null value of 1.00 if the change in the mediator under consider-



**Figure 1.** Trial profile. Information about the nursing home placement status (placed, deceased, still at home) and date of placement was known for all patients.

**Table 2** Univariate Cox proportional hazard ratios for the effect of each time-invariant and time-dependent variable on time to nursing home placement

	Hazard ratio (95% CI)	p Value*
Time-invariant predictors		
Group (intervention vs usual care)†	0.714 (0.544–0.937)	0.0153
Caregiver gender (female vs male)†	1.237 (0.939–1.629)	0.1310
Caregiver age	1.005 (0.990–1.020)	0.5163
Patient age	1.013 (0.996–1.030)	0.1285
Patient income‡	0.840 (0.769–0.918)	0.0001
Year of study entry§	0.908 (0.863–0.955)	0.0002
Time-dependent predictors		
Global Deterioration Scale at baseline		
5 vs 4	14.529 (1.994–105.838)	0.0083
6 vs 4	46.154 (6.434–331.098)	0.0001
7 vs 4	33.049 (4.420–247.081)	0.0007
Caregiver physical health	1.287 (1.059–1.565)	0.0113
Patient physical health	1.228 (1.042–1.447)	0.0141
Average satisfaction with support network	0.830 (0.757–0.910)	<0.0001
Frequency of memory and behavior problems	1.042 (1.033–1.052)	<0.0001
Reaction to memory and behavior problems	1.032 (1.026–1.039)	<0.0001
Depressive symptoms	1.049 (1.029–1.070)	<0.0001
Caregiver burden	1.038 (1.028–1.048)	<0.0001

\*  $\chi^2$  test.

† Treatment group was coded as a dichotomous variable (intervention = 1; usual care = 0) as was caregiver gender (female caregivers = 1; male caregivers = 0).

‡ Patient income was log transformed.

§ Year of study entry was coded as 1987 = 0 to 1997 = 10.

ation is both predictive of placement rate and an effect of the intervention. The proportion of the intervention effect that could be attributed to each mediator was determined from the natural logarithms of the hazard ratios for the intervention condition from models with and without the mediator in question. For example, we determined that 22.6% of the baseline-adjusted intervention effect on nursing home placement rates could be attributed to treatment-induced changes in depression from the natural logarithms of the relevant hazard ratios  $[(\ln [0.717] - \ln [0.773]) / \ln (0.717) = 0.226, \text{ or } 22.6\%]$ .

Neither change in caregiver nor patient physical health mediated the intervention effect on nursing home placement. This can be inferred from the fact that the change scores did not predict nursing home placement rates and the intervention effect was still significant with nearly the same hazard ratio after including changes on these time-dependent variables in the model. Although changes in dementia severity did predict nursing home placement rates, these changes did not mediate the intervention effect, as indicated by the fact that change in dementia severity did not alter the size of the hazard ratio associated with the intervention.

There was evidence for partial mediation effects for the remaining time-dependent variables listed in table 4. The largest effects were observed for changes in caregiver reaction to patient memory and behavior problems, satisfaction with social support, and caregiver burden. Each of these mediators was significantly affected by the intervention,

and these intervention-induced changes accounted for at least 30% of the intervention's effect on nursing home placement rates when examined individually. Most striking was the effect of the intervention through decreasing caregiver reaction to patient behavior, which accounted for 48.7% of the impact of the intervention on nursing home placement. Depressive symptoms and frequency of memory and behavior problems were significant, but weaker, individual mediators of the intervention effect.

The proportional hazards models that included all the time-invariant covariates and multiple time-dependent changes from baseline simultaneously indicated that the model with changes in caregiver reaction to patient memory and behavior problems, satisfaction with social support, and depression included together reduced the hazard ratio for the intervention condition to 0.879 ( $\chi^2 = 0.689, p = 0.406$ ). The comparison of this hazard ratio and the reference value of 0.717 indicated that, collectively, these three mediators accounted for 61.2% of the intervention effect on nursing home placement rates  $[(\ln [0.717] - \ln [0.879]) / \ln (0.717) = 0.612]$ .

