

A report by the  
Alzheimer's Association and  
National Alliance for Caregiving

# Families Care: Alzheimer's Caregiving in the United States 2004



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*Preface*

*Statement of the Alzheimer's Association and the National Alliance for Caregiving*

Families are the heart and soul of the health and long term care system for an estimated 4.5 million people in the United States who have Alzheimer's disease. This report provides new evidence of the overwhelming challenges that Alzheimer caregivers confront day in and day out, as they struggle to meet the needs of their loved ones and to balance the competing demands of caregiving, work, and other family responsibilities.

The data presented here is based on further analysis of a national survey of persons providing unpaid care for relatives and friends, which was conducted in late 2003.<sup>1</sup> We commissioned this additional analysis of the data to look specifically at caregivers of persons age 50 and older who are suffering from Alzheimer's, dementia, or mental confusion and to compare them with caregivers of all other persons in the same age group.<sup>2</sup>

The picture of Alzheimer caregiving that emerges is compelling and demands immediate attention and action from policy makers, providers, and advocates. Three broad and crucial points emerge from the data.

***First: Caregivers of persons with Alzheimer's disease and other dementias shoulder a particularly heavy burden of care. Compared with other caregivers, the type of care they provide is more physically and emotionally demanding and more time-consuming, and it takes a heavier toll on work and family life. But they are not getting the help and support they need.***

Measuring the type of activities performed and the time involved in care, the survey categorizes nearly two-thirds of Alzheimer caregivers (61%) as having the heaviest burdens of care, compared with less than half (46%) of other caregivers.

- 65% of caregivers provide the most difficult kinds of personal care – e.g. bathing, feeding and dealing with incontinence -- tasks that are even harder to do for a person with dementia who may be confused, disoriented, and unable to assist in even these most basic activities of daily living.
- They spend more hours a week providing that care than do other caregivers. Nearly 1 in 4 provide what the survey defines as “constant care” – committing 40 hours a week or more.
- They do so for a long time -- 71% for more than a year and 32% for five years or more.

Like other caregivers, the majority of Alzheimer caregivers work full or part time. But even more than other caregivers, their responsibilities at work are adversely affected by the demands of caregiving. Two thirds of working Alzheimer caregivers reported that they missed work because of their caregiving responsibilities; 14% gave up work entirely or chose early retirement; 13% cut back on their work hours or took a less demanding job; 8% turned down a promotion; 7% lost job benefits. For the caregiver who is trying to balance competing obligations, on family income and the caregiver's own retirement security, and for the employer who bears the cost of reduced productivity there is an adverse affect.

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<sup>1</sup> The results of the original survey, conducted for the National Alliance for Caregiving and AARP, were released in 2004 in a report titled, *Caregiving in the U.S.*

<sup>2</sup> In this paper, the terms “Alzheimer caregiver” and “dementia caregiver” are used interchangeably and inclusively to include all in the survey who reported that they were caring for a person with Alzheimer's, dementia, or mental confusion .

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Caregiving also takes a large personal toll on the dementia caregiver and her/his family: 55% have less time for other family members; 49% give up vacations, hobbies or social activities; 30% get less exercise than before. Over 40% report high levels of emotional stress. One in five dementia caregivers is in fair or poor health and 18% say that caregiving has made their health worse.

These caregivers are not only taking on enormous responsibility at great personal cost, they are doing it without the help and support they need. While many caregivers get help from other family members, only about half use any paid help or supportive services. Three out of four Alzheimer caregivers have unmet needs. One in three say they need time for themselves, help in balancing work and family responsibilities, and help in managing stress, but only 9% use respite services and only 11% participate in support groups.

This is the picture of caregiving that has led the Alzheimer's Association, the National Alliance for Caregiving and other caregiver advocates, and state and federal policy makers to fight for supportive services and financial assistance for family caregivers in general and Alzheimer caregivers specifically. We will continue that fight.

But this is not the whole story. A closer look at the data reveals a more complex picture and suggests the need for a more comprehensive approach to programs and policies designed to support and sustain family caregiving.

***Second: Family relationships change when Alzheimer's strikes and intense caregiving occurs regardless of living arrangements. Adult children are most often the primary caregiver, even when a spouse is present. Most family caregivers do not live with the person for whom they are caring, but they still provide a great deal of care and support, even when their loved one is in a residential care facility.***

This survey reveals how family roles and relationships change as persons age and become frail, and particularly when Alzheimer's strikes. The majority of the caregivers in this survey were caring for a parent, parent-in-law, or grandparent, most of whom were widowed or otherwise single. But even among the 25% of care recipients who were married, the primary caregiver for the person with dementia was more often a child than a spouse. Only 6% of the caregivers in the survey were spouses. This is not surprising, given that the average age of the care recipient was 78. Many of these older persons cannot provide the level of care their spouses need without substantial help from their children.

The survey also shows the extent to which families assume responsibility for care, regardless of their living arrangements. Seven in 10 Alzheimer caregivers report that other family members help with some of the care. While 53% identified themselves as the primary caregiver, less than half were actually living with the person with dementia. In most cases, they were caring for a person who was living in their own home, either alone (22%) or with a spouse (14%), or in a nursing home, assisted living facility or other residential care community (22%).

The data indicate that Alzheimer caregivers spend a lot out-of-pocket, even when the person with dementia is not the caregiver's dependent for tax purposes. Among non-spouse caregivers, nearly half (49%) provided financial assistance averaging \$218 a month.

This picture indicates the need for flexibility in caregiver support programs to meet the particular needs of caregivers and care recipients in a variety of living arrangements and family relationships. It also points out that tax proposals, which would provide important financial help to those caregivers whose loved one is their spouse or dependent for tax purposes, will not reach many of the caregivers who are making significant financial sacrifices, both in out of pocket expenses and reduced earnings, to provide

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care. Other mechanisms – including direct funding of services for both the caregiver and the care recipient -- are needed to provide the assistance and support these families need.

***Third: Alzheimer caregiving is about much more than activities of daily living (ADL). Caregivers face special challenges arising from their loved ones' cognitive impairment, and even more than other caregivers, they are addressing basic health care needs and struggling to negotiate the care system. They are looking for information and help in carrying out these broader responsibilities.***

While caregiver support programs and policies tend to be defined and organized around activities of daily living like bathing, feeding, dressing, and toileting, caregivers report that this is only part – though a demanding and time-consuming part – of what they do. Beyond meeting these ADL needs, they are addressing a host of other care issues themselves, and they are trying to find help for their loved ones from a service delivery system that may not always be responsive to their needs.

Some of the most challenging non-ADL issues are quite unique to dementia care and arise from the impaired memory, cognition, and judgment of a person with dementia. They emerge in this survey as unmet needs. Nearly one-third of Alzheimer caregivers say they need help in managing challenging behaviors, including wandering – a need that is rarely mentioned by the non-dementia caregiver. They also are looking for ideas for easy activities they can do with their loved one in spite of the cognitive impairment.

Many Alzheimer caregivers take on the job of care manager. Though nearly half get by without any paid help or supportive services, Alzheimer caregivers were more likely to use services than non-dementia caregivers. They made more use of transportation services (24% vs. 17%), meals on wheels (18% vs. 12%), and adult day care (16% vs. 2%). Nearly half (43%) reported that they were managing services and 27% have looked for financial help for their loved one. At twice the rate of other caregivers, they say they need help in choosing an assisted living facility, a nursing home, or a home care agency.

Finally, Alzheimer caregivers are dealing with a lot of health care issues, many of which mean negotiating the Medicare system. Their loved ones have chronic co-morbid conditions, in addition to their dementia, that require a lot of management, including heart disease, stroke, mental illness, cancer, and diabetes. Nearly half described their care recipients as “frail” and 40% said they were “disabled.” This adds to the job of caregiving.

- The majority of Alzheimer caregivers (53%) give medicines and injections – a basic health care task for those with chronic disease. This is because over 90% of care recipients are taking prescription drugs, but most of them cannot manage their own medications.
- Half (52%) have made modifications to their loved one's home.
- Half (48%) have obtained assistive devices to accommodate their needs.
- Like other caregivers, they want help in talking to their doctors and other health care providers.
- They also want help in making end-of-life decisions.

These data suggest a critical role for the physician, who needs to recognize the family as the primary care provider and help them in that role. The Alzheimer's Association and the aging network are available to provide information, support and services for Alzheimer families and can address a number of the unmet needs identified in this report. But for most families, the caregiving role begins in the doctor's office or a hospital, when a diagnosis is made or a crisis occurs. At that point, the physician can play a critical role, by assessing the family care environment, identifying the needs of both the patient and the caregiver, and making the connection between the family and the community agencies available to help.

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The Alzheimer’s Association has demonstrated that when the physician takes this proactive role, it has a significant impact on the health and well being of both the person with dementia and the caregiver and can result in less use of hospitals and emergency rooms.

## **Policy Recommendations**

Congress must act on two fronts to address the needs identified in this report.

### First: Expand Direct Caregiver Services and Provide Financial Supports

Congress has put in place a number of programs to assist states and the aging network in developing caregiver support services. They are providing important services to the families they have been able to reach and have helped to raise awareness of caregiver needs, but they are funded at levels that fall far short of their needs. Congress can take immediate steps to build on existing caregiver support programs to address many of the unmet needs identified in this report, by:

- Expanding the highly successful Alzheimer’s Disease Demonstration Grants to the States to support program development in all 50 states, to fill gaps in services to Alzheimer families and to integrate caregiver support into state health and long term care systems
- Increasing funding for the National Family Caregiver Support Program to enhance caregiver support efforts of the aging network
- Expanding respite services and training of respite workers for persons with care needs across the life span.

In addition, Congress should help families deal with the high cost of caregiving and long term care, by enacting a \$3000 caregiver tax credit, improving consumer protections for long term care insurance, and making long term care insurance premiums deductible for all tax payers.

### Second: Build a Caregiver-Centered Health and Long Term Care System

Critical as these more traditional caregiver support programs are, it is time to open a second front to address the much broader and far-reaching challenge of Alzheimer caregiving in the 21<sup>st</sup> century. This will require changes in health and long term care policy and practice, led by changes in Medicare and Medicaid, to put the caregiver and the person with Alzheimer’s at the center of a coordinated care system that is organized to meet the overall needs of both. This would include:

- A requirement and reimbursement for caregiver assessment as a basic component of evaluation and management of persons with dementia and other chronic conditions in Medicare and Medicaid.
- Medicare payment to physicians for training of and ongoing consultation with caregivers of persons with dementia and other chronic diseases and disabilities.
- A targeted chronic care benefit in Medicare, which includes caregiver assessment, training and consultation, to manage beneficiaries with complex medical conditions including dementia and to prevent acute care crises, excess disability, unnecessary hospitalization and premature nursing home placement.

# **Caring for Persons with Alzheimer's: 2004 National Survey**

**Alzheimer's Association  
and  
National Alliance for Caregiving**

**September 2004**

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## I. Introduction

The study reported here provides a view of Alzheimer's caregiving – from the responsibilities involved, to the impacts on unpaid caregivers' lives, to the unmet needs for support and information – all seen through the eyes of family members and friends helping someone 50 or older living with Alzheimer's disease.

Over and over, the study reveals the difficulties and challenges involved in caring for someone with Alzheimer's. Compared to all unpaid caregivers, the spouses, adult children and others helping people with Alzheimer's tend to perform more difficult types of caregiving tasks, commit more time to care, and make considerable sacrifices to help their loved ones. They also face a number of unmet needs, from personal support, to information about basic care, to guidance about getting services.

The following report discusses the needs and experiences of individuals helping care for relatives and friends age 50 and older who have Alzheimer's disease. It is based on a survey of Americans caring for anyone 18 or older, 20% of whom are caring for individuals 50 and older with Alzheimer's, dementia, or other mental confusion. In the report we analyze the answers of the Alzheimer's caregivers, and compare them to people providing care to non-Alzheimer's family members or friends 50 and older.

The definition of caregivers for this study is adults providing unpaid care to relatives or friends 50 and older to help them take care of themselves. Unpaid care may include activities such as helping a grandmother with grocery shopping, driving a neighbor to the doctor, helping prepare meals for a friend, and providing constant care for an aging mother.

## II. Summary of Findings

Caregivers who help someone 50 or older with Alzheimer's carry heavier burdens than other caregivers. They sacrifice their own personal time, hobbies, family time, vacations, careers, and for some, their own health, in order to respond to the challenging and changing demands of caregiving. And they have a host of unmet needs for support and help.

### Demographic profile of Alzheimer's caregivers and recipients

- A typical individual helping someone with Alzheimer's is a woman, 48 years old, married, and employed; has at least some college education; and has no children in the home.

While a majority of Alzheimer's caregivers are women (59%), four in ten (41%) are men.

Fully half of Alzheimer's caregivers are working *full time*.

- Like other caregivers, most Alzheimer's caregivers are helping relatives (87%). The most common caregiving relationship is between a parent and child: 57% of caregivers are helping their mother (36%), mother-in-law (11%), father (8%), or father-in-law (2%).
- The typical Alzheimer's care recipient is 78 years old, a woman, and widowed. A full third of Alzheimer's recipients (35%) are 85 years old and older, compared to 20% of non-Alzheimer's recipients.



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- 23% of caregivers report living with the care recipient. Two in ten (19%) say the recipient lives in a nursing home or an assisted living facility (12% and 7% respectively), whereas the same is true for just 7% of non-Alzheimer’s recipients (4% and 3%).
  - Four in ten Alzheimer’s recipients (42%) live in their own home, either alone (22%), with a spouse (14%) or someone else (7%).

### **The heavy burdens of Alzheimer’s caregiving**

Compared to other care recipients, those with Alzheimer’s tend to be older, frailer, and more likely to be described as disabled. They rely heavily on caregivers for help with the most difficult daily tasks – both on the part of the recipient and caregiver – as well as demand a considerable amount of time from the caregiver.

- Two-thirds of Alzheimer’s caregivers (65%) help with one or more Activities of Daily Living (ADLs), such as getting out of beds and chairs and getting dressed. Alzheimer’s caregivers are considerably more likely than other caregivers to help with the *most difficult* ADLs: dealing with incontinence (32% *v.* 13%), bathing (35% *v.* 25%), and feeding (28% *v.* 18%).
- 23% of Alzheimer’s caregivers provide “constant care,” that is, they commit 40 or more hours per week to caregiving.
- Alzheimer’s caregivers not only carry the heaviest burdens and expend the most time, but they have been providing care for a long time. Seven in ten (71%) have cared for the recipient for more than a year and one third (32%) report a commitment of five years or more (compared to 59% and 27% among other caregivers).
- Half of Alzheimer’s caregivers (53%) are primary caregivers, with 30% providing *all* of the unpaid care and 23% providing *most* of this care.

