Variation in cost of informal caregiving and formal-service use for people with Alzheimer's disease

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Abstract

This study used a geographically diverse sample to estimate the total cost of informal care and formal services for community-residing Alzheimer's disease (AD) care recipients. Baseline data were used for 1200 family caregivers from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study, a multisite intervention trial. The replacement-wage-rate approach estimated informal cost. Formal services were assigned a cost based on secondary sources. Annual cost per care recipient amounted to $23,436 for informal care and $8,064 for formal services. Variation in informal cost was almost entirely due to instrumental activities of daily living (IADLs) assistance. Cross-site differences in cost persisted after controlling for caregiver and care-recipient characteristics. Geographic variation may suggest regional preferences or ethnic/cultural values. Further study is needed to determine whether this reflects differences in access or availability or how including a control group for care recipients with nondementia diagnoses might have affected these findings.

Key words: Alzheimer's disease, dementia, care recipient, geographic variation, economic burden

Introduction

It is now recognized that caring for people with Alzheimer's disease (AD) represents a large unpaid burden. Up to four million Americans have AD or a related disorder, and the majority of persons with dementia lives at home and are cared for by family or friends.[1] Home-based care typically includes the use of formal services available from community agencies. However, there is a great deal of variation in the use of formal services, and informal care represents a significant proportion of home-care costs. A recent review of community-based cost studies found that estimates of the proportion of total community-based costs represented by informal care range between 36 and 85 percent.[2]

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A number of previous studies have attempted to quantify the total cost of caring for persons with AD at home, including the costs of formal services provided by agencies as well as the informal care provided by family and friends.[3-8] Studies estimating community-based long-term care costs often lack sufficient sample size or geographic/ethnic diversity. For example, the sample used for the study by Rice and colleagues[5,6,9] included only 93 community-dwelling care recipients (88 percent of whom were white) from five California counties. The Leon et al. study,[4] which used an 88 percent white sample, was more geographically representative (13 US sites in nine states) but included just 354 community-dwelling care recipients. Most recently, Langa et al.[10] estimated the cost of informal caregiving for the elderly with dementia using data from the nationally representative 1993 Asset and Health Dynamics (AHEAD) study. Just over 10 percent (804) of the 7,443 study participants were identified as having some level of dementia as assessed using the Telephone Interview for Cognitive Status, an instrument patterned on the Mini-Mental State Examination (MMSE). The Langa et al. study was able to provide national informal-care estimates using a population-based sample. However, as with other previous studies measuring informal-care cost, there was no analysis of the potential regional variation in cost and no data on formal-service use. Regional variability in formal-service availability or supply may impact both informal-care provision and formal care-service utilization.

Racial and ethnic differences in caregiving can also affect cost estimates by influencing family caregiver decisions about formal-service use and informal-care provision.[11-13] A recent review of studies comparing dementia caregiving experience of two or more racial, ethnic, or cultural groups suggested that further examination of the use of services by diverse groups of caregivers is warranted.[14]

This study extends the work of previous literature on the cost of community-based caregiving for AD by estimating costs using a large ethnically and geographically diverse sample of AD care recipients. Detailed information on the types and amounts of informal care and formal services for 1207 care recipients were used to address the following questions:

> 1. What is the total cost of care for informal and formal services that support the activities of daily living (ADLs) and instrumental activities of daily living (IADLs) for community residing AD care recipients?
>
> 2. Is there geographic variation in the cost of this care after controlling for caregiver and care-recipient characteristics?

Data and methods

Parent study

The data used in this study were derived from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study,[15] a multisite trial designed to characterize and test promising behavioral, social, technological, and environmental interventions for AD family caregivers. The REACH study (1995 to 2000) was funded by the National Institute on Aging (NIA) and the National Institute for Nursing Research (NINR) at the NIH. Six sites developed and implemented the interventions (Birmingham, Boston, Memphis, Miami, Palo Alto, and Philadelphia) and a seventh site (Pittsburgh) served as the coordinating center to assure standardization and quality control. The data used for this study were baseline measures acquired prior to the start of the interventions. Future work will take advantage of the post-intervention data to examine potential changes in cost over time.

