Caregiver Supports: Outcomes From the Medicare Alzheimer's Disease Demonstration

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A randomized 3-year study assessed the effect of expanded community-based services and case management on 5,254 caregivers of dementia clients. A tested policy concern was whether the financing of formal care would result in a reduction of informal assistance. Unmet needs task assistance for the demonstration's treatment group caregivers decreased by 30 percent within 6 months and by about 20 percent over 36 months relative to controls. While treatment group members used slightly more formal care over time, there were no differences between treatment and control groups in primary caregiver hours after 36 months, or in the number of tasks in which primary or secondary caregivers provided assistance.

INTRODUCTION

The support network which can augment a primary caregiver's efforts to maintain a person with dementia at home includes both informal caregivers and formal service providers. Primary caregivers of frail elderly people spend, on average, 4 hours per day in caregiving activities (Stone, Cafferata, and Sangl, 1987). Assistance with the primary caregiving role, provided by other family members or friends, can buffer or mediate the primary caregiver's response to stressful aspects of caregiving (Pearlin, 1990). Services provided by paid non-family service providers, can also reduce the strain of caregiving by offering a respite from this role.

Historically, most of the long-term care(LTC) for functionally impaired elderly has been provided by informal caregivers (Shanas, 1979; Rivlin and Wiener, 1988). The national Long-Term Care Informal Caregiver Study found approximately 2.2 million caregiver's providing unpaid assistance to 1.6 million noninstitutionalized frail elderly (Stone, Cafferata, and Sangl, 1987). Soldo and Manton (1985) found that extremely disabled elderly living in the community turn to the formal care system only after care needs become more than primary and ancillary caregivers can handle alone.

One of the main barriers to the expansion of in-home and community-based care has been fear on the part of policymakers that paid care will erode the informal care being received by impaired elderly (Congressional Budget Office, 1977; Health Care Financing Administration, 1981). The critical concern is the extent to which families may shift care responsibilities, and the associated costs, to the public sector if expanded in-home and community-based services are available through public funding. One study estimated that over 27 million unpaid days of informal care are provided each week (Liu, Manton, and Liu, 1985).

The literature suggests several different ways that the introduction of formal services may impact on informal caregiving

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(Greene, 1983; Litwak, 1985; Noelker and Bass, 1989). Informal caregiving could be entirely replaced by formal services; the overall level of informal caregiving could be reduced; the level of informal caregiving could be shifted from one type of care to other types of care with which the caregiver is more comfortable providing or better able to provide; or informal care may be extended for longer periods of time, possibly increasing the total effort over time even when less care is provided in the short run.

Research from earlier LTC demonstrations indicates that a major shift from unpaid to paid care is unlikely. A re-examination of all the home and community-based LTC studies conducted between 1960 and 1988 (Hanley, Weiner, and Harris, 1991), found that, of 53 evaluations that studied the impact of formal services on the amount of informal care provided, 45 showed no significant change in informal care, 7 showed a statistically significant increase in informal care, and 4 found a statistically significant decrease in informal care. When reductions in caregiving were found, they reflected a redirection of family help rather than a reduction in their overall effort.

The general consensus among studies examining the substitution of formal care for the provision of informal care has been that the effect is small or statistically nonsignificant, see for example, the California, Chicago, and Minnesota Home Care Programs (Smith-Barusch and Miller, 1985), the Channeling Demonstration (Christianson, 1986), the Hospital Program Community Care Project in the Chicago area (Edelman and Hughes, 1990), and the Minnesota Pre-Admissions Screening/Alternative Care Grants Program (Moscovice, Davidson, and McCaffrey, 1988).

Studies focusing on persons with dementia have found that about half of the primary informal caregivers provide care with no outside assistance (Gwyther, 1989). Further, even when formal services were offered at low cost, empirical findings indicate caregivers of persons with dementia consistently underutilized the formal services available (Biegel et al., 1993). Until now, no experimental studies have examined the impact of formal care on the provision of informal care for persons with dementia, or of the affect of this assistance on caregivers themselves.

Intervention

Funded by HCFA, the Medicare Alzheimer's Disease Demonstration and Evaluation (MADDE) was designed to address policy issues related to the cost, benefits and effectiveness of expanded community-based services for persons with dementia and their caregivers. Demonstration goals included: developing a network of in-home community-based services to address the medical, mental health, and social support needs of persons with Alzheimer's disease and related disorders and their caregivers; providing education and support services to caregivers to minimize stress associated with caregiving and to enhance caregiving skills; creating opportunities for demented persons to be cared for in protective home environments but supporting the use of the most appropriate level of care whether in an institutional or community setting; and providing in-home and community-based services.

Criteria for enrollment in the demonstration were that all eligible applicants have a physician-certified diagnosis of an irreversible dementia, be enrolled in or be eligible for both Parts A and B of the Medicare program, have service needs due to cognitive or functional impairment, and reside in the demonstration's catchment area.

Case management was the foundation of the demonstration. It was viewed as the key service component for both the demented client and the caregiver. Case managers assessed client and caregiver needs, assisted the caregiver in determining the most appropriate mix of services to meet the client's needs, activated a plan of care with home and community-based services largely reimbursed under the Medicare demonstration, and monitored the quality of care provided. Two intervention models were implemented. These differed on the case manager-to-client ratio and the per-month service expenditure cap for each client. The differences in case-management intensity and service expenditure caps were designed to test the intervention at two different levels of funding. Model A sites operated with a target case manager to client ratio of 1:100 and had a monthly community service reimbursement limit or cap from $290 to $489 per month per client. Model B sites operated with a target case manager to client ratio of 1:30 and had a higher reimbursement limit of from $430 to $699 per month per client. The per month reimbursement caps in each model varied by site over time due to regional cost variations and inflation adjustments. Acute care and other skilled care services continued to be reimbursed as part of the regular Medicare benefit. Services reimbursed under the service cap included:

- Adult day care.
- Skilled and rehabilitation nursing.
- Therapies (i.e., speech, occupational, physical).
- Home health aide.
- Homemaker/personal care.
- Housekeeping.
- General chore (i.e., heavy cleaning).
- Home repairs and maintenance.
- Companion (i.e., friendly visiting, shopping and errands, telephone reassurance, and caretaker while caregiver attends educational and/or support groups).
- Home-delivered meals.
- Non-emergency transportation for client.
- Adaptive and assistive equipment.
- Medical supplies in conjunction with skilled and unskilled home care.
- Consumable care goods.
- Safety modifications to the home.

Except for Medicaid participants, clients and families paid a 20-percent copayment for any of the above demonstration services they used. The cost-sharing approach was incorporated to provide families with an incentive for cost consciousness. Case management and some caregiver support services were reimbursed separately from the capped demonstration benefits. Among these support services are caregiver education and training, caregiver support groups, and caregiver transportation to education and support groups. These services did not have copayment and were reimbursed by HCFA as part of each demonstration site's administrative overhead.