**Discussion.** The current analyses of data collected over an 18-year period indicate that, both before and after comprehensive covariate adjustment, the enhanced caregiver support intervention developed for spouse caregivers at NYU led to significant delays in nursing home placement. The covariate-adjusted

**Table 3** Covariate-adjusted Cox proportional hazard ratios of nursing home placement from a multivariable predictor model with time-invariant and baseline covariates

	Hazard ratio (95% CI)	p Value*
Time-invariant predictors		
Group (intervention vs usual care)	0.717 (0.537–0.958)	0.0247
Caregiver gender (female vs male)	1.249 (0.883–1.767)	0.2081
Caregiver age	1.004 (0.979–1.029)	0.7642
Patient age	1.015 (0.989–1.043)	0.2655
Patient income	0.839 (0.760–0.925)	0.0005
Year of study entry (0 = 1987 – 10 = 1997)	0.907 (0.859–0.957)	0.0004
Baseline values of time-dependent predictors		
Global Deterioration Scale		
5 vs 4	1.939 (1.332–2.824)	0.0006
6 vs 4	2.505 (1.578–3.977)	<0.0001
Caregiver physical health	1.079 (0.835–1.394)	0.5628
Patient physical health	0.982 (0.786–1.227)	0.8742
Satisfaction with support network	1.129 (0.997–1.279)	0.0552
Frequency of memory and behavior problems	0.987 (0.975–1.000)	0.0499
Reaction to memory and behavior problems	1.013 (0.999–1.027)	0.0743
Depressive symptoms	1.016 (0.988–1.044)	0.2791
Caregiver burden	1.009 (0.996–1.021)	0.1759

\*  $\chi^2$  test.

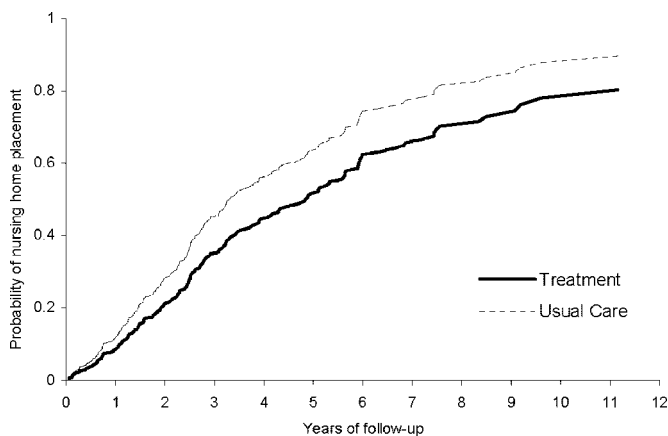
model indicated a median delay in placement of 557 days, or approximately 1.5 years. This is substantially larger than the median delay of 329 days that was reported in 1996 over a more limited time period for the first 206 participants.<sup>8</sup>

Delaying placement was not accomplished at the expense of caregiver well-being. Caregivers in the treatment group were not only able to keep their spouses at home with them longer, but, as the results of our mediation analysis indicate, the effects of the intervention on nursing home placement were largely achieved through improvements in caregiver well-being that we have reported previously<sup>10,11,36</sup>:

greater tolerance for patient memory and behavior problems, improved satisfaction with the support provided by family and friends, and fewer symptoms of depression.

Our results suggest that with sufficient counseling and support, it is possible to achieve outcomes that are beneficial to most family caregivers, older patients, and society. While nursing home placement may be necessary when caregivers are unable or unwilling to manage the care of their relatives at home, it typically does not reduce caregiver distress.<sup>5,39</sup> With placement, caregivers may encounter new stressors such as coping with guilt, feeling their relatives are not receiving adequate care, and conflicts with nursing home staff. Remaining at home longer is generally also to the advantage of patients with dementia, for whom nursing home placement can lead to increased confusion due to the strain of adapting to an unfamiliar environment<sup>40</sup> and increased risk of mortality.<sup>41</sup> Nevertheless, we recognize that nursing home placement may be the best option for some individuals. Caregivers should be supported in decisions to seek placement, and clinicians should be alert to circumstances where placement should be recommended to protect the caregiver's health and well-being.

This study had several limitations that should be addressed in future research. Despite utilization of random assignment, we found imbalances at baseline between treatment and control participants on several key measures. We entered these variables, along with other covariates, in our analyses to ad-



**Figure 2.** Probability of nursing home placement (1 – survival probability) as estimated from a Cox proportional hazards model. Curves are depicted for each intervention group at the mean value of the covariates.

