

Alzheimer's Disease **CAREGIVING IN THE U.S.**



*A special report from
the National Alliance for Caregiving*

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Table of Contents

I.	Introduction.....	1
II.	Overview of Methodology	1
III.	Key Findings	3
IV.	Detailed Findings.....	7
	A. Basics of the Caregiving Situation	7
	B. Caregiving Activities and Burden of Care	15
	C. Presence of Other Caregivers	22
	D. Care Recipient Living Situation.....	26
	E. Care Recipient's Condition	30
	F. Strain and Stress of Caregiving	33
	G. Impact of Caregiving on Work	38
	H. Information Sources and Needs	41
	I. Support for Caregivers.....	45
	J. Respondent Profile	49

Table of Figures

Figure 1: Main Problem or Illness Identified by Caregiver	7
Figure 2: Number of Care Recipients	8
Figure 3: Gender of Caregiver and Care Recipient	9
Figure 4: Age of Predominant Care Recipient	10
Figure 5: Age of Caregiver	11
Figure 6: Care Recipient Relation to Caregiver	12
Figure 7: Marital Status of Care Recipient.....	13
Figure 8: Duration of Care for Recipient.....	14
Figure 9: Choice in Taking on Caregiver Role.....	15
Figure 10: Hours of Care Provided.....	15
Figure 11: Help with Activities of Daily Living (ADLs)	17
Figure 12: Help with Selected ADLs Among Alzheimer's Caregivers	17
Figure 13: Help with Instrumental Activities of Daily Living (IADLs)—for Adult Recipients.....	18
Figure 14: Help with Other Supportive Activities—for Adult Recipients	20
Figure 15: Level of Care Index	21
Figure 16: Components of Level of Care by Burden Category Among Alzheimer's Caregivers	21
Figure 17: Presence of Other Unpaid Caregivers.....	22
Figure 18: Primary Caregiver Status	24
Figure 19: Use of Paid Services	25
Figure 20: Predominant Caregiver Among Unpaid and Paid Helpers	25
Figure 21: Where Care Recipient Lives.....	27
Figure 22: Who Care Recipient Lives With.....	28
Figure 23: Caregiver Distance from Care Recipient	29
Figure 24: Frequency of Visits.....	30
Figure 25: Types of Care Recipient Conditions	31
Figure 26: Use of Prescription Medicine.....	32
Figure 27: Medication Management	32
Figure 28: Ease of Coordinating Care	33
Figure 29: Caregiver Health	33
Figure 30: Impact of Caregiving on Caregiver's Health	34
Figure 31: Physical Strain of Caregiving	35
Figure 32: Emotional Stress of Caregiving	36
Figure 33: Time for Family and Friends.....	37
Figure 34: Financial Hardship of Caregiving.....	38
Figure 35: Concurrence of Employment and Caregiving	38
Figure 36: Current Employment Status of Caregiver	39

Figure 37: Work Accommodations Due to Caregiving	40
Figure 38: Sources Used for Caregiving Information.....	41
Figure 39: Internet Usage for Caregiving Information.....	42
Figure 40: Caregiving Information Sought Online.....	43
Figure 41: Caregiving Training	43
Figure 42: Caregiving Information Needs	44
Figure 43: Use of Services	46
Figure 44: Home Modifications.....	46
Figure 45: Use of Technology in Caregiving.....	47
Figure 46: Reaction to Caregiving-Related Policies	48
Figure 47: Profile of Respondents	49

I. Introduction

The purpose of this study is to present a portrait of family caregivers of individuals who have Alzheimer's disease, dementia, or mental confusion. This portrait emerges from a national study of caregivers conducted in 2009. The study examined:

- Demographic characteristics of Alzheimer's caregivers and care recipients
- The nature of caregiving activities as well as whether other unpaid or paid caregivers also provide help
- How caregivers' work, social life, and health are affected by caregiving
- Information needs and information sources
- What public policies would support caregivers
- Use of technology

II. Overview of Methodology

This report is based primarily on quantitative telephone interviews with 423 family caregivers age 18 or older who care for someone age 50 or older who has Alzheimer's disease, dementia, or mental confusion as well as 968 caregivers of individuals age 50+ without this type of condition. Caregivers are defined as those who provide unpaid care to an adult as described in the following question:¹

In the last 12 months, has anyone in your household provided unpaid care to a relative or friend 50 years or older to help them take care of themselves? 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.