A total of eight sites located in different geographic regions of the United States were funded, four operated under Model A (low resource) criteria and four operated under Model B (high resource) criteria. The sites became operational in December 1989 and served clients and their families until November 31, 1994. Clients entered the study during a 2-year enrollment window. After randomization to the treatment or control group, clients were followed for a maximum of 36 months.[1]

Hypotheses

As part of the MADDE demonstration intervention, case managers assessed the caregiving situation of each client by identifying the primary caregiver's level of caregiving and the extent of other family members and friends involvement in caregiving. If the primary caregiver was physically or emotionally overburdened with the caregiving role, the case manager's role was to encourage greater assistance by other family members and/or bring in formal paid providers to provide help with the client's care. This analysis tests five hypotheses related to caregiver support network outcomes for the treatment and control group in the demonstration:

- There will be no difference in the number of hours the primary caregiver spends assisting in the care of the client in the treatment group compared with the control group.
- There will be no difference in the amount of assistance for activities of daily living (ADL) and instrumental activities of daily living (IADL) provided by primary caregivers in the treatment group compared with the control group.
- There will be an increase in the amount of ADL/IADL task assistance provided by secondary caregivers in the treatment group compared with the control group.
- There will be more ADL/IADL task assistance provided by formal service for clients in the treatment group compared with the control group.
- There will be fewer unmet service needs with ADL/IADL tasks for clients in the treatment group compared with the control group.

The two intervention models were expected to have similar effects on client and caregiver outcomes, but the magnitude of the effect was expected to be greater under the high resource model than under the low resource model because of the more intensive case management and higher monthly spending caps.

METHODS

Study Sample

The evaluation used an experimental research design with participants randomly assigned to either a treatment group eligible for community services reimbursement and case management, or a control group which received no expanded benefit reimbursement but could, at their own expense, purchase available community services. The total demonstration sample included 8,138 individuals who received a baseline assessment prior to randomization into approximately equal treatment and control groups. The statistical methodology used for the present analysis requires a minimum of two data points per study participant in order to estimate the slope of a caregiver's activity over time. For this reason, 189 clients were excluded because they had no informal caregiver at baseline. An additional 2,695 were excluded from the analysis because they had only one assessment while they lived in the community. Data collected after a client had a change in primary caregiver or was institutionalized were not considered in assessing caregiver outcomes.

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[1] The demonstration sites were selected in a national competition based on their operational ability, the likely prevalence of dementia in the population, and a representation of urban-rural and regional differences. The sites were not selected to produce a national probability estimate of the dementia population or of any particular community characteristics.

Table 1
Study Sample: Caregiver Support Network Analysis

Site	Total	Control	Treatment
Total	5,254	2,547	2,707
Florida	782	384	398
Illinois	627	314	313
Minnesota	888	424	464
New York	631	318	313
Ohio	565	254	311
Oregon	693	333	360
Tennessee	656	318	338
West Virginia	412	202	210
Assessment Interval	Total	Original[1]	Expanded[2]
Total Observation	19,929	17,796	2,133
Baseline	5,254	4,422	832
6 Months	4,321	4,321	—
12 Months	3,217	3,217	—
18 Months	2,590	2,560	30
24 Months	2,702	1,963	739
30 Months	78	54	24
36 Months	1,767	1,259	508

[1] The original sample was reassessed at 6-, 12-, 18-, 24- and 36- month intervals. The 30-month reassessments were obtained retrospectively for those who died between 27 and 33 months.

[2] The expanded sample was interviewed at baseline and then at the 24- and 36-month intervals. The 18-month reassessments were obtained retrospectively for those who died between 15 and 21 months. The 30-month reassessments were obtained retrospectively for those who died between 27 and 33 months.

SOURCE: Medicare Alzheimer's Disease Demonstration Evaluation, 1989-94.

The caregiver support network analysis is, therefore, based on 5,254 clients who received a baseline assessment and up to 5 reassessments over the 36-month study period. This produced a total of 19,929 observations. This subset of clients are used for all descriptive statistics. The sample sizes for the five outcome measures vary slightly due to missing data (less than 3 percent overall). The baseline sample size by site and observations by reassessment period are both shown in Table 1. At the end of the 3-year study period, 34 percent of the initial sample was still residing in the community and received a 36-month, final reassessment. Attrition from the study has been given detailed attention in a separate analysis examining nursing home placement and mortality rates. This work has shown no differential attrition from either treatment or control group (Miller et al.). Statistical power for the analysis is high, with an ability to detect differences of less than 5 percent between treatment versus control comparisons and comparisons involving each model separately (alpha=.05, power=.99). For comparisons involving site level subgroups the effect broadens to 10 percent (alpha=.05 one-tailed, power=.80) for all but the smallest enrollment site (i.e., West Virginia). These are conservative power estimates because they are based only on the count of the baseline cases for whom at least two data points were available. At least two data points are needed to estimate the slope. If all observations are included in the slope estimate, the effective sample increases from 5,254 cases to 19,929. With this sample size, power approaches .80 or greater in 7 of the 8 sites (alpha=.05), with an ability to detect a difference between groups of about 5 percent. Power in West Virginia at this effect is .65. The means test comparisons (Table 3) use cases, the HLM comparisons (Table 4) are based on observations.

Model Specification

Based on a review of the informal caregiver literature, a set of client and caregiver characteristics were selected as control variables for the analyses of five caregiver support network outcome measures. The control variables in the model included: (a) group assignment and model, (b) client characteristics, and (c) caregiver characteristics. Client and caregiver data were obtained from baseline assessment interviews conducted with the client's primary caregiver. All assessment data are self-reported by the primary caregiver. Client and caregiver functional status was measured by a version of the Katz ADL scale (Katz and Akpom, 1976), Lawton and Brody's IADL scale (Lawton and Brody, 1969). Client behavioral problems were assessed using an adaptation of the index developed by Zarit, Todd, and Zarit (1986). Client cognitive status was measured by the mini-mental status examination (MMSE) (Folstein, Folstein, and McHugh, 1975). These scales and indices are widely used because of their reliability and predictive validity. The specific items and scale ranges are shown in the Technical Note.

The five outcome measures are:

- *Primary Caregiver Hours Per Week.* The primary caregiver's level of involvement was measured as the average number of hours per week spent helping and assisting the client with tasks he/she was unable to perform alone. At baseline, primary caregivers were spending on average 86.2 hours per week (12.3 hours per day) providing care.
- *Primary Caregiver ADL/IADL Tasks.* Support provided by the primary caregiver was measured by summing the number of ADL tasks (eating, transferring, dressing, bathing, toileting) and IADL tasks (meal preparation, shopping, routine housework, managing money, laundry, medications, telephoning, and heavy chores) for which the primary caregiver was the principal provider (i.e., the person who helped most with the task). At baseline, primary caregivers were the principal providers of care on an average of 8.1 of the 13 possible ADL/IADL tasks.
- *Secondary Caregivers Assistance With ADL/IADL Tasks.* Informal care provided by family members and friends, other than the primary caregiver, was measured by summing the number of ADL/IADL tasks with which a secondary caregiver provided any help. At baseline, secondary caregivers were helping with an average of 3.3 ADL/IADL tasks. (The score on the index can range from 0 to 13).
- *Formal Providers Assistance With ADL/IADL Tasks.* Assistance by paid service providers was measured by summing the number of ADL/IADL tasks with which a paid provider helped. At baseline, formal providers were assisting with 2.5 tasks. (The score on the index can range from 0 to 13).
- *Unmet Need for Assistance With ADL/IADL Tasks.* Caregiver unmet need for assistance was measured by an index summing the number of ADL and IADL tasks with which the primary caregiver reported not having enough help. At baseline, primary caregivers on average reported 1.7 unmet task needs on the 13-point unmet need index.