REACH enrolled over 1200 family caregivers over the age of 21 who lived with and provided a minimum of four hours of supervision or direct care per day for an AD family member for at least six months. Caregivers were excluded if they were involved in another caregiving intervention study or had an acute or terminal illness that impeded participation for the 18 months of the study. Similarly, care recipients were excluded if they had a terminal or severe illness or disability other than AD that would prohibit their participation. Care recipients had to have a medical diagnosis of probable AD or a MMSE[16] score < 23 and either one limitation in their ADL,[17] or two dependencies in their IADLs.[18] Planned nursing-home admission of the care recipient within six months of study entry also excluded a caregiver/care recipient dyad. All six study sites used the same inclusion and exclusion criteria.

Measures

Informal-care hours. Caregivers were asked if they provide assistance with each IADL, including use of the telephone, shopping, food preparation, housekeeping, laundry, transportation, medications, and financial management. They were then asked, "On average, how much time do you spend per day helping with all of the above activities?" This amount was converted to monthly IADL hours.

Caregivers were also asked if they provide assistance with each ADL, including getting in and out of a bed, chair, or wheelchair; eating meals; bathing; dressing; toileting; or grooming. For each individual activity, the caregiver was also asked how often they helped the care recipient in the past week and, on average, how much time each assistive activity took. The frequency was multiplied by the amount of time and converted to total hours per month per ADL. Total time spent helping with ADLs was then computed by summing the totals for each type of ADL assistance. Finally, total informal-care hours were calculated by adding the total monthly IADL and ADL hours.

Formal-service use. Caregivers reported the formal services their care recipients received over the past month. Formal services included visiting homemaker, home health aide, visiting nurse, formal transportation services, meal delivery, and daycare program.

Informal-care cost estimates. The replacement-wage-rate approach was used to apply dollar values to informal-care hours. This approach, used in a number of studies,[6,9] assigns the market rate of an equivalent service to an hour of informal care. To get IADL costs, hours were multiplied by the national average hourly wage rate ($7.14) for maids and housekeepers. The study was limited by the measure of IADL time, which was not separated by task but asked collectively, lumping together more complex tasks (such as assisting with finances) with tasks requiring less skill (such as housekeeping). However, prior studies found that the greatest number of IADL hours is for housekeeping tasks, and recent estimates of IADL costs have used one rate for all IADL tasks.[4,9]

For ADL cost, the hours for each activity (e.g., bathing, dressing) were multiplied by the national average hourly wage rate ($8.31) for home health aides. Wage rates for both IADL and ADL hours were taken from the Occupational Employment Statistics Survey (Bureau of Labor Statistics, 1997). These figures were inflated by a benefit inflation factor to better reflect total compensation.

Formal-care cost estimates. Each type of formal service was assigned a cost based on secondary sources. All costs were converted to 1997 dollars. The National Association for Home Care (NAHC) Web site (*www.nahc.org*) was the source for the rate for a homemaker ($51 per visit), for a home health aide ($53 per visit), and for a visiting nurse ($96 per visit). The Administration on Aging (AOA) Elderly Nutrition Program fact sheet (*www.aoa.gov*) provided the cost for meals delivery ($5.31 per meal). Transportation was estimated at 40 miles per roundtrip, $0.31 per mile or $12.40 per trip. The daycare program was assigned a cost of $43.13 per day based on a National Adult Day Services Association (NADSA) 1997 survey, and is available on the National Council on the Aging Web site (*www.ncoa.org*).

Secondary caregiver. Caregivers were asked, "On how many days in the past week have other family members or friends provided unpaid help?" Responses were categorized into three groups: no help, one to six days of help, and seven days of help.

Revised Memory and Behavior Problem Checklist[19] (RMBPC) "bother" score. Caregivers were queried about 24 disruptive, depressive, and memory-related problem behaviors the care recipient might have exhibited over the past week. For each positive response, they were also asked how bothered or upset they were by the behavior using a 5-point scale response ranging from "not at all" (0) to "extremely" (4) bothered. For this report, behaviors not manifested by the care recipient were assigned a bother score of 0, corresponding to "not at all." Bother scores totaled across the 24 items can range from 0 to 96.

MMSE score. Cognitive impairment was appraised using the MMSE. Scores can range from 0 to 30, with 23 or below suggesting cognitive impairment.

