



CAREGIVING COSTS

Declining Health in the
Alzheimer's Caregiver as
Dementia Increases in
the Care Recipient

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About Alzheimer's Immunotherapy Program

The Alzheimer's Immunotherapy Program (AIP) of Janssen Alzheimer Immunotherapy and Pfizer Inc. is an equal collaboration committed to delivering comprehensive and meaningful solutions to address the needs of people affected by Alzheimer's disease. We believe that it is possible to reduce the burden of disease through early intervention in the illness. The AIP is harnessing the combined scientific experience, expertise and scale of our respective companies to advance patient care worldwide.

About National Alliance for Caregiving

Established in 1996, National Alliance for Caregiving is a non-profit coalition of national organizations focusing on family caregiving research. Alliance members include grass-roots organizations, professional associations, service organizations, disease-specific organizations, government agencies, and corporations. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues.

Recognizing that family caregivers make essential social and financial contributions toward maintaining the well-being of those they care for, the Alliance is dedicated to being the foremost national resource on family caregiving research to improve the quality of life for families and care recipients.

We would like to thank Donna Wagner, Ph.D., for her review of the study

For more information, visit www.caregiving.org

Empowering Family Caregivers through Research, Awareness & Advocacy

Executive Summary

Many studies have shown that the health of family caregivers can be adversely affected, especially as their caregiving continues and becomes more intense. This study looked at Alzheimer's caregivers in the REACH 1 project (Resources for Enhancing Alzheimer's Caregiver Health) to see if their health use was different from non-caregivers and, if so, how much more that care was estimated to cost.

The results: in the 18 months of the study, the caregivers' self-reported health declined steadily and significantly. For example, emergency room visits and hospital-based services doubled over that time. There was an overall 25% trend in increased use of all types of health services. The best predictor of this increased health care utilization was those caregivers who had fair or poor self-reported health at the beginning. Caregivers were asked to rate their health as Excellent, Very Good, Good, Fair or Poor.

The median cost of health care service use was calculated for caregivers and non-caregivers. Healthcare for family caregivers providing care for someone with Alzheimer's cost an average of \$4,766 more per year.

Introduction

The health effects of family caregiving on the caregiver have been well documented by researchers.¹ Health effects are especially pronounced among those caregivers caring for persons with Alzheimer's disease (AD). These caregivers are most likely to report higher levels of burden and stress than other caregivers and to face unique challenges in providing care due to the cognitive and physical disability experienced by care recipients. Although there has been clear documentation of the adverse effects experienced by caregivers to persons with AD, little empirical attention has been given to the resulting use of health care services by these caregivers and the associated costs.

The purpose of this study was to examine the use of formal health care services (as defined below) in a large sample of AD caregivers who were providing care for moderately to severely impaired AD patients at home. The following questions were addressed in the study:

- What is the prevalence of formal health service use among AD caregivers and how does this compare with rates of service use among non-caregivers?
- Does health service use by a caregiver relate to the AD care recipient's increasing dementia?
- Is there a financial impact of a change in caregivers' health?

¹ Schulz, R, & Sherwood, P. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing*, Vol. 108 (9-Supplement), 23-27, PMID: 18797217. PMCID: PMC2791523.

The Sample

Data from the REACH 1 study was used to examine the research questions above. Resources For Enhancing Alzheimer's Caregiver Health (REACH) is a project started in 1995 by the National Institutes of Health to explore ways in which families who are caregiving for someone with AD can better manage the difficult tasks associated with this care. The REACH project, for example, includes skills training and behavioral management. The research is coordinated by the University of Pittsburgh and involves several researchers around the country.² The REACH project includes testing of the support interventions as well as data collection on 1,222 family caregiver and care recipient pairs recruited at six sites around the country including: Birmingham, AL; Boston; Miami; Palo Alto, CA; and Philadelphia.

The family caregivers were a diverse group and included African Americans, Hispanics (both English and Spanish-speaking), and Whites. The support interventions tested with the caregivers and their care recipients included educational, behavioral and environmental modifications. Study sample members were assigned to either a control group or an intervention group lasting six months. Caregivers were eligible to participate in the study if they were over the age of 21, able to complete a screening form, living with and caring for someone with AD for at least the previous six months. Respondents were also required to be spending at least four hours a day in their caregiving activities.