Analysis

T-tests and Chi-square statistics were computed to compare the treatment and control groups on each of the selected control variables at baseline (Table 2). T-tests

Table 2
Baseline Variables Used as Controls for Caregiver Support Network Outcomes[1]

	Treatment Group (*N*=2,707)			Control Group (*N*=2,547)		
Baseline Predictors	Mean	SD	Percent	Mean	SD	Percent
Age	78.3	8.0	—	78.3	8.4	—
Sex (Male)	—	—	38.0	—	—	40.6
Ethnicity (Minority)	—	—	12.6	—	—	13.5
Functional Dependency[2]	0.0	1.0	—	0.1	1.0	—
ADL Impairment[3]	3.7	3.2	—	3.5	3.2	—
IADL Impairment[4]	12.7	3.6	—	12.6	3.7	—
MMSE[5]	14.8	8.6	—	15.2	8.6	—
Behavioral Problems[6]	8.2	3.8	—	8.2	3.8	—
Hospitalized Prior 6 Months	—	—	21.2	—	—	20.5
Medicaid Eligible	—	—	6.4	—	—	6.6
Caregiver Characteristics						
Age	63.0	—	14.2	62.5	14.4	—
Relationship	—	—	—	—	—	—
Spouse	—	—	48.6	—	—	48.6
Married Child	—	—	27.3	—	—	27.4
Unmarried Child	—	—	15.7	—	—	14.4
Other	—	—	8.3	—	—	9.5
Lives With Client	—	—	74.0	—	—	73.1
Income Less Than $15,000	—	—	45.0	—	—	45.4
Caregiver Functional Limitation[7]	1.0	2.0	—	1.0	1.9	—
Caregiver Health Poor/Fair	—	—	21.9	—	—	21.7
Secondary Caregiver Assistance[8]	3.2	4.4	—	3.3	4.5	—
Formal Provider Assistance[9]	2.5	3.9	—	2.5	3.7	—

[1] There were no significant differences ($p < .05$) between the treatment and control groups on any of the baseline measures.

[2] The measure is a standardized score (including ADL, IADL and mental impairment) with a mean of 0 and a standard deviation of 1. Scores ranged from -2.6 to +1.8. Higher scores indicate a higher level of functional dependency.

[3] Scores can range from 0 to 10. Higher scores indicate greater ADL impairment.

[4] Scores can range from 0 to 16. Higher scores indicate greater IADL impairment.

[5] Scores can range from 0 to 30. Lower scores indicate greater cognitive impariment.

[6] Scores can range from 0 to 19. Higher scores indicate a greater number of behavior problems.

[7] Scores can range from 0 to 13. Higher scores indicate greater functional limitations.

[8] Scores can range from 0 to 39. Higher scores indicate greater assistance with ADL/IADL tasks by secondary caregivers.

[9] Scores can range from 0 to 39. Higher scores indicate greater assistance with ADL/IADL tasks from formal providers.

NOTES: SD is standard deviation. ADL is activities of daily living. IADL is instrumental activities of daily living. MMSE is mini-mental status examination.

SOURCE: Medicare Alzheimer's Disease Demonstration Evaluation, 1989-94.

were also computed to compare the treatment and control groups on each of the five outcome measures and each time period (Table 3).

Correlations were computed between all independent variables to identify any potential multi-collinearity problems associated with simultaneously entering the selected independent variables into a statistical model. Based on a review of the correlation matrix, ADL, IADL, and MMSE were combined into a single measure referred to hereafter as functional dependency. The functional dependency index was created by standardizing each of the three variables, adding the standardized variables together, and then standardizing the resulting dependency index. Cronbach's alpha for the functional dependency index is .80. To eliminate collinearity problems between caregiver relationship and marital status, a dummy variable, caregiver type was created: spouse versus other categories, unmarried child versus other categories; and married child versus other categories.

A two-stage hierarchical linear model (HLM) was the statistical method for testing the study hypotheses. This method tests the effects of the independent

Table 3

Mean Scores on the Caregiver Support Network Outcomes at Each Reassessment Interval[1]

	Treatment Group			Control Group		
Outcome Measure	*N*	Mean	Standard Deviation	*N*	Mean	Standard Deviation
Primary Caregiving Hours						
Baseline	2,707	87.3	58.3	2,547	85.1	59.0
6 Months	2,221	66.9	50.9	2,100	*63.2	51.7
12 Months	1,658	67.8	52.7	1,559	66.2	54.6
18 Months	1,365	63.4	53.5	1,225	64.0	55.9
24 Months	1,430	64.1	53.4	1,324	65.0	56.4
36 Months	911	69.9	58.2	856	67.8	58.5
Primary Caregiver is Principal Provider of ADL/IADL Tasks[2]						
Baseline	2,707	8.2	3.6	2,547	*8.0	3.6
6 Months	2,266	7.9	3.8	2,142	*7.7	4.0
12 Months	1,724	7.9	2.6	1,621	7.7	2.9
18 Months	1,454	7.9	4.2	1,324	**7.4	4.3
24 Months	1,540	7.9	4.3	1,380	*7.5	4.4
36 Months	987	8.0	4.5	922	7.8	4.5
Secondary Caregivers Assist With ADL/IADL Tasks[3]						
Baseline	2,707	3.3	4.4	2,547	3.2	4.6
6 Months	2,266	2.2	3.7	2,142	2.3	3.9
12 Months	1,724	2.1	3.5	1,621	2.2	3.8
18 Months	1,454	1.9	3.5	1,324	2.0	3.5
24 Months	1,540	1.8	3.5	1,380	*2.2	4.0
36 Months	987	2.0	3.9	922	2.2	4.0
Formal Providers Assist With ADL/IADL Tasks[4]						
Baseline	2,707	2.5	3.9	2,547	2.5	3.7
6 Months	2,266	3.4	4.1	2,142	**3.0	4.5
12 Months	1,724	3.7	4.4	1,621	3.5	4.8
18 Months	1,454	4.1	4.5	1,324	3.8	5.0
24 Months	1,540	4.6	5.0	1,380	4.3	5.3
36 Months	987	5.4	5.5	922	*4.7	5.3
Unmet Needs for Assistance With ADL/IADL Tasks[5]						
Baseline	2,707	1.8	2.2	2,547	1.8	2.1
6 Months	2,266	1.2	2.2	2,143	***1.8	2.8
12 Months	1,724	1.2	2.9	1,621	***1.5	3.2
18 Months	1,454	1.1	2.8	1,324	***1.6	3.2
24 Months	1,540	1.0	2.8	1,380	***1.7	3.4
36 Months	987	1.2	3.1	922	***1.6	3.4

*$p < .05$.

**$p < .01$.

***$p < .001$.

[1] Mean scores are unadjusted.

[2] Scores can range from 0 to 13. Higher scores indicate caregiver is the principal provider of care on more ADL/IADI tasks.

[3] Scores can range from 0 to 39. Higher scores indicate greater assistance with ADL/IADL tasks by secondary caregivers.

[4] Scores can range from 0 to 39. Higher scores indicate greater assistance with ADL/IADL tasks from formal providers.

[5] Scores can range from 0 to 13. Higher scores indicate greater unmet needs.

NOTES: T tests were used to determine significant differences between treatment/control groups. ADL is activities of daily living. IADL is instrumental activities of daily living.

SOURCE: Medicare Alzheimer's Disease Demonstration Evaluation, 1989-94.

variables of interest in this article (treatment group assignment, experimental Model [A or B], and treatment site) on each of the outcome measures over time. HLM has several advantages for testing the stated hypotheses: (1) it does not require the time between assessments to be equivalent; (2) subjects need not have an equivalent number of assessments; (3) subjects who did not participate in the study for the entire 3-year time period can be included in the analysis; and (4) potentially confounding independent variables can be controlled.