The presence of Alzheimer's disease, dementia, or mental confusion was assessed in two subsequent questions:

What would you say is/was the main problem or illness your [relation] has/had for which he/she needs/needed your care?

Does your [RELATION] suffer from Alzheimer's or other mental confusion?

The interviews include 920 from a random sample of family caregivers, and to supplement the ethnic minority interviews achieved in that sample, 471 additional interviews with minorities. The interviews break out by race as follows: 800 White, non-Hispanic caregivers, 206 African-American caregivers, 200 Hispanic caregivers, 167 Asian-American caregivers, and 18 caregivers of another race.

¹ In most of the interviews, which were part of a larger caregiving study, respondents were asked whether they provided unpaid care to a person of any age. This report analyzes the subset of those interviews in which the recipient was age 50 or older as well as later interviews intended to supplement the number of respondents with recipients ages 50+.

The random sample interviews were reached using random digit dialing. Geographic density samples were used to target the oversample of African-Americans. For Hispanics and Asian-Americans, a combination of surname and density sampling was used. In addition, some Asian-American caregivers were pre-identified by screening members of a representative panel run by Knowledge Networks.

The survey results are weighted by household, based on the race/ethnicity and age of the householder, and type of household (family or non-family) reported by the initial respondent in each household. Weighting targets were derived from the Current Population Survey, 2008 Annual Social and Economic Supplement, conducted by the U.S. Census Bureau.

Respondents were given the option of conducting the interview in Spanish or English. The average length of the interview was 22.3 minutes. The survey was conducted between March 5 and June 17, 2009.

The margin of error for findings regarding caregivers of recipients with Alzheimer's, dementia, or mental confusion is plus or minus approximately 6.0 percentage points at the 95% confidence level. This means that 95 times out of 100, a difference of greater than six percentage points would not have occurred by chance. For caregivers of people who do not have this type of condition, the margin of error is 3.9 percentage points. For subgroups of Alzheimer's caregivers, the margin of error is larger.

The full questionnaire is presented in Appendix A to this report.

Reading this Report

The main graphics and tables in this report present results for all 423 Alzheimer's caregivers in the 2009 study. Comparison figures for 968 caregivers of individuals with other conditions are shown in mini-tables to the right of each graphic.

All percentages have been weighted and rounded. In addition, "don't know" or "refused" responses are not always presented in charts and tables. For these reasons, some charts and tables will not add to 100%. The results for multiple response questions may also add to greater than 100%.

For statistical purposes, the base number of respondents shown in each table or graphic is unweighted.

To signal differences between Alzheimer's and non-Alzheimer's caregivers, the report uses an asterisk to highlight any percentage that is significantly higher than the comparison figure.

When presenting differences between different racial/ethnic groups, any mention of Whites or African-Americans refer solely to non-Hispanic individuals.

III. Key Findings

Alzheimer's Caregivers Differ from Other Caregivers of Older Recipients

The experiences of family caregivers whose loved one age 50+ has Alzheimer's, dementia, or mental confusion are understandably different from other caregivers' experiences. The progressive nature of the disease and the particular path it tends to follow means the care recipients have distinctive needs. What are the two key differences?