At the beginning of the intervention trial, caregivers were not screened for depression or health status with the exception that those being treated for cancer were ineligible to participate in the study. Care recipients were eligible if they were assessed as having moderate to severe cognitive impairment and had at least one limitation in the Activities of Daily Living (ADL)—requiring personal care, such as bathing, dressing, feeding, toileting, etc.—or two needs in the Instrumental Activities of Daily Living (IADL)—such as housekeeping, handling finances, transporting to doctor's appointments, etc. This limited the caregiver sample to those with responsibilities that could be considered burdensome.

Caregivers were asked a standard, very reliable question about whether their health was excellent, very good, fair or poor. Data collected about caregiver health utilization included physician visits, visits to a nurse practitioner or other health care practitioner, short-term or overnight hospital stays, emergency room visits, medical testing, or visits to counselors, psychologists or psychiatrists, or clergy for help with personal problems. Medication use, self-rated health, and presence of chronic conditions were health status indicators for the caregivers.

² For additional information about REACH: www.nia.nih.gov/Alzheimers/ResearchInformation/

Sample Characteristics

For this study, we focused on a sample of AD family caregivers who provided care over an 18-month period in the home. Table 1 provides demographics of these caregivers. The average age of the caregivers was 61.7 years. More than half were Caucasian/White (58%), 23% were African American and 18% were Hispanic/Latino. All were unpaid, and most were either spouses (48%) or adult children (41%). The vast majority were female (82.8%) who were spending an average of 7.9 hours daily on care tasks. The average duration of caregiving was 4.3 years. The care recipients' average age was 78.7 years, and nearly half of them were men (42%).

Table 1.
Characteristics of Alzheimer's Caregivers and Care Recipients in Study

	Family Caregivers Providing In-Home Care N=583
Caregiver Age	
Mean Age	60.8 years
Care Recipient Age	
Mean Age	77.9 years
Caregiver Race	
White	53%
African American	27
Hispanic	21
Caregiver/Care Recipient Relationship	
Spouse	48%
Other than Spouse	52
REACH Intervention	
Intervention Group	68%
Control Group	32
Caregiver Gender	
Female	83%
Care Recipient Gender	
Female	58%
Revised Memory & Behavior Problem Checklist ³	
Mean	1.1

³ Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1992). Assessment of behavioral problems in dementia: The Revised Memory and Behavior Problems Checklist. *Psychology and Aging*, 7(4), 622-631.

What We Found

Not surprisingly, analysis of the data showed that, over the 18 months of the study, the AD care recipients as a group declined in the cognitive abilities as measured by the Mini Mental State Exam, and their need for assistance increased as measured by the ADLs and IADLs they needed help with. During this same time period, the health status of the

Table 2. Repeated Measures of Caregiver and Patient Status Indicators

	Baseline	Time 1	Time 2	Time 3	p-value
Care Recipient Status					
Mini-Mental State Exam	13.5	—	11.3	—	p < .001
Needs Help with ADLs ⁴	3.10	3.46	3.76	4.08	p < .001
Needs Help with IADLs	7.25	7.33	7.42	7.49	p < .001
Caregiver Health Status					
Self-rated health (1-5 scale)	3.02	2.97	2.99	2.91	p = .026
Depression (CES-D) ⁵	14.10	13.46	12.82	13.03	p = .002
Health Care Utilization (Ever)					
Emergency room visit	0.032	0.032	0.042	0.053	p = .069
Hospital use	0.027	0.025	0.032	0.057	p = .017
Doctor visit	0.474	0.478	0.492	0.492	p = .779
Nurse visit	0.091	0.078	0.100	0.078	p = .455
Counselor/mental health	0.167	0.173	0.167	0.123	p = .756
Psychiatric Medication Use					
Antidepressants	0.130	0.151	0.159	0.156	p = .087
Anti-anxiety medications	0.134	0.144	0.134	0.132	p = .693
Total	0.234	0.250	0.261	0.253	p = .170
Non-routine Use of Services					
Multiple hospital or ED visits	0.010	0.017	0.019	0.023	p = .088
> = 3 doctor visits	0.067	0.098	0.102	0.104	p = .018
> = 3 nurse visits	0.023	0.015	0.032	0.051	p = .824
> = 3 mental health visits	0.032	0.032	0.030	0.025	p = .389
> = 3 All services combined	0.163	0.195	0.216	0.195	p = .073

⁴ ADLs are personal care tasks, such as bathing, dressing, feeding, toileting and transferring. IADLs are instrumental activities of daily living such as cooking, housekeeping, handling finances, and transportation to doctor visits.