One of the applications of two-stage HLM models is growth curve analysis, which is used here. In the first stage of growth curve analysis, a regression line is estimated for each individual's outcome measure as a function of time. This level one analysis yields an intercept and a slope for each individual (in this case the caregiver). The intercept is approximately equal to the baseline value of the outcome measure for the individual. In cases where an individual's trajectory over time (such as for ADL tasks or unmet need) is non-linear, the intercept may vary from the baseline value. Caregivers assessed at fewer than two periods were excluded from the analysis because a slope could not be determined for them.

The second stage of the HLM evaluates the relationship between each of the second level predictors (in this analysis, the experimental variables and all potentially confounding control variables) with (1) the intercepts output from the level one equations and (2) the slopes output from the level one equations. In a simplified sense, the output from the second stage analyses resembles two ordinary least squares regressions where the first regression evaluates the relationships between the level two predictors and the baseline value of the outcome measure, and the second regression evaluates the relationship between the level two predictors and the change in the outcome measure over time. The advantage of HLM models over this simple regression example is that HLM methods adjust for the within group variance (in this case among the caregivers) and the between group variance (in this analysis, among sites). This leads to more efficient estimates and higher statistical power.[2]

Bryk and Raudenbush (1987) showed how this modeling framework can supply estimates of the mean trajectory, of individual variation around the means, of the reliability of measures of change, of the correlation between true status at any time and true rate of change, and of correlates of change. HLMs are elsewhere described as "multilevel models" (Goldstein, 1995) or "random coefficient models" (Gibbons et al., 1988; Longford, 1993). For a full explanation of HLM, refer to Hierarchical Linear Model - Applications and Data Analysis Methods (Bryk and Raudenbush, 1992).

The control group is the reference group for all of the HLM treatment/control comparisons presented in Table 4. A negative difference reported in the table means the treatment group intercept (shown as the baseline difference) or slope is lower for the treatment group compared with the control group. The slope differences presented in Table 4 are given in outcome measure units per month. The difference between groups at 36 months can be computed by multiplying the slope difference per month by 36 and adding the result to the intercept difference.

Two other variables were included in all of the HLM analyses: number of months in the study (ranging from 6 to 36) and cohort (which classified each client into 4 groups of equal size based on date of entry

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[2] HLM can have more than two levels, allowing for multiple nested subgroups. In this demonstration a hierarchical subgroup beyond caregiver (level 1) and site (level 2) conceptually might have included intervention Model (A and B). HLM procedures, however, do not produce stable results if the sample size at a level is too small. Eight sites is at the margin of an acceptable size. Recognizing this limitation, we tested demonstration effects using separate HLM models for Model A and Model B sites. Treatment status (another conceptual analytical level) was tested directly in all models as a main effect and as a interaction term with selected covariates.

Table 4
Summary of Hierarchical Linear Model Analyses of Caregiver Network Outcomes[1]

	Baseline[2]		36-Month
Outcome Measure	Mean or Difference	Slope[3]	Mean or Difference[4]
Primary Caregiving Hours Per Week			
Sample Mean	80.000	-0.520	61.280
Sample Treatment/Control Difference	0.750	-0.030	-0.330
Model A Treatment/Control Difference	1.200	-0.020	0.480
Model B Treatment/Control Difference	0.550	-0.060	-1.610
Primary Caregiver is Principal Provider of ADL/IADL Tasks			
Sample Mean	8.000	-0.014	7.490
Sample Treatment/Control Difference	0.065	*0.009	0.400
Model A Treatment/Control Difference	0.063	*0.013	0.530
Model B Treatment/Control Difference	0.075	0.005	0.250
Secondary Caregiver Assistance With ADL/IADL Tasks			
Sample Mean	2.900	-0.040	1.460
Sample Treatment/Control Difference	0.150	-0.000	-0.160
Model A Treatment/Control Difference	0.140	-0.004	-0.270
Model B Treatment/Control Difference	0.170	-0.000	-0.180
Formal Provider Assistance With ADL/IADL Tasks			
Sample Mean	2.600	0.080	5.500
Sample Treatment/Control Difference	0.050	0.006	0.280
Model A Treatment/Control Difference	0.060	0.001	0.100
Model B Treatment/Control Difference	0.070	0.013	0.540
Unmet Need for Assistance With ADL/IADL Tasks			
Sample Mean	1.800	-0.013	1.600
Sample Treatment/Control Difference	**-0.27	***-0.012	-0.700
Model A Treatment/Control Difference	**-0.33	**-0.019	-1.000
Model B Treatment/Control Difference	**-0.3	-0.007	-0.550

$^{*}p < .05$.

$^{**}p < .01$.

$^{***}p < .001$.

[1] The control group is the reference group for all comparisons.

[2] If the difference is negative, then the treatment group is lower than the control group.

[3] In units per month. If difference is negative, then the treatment group slope is less than the control group slope.

[4] Total difference between the treatment and control group at 36 months (baseline difference + 36 months x slope).

NOTES: ADL is activities of daily living. IADL is instrumental activities of daily living.

SOURCE: Medicare Alzheimer's Disease Demonstration Evaluation, 1989-94.

to the study. These are intended to adjust for unmeasured differences in caregiver outcomes that might be associated with attrition or program entry period dimensions.

Treatment site and model (A versus B) were confounded given that each site was assigned to be either a Model A or a Model B site and subjects were not randomized to site (the sites were in different States). This confounding prevented testing the model hypothesis in a single equation controlling for site effects. To eliminate this problem, separate HLM models were run for Model A and Model B, controlling for program site within each model. The treatment and control group differences are presented separately for Model A and B in Table 4.

To test whether there was a difference in treatment effect at any one of the experimental sites compared with the other sites, the difference between the treatment and control groups was compared with the average difference between the treatment and control groups at the other sites. This comparison was accomplished by creating seven effects—coded dummy variables to represent the eight different sites, and then interacting each of these variables with the variable indicating whether the client was in the treatment or control group. The HLM models for each outcome measure were then run using the site dummy variables in place of the model variable.

To summarize, the following HLMs were run for each outcome measure:

- To test the overall treatment effect regardless of model, an HLM was run with all control variables (Table 2), a variable representing Model (A or B), and a variable representing treatment group assignment. This model is referred to as Sample Treatment/ Control Difference under each of the five outcome measures tested in Table 4.
- To test for a greater treatment effect for Model B sites compared with the Model A sites, a separate HLM was run for each model. Each model was controlled for site differences in addition to the other control variables. These results are shown as Model A and Model B Treatment/Control Difference in Table 4.
- To test for a greater treatment effect at one of the sites compared with the mean treatment effect of the other sites combined, an HLM was run with all control variables, variables representing the site effects, a variable representing treatment group assignment, and a set of variables representing the interactions between treatment assignment and the site variables. These results are reported below, but do not appear in Table 4.
- To test for a treatment effect for those in the study with various characteristics (e.g., was the intervention more effective for older caregivers than younger caregivers), interaction terms between the control variables and the treatment group variable were added to the variables listed in the Technical Note. These results too are reported below, but do not appear in Table 4.