**Table 4** Covariate-adjusted Cox proportional hazard ratios of nursing home placement for change in each time-dependent predictor and for the treatment group\*

Time-dependent predictor added to the model‡	Change from baseline ( $b_{j+1}$ )			Treatment group ( $b_g$ )			% of Group effect mediated†
	HR (95% CI)	$\chi^2$	$p$	HR (95% CI)	$\chi^2$	$p$	
Global Deterioration Scale				0.742 (0.56–0.99)	4.04	0.0443	10.31
5 vs 4	12.059 (1.63–89.18)	5.95	0.0147				
6 vs 4	35.705 (4.81–265.30)	12.21	0.0005				
7 vs 4	25.405 (3.20–201.73)	9.36	0.0022				
Caregiver physical health	1.053 (0.82–1.35)	0.16	0.6851	0.734 (0.55–0.98)	4.27	0.0388	7.06
Patient physical health	1.139 (0.93–1.40)	1.55	0.2134	0.726 (0.54–0.97)	4.66	0.0309	3.76
Average satisfaction with support	0.853 (0.75–0.97)	5.68	0.0171	0.803 (0.59–1.09)	1.98	0.1597	34.05
Frequency of memory and behavior problems	1.048 (1.04–1.06)	72.64	<0.0001	0.770 (0.58–1.03)	3.09	0.0788	21.43
Reaction to memory and behavior problems	1.030 (1.02–1.04)	44.21	<0.0001	0.843 (0.63–1.13)	1.29	0.2565	48.66
Depressive symptoms	1.036 (1.01–1.07)	5.87	0.0154	0.773 (0.58–1.04)	2.94	0.0864	22.60
Caregiver burden	1.038 (1.03–1.05)	42.66	<0.0001	0.800 (0.60–1.07)	2.21	0.1367	32.94

\* Each row reports the results for a model that includes the change scores associated with one time-dependent predictor.

† The rightmost column in each row shows the reduction in the size of the intervention effect after accounting for the changes in the potential mediator in the model represented by that row.

‡ Added to the time-invariant and baseline covariates from table 3.

just our test of the intervention effect for baseline imbalances, but future studies might use stratified randomization techniques to ensure baseline equivalence on major covariates such as gender and disease severity. In addition, this project was conducted in a university hospital setting, and focused on spouse caregivers, few of whom were of minority ethnic backgrounds. More recent caregiver intervention projects have shown that culturally diverse family caregivers can respond well to appropriate psychosocial interventions offered in community settings.<sup>42</sup>

Interventions that help reduce nursing home utilization without overburdening family members will be essential for our society, which is confronted with a projected tripling of cases of AD in the decades ahead.<sup>43</sup> Given the average annual cost of \$60,000 for nursing home care in the United States in 2004,<sup>6</sup> a delay in placement of 1.5 years represents about a \$90,000 savings per patient. While our study did not collect sufficient information to conduct a careful cost-benefit analysis, the average nursing home cost savings for a single participant in the treatment group is far greater than the annual salary of a full-time counselor. Future research should include detailed cost-benefit analyses, but the results of this study suggest that wider dissemination of this intervention would be cost-effective health care policy.

The value of social support for family caregivers is not restricted to AD. For example, family support has been found to have positive effects on quality of life of caregivers for patients recovering from stroke.<sup>44</sup> Despite the fact that results from this project and others demonstrate the effectiveness of

evidence-based interventions for family caregivers, such specialized and individualized caregiver intervention programs are not widely available. Most caregivers in the United States do not receive individual or family counseling services from trained professionals. Typically, those who seek services are only provided referrals to support groups, even though recent research suggests that unstructured support groups may be far less effective at achieving desirable outcomes than individualized caregiver interventions.<sup>45</sup>

In community settings, caregivers frequently have even greater need for resources and patients more commonly have multiple etiologies underlying their dementia. Studies to determine the feasibility and effectiveness of counseling and support interventions in typical community settings are necessary. One promising recent study showed that community service providers can be trained to deliver effective, evidence-based caregiver intervention in caregivers' homes, and intervention improved caregiver depression, burden, and stress appraisal, while also improving patient quality of life and behavioral problems.<sup>46</sup> Further efforts to extend evidence-based caregiver interventions beyond research settings should be a high priority, given their potential benefit to caregivers, patients with dementia, and society.