Occupation. Caregivers identified the primary occupation they had for most of their working life. Those with more than one job at a given time were asked to report the job that was their primary source of income. If married, they reported similar information for their spouses. Jobs were coded using Nam-Powers Socioeconomic Status[20] (SES) scores that can range from 0 to 100. Higher scores suggest higher SES status. The maximum Nam-Powers SES job score identified was used.

Employment status. Caregivers employed at a job for pay, whether full or part time, were considered employed.

Health status. Caregivers self-rated their health on a 5-point scale ranging from "poor" to "excellent" with a higher score indicating better perceived health.[21] Caregivers similarly rated their care recipients' health.

Analytic techniques

All analyses were performed using baseline REACH data (preintervention). Descriptions of the interventions are reported elsewhere.[22] Sample descriptive statistics include measures of central tendency and dispersion for continuous variables and frequency distributions for categorical variables.

Multiple linear regression modeling was employed to determine if geographical site was independently associated with costs after adjusting for potential confounding factors. Separate models were fit for informal- and formal-service costs. The site with the lowest adjusted informal-care costs was the reference group for all regression analyses. F-tests, with 5 degrees of freedom (number of sites minus one), were used to test for a significant association between site and costs. To perform pair-wise comparisons of the sites, we fit six of each type of regression model. For each of the six models, a different site was used as the reference group. In addition to site, other independent variables included in the models were sociodemographic variables (care-recipient age and gender, caregiver employment status, and Nam-Powers SES score), relationship of caregiver to care recipient (spouse vs. child vs. other relative), caregiver and care-recipient health, care-recipient MMSE score, caregiver RMBPC bother score, and number of days/week that a secondary caregiver was available. Square root transformations were performed to normalize the cost (dependent) variables. Model adequacy was assessed by examining the r-square value and residual plots.

A large percentage of caregiver-care-recipient dyads did not use formal services (n = 420, 34.8 percent). A multiple-logistic-regression model adjusting for the factors above was developed to ascertain if site was independently associated with formal-service use. The Wald chi-square test was used to test for a significant association between site and the odds of having any formal-service costs. The Hosmer-Lemeshow goodness-of-fit statistic was calculated to examine the evidence of lack of fit for the final logistic model.[23] The formal-service-cost linear regression model included only dyads with formal-service use.

Results

Sample characteristics

The majority of caregivers were female (81.5 percent) and averaged 61.7 years of age. Of the caregivers, 48.1 percent were spouses. Over half of the sample was Caucasian/white (56.0 percent), but minority representation among the caregivers was substantial (24.1 percent African-American/black, 19.0 percent Hispanic/Latino, and 0.9 percent Other). Just over one-half of the care recipients were female (55.4 percent) and averaged 78.7 years. Care recipients, on average, exhibited impaired cognition (mean MMSE = 12.6) and were almost evenly divided between fair/poor (48.0 percent) and good/excellent (52.0 percent) health status. Table 1 portrays the site-specific sample characteristics.

Among the sites there are interesting differences. Notably, Philadelphia had the highest number of black caregivers (47.8 percent) and Boston the smallest (16.2 percent), whereas caregivers in Miami are very likely to be Hispanic (50.5 percent), which was not so in Birmingham (0.0 percent). Spousal caregivers are most common in Miami (65.5 percent), whereas child caregivers predominate in Palo Alto (57.3 percent) and were more likely to be employed (41.6 percent) than Miami caregivers (22.4 percent). Boston caregivers report the best health status, whereas those in Philadelphia report the worst. Boston caregivers were also the least bothered (RMBPC = 12.8), whereas those in Birmingham were most bothered (RMBPC= 19.5). Care recipients in Boston and Memphis demonstrate the most cognitive impairment (MMSE = 11) and Miami and Palo Alto the least (MMSE = 13.6). Philadelphia had the fewest male care recipients (33.7 percent) and the oldest (80.2 years) on average. Care recipients' health status was more likely to be reported poor to fair in Palo Alto and good or better in Miami.

Table 2 presents the monthly hours of informal care by type of care and the total monthly cost by site. The average total informal-care cost across all sites was $1,953 and ranged from $1,700 in Boston to $2,164 in Memphis. Assistance with ADLs accounted for just 46 of the total 227 caregiving hours per month (or 444 of the total $1,953 dollars). This amount varied little across site. In contrast, the majority of assistance provided at every site was for IADLs, and this type of assistance did vary geographically, from 150 hours per month in Boston to 206 hours in Memphis.