### **Making personal sacrifices**

Alzheimer’s caregivers expend time, energy, and emotional and financial resources to meet caregiving demands.

- Two-thirds (66%) have sacrificed one or more of the following in order to provide care: time for family and friends (55%); vacations, hobbies, and social activities (49%); or exercise (30%).
- 57% of Alzheimer’s caregivers work full or part time. Two thirds of working caregivers (66%) have missed work because of caregiving responsibilities.
- 20% are in just fair or poor health, and 18% report that caregiving has made their health worse. 12% of other caregivers reporting the same negative impact.
- Not counting those who care for a spouse, 49% of Alzheimer’s caregivers provide financial assistance as well as unpaid care. These caregivers expend an average of \$218 per month for the care recipient.
- On a five point scale where five is a great deal of emotional stress, 41% of Alzheimer’s caregivers rate their stress as a four or five, compared to 31% of all other caregivers.

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## How Alzheimer's caregivers cope

Caregivers cope with their responsibilities through a number of different mechanisms.

- The top coping mechanisms among Alzheimer's caregivers are praying (79%) and talking with friends and relatives (70%).
- Most Alzheimer's caregivers read about caregiving in books and other printed materials (58%), and four in ten (41%) have used the Internet as a way to cope.
- One third of Alzheimer's caregivers (33%) have gone to a professional or spiritual counselor to try to deal with caregiving stress, compared to just 22% of other caregivers.

## Caregivers need more support, information

With all of the heavy burdens, stress, and sacrifices involved in caring for someone with Alzheimer's, it is no surprise these caregivers express a number of unmet needs for information and support – both for themselves and the care recipient.

- Three quarters of Alzheimer's caregivers (74%) report unmet needs. Specifically they need more time for themselves (36%), help managing stress (34%), and information on managing challenging behaviors (31%) – this last need being much more pressing to Alzheimer's caregivers than to other caregivers (only 9% of other caregivers report this need).
- Despite heavy burdens and unmet needs, 47% of Alzheimer's caregivers report having used no paid help in past 12 months.

## III. Methods

The data used for this report come from on a 2003 national telephone survey conducted among 6,139 adults in the U.S. for the National Alliance for Caregiving and AARP. A total of 1,247 unpaid caregivers were interviewed, and results were published in the 2004 report entitled, *Caregiving in the U.S.* This report examines a subset of caregivers: 227 who report helping someone age 50 or older with Alzheimer's, dementia, or other mental confusion.

In the study, caregivers are defined as someone 18 years old or older who has “provided unpaid care to a relative or friend 18 years old or older to help them take care of themselves” in the past 12 months. Additionally, respondents were told: “Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you.” All caregivers included in the study help with one or more Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs). [See table at the end of this section for a full list of ADLs and IADLs].

“Alzheimer's caregivers” as used in this analysis are those who reported caring for someone 50 or older and who reported either a) Alzheimer's, dementia, or confusion is the recipient's “main problem or illness” in an open-ended question, or b) said the recipient suffers from “Alzheimer's or other mental confusion” in response to a closed-ended question.

Alzheimer’s caregivers are frequently compared to non-Alzheimer’s caregivers in this report. For comparison purposes, both of these groups include caregivers of adults who are 50 and older (227 Alzheimer’s caregivers and 749 non-Alzheimer’s caregivers).

This analysis uses an index developed in the original study to represent the intensity of care provided by the caregiver. The Level of Burden index classifies caregivers according to the number of hours they spend giving care, and the number and types ADLs and IADLs they perform. Level One reflects the lowest burden of care, with these caregivers helping with no ADLs and providing less than eight hours of unpaid care per week. Level Five comprises the heaviest burden, with these caregivers performing more than two ADLs and providing “constant care,” that is, more than 40 hours per week to caregiving.

The survey results are weighted by household, based on demographic data (gender, age, race, and household type) obtained from the randomly selected respondent in each household contacted.

The sampling tolerance for Alzheimer’s caregivers is  $\pm 6.5$  percentage points at the 95% confidence level, and  $\pm 3.6$  for non-Alzheimer’s caregivers. Statistically significant differences between Alzheimer’s caregivers and other caregivers are presented in the report text and represented in the graphs with an asterisk (\*).

Activities of Daily Living (ADLs)	Instrumental Activities of Daily Living (IADLs)
Getting in and out of beds and chairs Getting dressed Getting to and from the toilet Bathing or showering Dealing with incontinence or diapers Feeding	Managing medicines, pills, injections Managing finances Grocery shopping Housework Preparing meals Transportation Arranging or supervising services

#### IV. Detailed Findings

##### A. Demographic Profile of Alzheimer’s Caregivers

A typical caregiver helping someone 50 or older with Alzheimer’s, dementia, or other mental confusion<sup>1</sup> is a white woman, 48 years old, married, employed, has at least some college education, and no children or grandchildren in the home.

- Six in ten Alzheimer’s caregivers (59%) are women, and 41% are men.
- The average age of Alzheimer’s caregivers is 48 years old and 46 for non-Alzheimer’s caregivers. Half of Alzheimer’s caregivers (51%) are 50 and older, compared to 41% of other caregivers.

<sup>1</sup> Caregivers of people with Alzheimer’s, dementia, or other mental confusion either reported that Alzheimer’s or dementia is the recipient’s “main problem or illness” in an open-ended question, or reported in another question that the recipient suffers from “Alzheimer’s or other mental confusion.” In the remainder of this report, we refer to this group of caregivers simply as “Alzheimer’s caregivers.”

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- Alzheimer’s caregivers tend to be married (60%); yet 19% are single and 17% are separated or divorced.
  - Nearly four in ten caregivers (39%) helping someone with Alzheimer’s have a college degree. One-quarter (24%) have some college experience, and 37% have a high school diploma or less.
  - 50% of Alzheimer’s caregivers are employed full time. 43% are unemployed, with 20% retired.
  - Alzheimer’s caregiving crosses all income levels, with 49% reporting household incomes of less than \$50,000 per year and 43% making \$50,000 or more.

[See Figures 1 to 6 in the Appendix.]

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**Table 1: Demographic Profile of Those Caring for Individuals 50 Plus**

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	<b>Alzheimer's Caregivers</b>	<b>Non-Alzheimer's Caregivers</b>
<b>Gender</b>		
Male	41%	37%
Female	59	63
<b>Age of caregiver</b>		
Under 35 years old	19%	24%
35-49	29	36*
50-64	37*	30
65 or older	14	11
<i>Mean</i>	<i>48 years</i>	<i>46 years</i>
<b>Marital status</b>		
Married/living with partner	60%	63%
Single, never married	19	19
Separated/divorced	17	12
Widowed	4	6
<b>Educational attainment</b>		
High school or less	37%*	30%
Some college	21	27
Technical school	3	3
College grad	25	25
Grad school	14	15
<b>Current employment</b>		
Employed full-time	50%	48%
Employed part-time	7	11*
Not employed	43	41
<b>Household income</b>		
< \$30K	23%	21%
\$30K-\$50K	26	24
\$50K-\$75K	18	18
\$75K-\$100K	8	10
\$100K+	17	17
<b>Children in HH</b>		
Yes	32%	38%
No	67*	61

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## B. Profile of Alzheimer's Recipients of Care

### **Relationship between caregiver and recipient**

Alzheimer's caregivers, like other caregivers, are mostly caring for members of their family (87%). The most common relationship is between a parent and child: 57% of caregivers are helping their mother (36%), mother-in-law (11%), father (8%), or father-in-law (2%). An additional 16% provide care to a grandparent. Only 6% are caring for a spouse. [See Figure 7 and Table 1.]

Thirteen percent of Alzheimer's caregivers are helping non-relatives.

### **Care recipient demographics**

A typical Alzheimer's care recipient is a woman in her late seventies, who is widowed. [See Figures 8 to 10.]

- 71% of caregivers report helping a woman with Alzheimer's, and 25% assist a man.
- Recipients suffering from Alzheimer's tend to be older than other recipients. The average age of Alzheimer's care recipients is 78, compared to age 73 for non-Alzheimer's recipients age 50 and older. A full third of Alzheimer's recipients (35%) are 85 years old and older, compared to 20% of non-Alzheimer's recipients.
- Just as Alzheimer's recipients are older than other recipients, they are also more likely to be widowed. 58% of Alzheimer's caregivers report their recipient is widowed, compared to 48% of other recipients. 25% are married, compared to 30% of non-Alzheimer's recipients.

### **Living arrangements**

Most Alzheimer's caregivers live in very close proximity to the person for whom they provide care. Nearly one quarter (23%) live in the same household as the care recipient, and 48% say they are within 20 minutes of the recipient. 19% live between 20 minutes and two hours away, and just 10% live farther than two hours away from the person they provide care. [See Figure 11.]

While 23% of Alzheimer's caregivers – the same proportion reported among non-Alzheimer's caregivers – live with the care recipient, distinctions emerge between these groups with living arrangements outside the caregiver's home. [See Figure 12.]

- A plurality of Alzheimer's caregivers (42%) reports the recipient lives in his or her own home, either alone (22%), with a spouse (14%) or someone else (7%). Non-Alzheimer's recipients, however, are more likely to live alone (32%) or with a spouse (19%) in their own home.
- Two in ten report the recipient living in a nursing home or an assisted living facility (12% and 7% respectively), whereas the same is true for just 7% of non-Alzheimer's recipients (4% and 3%).
- 12% of Alzheimer's recipients live in someone else's home, compared to 6% of non-Alzheimer's; and

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- 3% of both Alzheimer’s and non-Alzheimer’s recipients reside in an independent living or retirement community.

### **Health of Alzheimer’s care recipients**

Illness. The presence of Alzheimer’s was assessed in the questionnaire via two questions: 1) an open-ended question probing for the recipient’s *main* illness or problem, and 2) a question asking specifically whether the recipient has Alzheimer’s or other “mental confusion.” Answers regarding Alzheimer’s in both questions were combined to comprise our group of Alzheimer’s caregivers.

A plurality of Alzheimer’s caregivers (31%) report that Alzheimer’s, dementia, or mental confusion is their recipient’s main illness or problem. 14% report old age as the main problem, and 10% say heart disease. [See Figure 13.]

Alzheimer’s caregivers are much more likely than others to describe the person they care for as frail (43% *v.* 28% of others) or disabled (40% *v.* 29%). [See Figure 14.]

Medication management. A large majority of both Alzheimer’s (92%) and other caregivers (91%) report their recipient takes prescription medicine. However, Alzheimer’s caregiving demands much greater oversight in giving and managing medication than caregiving for other recipients.

- Nearly three-quarters of Alzheimer’s caregivers (73%) say their recipient needs help taking or managing prescription medicine, compared to just 32% of non-Alzheimer’s caregivers. [See Figure 15.]
- Just 20% of Alzheimer’s caregivers say the recipients manage medication well on their own, whereas 58% of non-Alzheimer’s caregivers report the same.

### **C. Intensity of Caregiving**

Caregiving for someone with Alzheimer’s is challenging and time-consuming work. These caregivers expend more time providing care and are much more likely than other caregivers to perform the most difficult caregiving tasks involved in day-to-day living.

### **Activities performed**

Activities of Daily Living (ADLs): Personal care. Activities of Daily Living (ADLs) include the following activities: help with getting out of beds and chairs, getting dressed, getting to and from the toilet, bathing or showering, dealing with incontinence, and feeding. Alzheimer’s caregivers provide considerably more help with these difficult tasks than do those helping people without Alzheimer’s. Two thirds of Alzheimer’s caregivers (65%) report helping with one or more ADL, compared with just half (52%) of non-Alzheimer’s caregivers. Additionally, 40% of Alzheimer’s caregivers help with three or more ADLs (*v.* 25%). [See Figure 16.]

Looking at specific ADLs, Alzheimer’s caregivers are more likely than others to help the recipient:

- Get in and out of chairs and beds (46% *v.* 38% of non-Alzheimer’s caregivers);
- Get dressed (44% *v.* 28%);
- Bathe or shower (35% *v.* 25%);
- Get to and from the toilet (33% *v.* 23%);
- Deal with incontinence or diapers (32% *v.* 13%); and
- By feeding him or her (28% *v.* 18%). [See Figure 17.]

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Instrumental Activities of Daily Living (IADLs): Managing everyday living. Instrumental Activities of Daily Living (IADLs) include helping with transportation, grocery shopping, housework, managing finances, giving medicines, preparing meals, and arranging or supervising services. Virtually all Alzheimer’s caregivers (98%) and other caregivers (100%) help with at least one IADL, and eight in ten of both Alzheimer’s caregivers (80%) and non-Alzheimer’s caregivers (82%) assist with three or more IADLs.

While Alzheimer’s caregivers are more likely to help with a number of ADLs, they are no more likely to help with a number of IADLs than non-Alzheimer’s caregivers. Specifically, Alzheimer’s caregivers provide help with:

- Providing or arranging transportation (82% *v.* 83%);
- Grocery shopping (70% *v.* 80%);
- Managing finances (63% *v.* 62%);
- Housework (62% *v.* 72%);
- Preparing meals (56% *v.* 60%);
- Giving medicines, pills, or injections (53% *v.* 41%); and
- Arranging or supervising services from an agency (43% *v.* 30%). [See Figure 18.]

### **Frequency of visits and hours of care**

Both Alzheimer’s and other caregivers frequently visit their recipients. 23% of both live with the recipient, and roughly six in ten (61% of Alzheimer’s and 57% of others) visit their recipient once a week or more. Only 6% of Alzheimer’s caregivers and 8% of other caregivers report visiting the recipient a few times a year or less often. [See Figure 19.]

Half of Alzheimer’s caregivers (52%) report spending more than eight hours per week providing care. Compared to 16% of non-Alzheimer’s caregivers, 23% of Alzheimer’s caregivers spend 40 or more hours in a typical week, providing “constant care.” [See Figure 20.]

In addition to making a considerable time commitment to caregiving each week, Alzheimer’s caregivers have been doing this work for longer periods of time than others. Fully seven in ten (71%) have been providing care for more than a year to their recipient, compared to 59% of other caregivers. [See Figure 21.]