⁵ CES-D = Center for Epidemiologic Studies Depression Scale

family caregivers was mixed. Self-rated health scores declined steadily and significantly over the 18 months—on average from 3.02 at the beginning to 2.91 at 18 months. Caregiver depression as measured by the CES-D⁶ test was mixed over time as well. However, the use of medical services by the caregivers including emergency room visits, hospital-based services and increased use of primary care services and mental health service use did increase over time. But only the emergency room use and hospital-based services increase were statistically significant (see Table 2).

To better understand these trends, we calculated service utilization based upon the rate of healthcare use per 100 caregivers. As shown in Table 3, the rate of increased use for all healthcare services was statistically significant. In fact, caregiver hospital or emergency room visits doubled from beginning to end of the 18-month period, from 6.3 stays to 12.5 total visits per 100 caregivers. Overall, caregivers' use of all types of healthcare services increased significantly from 106.8 visits per 100 caregivers at the beginning to a peak of 133.3 visits at 12 months and a slight drop to 124.4 visits per 100 at 18 months. This overall time trend of a 25% increase in use of all types of services combined was statistically significant.

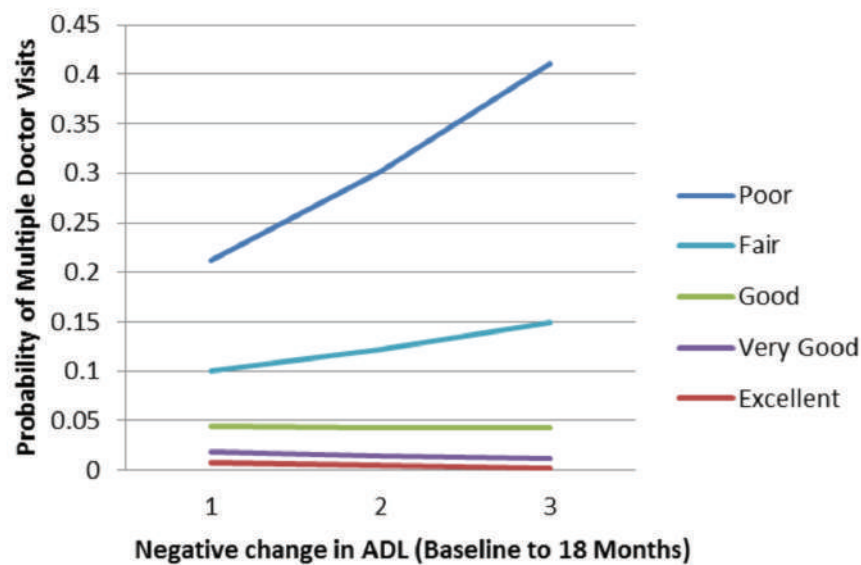
Table 3. Summary of Healthcare Use by Caregivers over Time (Visits per Month)

	Baseline	Time 1	Time 2	Time 3	p-value
Visits per 100 caregivers					
Hospital-based Services					
Hospital use	3.0	2.5	3.8	7.0	p = .013
Emergency room visits	3.2	4.0	5.1	5.5	p = .052
Subtotal, hospital-based services	6.3	6.4	8.9	12.5	p = .004
Primary Care					
Doctor visits	76.9	93.2	99.8	95.5	p = .010
Nurse visits	23.6	15.3	24.6	16.5	p = .565
Subtotal, primary care	100.6	108.5	124.4	111.9	p = .114
Total Healthcare Services	106.8	114.9	133.3	124.4	p = .034
Mental Health/Counselor	36.8	31.9	35.9	27.7	p = .393
Total Use of All Services	143.5	146.7	169.0	152.0	p = .279

⁶ Center for Epidemiologic Studies Depression Scale

Predictors of this health care utilization were, most importantly, caregiver self-reported health status at baseline. The interaction of measures of care recipient decline and caregiver health care use was most striking among those caregivers who had poor or fair self-reported health status at baseline. This finding suggests that the caregiver group most vulnerable to the effects of increasing dependence of the care recipient is those with lower self-reported health (see Figure 1).