Intensiveness of Caregiving Role

First, Alzheimer's caregivers are in more time-intensive and labor-intensive roles. Specifically, they are more likely to:

- Spend a greater amount of time providing care—an average of 22 hours per week, compared to 17 hours per week for non-Alzheimer's caregivers
- Provide help with the types of personal care classified as Activities of Daily Living (ADLs), in particular dressing, bathing, feeding, dealing with incontinence, and getting in and out of beds and chairs
- Help with managing finances, arrange or supervise paid services, and advocate for their loved one with care providers or government agencies
- Experience a high level of physical strain in caring for their loved one

The only task that Alzheimer's caregivers are less likely than non-Alzheimer's caregivers to help with is grocery shopping.

Medication management is much more likely to be an issue when Alzheimer's or dementia is present. Eight in ten Alzheimer's caregivers say their loved one needs oversight to make sure medication is taken in the right amount at the right time, compared to one-third of caregivers whose loved one does not have Alzheimer's or dementia. Accordingly, Alzheimer's caregivers are more likely than non-Alzheimer's caregivers to help give medications, pills, or injections (54% vs. 36%).

Coordination of care is another medical issue that is more prominent for caregivers whose loved one has Alzheimer's or dementia. One-third of them (33%) find it difficult to coordinate care between all the health care and service providers who gave care or treatment to the care recipient, while one-fifth of non-Alzheimer's caregivers do (21%).

Impact on the Caregiver

The second way in which caregivers whose recipient has Alzheimer's or dementia are distinct from others is that their experience takes a greater toll on them. Alzheimer's caregivers are more likely than non-Alzheimer's caregivers to:

- Experience a moderate to high level of emotional stress
- Have less time for family and friends as a result of caregiving
- Suffer worsening health as a result of caregiving

Employed Alzheimer's caregivers also indicate that their role results in impacts at work. Seven in ten make some sort of adjustment at work to accommodate their caregiving, with the most common being flexing work hours or taking time off to provide care (68%). In addition, 14% take a leave of absence, 10% reduce work hours or take a less demanding job, 5% turn down a promotion, and 10% stop work entirely or take early retirement. 5% say they lose job benefits. Similar proportions of caregivers whose recipient does not have Alzheimer's disease or dementia report these impacts at work.

Certain Subgroups of Alzheimer's Caregivers Experience Even Greater Impacts

Alzheimer's caregivers are not uniform demographically and their caregiving situations vary widely. Demographically, for instance:

- Two-thirds are women, but one-third are men.
- Their average age is 51, but one in seven are 18 to 34 and a similar proportion are 65 or older.
- 63% are married or living with a partner, while 6% are widowed, 15% are separated or divorced, and 16% are single.
- Three in ten have children or grandchildren under the age of 18 in their household.
- Three-quarters were employed at some point while caregivers.
- They live in urban (28%), suburban (40%), and rural (31%) locations.

With regard to their caregiving situation:

- Six in ten care for a parent or parent-in-law, whereas others care for a grandparent, a spouse, some other relative, or a friend/neighbor.
- On average, they have provided care for four years, but 23% have been in their role for less than one year and 12% have been caregivers for 10 years or more.

- They are evenly split between those who feel they had a choice in taking on the responsibility of providing care and those who feel they had no choice.
- One in five live with the person to whom they provide care (21%), 48% say their loved one lives in his/her own home, 13% report he or she lives in a nursing home, and the remainder have some other living arrangement.
- They are almost evenly split between those who consider themselves to be the primary unpaid caregiver and those who say they are not. Primary caregivers include 22% who are sole caregivers.
- There is a relatively even balance of caregivers who report their loved one receives paid help from aides, housekeepers, or others, and those who say there is no paid help.
- Finally, the mix of tasks the caregiver helps with and the hours they spend doing so varies widely. Taking that mix into account, 36% of Alzheimer's caregivers are in high burden situations, 26% have a medium burden, and 37% have a low burden.

The results show that four particular subgroups of Alzheimer's caregivers are more likely to experience greater negative impacts: (1) primary caregivers, (2) co-resident caregivers, (3) those with a high burden of care, and (4) those who feel they had no choice about taking on their role. They are consistently more likely to report physical strain, high emotional stress, less time with family and friends, worsening health, and employment changes.