RESULTS

Sample Description

Table 2 shows the client and caregiver characteristics of the study sample at baseline on each of the control variables included in the analysis. The treatment and control groups were equivalent at baseline on all of the independent variables. Most of the clients in the demonstration were on average quite old and exhibited severe cognitive impairment coupled with moderate to severe physical impairment. The average client was 79 years old, almost 40 percent were male, and 13 percent were minorities. Caregivers reported many limitations in the clients' physical functioning. The mean score on the ADL impairment index was 3.7 with a score of 10 indicating total dependency. Impairment in IADL was even higher. Almost all of the clients required some assistance with one or more of the eight IADL tasks. The mean score on the IADL impairment index was 12 with a score of 16 indicating total dependency.[3] On the

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[3] A simple sum has been used in combining ADL and IADL task items into aggregate outcome measures of task assistance. This implicitly treats all tasks equally. This is the prevailing method by which ADL/IADL task needs scales are created, although work has been done seeking to differentially weight items (Finch, Kane, and Philp, 1995) or creating typologies across multiple data items (Manton et al., 1994) to better represent the relative difference in service support among the varied tasks. The application of these procedures results in a classification of cases weighted by their conditions. In recognition of such work we explored the both hierarchical structure of the two functional domains in the MADDE data set and possible typologies that might be built combining cognitive function, behavior, and functional ability measures. For the study sample it appears that particular needs that are unmet or problematic vary by individual circumstances, and not necessarily in a linear or hierarchical structure. Moreover, there is some evidence that the provision of low levels of assistance allow the caregivers to focus more of their time on more demanding tasks. Fixing specific problems, rather than providing a full array of support seems to be what differentiates the treatment groups' success in reducing unmet need. The above noted weighting schema do not capture these dynamics. While we agree with the idea that ADL tasks are not equal in their demands, we believe that more work is needed to develop a consensually accepted approach to this weighting. For this reason, we elected to stay with prevailing practice and used the simple summed scales. Analysis reported later in the article explicitly examines the tasks and task substitution alluded to here.

MMSE, the average client scored 15 on the 30-item scale. Scores of 17 and lower on the MMSE indicate moderate-severe cognitive impairment. On another index measuring client behavior problems that can be difficult for a caregiver to cope with and manage, caregivers reported on average experiencing problems in 8 of the 19 categories. About one-fifth of the clients had been hospitalized at least once in the 6 months prior to entering the study. Only a small proportion of the clients were Medicaid eligible. Many people who were on Medicaid were excluded from the study because they were already receiving services comparable to those offered by the demonstration.

The average age of the primary caregiver was 63 years. The majority of the primary caregivers were either a spouse or a married child, followed by unmarried children, and other relatives or friends. Almost three-fourths of the clients lived with the primary caregiver. The average income for primary caregivers was $30,000. The health and functional status of the primary caregivers were quite good. On a 13-item index of IADL/ADL activities, the average caregiver reported having some difficulty with only one activity. More than three-fourths of the caregivers reported their health was excellent or good compared with other people their age. On average, primary caregivers received assistance from a secondary caregiver with three ADL/IADL tasks which the client was unable to perform independently. Assistance from formal providers with ADL/IADL tasks was slightly lower, an average of two tasks.

Study Outcomes at Fixed Points in Time

Table 3 presents unadjusted mean scores on the five caregiver support network outcome measures at baseline and each reassessment interval. Both the treatment and control groups reported dramatic decreases in hours of caregiving per week between baseline and the 6-month reassessment (approximately 21 hours, $p < .001$). The steep decrease in caregiving hours, which then leveled off for both the treatment and control groups at subsequent intervals may be due to an over-reporting of caregiving hours at baseline. At the 36-month reassessment, treatment group caregivers were providing 70 hours per week of care–2 hours more than the care provided by control group caregivers—a difference that is not statistically significant.[4]

The number of ADL/IADL tasks for which the primary caregiver was the principal provider of assistance was higher for the treatment group at baseline, 6, 18, and 24 months ($p < .05$). The two groups received similar levels of assistance from secondary caregivers at baseline and each reassessment, except the 24-month interval when the control group received more assistance ($p < .05$). The treatment and control group were receiving equivalent formal provider assistance with ADL/IADL tasks at baseline. Both groups received increasing assistance with ADL/IADL tasks from formal providers over time. The treatment group was receiving more assistance from formal providers at 6 and 36 months, a small but significant difference ($p < .05$).

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[4] All data on caregiver hours, task participation, etc. shown in Tables 3, 4, 5, and 6 are from caregiver self-report. Data collection was comparable between treatment and control groups, being conducted by the evaluator's field staff and not the demonstration sites. There was no independent verification for either group. The basis for our conclusion that there may have been overreporting of hours derives from the trend in the data for comparable levels of hours being reported at time of application, and then dropping off for both groups by essentially the same amounts at 6 months, and remaining relatively constant after that. There is no basis for an assumption that the treatment group was biased toward high or low reporting relative to the controls given the parallel levels. If there is any bias in the reporting, it seems to be comparable between the treatment and controls. The reported caregiver hours are consistent with the approximately 66 hours per week found in an earlier study of people with Alzheimer's disease (Rice et al., 1993).

At baseline, treatment and control group caregivers reported unmet need for assistance on an average of about 1.8 ADL/IADL tasks which the client could not perform independently. This rate declined by 33 percent among the treatment group by 6 months and remained at this reduced level. Among controls the level of unmet need declined by 12 percent, but over a longer period. At each reassessment interval, unmet need for treatment group caregivers was significantly less than control group caregiver unmet needs ($p < .01$).

EFFECTS OF THE INTERVENTION: ASSESSING CHANGE OVER TIME

Primary Caregiver Hours

Treatment Effect

Table 4 presents the results of the HLM analysis. The mean intercept for the HLM model conducted for this analysis is 80.0 hours. The intercept is approximately equal to the mean number of caregiving hours per week at baseline. The rate of decline in caregiving hours for the sample averaged -.52 hours per month, or 18.7 hours over the 3-year duration of the study (mean slope - .52 hours x 36 months). The mean number of hours of care provided by treatment and control group primary caregivers at baseline was not significantly different as was expected, given that clients were randomized. As hypothesized, the difference in the rate of decline in caregiving hours between the treatment and the control group was also not significant (slope = -.03).

Model Effect

To test for a difference in treatment effect between models while controlling for site differences, the fully specified HLM model (including site dummy variables) was run separately for Model A and Model B caregivers. There was no significant treatment effect in either model. This is consistent with the hypothesized lack of impact on primary caregiving hours over time.

Site Differences

To test whether the treatment effect varied for the eight demonstration sites, terms representing the interaction between site and treatment group were entered into the HLM model. None of the interactions were significant, indicating no treatment effect on primary caregiving hours in any of the demonstration states.

Subgroup Analyses

To determine whether the intervention effect on primary caregiving hours varied by client or caregiver characteristics, interactions between the treatment group assignment and client age, sex, ethnicity, functional dependency, behavioral problems, prior hospitalization, and Medicaid eligibility were examined. Interactions between treatment group assignment and caregiver income, coresidency, functional limitations, and health status were also examined. None of the interactions were significant, indicating there were no differences in primary caregiving hours between the treatment and control groups for any of the subgroups examined.

Primary Caregiver ADL/IADL Tasks

At the outset of the study, primary caregivers were, on average, the principal providers of care on 8 of the possible 13 ADL/IADL tasks. As shown in the second grouping in Table 4, the number of tasks for which the primary caregiver was the principal provider declined over time by approximately one-half of a task (mean slope = -.014 per month x 36 months). The rate of decline was slower for the treatment group than the control group (.009 of a task per month or .4 of a task at the end of 3 years, $p < .05$). While the difference is significant, the .4 task difference is quite small relative to the mean number of tasks performed by primary caregivers at 36 months (7.5 tasks). No difference in treatment effect was found between models, demonstration sites, or client and caregiver subgroups using analyses similar to those discussed previously.