Table 3 delineates monthly formal-service use by type and cost by site. Two-thirds (n = 787, 65.2 percent) of the entire sample reported some formal-service use, with an average total formal-service cost of $672 for all subjects or $1,031 for those reporting any formal-service use. Homemakers, home health aides, and adult daycare were the most frequently used services across all sites.

The Boston site reported the highest formal-service utilization, with 86.9 percent of caregiving dyads using some service at an average monthly cost of nearly $1,200. Memphis and Birmingham reported the lowest formal-service usage and corresponding costs. Meal delivery was the least frequently used service for every site.

There was great variation in the use of visiting nurses and adult daycare services. Just 12 percent of Miami participants used a visiting nurse, as compared with 46 percent in Boston. Sixty-two percent of the Boston site participants had used adult daycare services in the previous month, as compared with 12 percent for the Birmingham site.

Multivariate analyses

Informal-care costs. Table 4 shows the results of multiple regression analyses designed to assess the independent association of site and informal-care costs. The results are based on a model with the Miami site as the reference group. Miami had the lowest informal-care costs after adjusting for potential confounding factors. Adjusted informal-care costs did vary significantly among the sites. Pair-wise comparisons of the sites revealed that informal-care costs in Miami were significantly lower than Birmingham, Memphis, and Palo Alto ($p < 0.05$), averaging $16.48, $25.22, and $28.05 less per month than these sites, respectively (calculated by squaring the parameter estimates). Memphis and Palo Alto had the highest adjusted informal-care costs, with both sites having significantly higher costs than Boston and Philadelphia in addition to Miami. Informal-care costs were not significantly associat-

Table 1. Sample characteristics by site

Variable	All sites (n = 1207)	Birmingham (n = 133)	Boston (n = 99)	Memphis (n = 245)	Miami (n = 220)	Palo Alto (n = 255)	Philadelphia (n = 255)
Caregiver							
Age: Mean (SD)	61.7 (13.6)	62.2 (12.9)	62.1 (12.7)	61.9 (13.0)	68.1 (11.5)	56.8 (13.9)	60.6 (14.3)
Ethnic group (%)							
White	56.0	57.9	78.8	58.4	49.6	57.3	48.2
Black	24.1	42.1	16.2	39.6	0.0	0.0	47.8
Hispanic	19.0	0.0	2.0	0.8	50.5	42.8	2.0
Other/missing	0.9	0.0	3.0	1.2	0.0	0.0	2.0
Relationship to care recipient (%)							
Spouse	48.1	47.4	53.5	49.8	65.5	38.4	39.2
Child	44.3	44.4	38.4	41.2	30.0	57.3	49.0
Other	7.6	8.3	8.1	9.0	4.6	27.3	11.8
Nam-Powers SES score: Mean (SD) (n = 1197)	62.0 (23.8)	63.4 (21.4)	68.0 (21.4)	60.7 (24.3)	67.6 (23.6)	61.4 (25.6)	55.1 (22.1)
Employed (%) (n =1206)	31.5	30.1	34.3	27.4	22.4	41.6	32.9
Self-report health status (%) (n = 1206)							
Poor	6.7	4.5	3.0	7.8	8.2	5.5	8.2
Fair	32.3	33.1	19.2	32.2	34.7	28.6	38.4
Good	33.4	36.8	33.3	31.8	34.7	33.7	31.8
Very good	19.0	15.8	33.3	19.2	14.6	22.8	14.9
Excellent	8.6	9.8	11.1	9.0	7.8	9.4	6.7
RMBPC bother score: Mean (SD) (n = 1152)	16.7 (13.7)	19.5 (15.1)	12.8 (12.4)	16.0 (14.1)	17.1 (13.2)	18.8 (13.4)	15.3 (13.4)
Care recipient							
MMSE score (n = 1171)	12.6	13.1	11.3	11.1	13.6	13.6	12.3
Male (%)	44.6	38.4	51.5	44.9	49.6	51.4	33.7
Age: Mean (SD) (n = 1204)	78.7 (8.2)	78.3 (8.4)	77.5 (8.4)	77.7 (7.4)	79.7 (7.5)	77.8 (9.2)	80.2 (7.9)
Self-report health status (%)							
Poor	17.6	12.8	12.1	18.8	12.7	21.2	21.6
Fair	30.4	36.1	29.3	29.0	23.6	37.7	27.8
Good	30.1	29.3	35.4	29.0	36.4	23.9	30.2
Very good	14.3	13.5	11.1	13.5	17.7	13.3	14.5
Excellent	7.7	8.3	12.1	9.8	9.6	3.9	5.9