The top areas in which Alzheimer's caregivers need information or help, in general, are thinking of easy activities to do with the recipient, keeping him or her safe at home, finding time for themselves, and managing emotional and physical stress. Roughly four in ten Alzheimer's caregivers say they need help or information on each of these topics.

The Alzheimer's caregivers with a high burden are particularly likely to cite a need for help or information about finding time for themselves, managing emotional/physical stress, seeking easy activities to do with their care recipient, managing end of life decisions, managing incontinence or toileting, and moving or lifting their loved one. They are also more likely to have used a respite service or sitter.

Ideas to Help Alzheimer's Caregivers

Alzheimer's caregivers respond positively to several policy ideas intended to support caregivers. Of six national policies or programs presented as potential ways to help them, the most popular is a caregiver tax credit of \$3,000; six in ten Alzheimer's caregivers rate it as their first or second most preferred policy. One in three prefer respite services where someone would take care of their loved one to give them a break, and an equal share prefer a voucher program where they could be paid minimum wage for at least some of their caregiving hours.

Technology also holds some promise for assisting those who care for someone with Alzheimer's disease or dementia. Half of them use some sort of technological device to help with their caregiving, most commonly an electronic organizer or calendar or an emergency response system such as Lifeline—about one in five use each. An electronic sensor that detects safety problems in the home could also be particularly useful in the earliest stages of the disease, to help protect the care recipient should she or he leave the stove on, wander away, or fall. Currently, only about one in eight Alzheimer's caregivers use such a device.

Clearly caregivers of individuals with Alzheimer's, dementia, or mental confusion have needs beyond those of the typical caregiver, and among them, those who are co-resident with their loved one, serving as the primary caregiver, or experiencing a high burden situation bear even greater impacts. It is important to continue and expand on the delivery of programs, services, information, policies, and technology that can assist these caregivers.