### **Level of Burden**

To give a sense of the burden caregivers have in helping recipients, we created the Level of Burden index, derived from the amount of time caregivers spend per week providing care, and the number and types of activities performed for the care recipient. The Level of Burden index classifies caregivers into one of five levels. Each successive level involves a higher degree of caregiving responsibility or demand. “Level One” caregivers perform no ADLs, and devote relatively few hours per week providing care. “Level Five” caregivers reflect those with the heaviest burdens; they help with at least two ADLs and provide 40 or more hours per week of care.

Alzheimer’s caregivers shoulder a heavier burden than other caregivers. [See Figure 22.]

- 61% of Alzheimer’s caregivers fall into Levels Three, Four, or Five, compared to 46% of other caregivers.
- While slightly more than one third of Alzheimer’s caregivers (35%) are in Levels One and Two, fully half of other caregivers (51%) fall into these lower categories of burden.



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## Home modifications and assistive devices

Modifying the home and obtaining assistive devices are two ways to make giving care easier on the caregiver as well as make life safer for the recipient. Slightly more than half of Alzheimer’s caregivers (52%) have made modifications in the home of the recipient, compared to 39% of other caregivers. Obtaining assistive devices, such as a bathing bench and a magnifying glass, is also somewhat common among Alzheimer’s caregivers (48%) and others (46%). [See Figure 23.]

## D. Caregiver Support

### Unpaid help

Fifty-three percent of Alzheimer’s caregivers act as primary caregivers – that is, either they are the sole provider of unpaid care for the person they help (30%) or they consider themselves as providing *most* of the unpaid help (23%). Similar proportions of other caregivers find themselves in these roles. [See Figure 24.]

Among Alzheimer’s caregivers reporting some type of other unpaid care (69%), most report help from the recipient’s relatives, primarily a daughter (48%) or son (31%). 10% of these caregivers report help from the recipient’s spouse. [See Figure 25.]

### Paid care

Perhaps because of the higher demands and burdens involved, Alzheimer’s caregivers are more likely to report some type of paid care in the last 12 months: 53% of those whose recipient is not in a nursing home report paid care, compared to 41% of other caregivers.

Specifically, Alzheimer’s caregivers report help from:

- An aide or nurses hired through an agency or service (36%);
- A housekeeper hired to clean or cook (24%);
- An aide or nurse hired independently – that is, not through an agency or service (13%); and
- Other people who are paid to help the recipient (19%). [See Figure 26.]

## E. The Strain and Stress of Caregiving

### Impact of caregiving on physical and emotional health

Most Alzheimer’s caregivers say they are in good health. In fact, eight in ten describe their health as excellent (25%), very good (32%), or good (23%). 20% considers their health fair (13%) or poor (7%). These proportions do not differ significantly among non-Alzheimer’s caregivers. [See Figure 27.]

Nearly three quarters of Alzheimer’s (73%) and other caregivers (77%) say caring for their recipient has had no affect on their own health, but 18% of Alzheimer’s caregivers perceive a link between caregiving responsibilities and a decline in their own health, compared to 12% of non-Alzheimer’s caregivers. [See Figure 28.]

Caregiving appears to take a larger toll on emotional health than one’s physical well being, especially for Alzheimer’s caregivers. On a scale of one to five, with five being “very emotionally

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stressful” and one being “not at all stressful,” 41% of Alzheimer’s caregivers rate their situation as a four or five, compared to 31% of other caregivers. [See Figure 29.] Only half as many (22%) say caregiving is a physical strain, rating it a four or five on a similar scale. Non-Alzheimer’s caregivers are less likely to rate their situation as a four or five (13%). [See Figure 30.]

### **Impact of caregiving on family and leisure activities**

Caregiving also exacts a price in time for oneself and others. Two thirds of Alzheimer’s caregivers (66%) report one or more of the following effects of caregiving:

- Having less time for family or friends (55%);
- Having to give up vacations, hobbies, or social activities (49%); and
- Getting less exercise (30%).

These impacts of caregiving do not differ between Alzheimer’s and non-Alzheimer’s caregiving. [See Figure 31.]

### **Impact of caregiving on work**

For those who are working or have worked at some time while providing care (74% total), caregiving demands affect both the employed and the employer. A majority of these caregivers (70%) says caregiving has interfered in one way or another with their job:

- Going in late, leaving early, or taking time off during the day to provide care (66%);
- Taking a leave of absence (18%);
- Going from working full time to part time, or taken a less demanding job (13%);
- Giving up work entirely (8%);
- Turning down a promotion (8%);
- Losing job benefits (7%); and
- Choosing early retirement (6%).

Non-Alzheimer’s caregivers report similar effects on work life, although they are slightly less likely to say they have had to go into work late, leave early, or take time off during the day (57%) and only 2% have chosen early retirement. [See Figure 32.]

### **Financial hardship**

Not counting Alzheimer’s caregivers who care for their spouse, 49% provide some financial assistance to the care recipient. These caregivers spend an average of \$218 in a typical month on the recipient’s care.

However, the majority of Alzheimer’s caregivers say they feel little or no financial hardship as a result of providing care. On a scale of one to five, where five means “very much a financial hardship,” 64% rate their situation a one and another 10% rate it a two. [See Figure 33.]

## **F. Coping with Stress**

Just as Alzheimer’s caregivers are more likely than others to report a great deal of emotional stress, they are also more likely to use a number of coping strategies to deal with this stress. [See Figure 34.] The most common coping mechanisms are praying (79% of Alzheimer’s caregivers *v.* 70% of non-Alzheimer’s caregivers), and talking with friends or relatives (70% *v.* 58%).

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Fifty-eight percent of Alzheimer's caregivers cope by reading about caregiving in books or other materials, and 41% use the Internet to find information or support. Other caregivers are less likely to do each of these: 42% read about caregiving in books and 34% have gone online. Among Alzheimer's caregivers who use the Internet, 87% have sought information about the recipient's condition and treatment, 53% looked for information about services for the recipient, and 46% searched for support or advice from people with similar caregiving experiences.

Alzheimer's caregivers are also more likely than their counterparts to have gone to a professional or spiritual counselor about their caregiving situation. One third of Alzheimer's caregivers (33%) have done so to cope, as have just 22% of other caregivers.

Similar proportions of Alzheimer's and non-Alzheimer's caregivers cope through exercise (44% and 42% respectively) and by taking medication (12% and 10%).

### **G. Use of Supportive Services**

Given the heavier burdens placed on Alzheimer's caregivers, it is not surprising that 56% have used one or more supportive services compared to 45% of non-Alzheimer's caregivers. Yet 44% of those helping someone with Alzheimer's have not used any support services.

Alzheimer's caregivers are more likely than others to have used each type of supportive service tested in the survey:

- Requested information about how to get financial help for the care recipient (27% *v.* 21% of other caregivers);
- Had an outside service provide transportation for the person they help (24% *v.* 17%);
- Had an outside service such as Meals on Wheels deliver meals to the care recipient (18% *v.* 12%);
- Enrolled the recipient in Adult Day Care (16% *v.* 2%);
- Enrolled the recipient in a recreation program or camp (12% *v.* 6%);
- Took part in support groups for caregivers (11% *v.* 6%); and
- Used a respite service to take care of the recipient in order to free up time (9% *v.* 5%). [See Figure 35.]

### **H. Unmet Needs for Help, Information, and Support**

We asked caregivers if they need more help or information about fourteen issues that caregivers commonly face. [See Figure 36.] Three quarters of Alzheimer's caregivers (74%) and 70% of other caregivers report one or more unmet needs in these areas.

Roughly the same numbers of Alzheimer's and other caregivers report unmet needs both in terms of dealing personally with caregiving stress or help with basic care issues.

#### **Personal support**

- Finding time for themselves (36% of Alzheimer's and other caregivers);
- Managing emotional and physical stress (34% of Alzheimer's caregivers *v.* 30% of others); and
- Balancing work and family responsibilities (30% *v.* 31%).

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### Basic care issues

- Easy activities to do with the person they care for (35% of Alzheimer’s caregivers *v.* 28% of others);
- Keeping the recipient safe at home (34% *v.* 35% of non-Alzheimer’s caregivers);
- Making end-of-life decisions (26% *v.* 21%);
- How to talk with doctors and other healthcare professionals (23% *v.* 25%);
- Moving or lifting the recipient (23% *v.* 17%);
- Managing incontinence or toileting problems (17% *v.* 11%); and
- Finding non-English language materials (5% *v.* 9%).

However, Alzheimer’s caregivers register considerably more need in two areas:

- Managing challenging behaviors, such as wandering (31% of Alzheimer’s caregivers *v.* 9% of others); and
- Choosing a home care agency (22% *v.* 14%), an assisted living facility (22% *v.* 11%), or a nursing home (14% *v.* 7%).

### I. Where Caregivers Would Turn for Help and Information

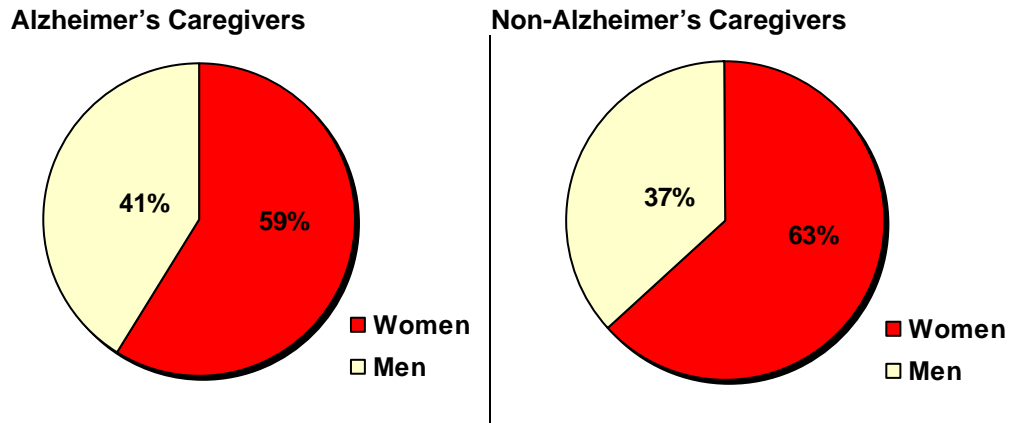
When asked where they would turn for help, Alzheimer’s caregivers say they would reach out to:

- The Internet (31%);
- Doctors (26%);
- Other health professionals (12%);
- A family or friend (9%);
- Books, magazines, or the library (7%);
- A government agency (7%);
- A senior citizen’s center (7%); and
- An aging association, group, or organization (6%).

Other caregivers respond similarly, with the exception that they are more likely to turn to family and friends (15%) and less likely to go to an aging association, group, or organization for help (1%). [See Figure 37.]

## **APPENDIX: Graphs**

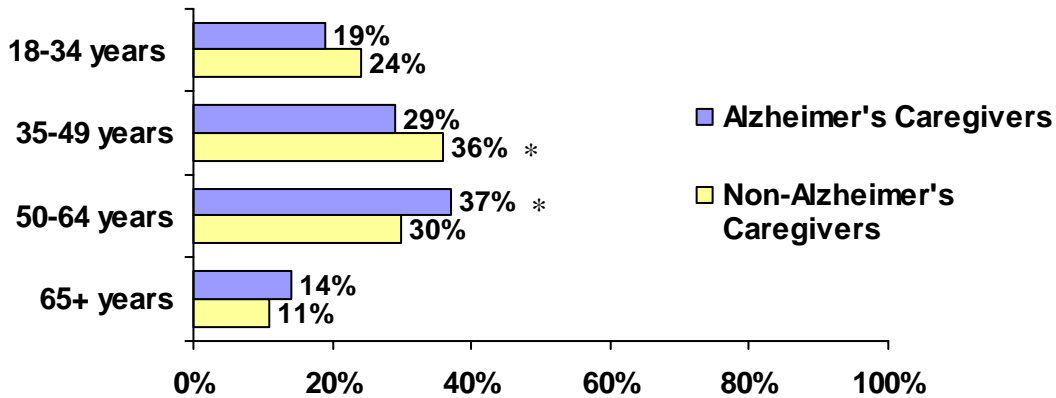
**Figure 1: Caregiver Gender**



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 2: Age of Caregivers**

Q. Just to be sure I speak to people of all ages, how old were you on your last birthday?

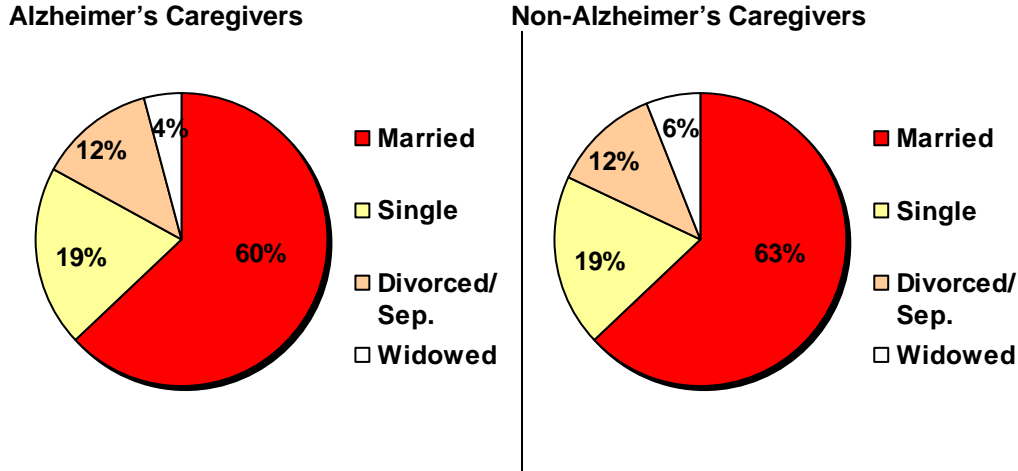


Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

\* Asterisks throughout the appendix indicate statistically significant differences at the 90% or 95% level.