Table 2. Monthly hours of informal care by type of care and total monthly cost by site

Type of care	All sites (n = 1207)	Birmingham (n = 133)	Boston (n = 99)	Memphis (n = 245)	Miami (n = 220)	Palo Alto (n = 255)	Philadelphia (n = 255)
Total informal care hours	227	230	196	252	217	238	210
Total informal care cost	$1,953	$1,973	$1,700	$2,164	$1,868	$2,049	$1,816
ADL hours							
Bed	7.4	5.9	8.0	7.9	8.9	8.0	5.6
Eating	9.4	9.7	10.5	7.2	9.5	10.3	10.0
Bathing	6.5	5.6	7.7	6.3	5.9	5.7	7.8
Dressing	9.7	10.7	7.8	9.4	10.0	10.5	9.1
Toileting	7.9	6.4	8.0	9.5	5.7	8.0	9.0
Grooming	4.8	5.4	4.3	5.8	3.6	5.0	4.6
Total ADL hours	45.7	43.8	46.3	46.1	43.6	47.5	46.2
Total ADL cost	$444	$424	$449	$447	$423	$461	$448
Total IADL hours	181	186	150	206	173	191	164
Total IADL cost	$1,510	$1,549	$1,251	$1,716	$1,445	$1,588	$1,368

ed with caregiver and care-recipient relationship (e.g., spouse, sibling), care-recipient age, or care-recipient sex. Care-recipient health status and MMSE score were inversely associated with informal-care costs. Employed caregivers reported less informal-care costs and bothered caregivers reported more.

Formal-service costs. Table 5 shows the results of the multiple logistic regression model fit to examine the independent association of site on having any formal-service costs. The odds of having any formal-service costs differed significantly by site. Birmingham had the lowest odds of having any formal-care costs among the sites, after adjusting for potential confounding factors, significantly different from Philadelphia, Palo Alto, and Boston. Boston had significantly higher odds of having any formal-service costs than any other sites.

Higher socioeconomic status, as measured by the Nam-Powers SES score, was associated with higher odds of having any formal-service costs. Care-recipient age was also positively associated with odds of having any formal-service costs. MMSE scores and bother scores on the RMBPC were negatively associated with odds of having any formal-service costs.

Multiple linear regression analyses, restricted to those who used any formal service, revealed a significant association between formal-service costs and site. Given any formal-service costs, they were lowest at Palo Alto, significantly less than all sites except Memphis. Boston dyads with any formal-service costs had the highest. This result was statistically significant ($p < 0.05$) compared with Palo Alto, Memphis, and Philadelphia, with Boston dyads averaging $66.01, $43.74, and $21.78 more per month in formal-service costs than these sites, respectively. Formal-service costs were significantly higher among employed caregivers (approximately $26 more per month) than non-employed caregivers. As in the informal-care cost model, care-recipient health status and MMSE score were negatively associated with formal-service costs.

Discussion

Our estimates of total annual caregiving cost per care recipient amounts to $23,436 for informal costs and $8,064 for formal service (1997 dollars). This total figure only represents home-based care excluding medical services, institutional care, and caregiving time spent by secondary caregivers. Nevertheless, our informal-care estimates are considerably larger than the $13,859 per person informal-care cost estimated by Leon and coauthors (adjusted to 1997 dollars).[4] Considering their use of lower wage rates does not account for the magnitude of the difference. Our estimates are close to those found by Langa et al.[9] using their high range estimate of cost for their most severe care recipients.