Figure 1. Probability of Multiple Doctor Visits Reported at 18 Months Associated with Negative Changes in Care Recipient ADLs, by Caregiver Health Status at Baseline



Estimating Costs

In order to estimate the costs associated with higher rates of health care use by caregivers, we compared caregivers (average age of 61) with non-caregiver women between the ages of 45-64. Data from the Medical Expenditure Panel Survey (MEPS)⁷ allowed us to estimate the marginal costs associated with caregiver health care use compared with non-caregivers of a similar age. Table 4 shows that emergency room use was twice as high for the caregivers as for similar aged non-caregiving women (2.6 visits per month/100 women contrasted with 5.5 visits per month/100 caregivers). Physician visits were nearly triple for the caregivers when compared to non-caregivers (95.5 per month/100 contrasted to 34.3 per month/100).

The median cost of health care service was used to calculate the cost difference between the caregivers and the non-caregiving women. This calculation, outlined in Table 4, suggests that a caregiver providing care for an individual with AD on average costs \$4,766 more per year (per person) than a non-caregiver.

Table 4. Utilization and Cost for Women Aged 45-64 and AD Caregivers

	Median cost per person	Utilization rates per month for 100 women aged 45-64	Cost per month for 100 women aged 45-64	Utilization rates per month for 100 AD caregivers	Cost per month for 100 AD caregivers	Average annual per person excess utilization cost for AD caregivers
Emergency Room Visits	\$395 ⁸	2.6	\$1,027	5.5	\$2,172	\$137
Physician Office Visits	\$243	34.3	\$8,335	95.5	\$23,206	\$1,785
Hospital Use	(9.8% vs. 68.4% @ \$5195 per person = \$50,911 vs. \$335,338)					\$2,844
Total						\$4,766

⁷ Ezzati-Rice, T.M., Kashihara, D. & Machlin, S.R. (2004) Health care expenses in the United States 2000. Rockville, MD: Agency for Healthcare Research and Quality. MEPS Research Findings, No. 21, AHRQ Pub. No. 04-0022.

⁸ Cost data from MEPS (Medical Expenditure Panel Survey)

Conclusions and Implications

The findings suggest that the strain of caring for someone with AD can cause family caregivers to use health care services at higher rates than non-caregivers of the same age, including rates for emergency room visits, hospital use, and doctor visits. Overall, caregivers showed a 25% increase in the utilization of all types of services combined over the 18-month time period of the study. This was especially true for caregivers who initially reported their health as only fair or poor and for those whose care recipient became more disabled over that time. The estimated \$4,766 more annually in health care services for caregivers whose average age is 61 could become a substantial cost to Medicare when the caregiver turns 65.

The results suggest that caregiver assessments would be valuable in identifying those at risk of having their own health decline. These assessments, done by a health care professional, look at the caregiver's health, ability and willingness to do what tasks may be required as well as the caregiver's need for support. The assessment should be done at the same time as an initial diagnosis of dementia is confirmed for the care recipient. And as the care recipient's dementia increases, the family caregiver assessments should be repeated to ensure that the caregiver is getting the support she or he needs.

In considering just general risks to caregiver health, primary care doctors should also be sensitive to whether their middle-aged and older patients are family caregivers. They should be asking "Are you caring for a relative or friend?" as a potential risk factor that may cause stress or even physical strain. One tool that will be helpful for this is the "Caregiver Self-Assessment," a one page tool that can be downloaded from the American Medical Association website or from www.caregiving.org. The doctor can also refer the caregiver to the local Alzheimer's Association chapter or the local area agency on aging for community resources.

Evidence-based caregiver interventions such as the REACH program, along with respite care, would be a good beginning in caregiver support. Those caregivers with fair or poor health are an obvious first target.

This study is not definitive on the extent to which the AD caregiver is more likely than other caregivers or non-caregivers to experience serious health effects of caregiving. It is, however, suggestive of this finding and should be viewed as a call for additional research about the relationship between the type of caregiving and the health care utilization and health outcomes associated with caregiving. To date, health care utilization studies have focused on the care recipient rather than the caregiver. These new findings suggest we need to expand the focus to the family caregiver to obtain a more comprehensive picture of the overall effect of caregiving from both a personal and a societal perspective.



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