**Figure 3: Marital Status of Caregivers**

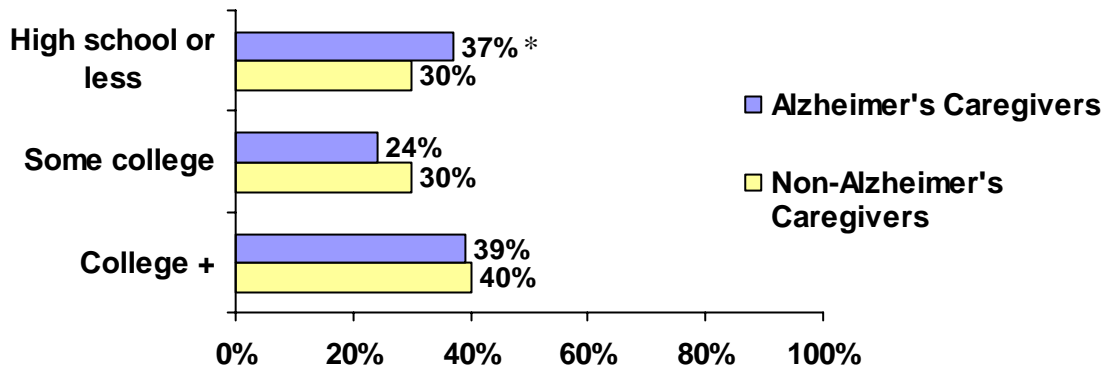
Q89. Are you currently: married, living with a partner, widowed, separated, divorced, or single, that is, never been married?



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 4: Caregivers' Education**

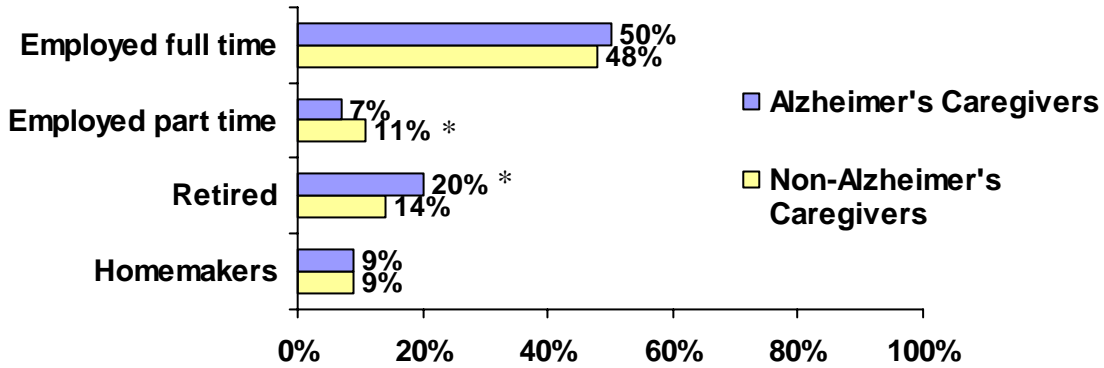
Q94. What is the last grade of school you completed?



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 5: Caregivers' Employment Status**

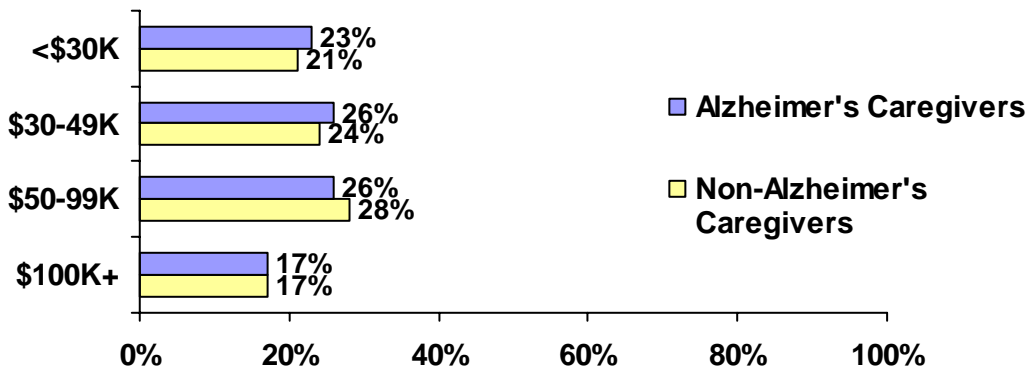
Q39. Now I have a few questions about you. Are you currently working full time, working part time, a student, disabled, retired, a homemaker, unemployed and looking for work, or something else?



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 6: Caregivers' Household Income**

Q95. Last year, what was your total annual household income from all sources, before taxes?



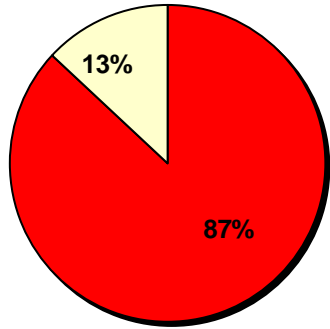
Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.



## Figure 7: Relationship between Caregiver and Care Recipient

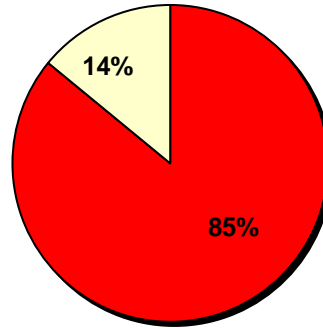
Q1b. What [is/was] this person's relationship to you?

**Alzheimer's Caregivers**



■ Relatives □ Non-relatives

**Non-Alzheimer's Caregivers**



■ Relatives □ Non-relatives

Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

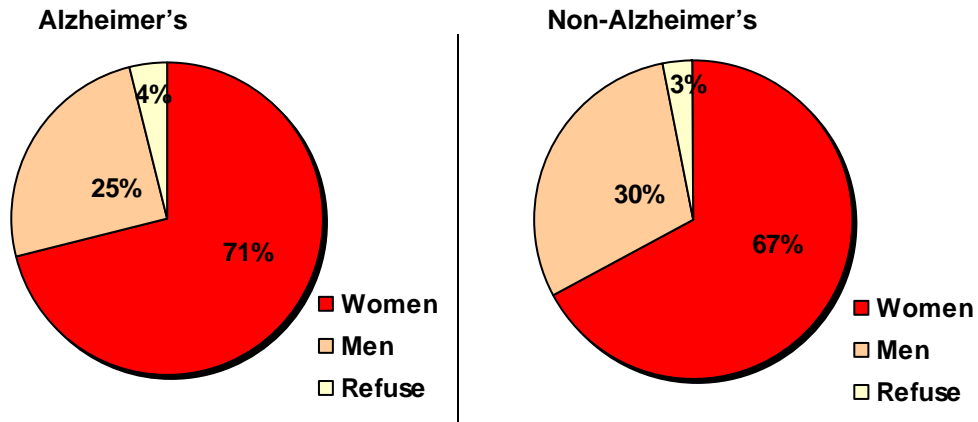
### Table 1: Relationship of Care Recipient (Top Mentions)

Q1b. What [is/was] this person's relationship to you?

	Alzheimer's Caregivers	Non-Alzheimer's Caregivers
Relatives (Net)	87%	85%
Mother	36%	35%
Grandmother	11%	10%
Father	8%	11%
Mother in law	11%*	6%
Spouse	6%	6%
Father in law	2%	2%
Sibling	*	4%*
Daughter/Son	*	1%
Non-relative (Net)	13%	14%

Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

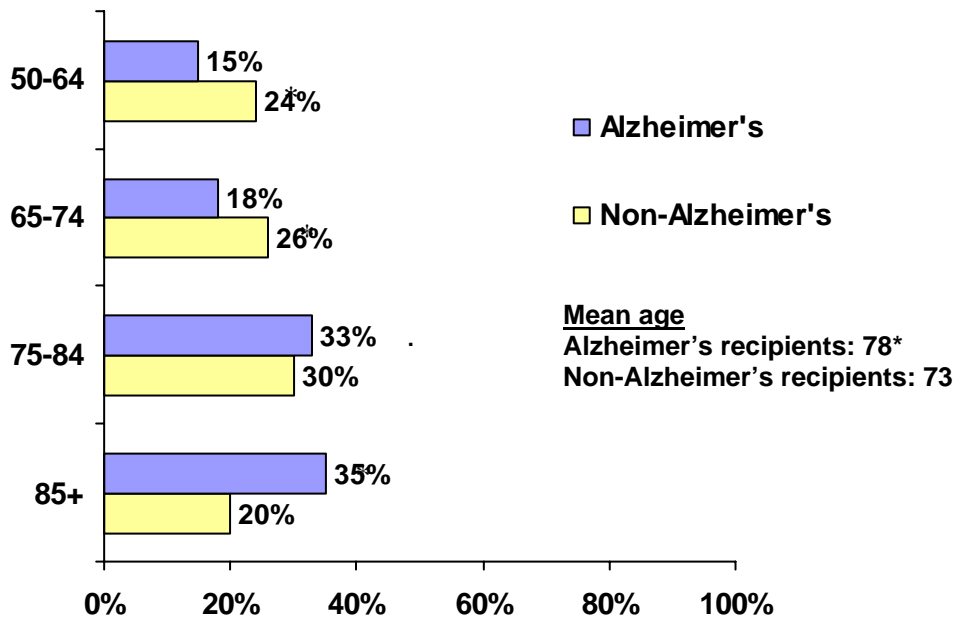
**Figure 8: Care Recipient Gender**



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 9: Age of Care Recipient**

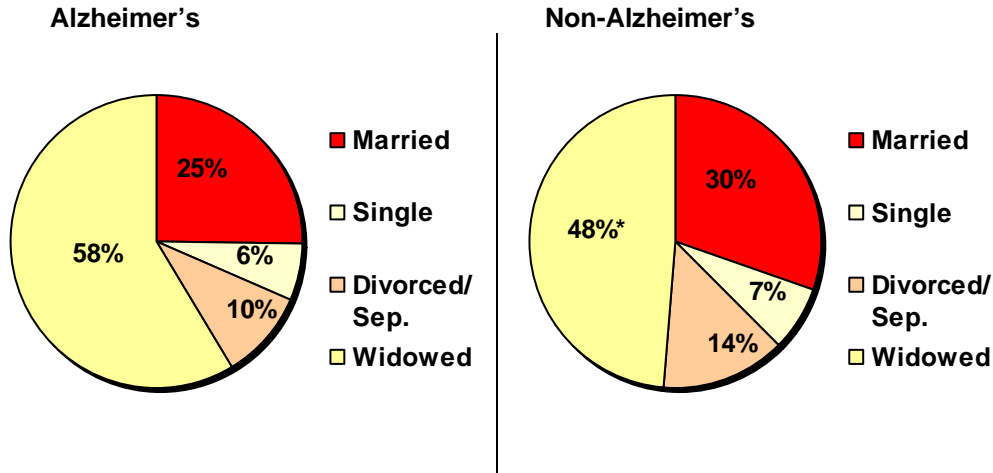
Q3. How old [is/was] your (care recipient)? PROMPT: Your best estimate is fine.



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 10: Marital Status of Care Recipients**

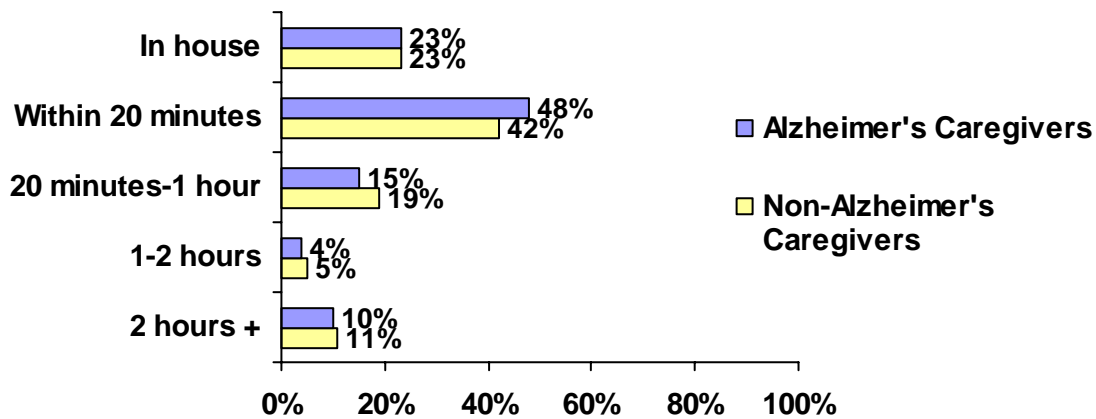
Q2. [Is your (care recipient) currently/Was your (care recipient)] widowed, married, living with a partner, separated, divorced, or single - that is never been married?



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 11: Distance of Caregiver to Recipient**

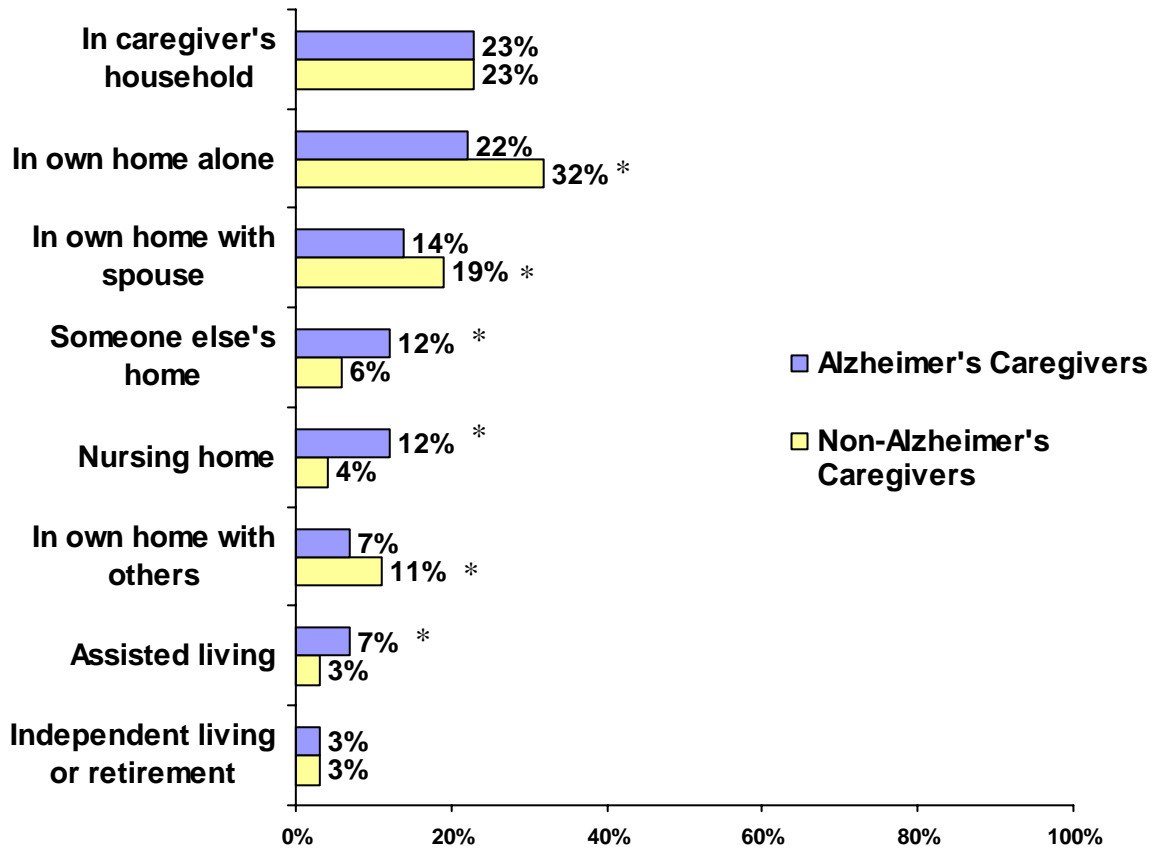
Q4. [Does/Did] your (care recipient) live in your household, within twenty minutes of your home, between 20 minutes and an hour from your home, a one to two hour drive from your home, or more than two hours away?



