



The MetLife Study of Alzheimer's Disease: The Caregiving Experience



MetLife Mature Market Institute®

in conjunction with

LifePlans, Inc.

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The MetLife Mature Market Institute®

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LifePlans, Inc., a risk management and consulting firm, provides data analysis and information to the long-term care insurance industry. The firm works with insurers, the Federal Government, industry groups and other organizations to conduct research that helps these groups monitor their business, understand industry trends, perform effective advocacy, and modify their strategic direction. For more information, contact:

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Executive Summary

Today about 4.5 million Americans are living with Alzheimer's disease.¹ More than two-thirds are at home in the community, being cared for by family and friends. Their illness has an immense impact on their families.

The MetLife Mature Market Institute commissioned research by LifePlans Inc. to find out how families shoulder the burden of Alzheimer's disease (AD)* as compared to physically debilitating illnesses. All care recipients had long-term care insurance policies and were receiving benefits. The researchers analyzed data from interviews with primary caregivers and compared those caring for someone with dementia to those caring for a loved one with physical illnesses only.

The study found that those who were caring for family members with Alzheimer's disease provided more hours of care, experienced greater stress and were more likely to indicate that caregiving had impacted their health than other caregivers. The financial impact of caring for a family member with dementia in the community was also greater. The majority of working caregivers experienced disruption in the workplace regardless of the cause of their family member's need for care, but spouses of family members with Alzheimer's disease were more likely than other spousal caregivers to have had to quit a job because of caregiving responsibilities. Findings also suggest that the presence of long-term care insurance benefits can make a difference in caregiver well-being.

**NOTE: Alzheimer's disease is the most common cause of dementia among older people. Clinical records will sometimes use the broader term dementia as the diagnosis rather than the specific disorder. For the purpose of this report, use of the term Alzheimer's disease (AD) will encompass individuals with Alzheimer's disease as well as other similar dementias.*



Study Highlights

Caregiving Help

- ◆ Alzheimer's disease caregivers provided an average of 47 hours of care weekly, compared to 33 hours by caregivers for physically impaired individuals.
- ◆ Individuals with Alzheimer's disease needed more help with personal care tasks known as Activities of Daily Living (ADLs), more assistance with activities such as transportation, shopping, managing finances and cooking known as Instrumental Activities of Daily Living (IADLs) and more hours of companionship care (including supervision for safety).
- ◆ On average, an individual with Alzheimer's disease had 12.3 limitations (3.8 ADL and 8.5 IADL), compared to 10.7 for the physically impaired (3.3 ADL and 7.4 IADL).

Caregiver Stress

- ◆ Compared to peers caring for people with purely physical impairments, caregivers of persons with Alzheimer's disease experienced more stress on all measures.
- ◆ Caring for someone with Alzheimer's disease added 13.5% to a caregiver's stress.

Caregiver Health

- ◆ While caregivers generally reported that they were in good health, over 32% of Alzheimer's caregivers indicated that their health had gotten worse because of caregiving compared to under 22% of those caring for a physically impaired family member.

- ◆ Individuals caring for a family member with Alzheimer's disease were 45% more likely to report that caregiving had caused their health to worsen than those caring for a family member with a physically disabling condition.

Disruption for Working Caregivers

- ◆ Spouses of individuals with Alzheimer's disease were at the highest risk of quitting work due to caregiving responsibilities — 10.6% had left their jobs to provide care, compared to 4% of the other caregiving spouses.
- ◆ Almost all working family caregivers had rearranged their work schedules. Taking time off without pay to provide care was a common disruption for non-spouse caregivers.

Cost of Care²

- ◆ Caring in the community for someone with Alzheimer's disease cost 31% more overall than caring for a person with serious physical ailments.
- ◆ For an individual with Alzheimer's:
 - Total average cost of services annually, considering paid and unpaid care, was \$77,447, compared to \$59,088 for a person with serious physical problems.
 - On average, services provided by the family caregiver were valued at \$43,066 annually, versus \$30,538 when a person had purely physical disabilities.
 - On average, the cost for paid services annually was \$34,381 versus \$28,550 when a person had physical disabilities.



What We Know about Dementia and Caregiving

Caring for someone with dementia exacts an enormous toll—whether measured by hours of unpaid care given each week, emotional stress, work disruptions, risks to the caregiver’s own health or the cost of formal (paid) care.^{3,4,5} Of the approximately 4.5 million Americans now suffering from Alzheimer’s disease, more than two-thirds live at home, cared for by family and friends. Estimates of the total cost of Alzheimer’s disease in the United States range as high as \$88.3 billion annually (in year 2000 dollars).⁶ Alzheimer’s disease can turn a family’s life upside down as it is families who bear the brunt of care. With the number of persons having Alzheimer’s disease expected to triple by the year 2050, to 13.2 million, vastly more families will find themselves in the caregiving role.⁷