Table 3. Monthly use of formal services by type of service and monthly forman service cost by site

	All sites (n = 1207)	Birmingham (n = 133)	Boston (n = 99)	Memphis (n = 245)	Miami (n = 220)	Palo Alto (n = 255)	Philadelphia (n = 255)
Total formal service cost	$672	$521	$1,198	$497	$765	$582	$725
Percent using							
Any service	65.2	52.6	86.9	55.9	65.0	68.2	69.4
Homemaker	26.8	19.6	25.3	20.4	41.8	28.2	23.1
Home health aide	28.8	28.6	50.5	22.0	31.4	20.0	33.7
Meals delivered	10.5	3.8	14.1	4.1	10.5	14.1	15.3
Transportation	21.0	6.8	37.4	9.0	20.9	24.7	29.8
Visiting nurse	21.3	25.6	45.5	22.5	12.3	13.7	23.9
Daycare (CG or CR)	27.1	12.0	61.6	19.2	18.2	34.9	29.0

As expected, and consistent with the literature, our costs for AD caregiving are greater than estimates for caregiving to physically disabled or frail elderly.[24-26]

The Rice et al.[6] annual informal caregiving cost estimate of $41,752 (adjusted to 1997 dollars) for community dwelling persons with AD, is considerably higher than ours. Care recipients in their sample were slightly more cognitively impaired than those in the REACH study (mean MMSE = 10.9, SD = 8.5 as compared with mean MMSE = 12.6, SD = 7.6 for REACH). Nevertheless, their estimate of informal costs for those with mild or moderate impairment (MMSE between 13 and 24) was $31,937.

However, their estimates included time spent on “behavior management” and “social/recreational” activities as well as time spent by secondary caregivers. Their estimates of primary caregiver time spent on ADLs and IADLs were 59 and 76 hours, respectively,[5] as compared with ours of 46 and 181 hours, respectively. Our two-fold greater IADL estimates suggest that perhaps time spent on “behavior management” may have been implicitly included in our caregivers’ responses. Future studies need to more carefully estimate time spent on behavior management.

In contrast to informal-care estimates, the Rice et al.[6] estimate for formal-service costs ($9,359, 1997 dollars) for care recipients with mild to moderate dementia is comparable to our estimate.

Across the six study sites, variation in informal cost was almost entirely due to differences in the number of monthly hours spent assisting with IADLs. Regression analyses revealed that the Miami site had the lowest informal costs, whereas Birmingham, Memphis, and Palo Alto costs were significantly higher.

Cross-site differences also clearly emerged with respect to formal-service use. Boston participants were the highest users of formal services, even after accounting for differences in caregiver and care-recipient characteristics. Caregiving dyads in Palo Alto and Philadelphia were also more likely to use formal services although less so than for Boston. These formal-service use differences may reflect access and availability differences. For example, in Massachusetts, caregivers are encouraged by their healthcare providers to use home health aides, and there are numerous adult daycare programs available. In contrast, caregivers in Memphis and Birmingham did not have as many formal-service programs available.

Formal-service availability may also influence the amount of informal care provided. For example, Tennessee, which had the lowest use of formal services and the highest informal costs, is ranked last in the nation in the provision of home and community services for older persons, and many formal services available require out-of-pocket expenditures. However, this inference should be interpreted with caution. Evaluation of the Medicare Alzheimer’s Disease Demonstration as well as other prior research has found that the availability of expanded community-based services and case management for AD caregivers did not significantly increase the amount of assistance received from formal providers, nor did it diminish the amount of support provided by informal caregivers.[27-35]

Geographic differences in the utilization of health services, more generally, has been documented in the literature.[36,37] Variation may suggest regional preferences, ethnic or cultural values, or socioeconomic factors. Further study is needed to determine whether differences reflect regional

Table 4. Results of regression analysis: Predictors of informal costs*		
Variable	**Parameter estimate (se)**	**p value**
Intercept	**55.28 (4.83)**	**0.0001**
Miami (reference group)	–	–
Boston	0.73 (2.01)	0.716
Philadelphia	1.97 (1.31)	0.132
Birmingham	**4.06 (1.52)**	**0.008**
Memphis	**5.02 (1.32)**	**0.0001**
Palo Alto	**5.30 (1.35)**	**0.0001**
Child caregiver	0.29 (1.18)	0.806
Other related caregiver	-0.02 (1.75)	0.992
Caregiver health	-0.30 (0.41)	0.460
Care recipient health	**-1.42 (0.37)**	**0.0001**
Care recipient male	0.06 (1.01)	0.954
Nam-Powers SES	0.00 (0.02)	0.934
MMSE	**-0.59 (0.06)**	**0.0001**
Care recipient age	-0.06 (0.05)	0.279
Employed	**-6.22 (0.99)**	**0.0001**
RMBC bother scale	**0.09 (0.03)**	**0.003**
Secondary CG 1 – 6 days	-0.96 (0.90)	0.287
Secondary CG 7 days	1.27 (1.17)	0.279
Overall site effect	F-value = 4.91	0.0002
F value	13.95	0.0001
R^2	0.18	
* Square root transformation of informal care costs.		