IV. Detailed Findings

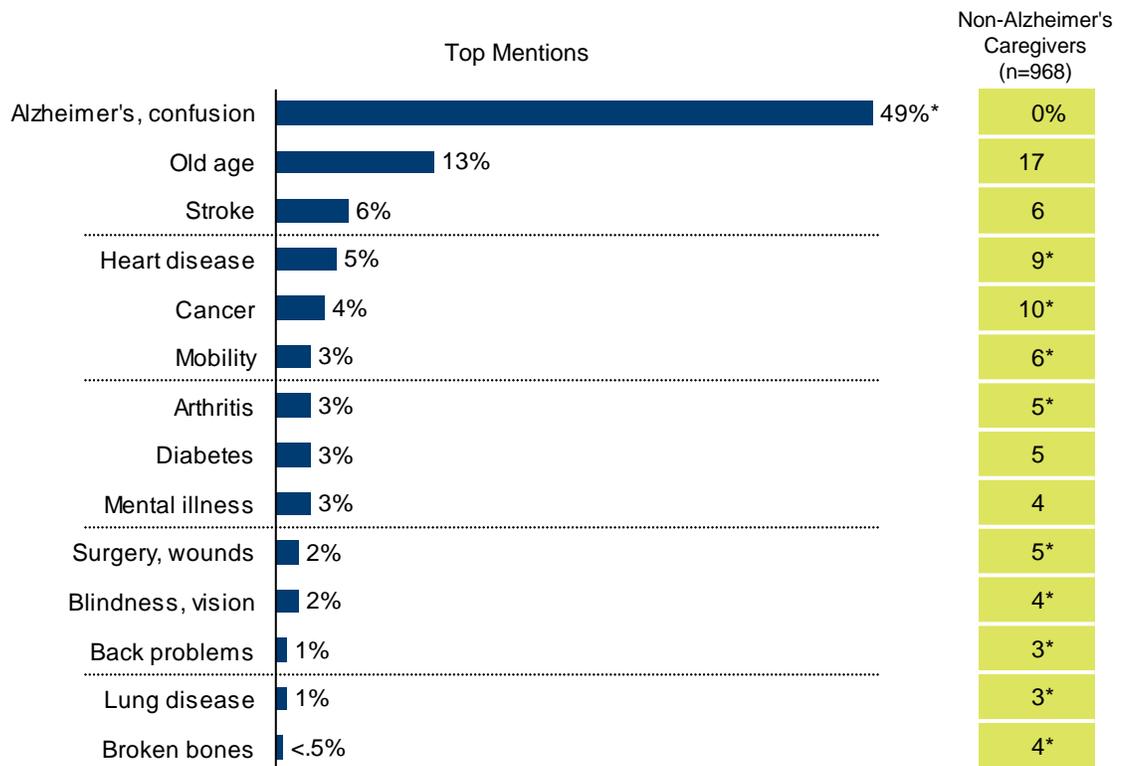
A. Basics of the Caregiving Situation

Care Recipient's Main Problem or Illness

Half of the caregivers whose recipient has Alzheimer's, dementia, or mental confusion volunteer that this is the *main* problem or illness for which their loved one needs care (49%). The other half of Alzheimer's caregivers acknowledge that their loved one has this type of condition when asked, but top of mind, they mention some other condition as the main problem for which care is needed. Specifically, 13% mention old age as the main condition, and small percentages specify stroke (6%), heart disease (5%), or cancer (4%) as the main problem.

Figure 1: Main Problem or Illness Identified by Caregiver
 Q18. What would you say is/was the main problem or illness your [relation] has/had for which he/she needs/needed your care?

Base: 2009 All Alzheimer's caregivers (n=423)



2009 Alzheimer's Caregiver Subgroups

- Caregivers whose loved one lives in assisted living or a nursing home are more likely than others to mention unaided that their loved one's main condition is Alzheimer's, dementia, or confusion (63% vs. 46%).

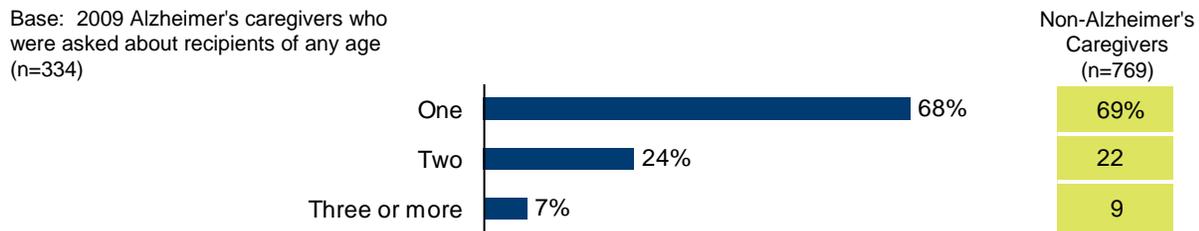
- Asians are more apt to say the main issue is just old age (27%), compared to African-Americans (4%) and Hispanics (7%). African-Americans are more likely than Whites to say Alzheimer's or confusion is the main problem (63% vs. 50%).

Number of Care Recipients

Two-thirds of Alzheimer's caregivers (68%) take care of one care recipient, 24% take care of two people, and 7% take care of three or more.²

Figure 2: Number of Care Recipients

Q2. How many people, including adults and children, do/did you provide this care for [in the past 12 months]?



2009 Alzheimer's Caregiver Subgroups

- The Alzheimer's caregivers with a high burden of care are more likely to have only one care recipient. Specifically, 78% of those in high burden situations have one recipient, compared to 62% of those with low to medium care burdens.
- Primary caregivers—those who provide all or the majority of the unpaid care for their recipient—are more likely than non-primary caregivers to report caring for only one person (78% vs. 61%).
- Along these same lines, 82% of Alzheimer's caregivers who live with their care recipient provide care to only one person, compared to 65% of those who live separately.
- The likelihood of caring for just one care recipient rises in relation to the age of the caregiver, with 66% of 18- to 64-year-old caregivers providing care to one person, compared to 88% of caregivers age 65+.
- Caregivers whose loved one lives with someone other than the caregiver are far more likely to say they provide care to two people (43%) than are those whose loved one lives alone (11%) or in an assisted living or nursing care facility (13%). One might hypothesize that they are more likely to care for a married couple, such as parents, grandparents, or an aunt and an uncle. In fact, the data show they are more likely to name a grandparent as their principal care recipient, but they are not more likely to care for a parent or an aunt/uncle.