Study Objectives and Methodology

Study Objectives

The objective of this study was to compare the experience of family caregivers caring for loved ones with Alzheimer’s disease to those caring for a family member with a physically disabling condition. Key study questions included:

- ◆ Do the family caregivers for individuals with Alzheimer’s disease differ in their demographic characteristics from those caring for loved ones with physical impairment?
- ◆ How do the needs of the individuals with Alzheimer’s disease differ from those whose disability stems purely from physical problems?
- ◆ What amount and type of care are the family caregivers of loved ones with Alzheimer’s disease providing? Is this different from that given to people with physical disabilities? What factors relate to the amount of care provided?
- ◆ Do the caregivers of individuals with Alzheimer’s disease, as compared to caregivers of those with physical problems, experience more, less or similar levels of stress or social isolation? What factors relate to the stress level reported?
- ◆ If the caregiver is employed, how does caregiving affect work? Is this different when Alzheimer’s disease is in the picture?
- ◆ How does caregiving affect the caregiver’s health?
- ◆ What costs are involved? How does the total community-based economic cost of caring (considering paid and unpaid care) for an individual with Alzheimer’s disease compare with that for a person with physical impairment?



Most long-term care insurance policies pay for services in the home as well as in assisted living or nursing home facilities. Benefits that pay for formal care at home or in a facility allow families to choose how they will blend their efforts with paid services. Since all of the care recipients in this study had long-term care insurance and were receiving benefits, the study also sought to compare where possible the caregiver experience in the presence of insurance with that of family caregivers in the overall population as reported in other studies.

Study Methodology

Researchers analyzed an existing database of information from insured persons and their primary family caregivers.⁸ To create the original database, eight long-term care insurance companies (representing 80% of the market) contributed a sample of claimants, as well as claims information to track formal service usage and costs. Every claimant in that sample (693) was at least 65 years of age, lived in the community and received long-term care insurance benefit payments. All had policies that paid for care at home or in a nursing home. Primary family caregivers were identified for 77% of the sample, and among the caregiver group, 423 (92%) participated in individual 20-30 minute telephone interviews about their caregiving experience. The interviews were conducted by trained clinicians.

Researchers separated the 423 pairs of individuals and their caregivers into two groups based on type of disability. The Alzheimer's disease group had 178 pairs (42%), including some who were coping with both dementia and physical ailments. The other 245 pairs (58%) were dealing with serious physical problems but not dementia. Table 1 shows the total caregiver sample and its subgroups.

Table 1: Family Caregiver Sample

Caregiver/Care Receiver Relationship	Alzheimer's Disease/Other Dementia	Physical Health Problems	Both Groups of Care Receivers
Spousal	91 (51%)	134 (55%)	225 (53%)
Non-Spousal	87 (49%)	111 (45%)	198 (47%)
Total	178 (42%)	245 (58%)	423 (100%)

Claims information from the participating insurance companies provided the means for determining the hours of paid services. The caregiver interviews indicated the hours and type of informal (unpaid) care. The national average hourly rate for paid home care services in the September 2005 *MetLife Market Survey of Nursing Home and Home Care Costs* established the costs per hour used in the cost calculations related to both the informal care provided and the paid services.



Caregiver Characteristics

The caregiver profile across the board was strikingly similar and did not vary by the care recipient's disabling condition.

- ◆ **Care receivers' age:** The average age of care recipients was about 79.
- ◆ **Caregivers' age:** Both sets of caregivers had an average age in the mid-60s. The average age of spousal caregivers was 75, compared to 51 for caregiving children and 60 for other types of unpaid caregivers.
- ◆ **Caregivers' gender:** Almost three-fifths of each caregiver group was female.
- ◆ **Care relationship:** About half of both groups were caring for a spouse, with just over one-third of both groups caring for a parent or parent-in-law.
- ◆ **Family situation:** About four-fifths of each group of caregivers was married. An even higher share, similar in both groups, had children. Typically, for both groups, their children lived nearby (within 25 miles) rather than with them.
- ◆ **Living arrangement:** About two-thirds of both sets of our caregivers lived with the person for whom care was being provided.
- ◆ **Education:** About half of caregivers in each of our groups were college graduates or held higher degrees.
- ◆ **Economic status:** As measured by home ownership, house value and median income, the two groups of caregivers were the same. Their median income category was \$40,000-\$49,000.
- ◆ **Caregiver health:** A slightly smaller share of those caring for an individual with Alzheimer's said their own health was fair or poor (15% versus 22% of caregivers of those with physical problems).

- ◆ **Length of caregiving:** Both groups of caregivers in our study had been providing services for roughly three years, with the Alzheimer's group delivering care a few months more. Of the Alzheimer's caregivers, 71% had provided care one to four years, as had 67% of the other caregivers.

Thus, the profile of our caregivers did not vary significantly based on the reason care was needed. Table 2 below summarizes the two groups.