preferences or differences in access or availability. If the latter, there is a concern that this may indicate unmet need or undue burden on the part of family caregivers living in certain areas. Caregivers need to be made aware of the variety of caregiver services that have been and could be developed. Intervention information should be evidence based as much as possible and include financial costs to caregiver (ranging from volunteer to professional services).

Conclusion

This paper provides an examination of the cost of community-based care for AD for a large, diverse sample. Our estimates reflect detailed service-use data reported by AD caregivers. Findings indicate that the cost of meeting AD patients' ADL and ADL needs might be even greater than recent estimates reported, although a limitation of the study is that no control group equivalent was provided for nondementia diagnoses such as arthritis or congestive heart failure. Further study is needed to determine whether including a control group for nondementia diagnoses would have affected results by providing a measure of costs associated with dementia only.

Results indicate that family caregivers continue to shoulder the majority of the financial burden for dementia care, regardless of any formal support received. Clearly, there is a need for policy approaches to ease family burden that are sensitive to geographic, racial, and ethnic differences. Ideally, equal access to services, if not equal use should be provided. Regional variation and access issues continue to exist and challenge the healthcare community to address them.

Table 5. Results of regression analysis: Predictors of formal service use and cost conditional on use*

Variable	Any formal service use			Formal service cost		
	Odds ratio	**(95% CIs)**	**p value**	**Parameter estimate**	**(se)**	**p value**
Intercept	–	–	0.119	**38.17**	**(6.22)**	**0.0001**
Miami (reference group)	–	–	**–**	–	–	–
Boston	**4.07**	**(1.73, 9.61)**	**0.001**	0.61	(2.30)	0.791
Philadelphia	1.20	(0.79, 1.83)	0.405	**-4.06**	**(1.65)**	**0.015**
Birmingham	0.66	(0.41, 1.05)	0.080	-3.54	(2.06)	0.087
Memphis	0.72	(0.48, 1.10)	0.128	**-6.00**	**(1.74)**	**0.0006**
Palo Alto	1.39	(0.89, 2.15)	0.148	**-7.51**	**(1.71)**	**0.0001**
Child caregiver	1.03	(0.70, 1.50)	0.896	2.16	(1.49)	0.148
Other related caregiver	1.20	(0.68, 2.13)	0.531	3.03	(2.19)	0.167
Caregiver health	0.92	(0.80, 1.05)	0.200	-0.28	(0.51)	0.585
Care recipient health	0.94	(0.84, 1.06)	0.344	**-2.17**	**(0.46)**	**0.0001**
Care recipient male	1.05	(0.76, 1.46)	0.774	-1.36	(1.25)	0.277
Nam-Powers SES	**1.01**	**(1.00, 1.01)**	**0.044**	0.03	(0.02)	0.203
MMSE	**0.97**	**(0.95, 0.99)**	**0.0003**	**-0.29**	**(0.07)**	**0.0001**
Care recipient age	**1.03**	**(1.01, 1.05)**	**0.0008**	0.00	(0.07)	0.986
Employed	1.22	(0.89, 1.69)	0.224	**5.13**	**(1.30)**	**0.0001**
RMBPC bother score	**0.988**	**(0.978, 0.997)**	**0.012**	-0.01	(0.04)	0.734
Secondary CG 1 – 6 days	1.09	(0.81, 1.45)	0.582	1.01	(1.15)	0.379
Secondary CG 7 days	0.93	(0.64, 1.36)	0.719	-0.45	(1.50)	0.767
Overall site effect	**Chi-square = 28.9 w 5df, p < 0.0001**			**F-value = 5.56, p = 0.0001**		
Hosmer-Lemeshow Statistic	8.03 (p = 0.431)					
F value				**5.23**		**0.0001**
R^2				**0.12**		

* Square root transformation of formal service costs.

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