Secondary Caregiver Assistance With ADL/IADL Tasks

Secondary caregivers on average were providing assistance to clients with three ADL/IADL tasks (average intercept = 2.9) at baseline (Table 4). There was no significant difference between the treatment and control group at the baseline intercept or the slope (slope = -.04 per month). The findings do not support the hypothesis that assistance provided by secondary caregivers in the treatment group would increase relative to the control group. No difference in treatment effect was found between models, demonstration sites, or client and caregiver subgroups. This finding was unanticipated as one of the case manager's roles was to maximize a client's caregiving network, including bringing in secondary caregiver support if primary caregivers were in poor health or overburdened.

Formal Provider Assistance With ADL/IADL Tasks

Clients were receiving assistance from formal service providers with an average of three ADL/IADL tasks (average intercept = 2.6) at the outset of the study (Table 4). Assistance from formal providers doubled over time (slope = .08), an increase of 2.9 tasks by 36 months. The increase was slightly faster for the treatment group, but the difference was not significant (slope = .006). This finding does not support the hypothesis that predicted increased assistance from formal providers for the treatment group compared with the control group. The lack of a treatment effect is unexpected given the additional community-based services made available under demonstration funding to the treatment group clients. No difference in treatment effect was found between models, demonstration sites, or client and caregiver subgroups.

Unmet Need for Assistance With ADL/IADL Tasks

Treatment Effect

Primary caregivers reported relatively few unmet needs for assistance with ADL and IADL tasks, yet as seen in Table 4, there is a notable treatment effect in the HLM analysis as shown by the slope term. At 36 months, unmet needs for the control group had decreased from 1.8 to 1.6, a 12-percent decline, while the treatment group level of unmet need declined to 1.3 at 36 months, a reduction of about 30 percent ($p < .001$) relative to baseline and 20 percent relative to the control group at 36 months[5]. These numbers vary slightly from the unadjusted means reported in Table 3. This disparity is, in part, an artifact of the HLM's attempt to fit the data to a linear function, and in part reflective of the multivariate adjustments of the HLM. Differences can occur at the intercept either due to baseline differences in the groups (which was not the situation here due to successful randomization), or

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[5] The goodness of fit of an HLM model is tested by iteratively tracking reductions in the -2log likelihood (iterations terminate when the likelihood fails to change). Statistical significance is tested using a chi-square. There is no convenient sample size independent metric like R^2 to interpret the amount of variance explained. All HLM models are statistically significant $p < .001$.

because of a non-linear response over time for one or both groups. There is some evidence of a non-linear response in Table 3. Unmet needs for ADL/IADL task assistance dropped rapidly for the treatment group during the first 6 months after enrollment. These rates then remained relatively flat over the remainder of the study period. Among controls, reported unmet need decreased slowly after baseline, but with minor rises and falls, although not reaching the levels of unmet need reported during their application to the program. Unlike primary caregiver hours (in which it appears that both samples of applicants may have reported higher baseline levels of need, perhaps with the expectation that this would influence their selection into the demonstration treatment group), the relative constancy of unmet need in the controls seems to argue against inflated reporting at time of application. However, even assuming that the prevailing level of unmet need may be closer to 1.6 tasks shown through the balance of 36 months rather than the 1.8 tasks reported at baseline, the simple means comparisons in Table 3 continue to show a significant treatment effect, as do the multivariate HLM comparisons in Table 4.

To further test the sensitivity of the HLM findings to the assumption of a linear change, the fully specified HLM models were run for 12- and 24-month reassessment intervals separately (not shown here). As the time lengthened, the estimated slope differences weakened (going from -.0391 at year 1 to -.0213 and -.0123 in years 2 and 3, respectively). All these results were statistically significant (p <.001 or lower). Thus the 36-month HLM analysis may underestimate the true treatment effect.

Model Effect

To test for a difference in treatment effect between models, the fully specified HLM model was run first for Model A and then for Model B. The magnitude of the intercept difference between the treatment and control group was approximately the same for Model A and B. The slope, however, was almost 3 times steeper for Model A than for Model B (-.019 versus -.007, p < .05). This finding is inconsistent with our hypotheses given that Model B clients would be greater than those of Model A given the presence of more resources.

Other Impacts

The treatment effect did not vary for the eight demonstration sites or for any of the client or caregiver subgroups examined.

ADL/IADL Assistance by Type of Provider

Recognizing that all functional tasks may not be of equal importance or complexity (e.g., Finch, Kane, and Philp, 1995) and that aggregations of needs combining multiple data items (Manton et al., 1994) are emerging as methods for classifying the functional capability, the analysis examined the specific ADL and IADL assistance needs in addition to summed need scores. In particular, the concern was to isolate differences between treatment and control groups on specific task need, and to elucidate which tasks were most sensitive in identifying the reduction in unmet needs.

To determine if there were differences between groups in the type of assistance received or if there was a substitution or shift in the types of care provided over time, primary caregiver, secondary caregiver, and formal provider assistance with specific types of ADL and IADL tasks were examined at baseline and 24 months. The data in Table 5 show similar patterns of caregiver assistance for both the treatment and control group. Over time, primary caregivers in both groups decreased assistance with a number of IADL tasks, while

Table 5
Type of ADL/IADL Assistance Provided by Primary Caregivers, Secondary Caregivers, and Formal Providers at Baseline and 24 Months[1]

Caregiver and Type of Care	Treatment Group (N = 2,707) Baseline	Treatment Group 24 Months	Treatment Group Percent Difference	Control Group (N = 2,547) Baseline	Control Group 24 Months	Control Group Percent Difference
Primary Caregivers	Percent			Percent		
ADL Assistance						
Eating	40.3	47.3	***7.0	36.8	43.2	**6.4
Dressing	54.7	53.0	-1.7	51.0	49.1	-1.9
Bathing	52.3	52.5	0.2	48.8	49.2	0.6
Transferring	27.1	32.1	**5.0	24.6	29.3	**4.7
Toileting[2]	34.4	43.7	***9.3	32.6	38.1	**5.5
IADL Assistance						
Meal Preparation	77.8	70.3	***-7.5	75.5	67.7	***-7.9
Shopping	84.9	78.2	***6.7	81.0	74.7	***-6.4
Housework	71.4	65.3	6.1	68.5	63.2	**-5.3
Laundry	71.8	68.5	-3.2	70.9	67.0	*-2.9
Medications[2]	77.0	72.0	**5.1	76.9	68.3	***-8.6
Money Management[2]	86.2	88.5	*2.4	84.5	85.0	0.6
Telephoning	71.7	71.0	-0.7	69.4	69.2	-0.2
Heavy Chores	53.7	51.4	-2.3	49.2	50.1	0.9
Secondary Caregivers						
ADL Assistance						
Eating	0.9	1.5	0.6	0.7	1.5	0.8
Dressing	2.6	2.2	-0.4	2.3	2.2	-0.1
Bathing	3.3	2.8	-0.5	4.3	3.2	-1.1
Transferring	1.0	0.8	-0.2	0.7	1.2	0.5
Toileting[2]	1.2	1.5	0.7	0.6	1.2	0.6
IADL Assistance						
Meal Preparation	4.4	3.2	-1.2	4.1	3.5	-0.6
Shopping	6.0	5.1	-0.9	8.3	6.2	-2.1
Housework	4.5	2.9	*-2.5	4.6	5.3	0.7
Laundry	6.5	4.6	*-1.9	6.2	4.3	-1.9
Medications[2]	4.0	2.9	-1.1	4.0	3.3	-0.7
Money Management[2]	9.9	6.8	**-3.1	11.0	8.6	*-2.4
Telephoning	2.8	1.9	-0.9	2.5	2.2	-0.3
Heavy Chores	16.7	13.5	*-3.2	18.2	13.6	**-4.6
Formal Providers						
ADL Assistance						
Eating	3.5	11.0	***7.5	4.3	11.2	***6.9
Dressing	8.0	19.5	***11.5	8.2	20.0	***11.8
Bathing	14.1	27.0	***12.9	12.2	25.9	***13.7
Transferring	2.4	7.6	***5.2	2.5	8.2	***5.7
Toileting[2]	4.1	13.0	***8.9	4.3	13.5	***9.2
IADL Assistance						
Meal Preparation	10.8	22.4	***11.6	11.8	23.5	***11.7
Shopping	4.3	14.4	***10.1	4.2	15.3	***11.1
Housework	14.5	28.9	***14.4	14.5	26.6	***12.1
Laundry	10.1	23.2	***13.1	11.2	22.2	***11.0
Medications[2]	7.3	17.1	***9.8	7.6	18.9	***11.3
Money Management[2]	1.1	1.8	0.8	1.1	2.2	*1.1
Telephoning	3.7	12.7	***9.0	3.6	14.5	***10.9
Heavy Chores	25.7	32.0	***6.3	28.4	32.2	*3.9