Table 2: Comparison of Caregivers' Characteristics by Type of Care Recipient Illness

	Alzheimer's Disease/Other Dementia (n=178)	Disabled by Physical Health Problems (n=245)
Mean Age of Care Receiver	79.4 years	78.6 years
Mean Age of Family Caregiver	64.3 years	65.5 years
Caregiver is Female	59.0%	60.4%
Caregiver is Married	79.1%	81.6%
Relationship to Care Receiver:		
Spouse	51.1%	54.7%
Child/Child-in-law	35.4%	34.7%
Other	13.5%	10.6%
Caregiver Has Children:		
Living in the house	85.4%	82.9%
Living within 25 miles	17.0%	19.9%
	62.6%	58.9%
Lives with Care Receiver:	66.6%	67.6%
Caregiver Education:		
College graduate	50.9%	51.2%
Caregiver Health Status:		
Excellent	35.0%	33.0%
Good/Very Good	49.7%	44.9%
Fair	11.3%	19.3%
Poor	4.0%	2.5%
Length of Caregiving	3.0 years	2.75 years



Profile of a Family Caregiver

This profile reflects the characteristics of many caregivers and the individuals they cared for who were part of this study.

Bill, a 75-year-old accountant, has been caring for his wife Ann age 75, who was diagnosed with Alzheimer's disease 3 years earlier. When Ann first got lost driving home from the grocery store, she'd been married to Bill for 46 years. After Alzheimer's disease was diagnosed, Bill promised to care for her at home. Their two daughters, both married, are dedicated to helping him fulfill this promise but worry about the toll this disease is taking. Laurie lives about 25 miles away. Kathy's home is in a neighboring state, about six hours away by car. They all are grateful that long-term care insurance enables them to hire some help for Ann's care and provide some respite for their father who feels he is unable to leave Ann alone. Ann left a pot burning on the stove on one occasion recently. When Bill smelled the burning from another room, he ran into the kitchen and found Ann sitting at the table a few feet from the stove unaware that there was a problem.

Betty, from the local home care agency, comes in for four hours every Monday through Friday to assist Ann. She gets Ann up from bed, helps her bathe and makes sure she puts on the clothes Bill has laid out the night before. Left to her own devices, Ann chooses things that are completely inappropriate for the season and is likely to pull out soiled items from the laundry basket. Bill on most days either heads off to his accounting firm or runs errands. If he has a meeting with a client and can't be back before Betty needs to leave, he arranges for a neighbor to be with Ann until he gets home.

When Bill is home, he sits nearby most of the time, chatting with Ann while he pays bills or handles the mail. Bill puts Ann to bed around 8:00. She has become incontinent so Bill often needs to assist with changing her at night. She usually cooperates with the bedtime routine, but still, Bill hurt his back while helping her.

Bill had no intention of ever retiring but now he's not so sure. He is currently working with just a few long-time clients so he can be with Ann the rest of the time. Kathy and Laurie take turns coming on the weekends to spend time with their mother and help out their father. Laurie's husband does the yard work, something Bill loved to do before he hurt his back helping Ann.

While Bill was at first reluctant to accept services to assist him with Ann's care, he now appreciates the time for himself that having Betty has given him. He is grateful that with Ann's long-term care insurance benefits he has the means to continue with this assistance and increase it if he should need to in the future. He understands that having this assistance and the support of his children are necessary, if he is to be able to continue caring for Ann at home without risking his own health.



Key Findings

Alzheimer's Disease: Better Health But Greater Impairment

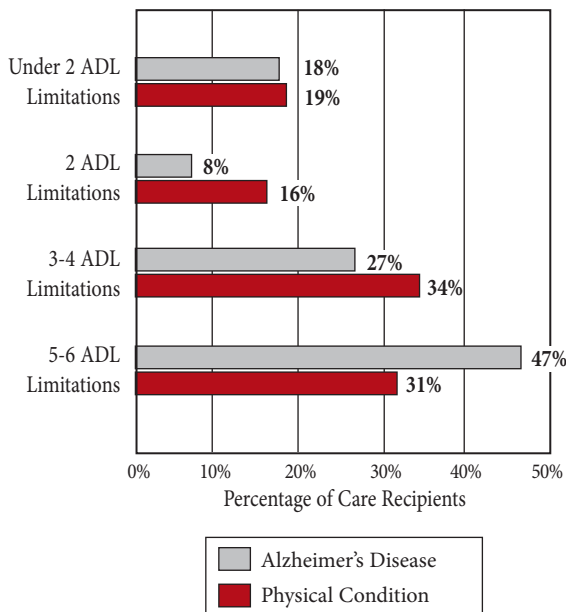
Health

As expected, since all of the care recipients qualified for long-term care insurance benefits, the majority of both groups of people in need of care had poor-to-fair health. However, one significant difference emerged between the two groups: one-sixth (16.7%) of those with Alzheimer's disease or a related disorder enjoyed *excellent* physical health.