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 12: Living Arrangements of Care Recipient**

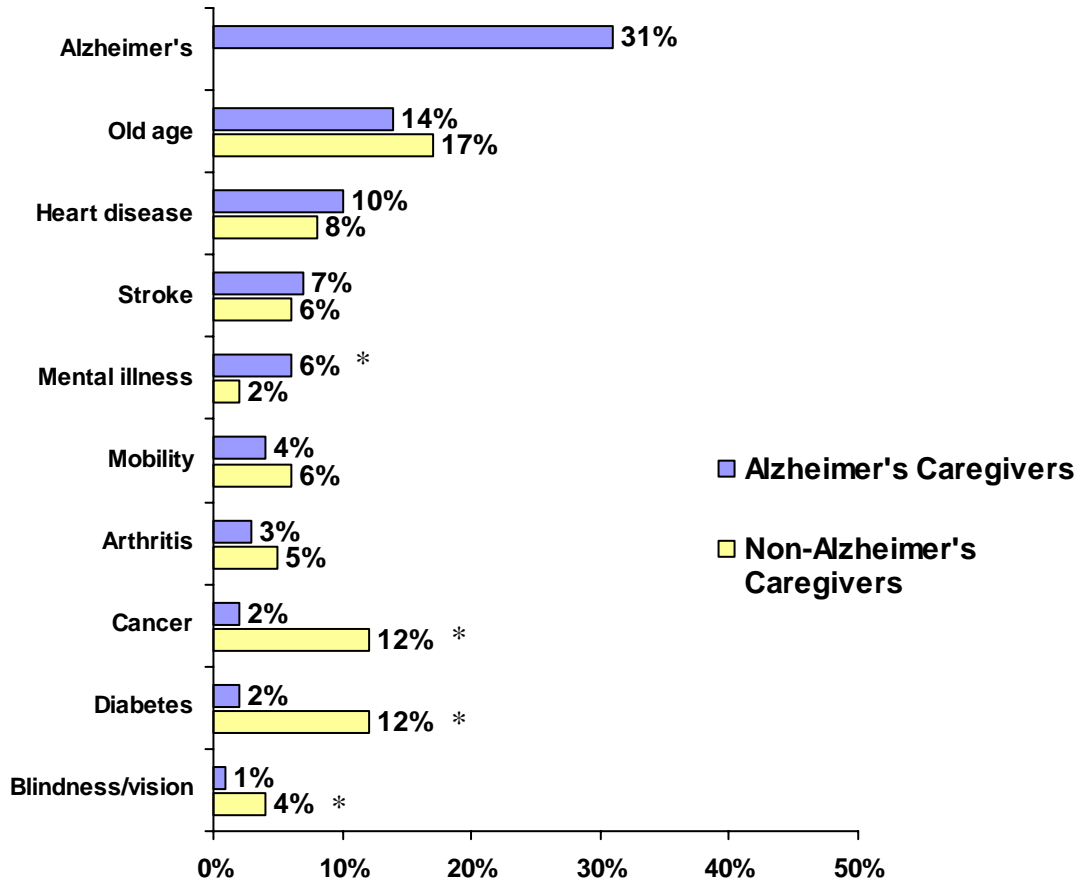
Q4. [Does/Did] your (care recipient) live in your household, within twenty minutes of your home, between 20 minutes and an hour from your home, a one to two hour drive from your home, or more than two hours away? Q6. IF NOT IN HH/DK/REF IN Q4: [Does/Did] your (care recipient) live in: his or her own home, someone else's home, an independent living or retirement community, in an assisted living facility where some care may be provided, a nursing home or facility, somewhere else?



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 13: Main Problems or Illnesses Identified by Caregiver**

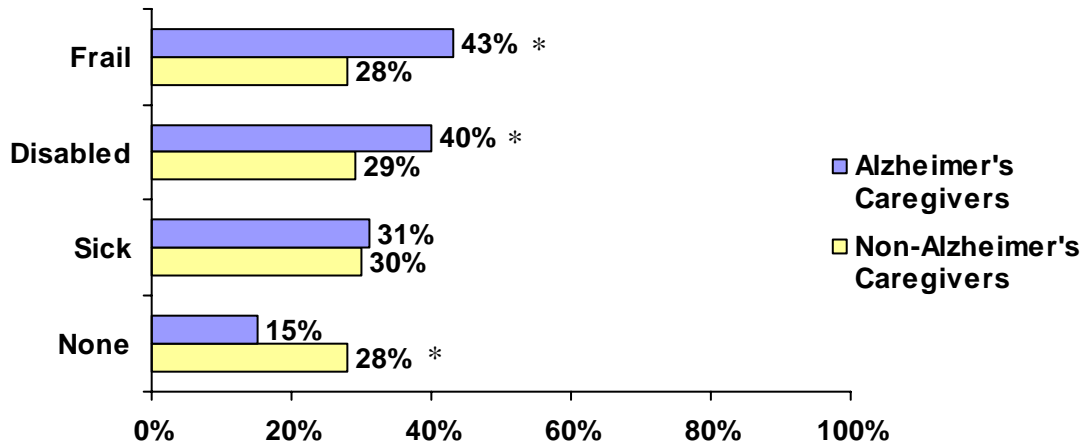
Q11b. What would you say [is/was] the main problem or illness your (care recipient) [has/had]?



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 14: Perception of Frail, Sick, Disabled**

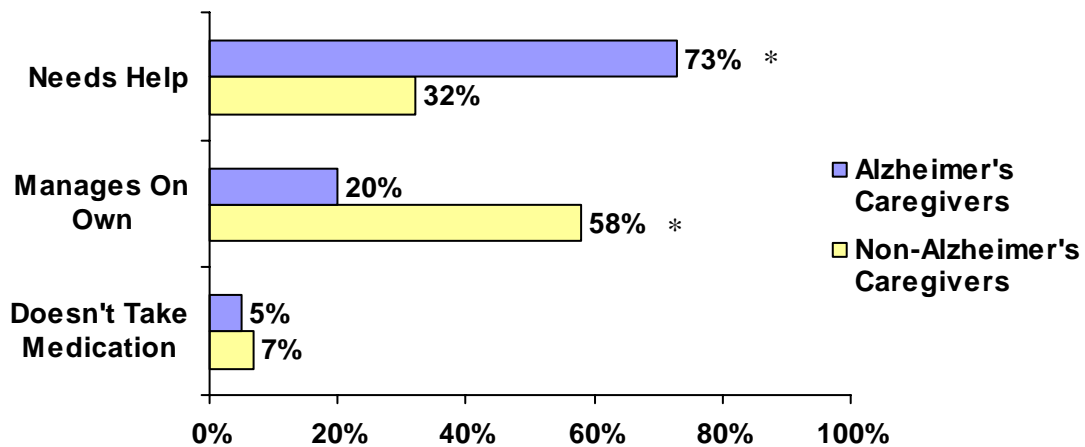
Q10. [Is/Was] your (care recipient) frail, sick, disabled, or none of these?



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

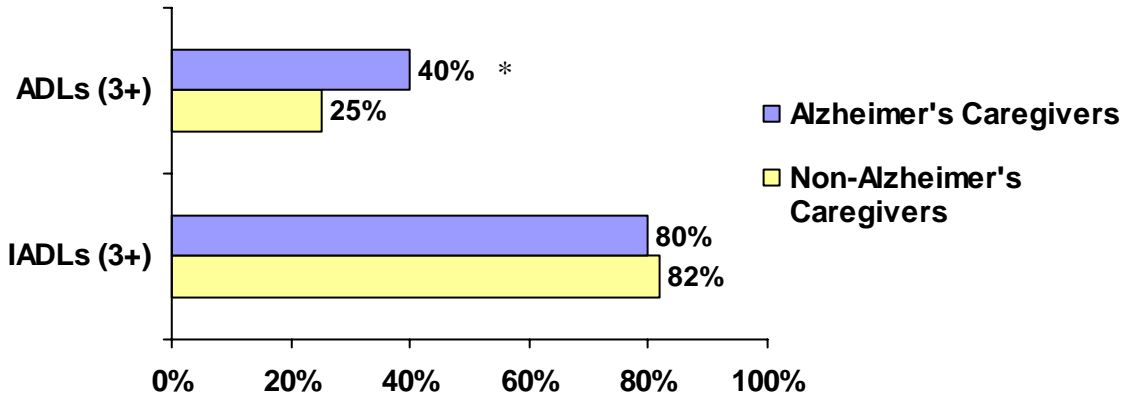
**Figure 15: Medication Management**

Q28. [Does/Did] your (care recipient) take any prescription medicine? IF YES: Q29. Would you say your [care recipient] [needs/needed] someone to oversee giving him/her medicine in the right amount and on time, or that he/she [manages/had managed] this well on his/her own?



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 16: Helps with Three or More Activities**

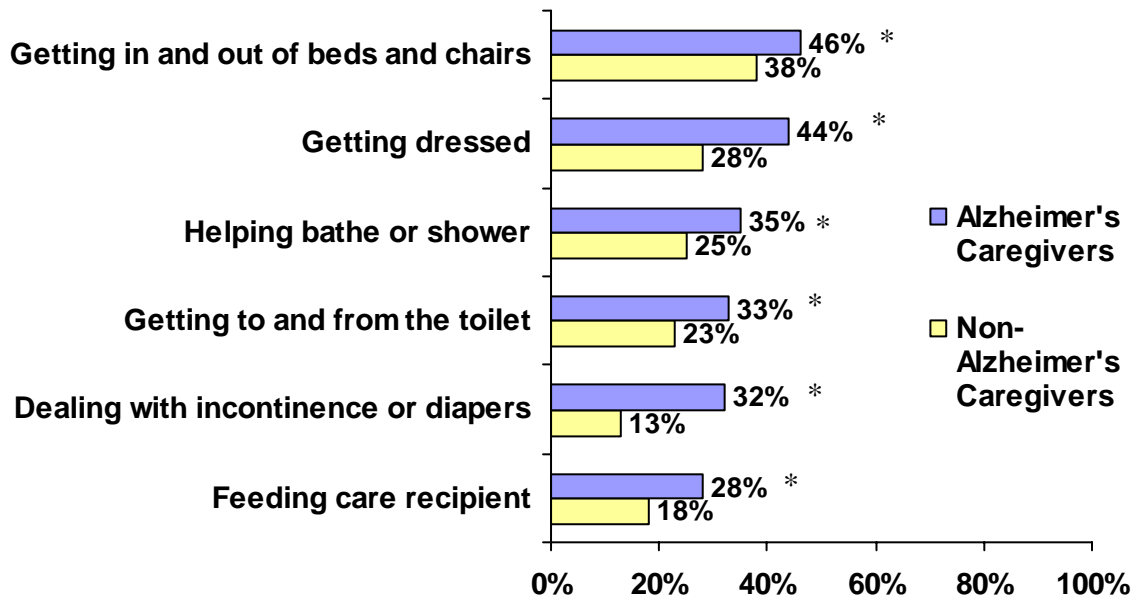


Base:

227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 17: Helping with ADLs**

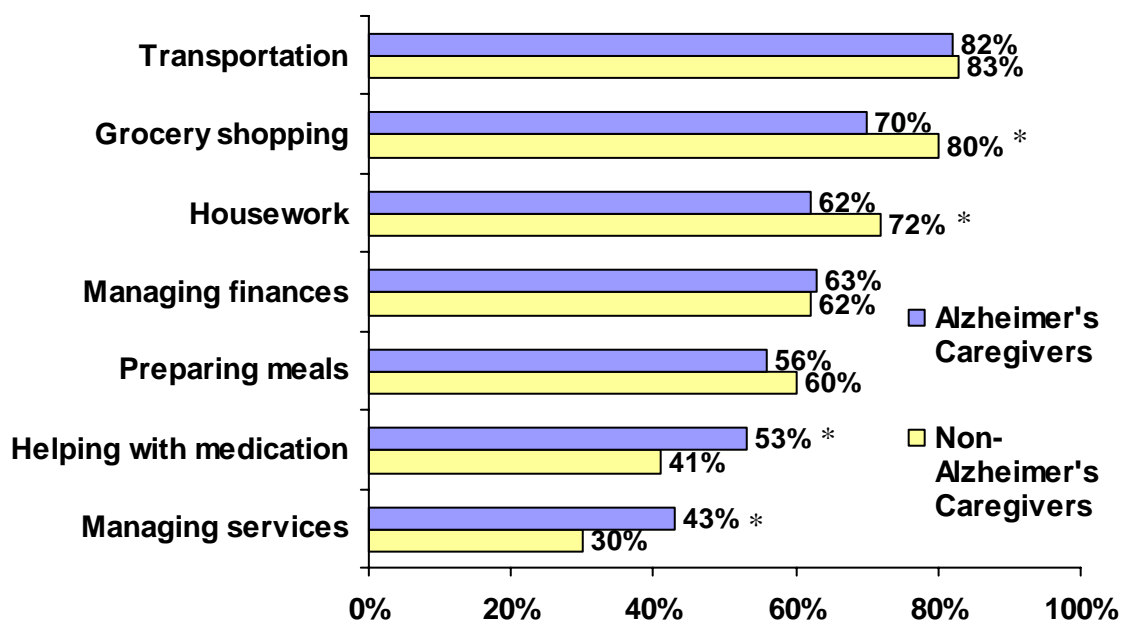
Q14-19. I'm going to read a list of kinds of help, which might be provided to a person, if the person cannot do this by him or herself. For each, just tell me if you [provide/provided] this kind of help. [Do/Did] you help your (care recipient)...