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## References

1. Eaker ED, Vierkant RA, Mickel SF. Predictors of nursing home admission and/or death in incident Alzheimer's disease and other dementia cases compared to controls: a population-based study. *J Clin Epidemiol* 2002;55:462-468.
2. Stevens A, Owen J, Roth D, Clay O, Bartolucci A, Haley WE. Predictors of nursing home placement in White and African American individuals with dementia. *J Aging Health* 2004;16:375-397.
3. Mausbach BT, Coon DW, Depp C, et al. Ethnicity and time to institutionalization of dementia patients: a comparison of Latina and Caucasian female family caregivers. *J Am Geriatr Soc* 2004;52:1077-1084.
4. Gaugler JE, Edwards AB, Femia EE, et al. Predictors of institutionalization of cognitively impaired older adults: Family help and the timing of placement. *J Gerontol B Psychol Sci Soc Sci* 2000;55b:P247-P256.
5. Schulz R, Belle SH, Czaja SJ, McGinnis KA, Stevens A, Zhang S. Long-term care placement of dementia patients and caregiver health and well-being. *JAMA* 2004;292:961-967.
6. MetLife market survey of nursing home & home care costs. Available at: <http://www.MatureMarketInstitute.com>. Accessed February 14, 2005.
7. Rhoades JA, Sommers JP. Trends in nursing home expenses, 1987 and 1996. *Health Care Financ Rev* 2003;25:99-114.
8. Mittelman MS, Ferris SH, Shulman E, Steinberg G, Levin B. A family intervention to delay nursing home placement of patients with Alzheimer disease: a randomized controlled trial. *JAMA* 1996;276:1725-1731.
9. Pastor PN, Makuc DM, Reuben C, Xia H. *Charterbook on trends in the health of Americans*. In: Health, United States. Hyattsville, MD: National Center for Health Statistics; 2002.
10. Mittelman M, Roth D, Coon D, Haley WE. Sustained benefit of supportive intervention for depressive symptoms in Alzheimer's caregivers. *Am J Psychiatry* 2004;161:850-856.
11. Mittelman MS, Roth DL, Haley WE, Zarit S. Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's disease: Results of a randomized trial. *J Gerontol B Psychol Sci Soc Sci* 2004;59B:27-34.
12. Haley WE, Levine EG, Brown SL, Bartolucci AA. Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychol Aging* 1987;2:323-330.
13. McKhann G, Drachman D, Folstein M, Katzman R, Price D, Stadlan EM. Clinical diagnosis of Alzheimer's disease: Report of the NINCDS-ADRDA work group under the auspices of Department of Health & Human Services Task Force on Alzheimer's disease. *Neurology* 1984;34:939-944.
14. Mittelman MS, Epstein C, Pierzchala A. *Counseling the Alzheimer's caregiver: A resource for health care professionals*. Chicago, IL: AMA Press; 2003.
15. Social Security Death Index on the World Wide Web. Available at: <http://www.ancestry.com.ezproxy.med.nyu.edu/search/rectype/vital/ssdi/article.htm>. Accessed February 2006.
16. Reisberg B, Ferris SH, de Leon MJ, Crook T. The global deterioration scale for assessment of primary degenerative dementia. *Am J Psychiatry* 1982;139:1136-1139.
17. Zarit SH, Orr NK, Zarit JM. *Families under stress: caring for the patient with Alzheimer's disease and related disorders*. New York, NY: New York University Press; 1985.
18. Brink TL, Yesavage JA, Lum O, et al. Screening tests for geriatric depression: Geriatric Depression Scale. *Clin Gerontol* 1982;1:37-43.
19. Roth DL, Burgio LD, Gitlin LN, et al. Psychometric analysis of the Revised Memory and Behavior Problems Checklist: factor structure of occurrence and reaction ratings. *Psychol Aging* 2003;18:906-915.
20. Stokes JP. Predicting satisfaction with social support from social network structure. *Am J Community Psychol* 1983;11:141-152.
21. Duke Center for the Study of Aging and Human Development. *Multidimensional Functional Assessment: The OARS Methodology*. Durham, NC: Duke University Press; 1978.
22. Allison PD. *Survival analysis using the SAS System: a practical guide*. Cary, NC: SAS Institute; 1995.