Functional Status

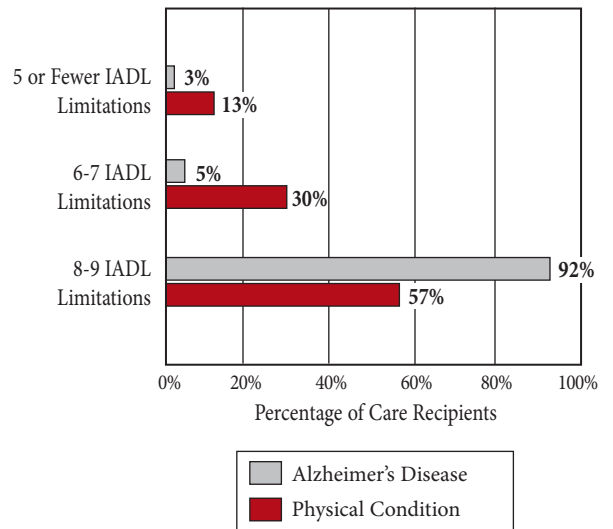
Both groups had heavy care needs, but the Alzheimer's group suffered greater functional impairment than those with physical conditions. They had more limitations in everyday activities such as bathing, dressing, getting up and down, using the bathroom and eating, known as the Activities of Daily Living (ADLs). Figure 1 below shows the number of ADL limitations for each group.

Figure 1: Activities of Daily Living Limitations by Type of Illness



There were also differences between the two groups in their limitations with completing tasks such as preparing meals, managing money, shopping and doing light housekeeping or laundry, known as the Instrumental Activities of Daily Living (IADLs). As Figure 2 below shows, those with Alzheimer's disease averaged more IADL limitations than those with physical conditions.

Figure 2: Instrumental Activities of Daily Living Limitations by Type of Illness



In summary, those with Alzheimer's disease or a similar disorder, on average, had more limitations in both the ADL (3.8 vs. 3.3 for those with physical conditions) and IADL (8.5 vs. 7.4) categories. Combining both categories they averaged 12.3 limitations as compared with 10.7 limitations for those with physical illnesses.



Alzheimer's Caregivers: More Hours For All Types Of Care

Hours of Care

On average, each week a person with Alzheimer's disease received about 47 hours of care from the family caregiver, compared to about 33 hours for an individual with physical problems. Thus, the Alzheimer's caregivers provided an additional 14 hours of care per week, 42% more hours of care than those caring for individuals with physical illnesses.

In the Alzheimer's group of caregivers, 40% delivered more than 40 hours of care weekly, with just 22% providing 9 or fewer hours, while 28% of caregivers for physically disabled persons were giving over 40 hours and another 28% were providing 9 or fewer hours of care weekly.

A key factor, holding all others constant, which impacted the hours of care given was the presence of Alzheimer's disease. As a factor it added 25% to the weekly hours of care. Other important factors contributing to the amount of care being provided were:

- ◆ *Living arrangement:* Caregivers living with the care recipient provided 63% more hours of care each week than did others.
- ◆ *Number of IADL and ADL limitations:* All other things being equal, each additional activity in which the individual had IADL limitations increased the hours of care by 21% and each ADL limitation added 16% to care hours.
- ◆ *Being a female caregiver:* When the caregiver was a woman, 17% more care hours were given each week.

Surprisingly, three factors made no significant difference in how much time the family caregiver spent:

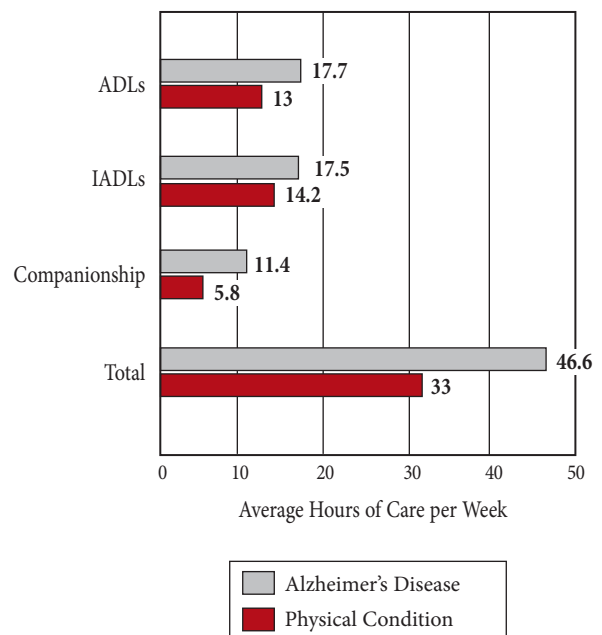
- ◆ *Amount of home care benefit:* A higher dollar amount for covered care did not lower the hours of informal caregiving.

- ◆ *Total hours of paid care each week:* More hours of paid care did not reduce hours of family care. Caregivers during interviews indicated that having long-term care insurance benefits for services at home enabled the family to provide more companionship, nurturing quality of life, rather than spending their time solely to meet basic needs.
- ◆ *Advanced age of caregiver:* Having a caregiver who is age 80 or older did not diminish the number of hours of family care each week.