*$p < .05$.

**$p < .01$.

***$p < .001$.

[1] Unadjusted scores. Only those caregivers with a 24-month reassessment were included in this analysis.

[2] $p < .05$ difference between the treatment and control at 24 months using chi-square test of significance.

NOTES: Chi-square tests were used to determine significant differences between types of assistance at baseline and 24 months within each group. ADL is activities of daily living. IADL is instrumental activities of daily living.

SOURCE: Medicare Alzheimer's Disease Demonstration Evaluation, 1989-94.

Table 6
Type of Unmet ADL/IADL Needs at Baseline and 24 Months[1]

	Treatment Group (*N* = 1,938)			Control Group (*N* = 1,893)		
Type of Unmet Need	Baseline	24 Months	Percent Difference	Baseline	24 Months	Percent Difference
	Percent			Percent		
ADL Assistance						
Eating	9.5	12.0	2.5	8.8	17.1	***9.7
Dressing	20.3	16.0	**-4.3	19.1	25.2	**6.1
Bathing	30.7	18.6	***-12.1	29.0	26.9	-2.7
Transferring	10.4	10.1	-0.3	11.8	15.4	*3.6
Toileting	14.1	14.2	0.1	12.8	19.8	***7.0
IADL Assistance						
Meal Preparation	24.1	11.8	***-12.3	24.2	19.8	*-4.4
Shopping	18.7	13.0	***-5.7	19.5	20.3	0.8
Housework	34.9	18.1	***-16.8	36.3	29.8	**-6.5
Laundry	17.3	11.2	***-6.1	16.9	20.7	3.8
Medications	9.8	1.7	***-8.1	10.5	4.5	***-5.9
Money Management	7.7	2.4	***-5.3	6.3	4.0	*-2.3
Telephoning	4.1	1.3	***-2.8	4.1	2.9	-1.2
Heavy Chores	28.4	17.3	***-11.1	29.3	25.6	-3.7

*$p < .05$.

**$p < .01$.

***$p < .001$ difference between the percentage of clients with unmet needs at baseline and 24 months by group (treatment, control). Chi-square tests were used to determine significant differences. Difference between the treatment and control group at 24 months is tested using chi-square test of significance.

[1] Unadjusted scores. Only caregivers with a 24-month reassessment were included in this analysis.

NOTES: ADS is activities of daily living. IADL is instrumental activities of daily living.

SOURCE: Medicare Alzheimer's Disease Evaluation Demonstration Evaluation, 1989-94.

increasing assistance with the majority of the ADL tasks. The relatively small amount of assistance being provided to primary caregivers by secondary caregivers at baseline decreased even further over time on most of the ADL and IADL tasks for both the treatment and control group. Assistance with ADL and IADL tasks by formal providers increased over time on almost every task, for both groups.

These data indicate that over time, presumably as the client's needs increase, formal providers are utilized by some of the caregivers to assist with all types of tasks. There remains, however, a major difference between the large proportion of clients in both groups who are receiving help from a primary caregiver and the small proportion of clients receiving help from a formal provider. Primary caregivers are getting some relief from formal providers mainly with tasks performed by homemaker chore/personal care workers such as meal preparation, shopping, housework, laundry, dressing, and bathing. On the other hand, formal providers are not providing substantial relief with two ADL tasks—transferring and toileting. These findings suggest that the demonstration service coverage produced a task-related pattern of service use approximately equal to that of those purchasing services out-of-pocket.

To explore more fully whether there were differences in how this assistance was targeted on unmet needs, Table 6 shows the proportion of cases at baseline and at the 24-month reassessment interval with specific unmet task needs. This sample only includes those individuals who had unmet needs at baseline and/or at 24 months.

The treatment and control groups had substantively different patterns of change in unmet needs. For the treatment group, there were reductions in unmet needs at 24 months on all of the IADL tasks and two of the ADL tasks. For the control group, there were significant reductions in unmet needs on only 4 of the 8 IADL tasks; but more importantly, there were significant increases in unmet needs on 4 of the 5 ADL tasks. Further, control group clients had a larger proportion of clients with unmet needs on every ADL and IADL tasks. In other words, the demonstration seems to have achieved a better match of services with client expressed task needs than were achieved by the control groups, even though overall service use and task assistance levels were similar.

SUMMARY AND DISCUSSION

The results support 2 of the 5 previously stated hypotheses.

- While there was an overall decline in primary caregiving hours for both groups, there was no difference in the rate of decline between the treatment and control groups. These findings support other research which shows no significant change in informal care hours when formal services are available.
- There was a small decline in the number of ADL/IADL tasks provided by the primary caregivers over time. Contrary to the hypothesis, which predicted no difference between groups, there was an unanticipated outcome. The rate of decline in primary caregiving tasks was significantly slower for the treatment group than the control group, although the effect was small ($p < .05$).
- The level of secondary caregiver assistance was low at baseline and declined for both the treatment and control group over time. This finding was unexpected, as one of the objectives of the case management intervention was to maximize the client's caregiving network by encouraging other family members and friends to assist with caregiving if the primary caregiver was in poor health and/or experiencing stress and burden as a result of caregiving.
- Consistent with the hypothesized demonstration effect, the number of unmet needs decreased significantly faster for the treatment group than the control group (30 percent reduction at 36 months for the treatment group versus a 12-percent reduction at 36 months for the control group). This difference in the reduction of unmet needs occurred even though caregiving by secondary informal caregivers and formal service providers was equivalent for the treatment and control groups.
- Assistance from formal providers with ADL/IADL tasks doubled over the 36-month study period. By the end of the study, the level of support from formal providers approached the level of support provided by primary caregivers (5.2 versus 7.6 ADL/IADL tasks). Although the rate of increase in formal support was equal for the treatment and control group, there is some evidence that the treatment group received a better match between the IADL/ADL task assistance needed and the services received.

The two models of care (Model A: low resource and Model B: high resource) were implemented to test the demonstration at different levels of funding. The lack of a differential impact between the two models on three of the outcome measures coupled with greater impacts in Model A sites than Model B sites on the other two outcomes (unmet needs and primary caregiver as provider of ADL/IADL tasks), suggests that more intensive case management (1:30 ratio versus 1:100) and larger monthly expenditures ($699 versus $430) for community-based services were not sufficient for differentiating caregiver support outcomes.