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 18: Helping with IADLs**

Q20-26. [Do/Did] you provide help for your (care recipient) with:

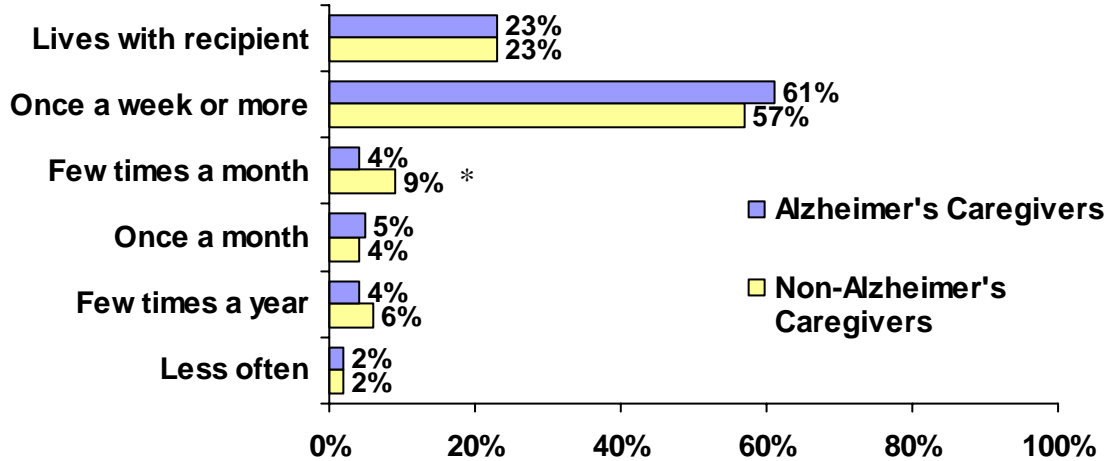


Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.



**Figure 19: Number of Visits to Care Recipient**

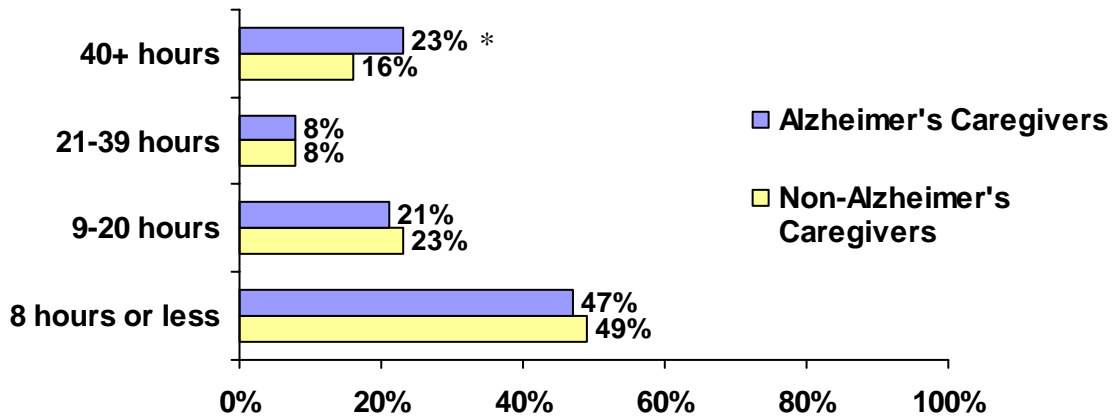
Q5. IF NOT IN HOUSEHOLD: On average, how often [do/did] you visit your (care recipient)? More than once a week, once a week, few times a month, once a month, few times a year, or less often?



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 20: Hours of Care Provided Per Week**

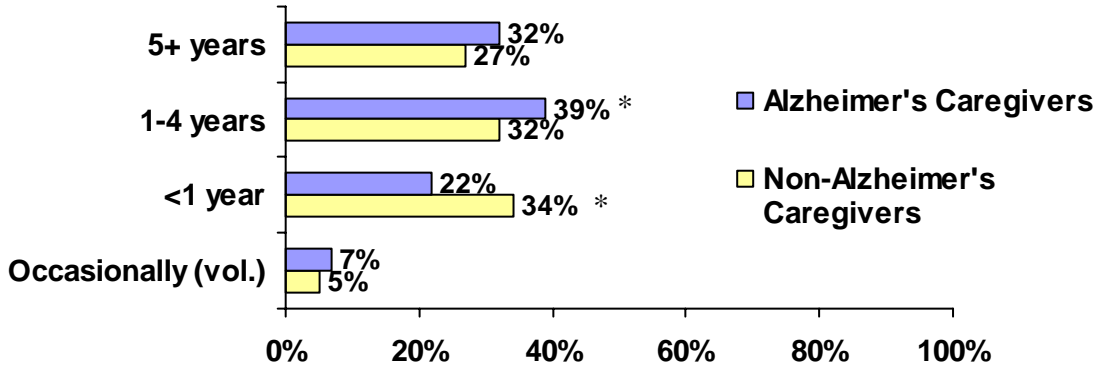
Q27. Thinking now of all the kinds of help you [provide/provided] for your (care recipient), about how many hours [do/did] you spend in an average week, doing these things?



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

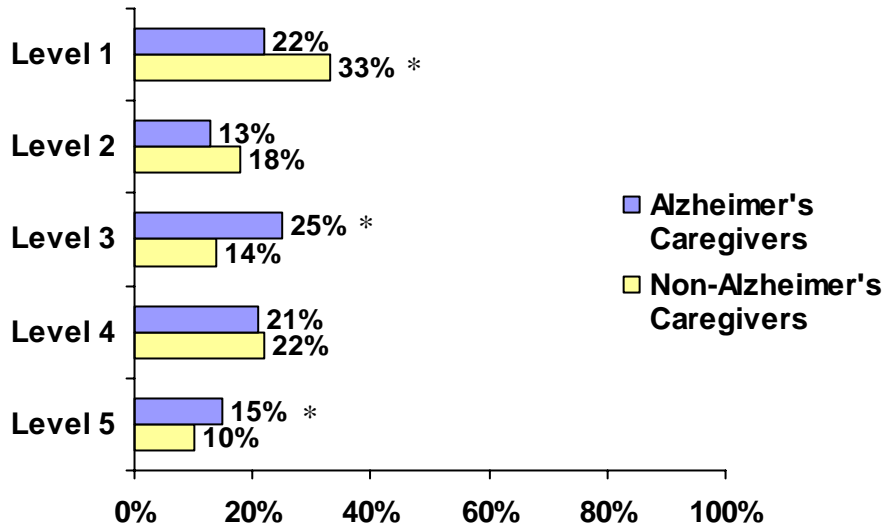
**Figure 21: Duration of Care for Recipient**

Q13. For how long [have you been providing/did you provide] help to your (care recipient)? PROMPT: Your best estimate is fine.



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

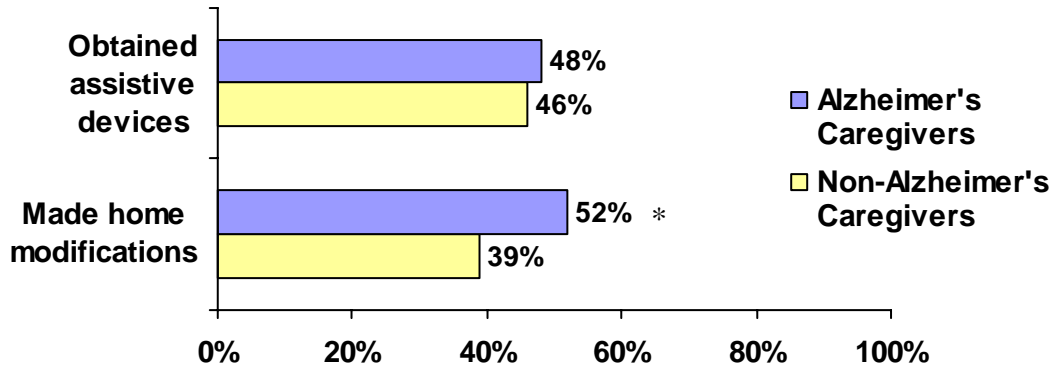
**Figure 22: Level of Burden**



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 23: Home Modifications and Assistive Devices**

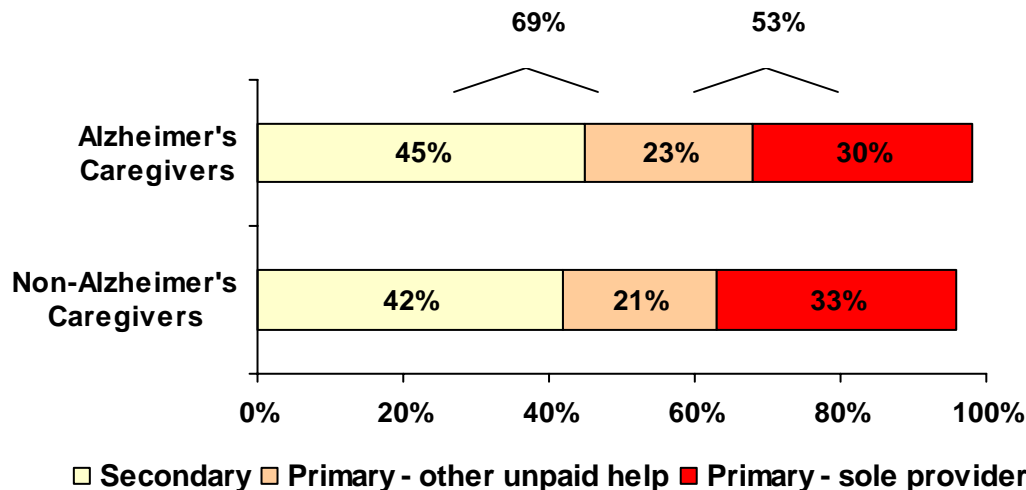
Q79, 81. Have you done or obtained any of these types of things to make it easier to care for your (care recipient): Obtained a bathing bench, magnifying lens for reading, or other helpful devices for your (care recipient); Had modifications made in the house or apartment where your (care recipient) [lives/lived] to make things easier?



Base: 227 Alzheimer’s caregivers in the U.S.; 749 non-Alzheimer’s caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving

**Figure 24: Caregiver Status**

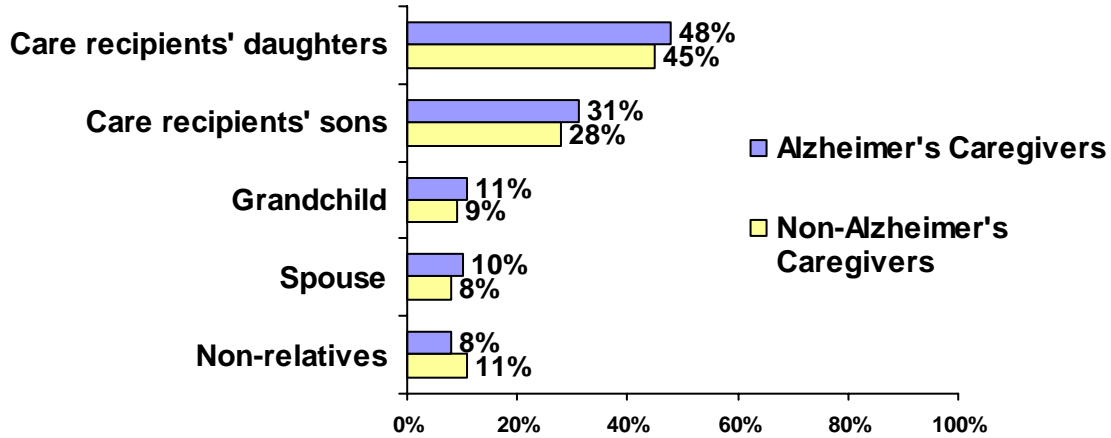
Q31. Has anyone else provided unpaid help to your (care recipient) during the last 12 months? Q33. IF YES: Who would you consider to be the person who [provides/provided] *most* of the unpaid care for you (care recipient): you yourself, or someone else?



Base: 227 Alzheimer’s caregivers in the U.S.; 749 non-Alzheimer’s caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 25: Other Unpaid Help Providers**

Q31. Has anyone else provided unpaid help to your (care recipient) during the last 12 months? Q32a. What relationship are they to your (care recipient)?

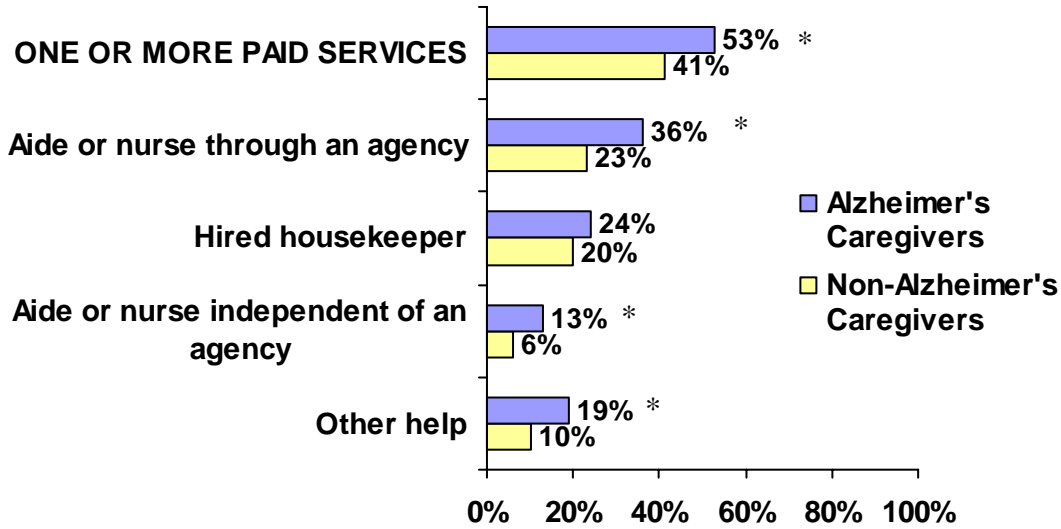


Base: 153 Alzheimer's caregivers and 478 non-Alzheimer's caregivers in the U.S. who report other unpaid help.

Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 26: Type of Paid Care**

Q34-37. IF NOT IN NURSING HOME: During the past 12 months, did your (care recipient) receive paid help from any of the following – regardless of who paid for it. First:

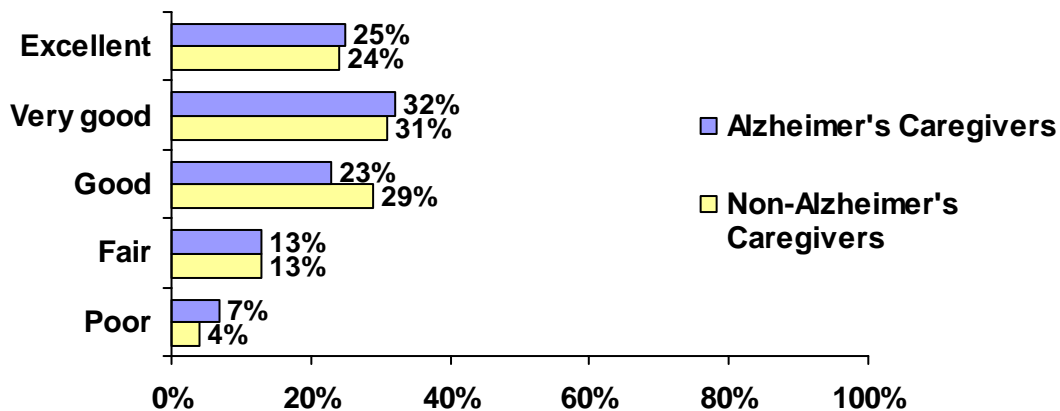


Base: 202 Alzheimer's caregivers and 722 non-Alzheimer's caregivers in the U.S. of recipients not living in a nursing home.

Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 27: Self-Described Health Status of Caregiver**

Q87. How would you describe your own health? Is it excellent, very good, good, fair, or poor?

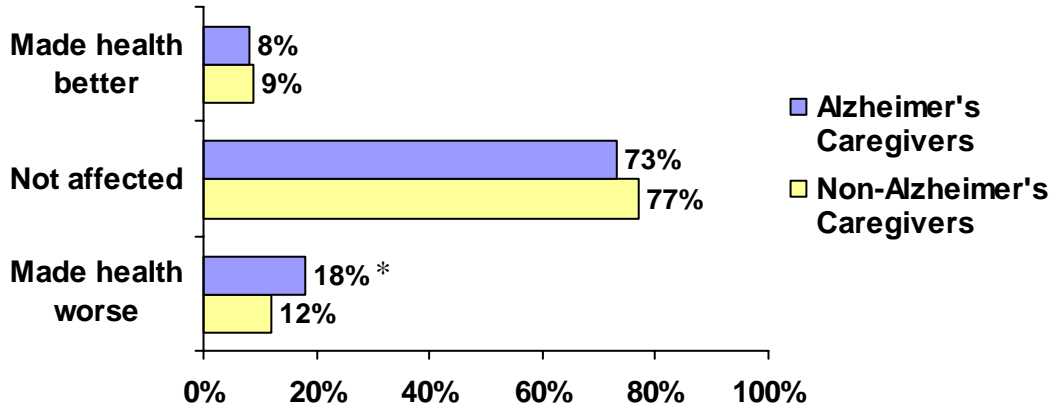


Base: 227 Alzheimer's caregivers in the U.S.

Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 28: Perceived Effect of Caregiving on Health**

Q88. How would you say taking care of your (care recipient) has affected your health? Has it made it better, not affected it, or made it worse?

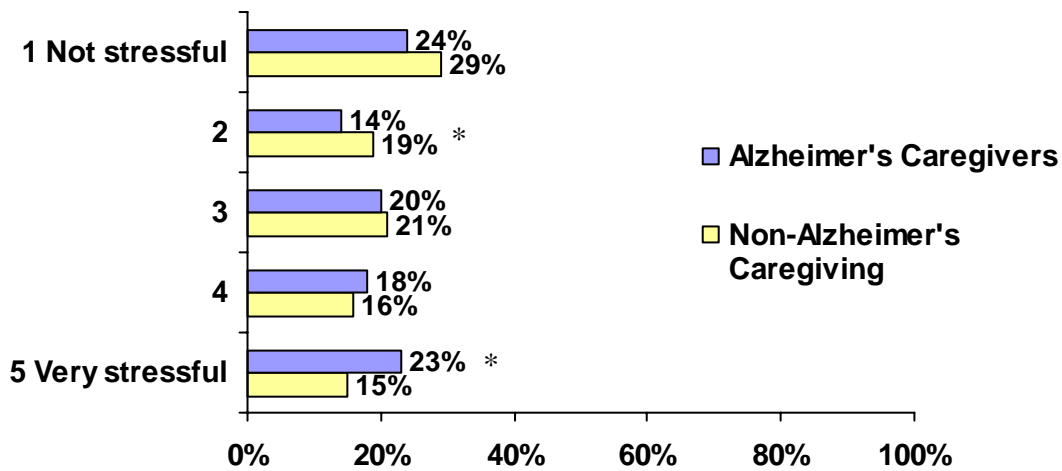


Base: 227 Alzheimer's caregivers in the U.S.

Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 29: Emotional Stress of Caregiving**

Q57. Using the same scale from 1 to 5, where 1 is not at all stressful and 5 is very stressful, how emotionally stressful would you say that caring for your (care recipient) [is/was] for you?

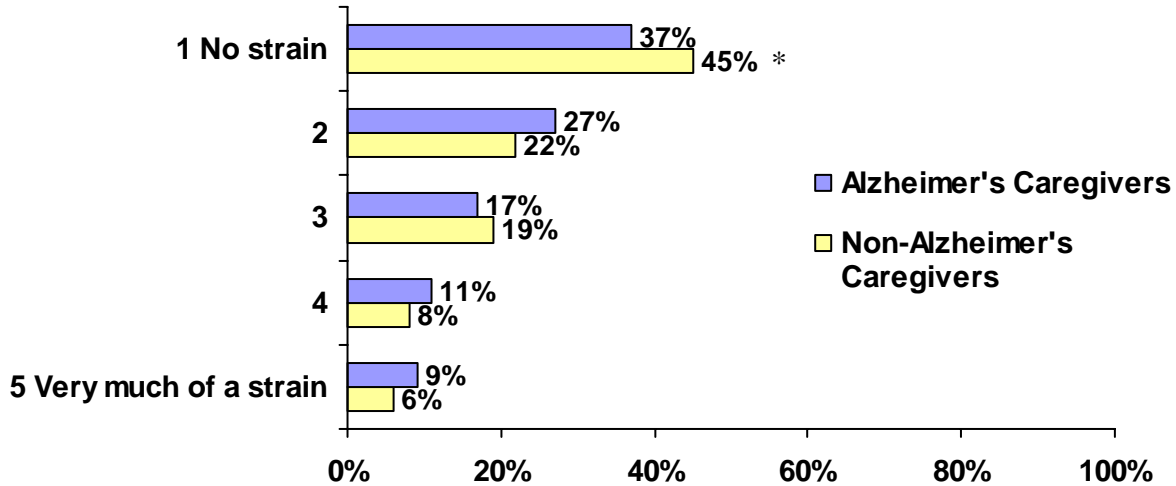


Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.

Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 30: Physical Strain on Caregivers**

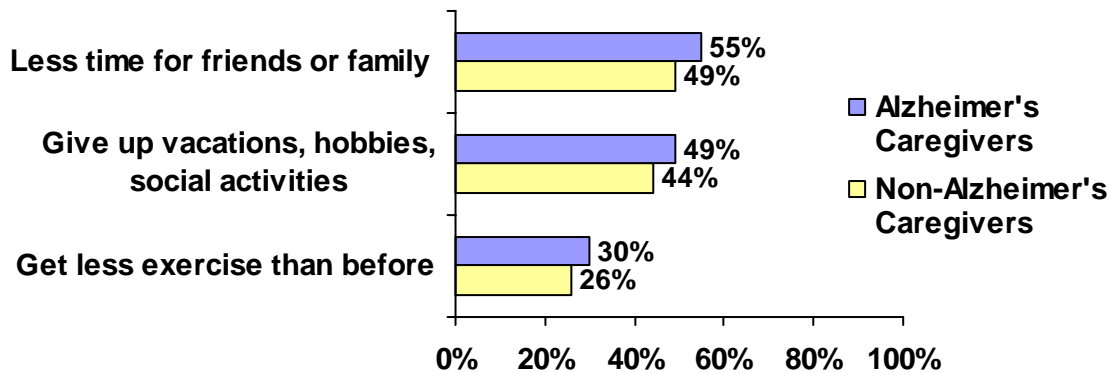
Q56. Think of a scale from 1 to 5, where 1 is not a strain at all and 5 is very much of a strain. How much of a physical strain would you say that caring for your (care recipient) [is/was] for you?



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 31: Impact of Caregiving on Family and Leisure Activities**  
% saying yes

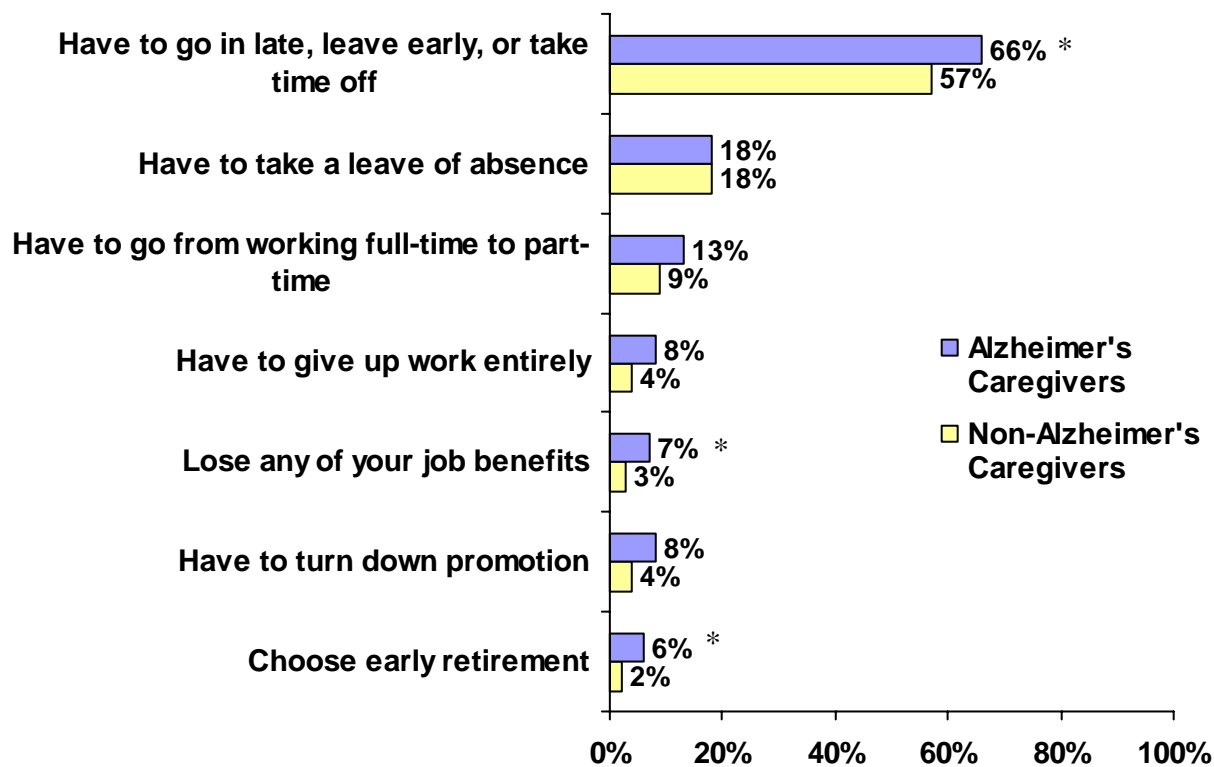
Q53-55. There may have been other ways in which providing care to your (care recipient) has affected your life. As a caregiver ...



Base: 227 Alzheimer's caregivers in the U.S.  
Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 32: Impact of Caregiving on Work**  
 % saying yes

Q41-47. IF WORKING WHILE A CAREGIVER: In your experience as both a worker and a caregiver, did you ever



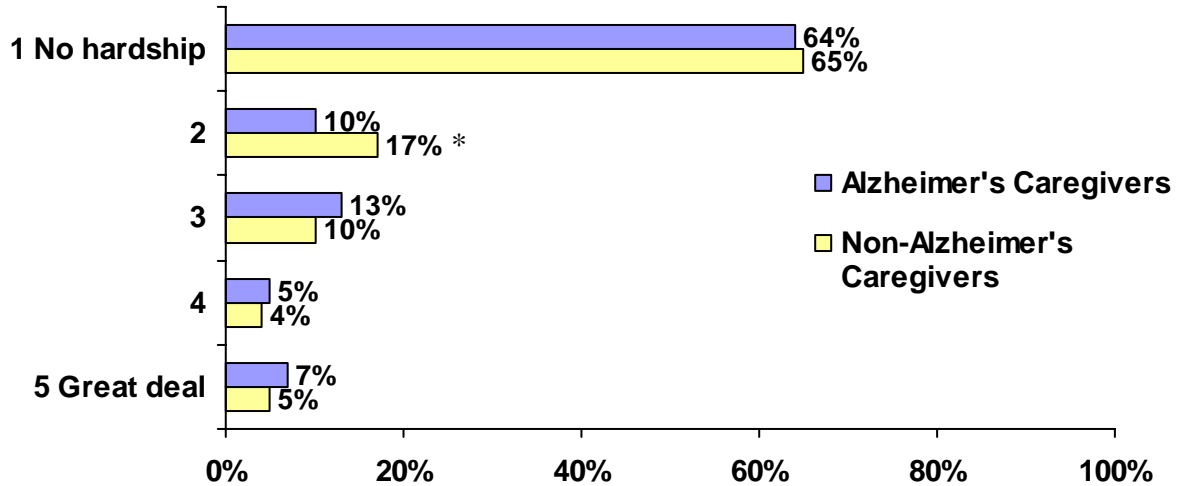
Base: 161 Alzheimer’s caregivers and 562 non-Alzheimer’s caregivers in the U.S. who are currently or have worked while caregiving.

Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.



### Figure 33: Financial Hardship on Caregivers

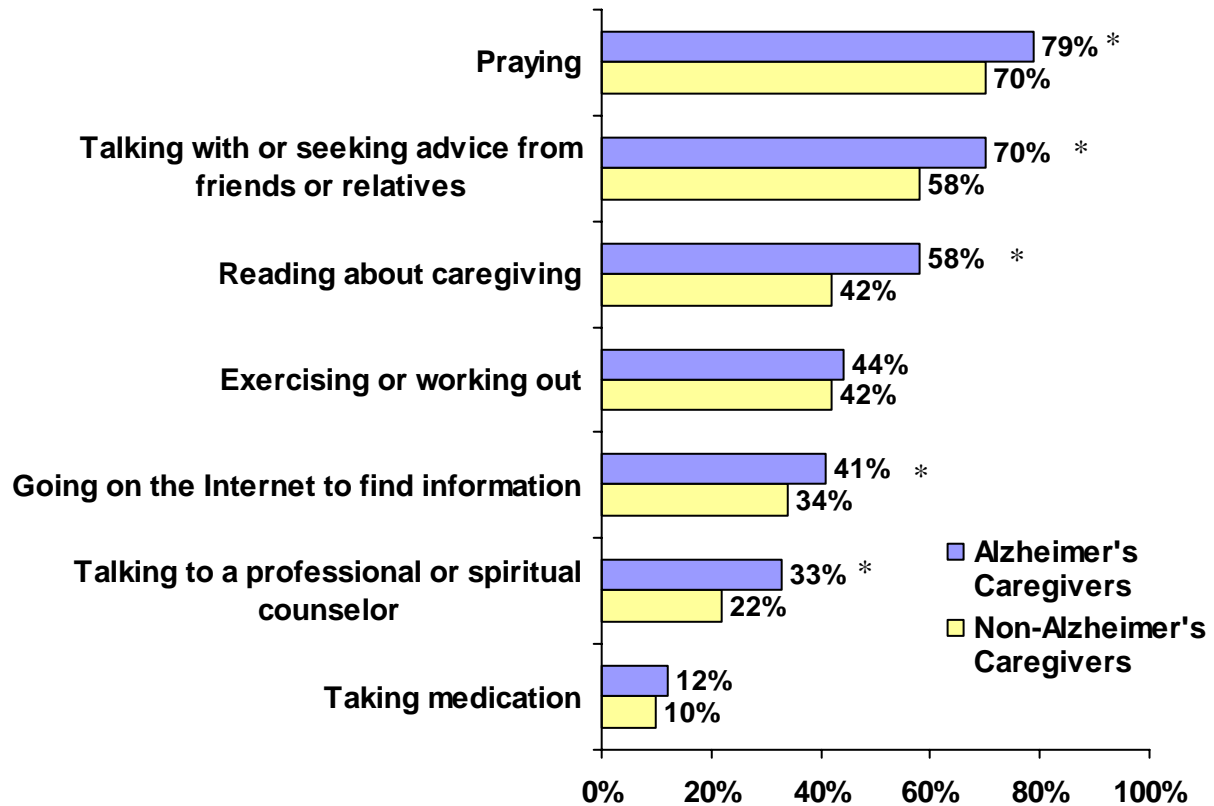
Q58. Using the same scale from 1 to 5, where 1 is no hardship at all and 5 is a great deal of hardship, how much of a financial hardship would you say that caring for your (care recipient) [is/was] for you?



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 34: Coping with Demands of Caregiving**  
% saying yes

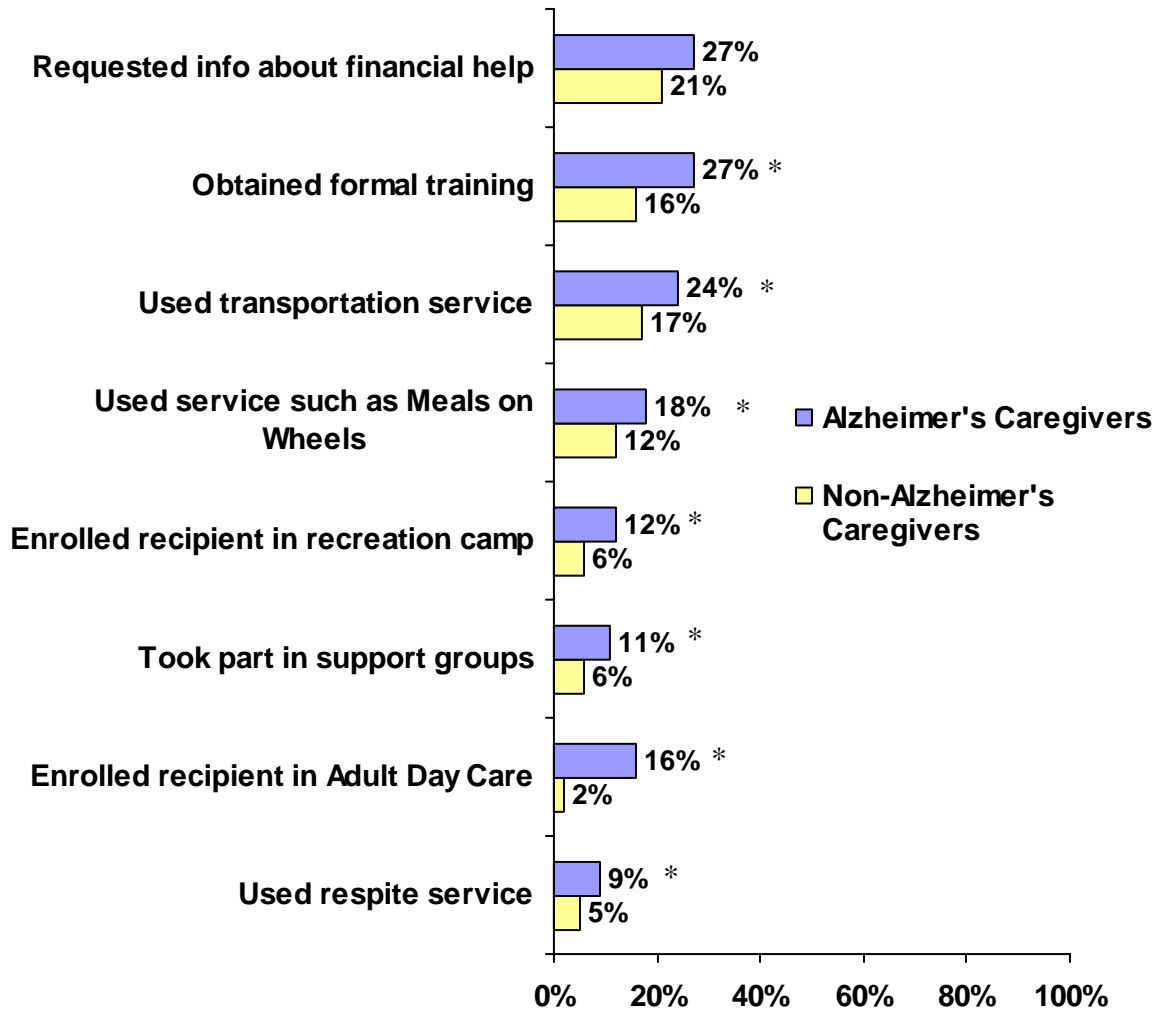
Q60-67. I'm going to read a list of ways that caregivers such as yourself have coped with the demands of caregiving. For each one, please tell me whether you have used any of these. [Have/Did] you ever [tried/try] to cope with caregiving stress by:



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 35: Use of Supportive Services**

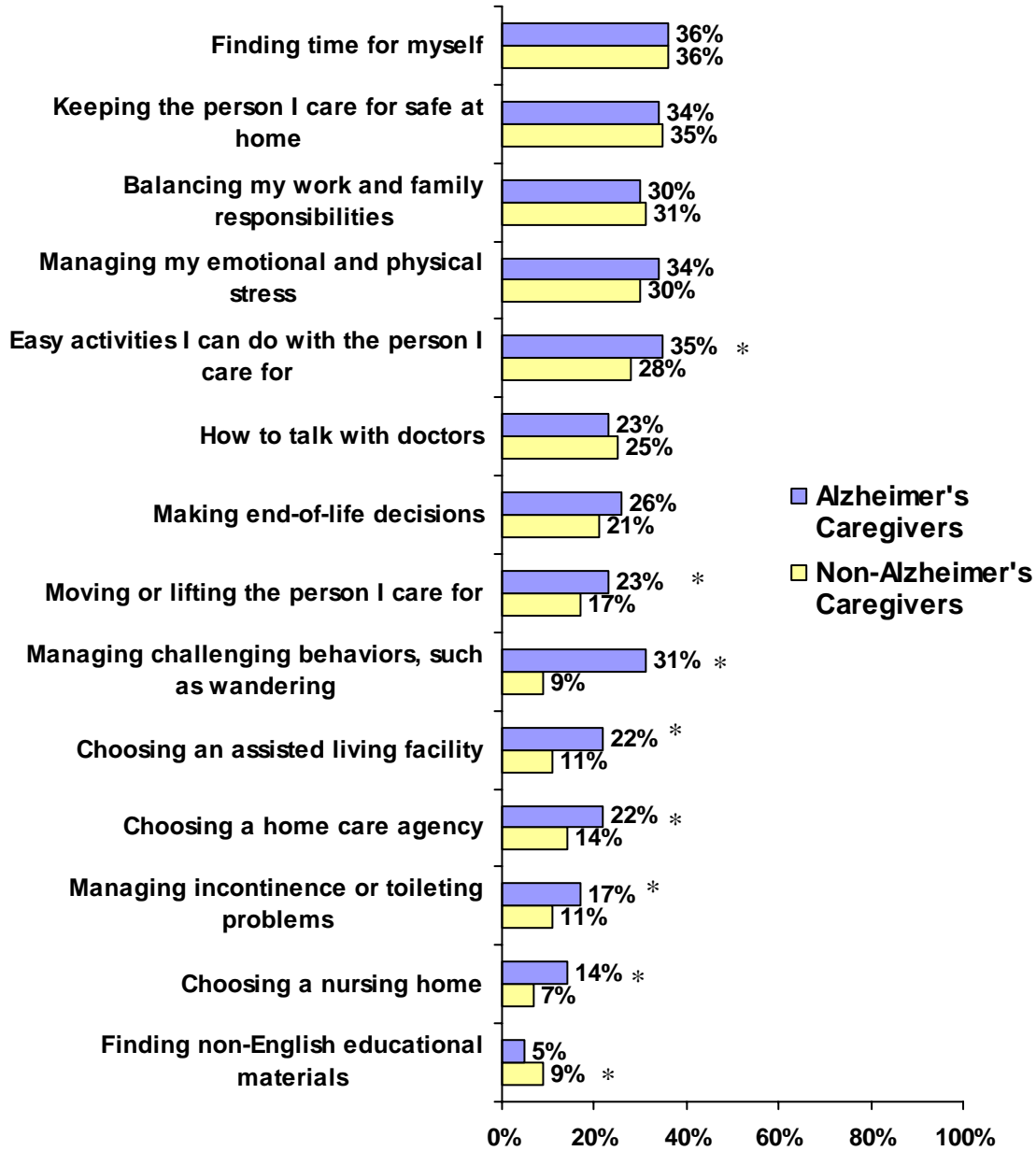
Q71-78. In your experience as a caregiver, [have/did] you ever...



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 36: Unmet Needs**  
% saying yes

Q82a-n. As a caregiver, on which of the following do you [need/needed] more help or information:

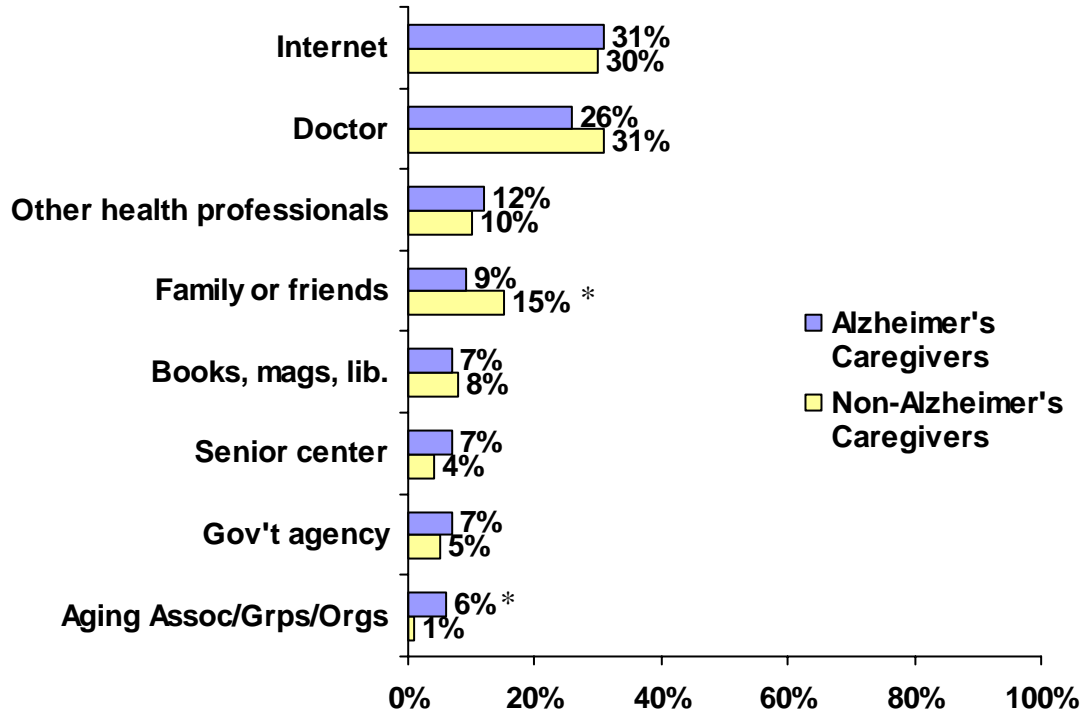


Bas

e: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

**Figure 37: Where Caregivers Would Go For Information (Top Mentions)**

Q83. If you were looking for information about some aspect of helping take care of your (care recipient), where would you turn? MULTIPLE RESPONSE



Base: 227 Alzheimer's caregivers in the U.S.; 749 non-Alzheimer's caregivers.  
 Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.