Type of Care

Individuals obtained help from their caregivers with ADLs and IADLs, as well as companionship care (needed company, including supervision for safety). Those with Alzheimer's disease received more of each type of care. Figure 3 below summarizes the average weekly hours of care provided by informal caregivers to both those with Alzheimer's disease and those with physical illnesses.

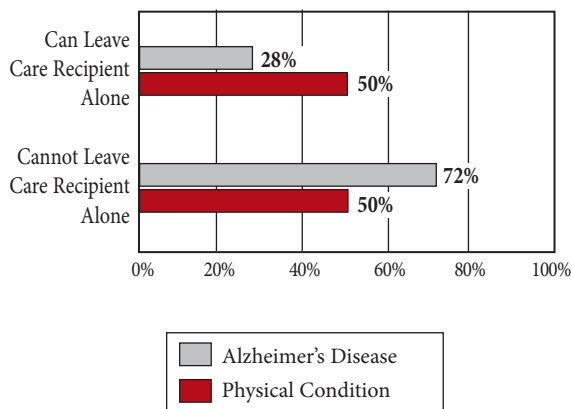
Figure 3: Type and Amount of Informal Care (Weekly) by Type of Illness





Persons with Alzheimer's disease required more help from their caregivers for bathing, continence, eating, managing money, taking medication and changing bandages. Individuals with physical disabilities needed more help with walking indoors. Because of the nature of Alzheimer's disease, supervision to protect the safety of the care recipient was an important consideration. As Figure 4 below shows, those caring for someone with Alzheimer's disease were more likely to report that their family member could not be left alone.

Figure 4: Ability to Leave Individual Alone by Type of Illness



Alzheimer's Care: A Stressful Experience

Providing care to a disabled elderly friend or relative can have profound effects on the caregiver's physical and emotional health.⁹ In this study, when asked, roughly three in five of all caregivers reported that caregiving does bother them at times. While overall the two groups of caregivers were similar in their response to this question, those caring for someone with Alzheimer's disease were more likely to indicate that caregiving bothered them "a great deal" (31% versus 24% of those caring for individuals with a physical illness.)

Stress Indicators

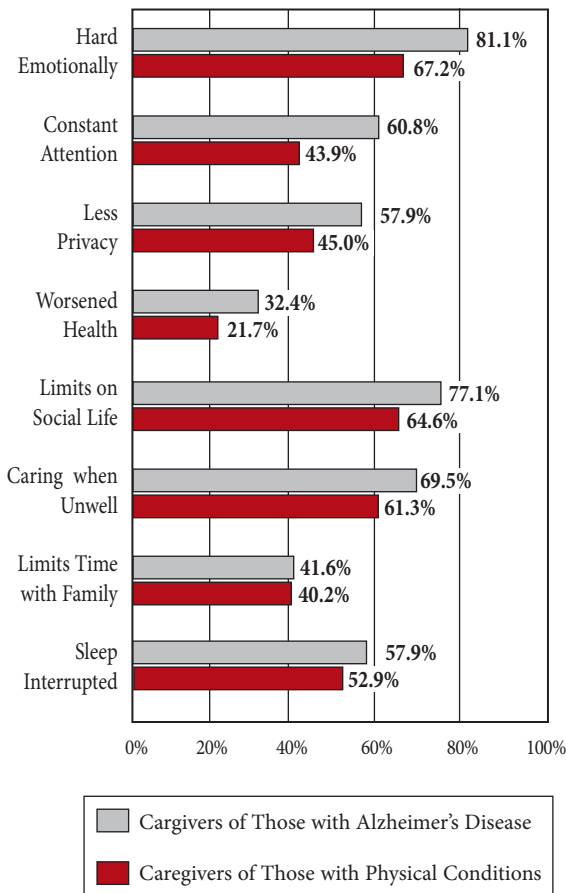
The following areas of potential stress were explored with both groups:

- ◆ Taking care of him/her is hard on me emotionally.
- ◆ I have to give him/her almost my constant attention.
- ◆ I don't have as much privacy when I take care of him/her.
- ◆ Taking care of him/her has caused my health to worsen.
- ◆ Taking care of him/her limits my social life or free time.
- ◆ I have to take care of him/her when I don't feel well enough.
- ◆ Taking care of him/her limits the time I have with my family.
- ◆ Taking care of him/her has caused my sleep at night to be interrupted.

On almost every dimension of stress, significant proportions of both groups of caregivers report that they experience it. Figure 5 on the next page summarizes the experience of both groups of caregivers.



Figure 5: Stress Experienced by Caregivers



As the above chart shows, those caring for someone with Alzheimer's disease more frequently identified each stressor than those caring for individuals with physical disabilities, with the differences being more significant in some areas than others. For example, dementia caregivers are 1.2 times more likely to agree that taking care of the individual is hard on them emotionally, 1.3 times more likely to agree that they do not have as much privacy as they would like, 1.2 times more likely to agree that they have more limits on their social life, and 1.4 times more likely to agree that they have to provide constant attention.