Formal services reimbursed by the demonstration were used as an adjunct or supplementation to primary caregiver efforts. While there were small decreases in primary caregiving on specific IADL tasks, caregiving was maintained or increased on 4 of the 5 ADL tasks. On average primary caregiver assistance with ADL/IADL tasks declined significantly less over time for the treatment group than the control group.

The equivalent use of assistance from formal providers by both groups suggests two conclusions. First, it indicates case managers may have made access to these services easier for the treatment group caregivers, but many control group caregivers were able to find and pay for these services on their own. Second, differences between the two groups in how formal provider assistance was used may be due, in part, to the unwillingness of some primary caregivers to use formal services for various tasks without encouragement from case managers (or other sources not measured here).

A logical extension of these findings is research into the relationship between unmet needs and caregiver burden, and whether reducing unmet needs helps caregivers retain their family members in the community.

TECHNICAL NOTE

Caregiver Support Network Outcomes: Model Specification

Independent Variables

Site

Experimental Variables

Group (1=Treatment Group)
Model (1=Model B: High Resource)

Client Characteristics

Age (20-103 years)
Sex (1=Male)
Ethnicity (1=Minority)
Functional Dependency Scale (-2.6 to +1.8)
Mini-Mental Status Examination (0-30)
Behavioral Problems Scale (0-19)
Hospitalized in Prior 6 Months (1=Yes)
Medicaid Eligible (1=Yes)

Caregiver Characteristics

Age (16-100 Years)
Relationship to Client
  Spouse (1=Yes)
  Unmarried Child (1=Yes)
  Married Child (1=Yes)
  Other (Omitted)
Income (0-11)
Lives With Client (1-Yes)
Functional Limitations Index (0-13)
Health Status (1-4)
Secondary Caregiver Assistance With ADL/IADL Tasks (0-13 Tasks)
Formal Provider Assistance With ADL/IADL Tasks (0-13 Tasks)

Outcome Variables

Caregiver Support Network

Primary Caregiver Hours Per Week (0-168 Hours)
Primary Caregiver ADL/IADL Tasks (0-13 Tasks)
Secondary Caregiver Assistance With ADL/IADL Tasks (0-13 Tasks)
Formal Provider Assistance With ADL/IADL Tasks (0-13 Tasks)
Unmet Need for Assistance With ADL/IADL Tasks (0-13 Tasks)

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REFERENCES

Biegel, D., Bass, D., Schulz, R., and Morycz, R.: Predictors of In-Home and Out-of-Home Service Use by Family Caregivers of Alzheimer's Disease Patients. *Journal of Health and Aging* 5(4): 419- 483, 1993.

Bryk, A.S., and Raudenbush, S.W.: *Hierarchiacal Linear Models.* Newbury Park, CA. Sage Publications, 1992.

Bryk, A.S., and Raudenbush, S.W.: Application of Hierarchical Linear Models to Assessing Change. Psychology Bulletin, 101(1):147-158, 1987.

Christianson, J.: Channeling Effects on Informal Care. Princeton, NJ. Mathematica Policy Research, 1986.

Congressional Budget Office: *LTC: Actuarial Cost Estimates,* A CBO Technical Analysis. Washington, DC. United States Government Printing Office, 1977.

Edelman, P., and Hughes, S.: The Impact of Community Care on Provision of Informal Care to Homebound Elderly Persons. *Journal of Gerontology* 45(2):74-78, 1990.

Finch, M., Kane, R.L., and Philp, I.: Developing a New Metric for ADLs. *Journal of American Geriatric Society* 43(8):877-84, 1995

Folstein, M., Folstein, S., and McHugh, P.: Mini-Mental State: A Practical Method for Grading the Mental State of Patients for the Clinician. *Journal of Psychiatric Research* 12(3):189-198, 1975.

Gibbons, R., Hedeker, D., Waternaux, C., and Davis, J.: Random Regression Models: A Comprehensive Approach to the Analysis of Longitudinal Psychiatric Data. *Psychopharmacology Bulletin* 24(3):438-443, 1988.

Goldstein, H.: *Multilevel Statistical Models, second edition.* New York. John Wiley & Sons, 1995.

Greene, V.: Substitution between Formally and Informally Provided Care for the Impaired Elderly in the Community. *Medical Care* 21(6): 609-619, 1983.

Gwyther, L.: Overcoming Barriers: Home Care for Dementia Patients. *Caring* 8(8):12-16, 1989.

Hanley, R., Wiener, J., and Harris, K.: Will Paid Home Care Erode Informal Support? *Journal of Health Politics, Policy and Law* 16(3): 507-521, 1991.

Health Care Financing Administration: *LTC: Background and Future Directions.* Washington, DC. Department of Health and Human Services, 1981.

Katz, S., and Akpom, C.A.: A Measure of Primary Sociobiological Functions. *International Journal of Health Services* 6(3):493, 1976.

Lawton, M.P., and Brody, E.: Assessment of Older People: Self Maintaining and Instrumental Activities of Daily Living. *The Gerontologist* 9(3):179-186, 1969.

Litwak, E.: *Helping the Elderly: The Complimentary Roles of Informal Networks and Formal Systems.* New York. Guilford Press, 1985.

Liu, K., Manton, K., and Liu, B.: Home Care Expenses for the Disabled Elderly. *Health Care Financing Review* 7(2):51-58, 1985.

Longford, N.: *Random Coefficient Models.* Oxford. Clarendon Press, 1993.

Manton, K., Newcomer, R., Vertrees, J., et al.: A Method of Adjusting Capitation Payment to Managed Care Plans Using Multivariate Patterns of Health and Functioning: The Experience of Social/Health Maintenance Organizations. *Medical Care* 32(3):277-297, 1994.

Miller, R., Newcomer, R., Clay, T., and Fox, P.: Effects of the Medicare Alzheimer's Disease Demonstration on Nursing Home Entry. *Health Services Research* (in press).

Moscovice, I., Davidson, G., and McCaffrey, D.: Substitution of Formal and Informal Care for the Community-Based Elderly. *Medical Care* 26(10): 971-981, 1988.

Noelker, L., and Bass, D.: Home Care for Elderly Persons: Linkages Between Formal and Informal Caregivers. *Journal of Gerontology* 44(2):563-570, 1989.

Pearlin, L.: Caregiving and the Stress Process: An Overview of Concepts and Measures. *The Gerontologist* 30(5), 583-594, 1990.

Rice, D., Fox, P., Max, W., et al.: The Economic Burden of Caring for People with Alzheimer's Disease. *Health Affairs* 12(2): 164-176, 1993.

Rivlin, A., and Wiener, J.: *Caring for the Disabled Elderly: Who Will Pay?* Washington, DC. The Brookings Institution, 1988.

Shanas, E.: The Family as a social Support System in Old Age. *The Gerontologist* 19(2):169-174, 1979.

Smith-Barusch, A., and Miller, L.: The Effect of Services on Family Assistance to the Frail Elderly. *Journal of Social Services Research* 9(1):31-46, 1985.

Soldo, B., and Manton, K.: Health Status and Service Needs of the Oldest Old: Current Patterns and Future Trends. *Milbank Memorial Fund Quarterly, Health and Society* 63(2):286-319, 1985.

Stone, R., Cafferta, G., and Sangl, J.: Caregivers of the Frail Elderly: A National Profile. *The Gerontologist* 27(5):616-626, 1987.

Zarit, S., Todd, P., and Zarit, J.: Subjective Burden of Husbands and Wives as Caregivers: A Longitudinal Study. *The Gerontologist* 26(3):260-66, 1986.

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