23. Hosmer DW, Lemeshow S. *Applied survival analysis: Regression modeling of time to event data*. New York, NY: Wiley; 1999.
24. Strain LA, Blandford AA, Mitchell LA, Hawranik PG. Cognitively impaired older adults: risk profiles for institutionalization. *Int Psychogeriatr* 2003;15:351-366.
25. Yaffe K, Fox P, Newcomer R, et al. Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA* 2002;287:2090-2097.
26. Cohen CA, Gold DP, Shulman KI, Wortley JT, McDonald G, Wargon M. Factors determining the decision to institutionalize dementing individuals: A prospective study. *Gerontologist* 1993;33:714-720.
27. Mittelman MS, Ferris SH, Shulman E, et al. A comprehensive support program: effect on depression in spouse-caregivers of AD patients. *Gerontologist* 1995;35:792-802.
28. Hebert R, Dubois MF, Wolfson C, Chambers L, Cohen C. Factors associated with long-term institutionalization of older people with dementia: data from the Canadian Study of Health and Aging. *J Gerontol A Biol Sci Med Sci* 2001;56:M693-M699.
29. Fisher L, Lieberman MA. A longitudinal study of predictors of nursing home placement for patients with dementia: the contribution of family characteristics. *Gerontologist* 1999;39:677-686.
30. Altman DG, Schulz KF, Moher D, et al. The revised CONSORT statement for reporting randomized trials: explanation and elaboration. *Ann Intern Med* 2001;134:663-694.
31. Berger VW. A novel criterion for selecting covariates. *Drug Information J* 2005;39:233-241.
32. Steyerberg EW, Bossuyt PM, Lee KL. Clinical trials in acute myocardial infarction: should we adjust for baseline characteristics? *Am Heart J* 2000;139:745-751.
33. Shrout PE, Bolger N. Mediation in experimental and nonexperimental studies: new procedures and recommendations. *Psychol Methods* 2002;7:422-445.
34. Baron RM, Kenny DA. The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. *J Pers Soc Psychol* 1986;51:1173-1182.
35. Judd CM, Kenny DA, McClelland GH. Estimating and testing mediation and moderation in within-subjects designs. *Psychol Methods* 2001;6:115-134.
36. Roth DL, Mittelman MS, Clay OJ, Madan A, Haley WE. Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease. *Psychol Aging* 2005;20:634-644.
37. Satagopan JM, Ben-Porat L, Berwick M, Robson M, Kutler D, Auerbach AD. A note on competing risks in survival data analysis. *Br J Cancer* 2004;91:1229-1235.
38. Tai BC, Machin D, White I, Gebisi V. On behalf of the EOI (The European Osteosarcoma Intergroup). Competing risks analysis of patients with osteosarcoma: a comparison of four different approaches. *Stat Med* 2001;20:661-684.
39. Skaff MM, Pearlin LI, Mullin JT. Transitions in the caregiving career: effects on sense of mastery. *Psychol Aging* 1996;11:247-257.
40. Mace NL, Rabins PV. *The 36 hour day: A family guide to caring for persons with Alzheimer disease, related dementing illnesses, and memory loss in later life*. New York, NY: Warner Books; 2001.
41. Aneshensel CS, Pearlin LI, Levy-Storms L, Schuler RH. The transition from home to nursing home mortality among people with dementia. *J Gerontol B Psychol Sci Soc Sci* 2000;55B:S152-S162.
42. Gitlin LN, Belle SH, Burgio LD, et al. Effect of multicomponent interventions on caregiver burden and depression: The REACH multisite initiative at 6-month follow-up. *Psychol Aging* 2003;18:361-374.
43. Sloane PD, Zimmerman S, Suchindran C, et al. The public health impact of Alzheimer's disease, 2000-2050: potential implication of treatment advances. *Annu Rev Public Health* 2002;23:213-231.
44. Mant J, Carter J, Wade DT, Winner S. Family support for stroke: a randomised controlled trial. *Lancet* 2000;356:808-813.
45. Sörensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist* 2002;42:356-372.
46. Teri L, McCurry SM, Logsdon R, Gibbons LE. Training community consultants to help family members improve dementia care: a randomized controlled trial. *Gerontologist* 2005;45:802-811.

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