Of particular note is the fact that dementia caregivers are 45% more likely to report that caregiving has caused their health to worsen. In short, while there is significant stress associated with caregiving in general, those caring for individuals with Alzheimer's disease experience greater levels of stress, averaging 4.2 stressors compared to 3.4 for other caregivers.

Alzheimer's Disease: A Key Contributor To Stress

The researchers looked at a number of independent factors and how they affected caregiver stress. The factors, in order of their impact on stress are:

- ◆ *Being a female caregiver:* When the caregiver is a woman, the stress increased by 24%.
- ◆ *Being a spousal caregiver:* Caring for a spouse increased the stress by 20%.
- ◆ *Being a working caregiver:* When the family caregiver also held down a paying job, the stress increased by 15%.
- ◆ *Caring for someone with Alzheimer's disease:* This disability increased the stress by 13.5%.
- ◆ *Number of ADL limitations:* Each additional limitation increased the caregiver's stress by 6%.
- ◆ *Number of hours of care provided weekly:* For every 10 additional hours of care given each week, the stress increased 2%.

Interestingly, having to provide help with more IADLs did not add to the caregiver's stress, nor did the caregiver's age.

Caregiver Health: Impacted By Alzheimer's Disease

As a whole, the caregivers in this study of care recipients with long-term care insurance coverage seem to be a healthy and resilient group of people. Most of them indicated their health was good or excellent (85% of those caring for a family member with Alzheimer's disease



and 78% of those caring for a family member with a physical condition). While the majority did not believe that caregiving caused their health to worsen, those caring for a family member with dementia were more likely to report that caregiving had negatively impacted their health, with over 32% indicating that caregiving “has caused my health to get worse” as compared with under 22% of those caring for a family member with a physically disabling condition.

Alzheimer’s Caregivers: Stretched At Work

Just over one-third of caregivers in this study were currently working for pay. An analysis of spousal and non-spousal caregivers showed:

- ◆ The mean age of working caregivers was 54. Among working caregivers, 17% were spouses, 67% children and 16% others (siblings, neighbors and friends).
- ◆ Caring for a spouse with Alzheimer’s disease increased the risk of having to quit a job. These spousal caregivers were almost 2.5 times as likely as other caregiving spouses to have quit a job to give care.
- ◆ Non-spouses, who tended to be in their early 50s, were more likely than spouses to have turned down a job because of caregiving. Non-spouses caring for someone with Alzheimer’s disease more often reported having done so.
- ◆ Among caregivers employed at the time of the study, about four out of five were experiencing workplace disruptions due to care responsibilities. More of the non-spouses had been forced to take time off without pay. Table 3 provides the details for both spousal and non-spousal caregivers.

Table 3: Workplace Disruptions Experienced by Employed Caregivers*

Caregiver Hours	Spousal Caregiver Caring for a Spouse with Alzheimer’s Disease/Other Dementia		Non-Spousal Caregiver Caring for Family Member with Alzheimer’s Disease/Other Dementia	
	Physical Conditions	Physical Conditions	Physical Conditions	Physical Conditions
Ever take time off without pay from a job because of taking care of him/her	12.5%	29.4%	44.2%	41.4%
Ever rearrange schedule at a job because of taking care of him/her	75.0%	88.9%	88.2%	83.6%
Ever quit a job because of taking care of him/her	10.6%	4.0%	14.0%	15.0%
Ever turn down a job because of taking care of him/her	5.5%	8.3%	20.7%	13.6%

**NOTE: Questions pertaining to taking time off without pay and rearranging schedules were asked only of those caregivers who are currently working. Questions pertaining to quitting a job or turning down a job were asked of all caregivers regardless of employment status.*

Somewhat surprising in this study was the fact that caregivers of those with Alzheimer’s disease or a similar dementia did not, in general, experience more job disruptions than those caring for individuals with physical illnesses. Other studies suggest, that in this area, for most employment-related items, a significantly higher percentage of those caring for individuals with Alzheimer’s disease or another dementia had problems with managing their workforce participation.¹⁰ Given that the care recipients in this study were all receiving long-term care insurance benefits and that the majority



of those in other studies did not have this source of reimbursement for services, the presence of insurance may somehow mitigate the necessity of making workplace accommodations (usually necessary during the day). Caregivers of those with insurance may be able to hire a paid caregiver to compensate for disruptions that could occur during the day.

Cost of Care: Higher For Those With Alzheimer’s Disease

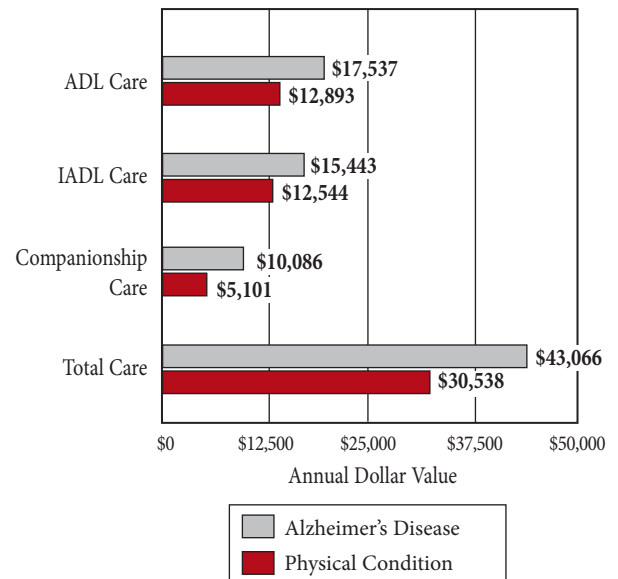
Estimating the total cost of care for a person requiring long-term care, who lives in the community, is difficult. Various studies of the costs of Alzheimer’s disease conclude that the proportion of total costs assumed by family care ranges between 36% and 85%.¹¹ Estimates of annual costs of family caregiving for a person with dementia are equally broad—from \$12,730 to \$57,937 (in year 2000 dollars).¹² These differences stem from different methods for valuing care, focusing on different populations and having incomplete information on paid (formal) and unpaid (family) care.

The presence of long-term care insurance benefits allowed caregivers in this study to establish a balance between family and paid care, in order to meet the needs of their family member. The benefits also made it possible to obtain an estimate of the dollar value of family caregiving for community-based care for individuals with a long-term care illness, when needs are most likely to be met by the combination of family and paid care.

Dollar Value of Family Caregiving

To value family caregiving time, researchers used the “Replacement Cost” approach, i.e., assigning an hourly dollar value based upon the tasks being done by family caregivers and what it would cost to hire someone with the skills to do these tasks if the caregiver did not do them. Based on the September 2005 *MetLife Market Survey of Nursing Home and Home Care Costs*, the “replacement cost” was \$19 per hour (home health aide rate) for a family caregiver providing ADL care and \$17 per hour (homemaker rate) for IADL tasks and companionship care. Figure 6 below compares the annual dollar value of family caregiving for individuals with Alzheimer’s disease and individuals with physically disabling conditions.

Figure 6: Annual Dollar Value of Family Caregiving by Type of Illness



The annual dollar value of family caregiving for an individual with Alzheimer’s disease is approximately \$43,000, about 41% higher than the annual dollar value of family caregiving for an individual with a physical illness. The biggest difference in the dollar value of family caregiving is in the area of companionship care. Over 23% of the total dollar value of



family care provided to individuals with dementia comes from companionship care, as compared with less than 17% of the total dollar value of family caregiving for those with physical illnesses. This finding is consistent with the concerns for the safety of those with Alzheimer's disease and the need for ongoing monitoring, even if it is not necessarily related to specific ADL and IADL limitations.

Paid Care

Paid care costs were also higher for Alzheimer's caregivers than for those caring for individuals with physically disabling conditions. This was shown by using the actual hours of care submitted at the time of claim for the care recipients' benefits under their long-term care insurance policies and calculating costs for the services received based on the September 2005 *MetLife Market Survey of Nursing Home and Home Care Costs*. Paid care costs for a family member with Alzheimer's disease in the community averaged \$34,381 annually versus \$28,550 for a family member with a physically disabling condition.

Total Care Costs

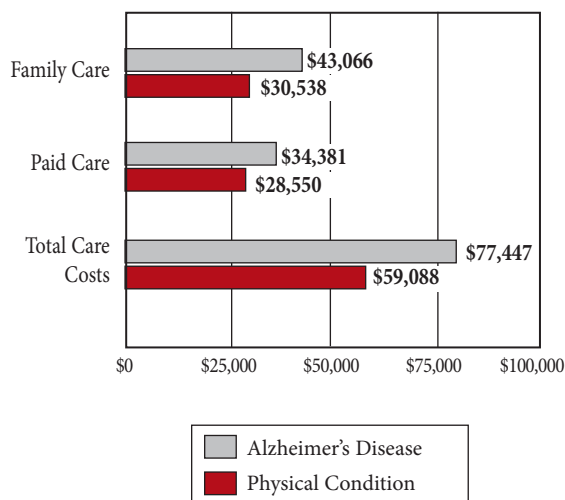
As Figure 7 indicates, the combined cost of formal (paid) care and family care, is substantial. It is clearly expensive to meet the long-term care needs of an individual in the community.

The total annual cost of services to care for a person with Alzheimer's disease in the community (via unpaid and paid services) is \$77,447 (\$43,066 of family care and \$34,381 of paid care). In comparison, the total care cost for someone with physical problems is \$59,088 (\$30,538 of family care and \$28,550 of paid care), making the cost of caring for someone with Alzheimer's disease 31% higher overall.

It is clear from this study that formal care supplements, but does not replace family caregiving. In the case of individuals with Alzheimer's disease, there is a greater percentage of the total care costs (paid and unpaid care) attributed to family caregivers, 56% of the cost compared to 51% for those caring for individuals with a physical illness.

Although family care was a large part of the total caregiving costs for both groups, the costs for paid care were also high. The presence of long-term care insurance allowed family caregivers to supplement the care they gave and have that care reimbursed through their family member's benefits. In most instances, without the presence of long-term care insurance, the care recipient or the caregiver would have had to pay substantial sums out of pocket for these added services.

Figure 7: Total Annual Long-Term Care Costs by Type of Illness





Conclusions and Implications

Family Caregivers: Committed Despite Significant Impact

First and foremost, this study underscores the tremendous efforts of family caregivers of individuals who require long-term care and live in the community. Family caregivers make an important contribution to both their family members and the society at large. Even with the presence of insurance to reimburse formal care, these caregivers are spending many hours each week to keep their loved ones home.

As the study indicates, the replacement value of services provided by family caregivers is significant. Without these efforts many of those being cared for would likely require facility care. Yet, caregiving is not without cost to the caregiver who is often stretched to the limit. This is especially true if that caregiver is providing assistance to a family member with Alzheimer's disease. The impact on the caregiver can be physical, emotional, social and financial.

Alzheimer's Caregivers: Increased Demands and Higher Stress

One might anticipate that the experience of caring for someone with Alzheimer's disease would be difficult in different ways from the experience of caring for someone with a physically disabling illness. The data in this study shows some expected and surprising differences.

The level of both ADL and IADL assistance from family caregivers is higher among individuals with Alzheimer's disease. Family caregivers in this group spend more hours per week providing care than those who are caring for family members with physical illnesses. In this study, researchers determined, holding other factors constant, that caring for someone with Alzheimer's disease serves to increase the weekly hours of care by 25%. The presence of dementia is therefore a key determinant in the amount of family care that is provided.

One would expect that caring for a relative, regardless of whether they have dementia or a physically disabling condition, would create a certain amount of stress. In this study, significant differences occurred in the stress levels of caregivers for those with Alzheimer's disease. These differences related to areas such as caregiver privacy, impact on caregiver health and the ability of the caregiver to have free time or social interactions. The study found, again holding all other factors constant, that caring for someone with Alzheimer's disease increases the overall stress of the caregiver by 13.5%.

Alzheimer's Disease: Higher Caregiving Costs in Time and Money

Despite the demands and stress of caregiving, the caregivers in this study were remarkably healthy and resilient. This study afforded a unique opportunity to gain clarity on the costs of long-term care in the community and to compare the costs of caring for individuals with Alzheimer's disease with the costs of caring for those with physical disabilities. Without question, the costs related to caring for individuals with Alzheimer's disease were higher both in terms of the value of time spent by family caregivers providing ADL, IADL and companion services for their loved ones and in terms of the actual costs for paid services provided to the care recipient.



Working Caregivers: Flexibility and Support Needed

As the study findings indicate, caregiving has a substantial impact in the workplace. A worker, who also is a family caregiver, will likely have to make workplace accommodations to manage caregiving responsibilities. And if care needs become too great, that caregiver may need to leave the workplace altogether or be forced to turn down a position for which he or she is qualified.

Evidence from this study suggests that having resources to pay for formal care, such as those available to care recipients who have long-term care insurance, helps limit workplace disruptions. Knowing their family member is receiving needed care while they are at work may allow these caregivers to stay on the job longer. Findings suggest that this may be especially true for those caring for a family member with dementia. While having resources to cover expenses alleviates disruptions, it does not eliminate them. Caregivers also need flexibility and support from their employers to allow them to balance both work and family responsibilities effectively.

Long-Term Care Insurance: Assisting Both Care Recipients and Their Family Caregivers

The study findings suggest that while the presence of paid care did not reduce the amount of care provided by the family, it may have changed the nature of that care. For those providing care to a family member with Alzheimer's disease, the insurance as a source of payment is especially important. Alzheimer's caregivers provide significantly more companionship care and they are more likely to report that they cannot leave their family member

alone. Safety concerns are paramount with this illness and the presence of benefits to cover paid services allows these caregivers time for themselves without needing to worry about their family member.

Family Caregivers: Valuable Resource with Needs of Their Own

As Americans are living longer the need for long-term care will continue to grow and family caregivers will be an increasingly important resource in the long-term care delivery system. The projected growth in the numbers of people suffering with Alzheimer's disease alone is staggering. It is critical that the needs of family caregivers are identified and supports are made available to them in order to allow them to continue to care for their loved ones and find time to care for themselves as well.



Endnotes

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- ¹² Moore, M., Zhu, C. and Clipp, E. (2001). *Informal Costs of Dementia Care: Estimates from the National Longitudinal Caregiver Study*. *The Gerontologist*, 56B(4), S219-S228.

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