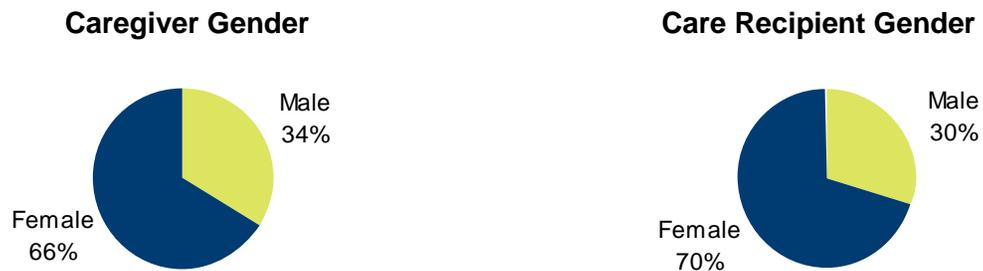
² Note: This count includes the principal care recipient age 50+, but also any recipients who are younger adults or children. Oversample interviews targeting only caregivers of 50+ recipients were excluded from this analysis since those respondents were not asked to include younger recipients in their count.

Gender of Caregiver and Care Recipient

Two-thirds of Alzheimer's caregivers are female (66%) and one-third are male (34%). A majority of caregivers' recipients are female (70%).

Figure 3: Gender of Caregiver and Care Recipient
Q9. [IF NEEDED] Would you mind telling me if your [relation] is/was male or female?
Caregiver gender recorded by interviewer

Base: 2009 All Alzheimer's caregivers
(n=423)



2009 Alzheimer's Caregiver Subgroups

- Alzheimer's recipients who are in a care facility—such as an assisted living facility or a nursing home—are more likely to be female than are the recipients who are still living in their own home (82% vs. 67%).
- Alzheimer's caregivers who have been taking care of a person for four years or more are also more likely than shorter-duration caregivers to have a female care recipient (77% vs. 65%).
- Recipients being cared for by a spouse are disproportionately males (62%).[†]

[†] Caution, n=32 for spousal caregivers.

Age of Care Recipient

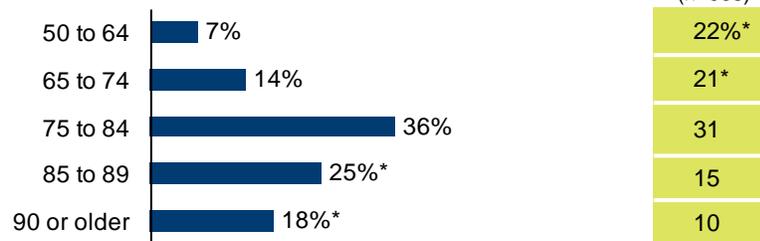
The average age of Alzheimer's care recipients is 81.0 years, six years older than recipients without Alzheimer's or dementia (75.0 years). In fact, eight in ten Alzheimer's caregivers (79%) report that their loved one is at least 75 years of age, compared to just over half of non-Alzheimer's caregivers who do (56%).

Figure 4: Age of Predominant Care Recipient

Q5. [IF 1 RECIPIENT] Now, I'd like to ask you some questions about the person for whom you provide/provided care. [IF 2+ RECIPIENTS] Let's focus on the person for whom you provide/provided the most assistance. How old is/was that person?

Base: 2009 All Alzheimer's caregivers (n=423)

Non-Alzheimer's Caregivers (n=968)



2009 Alzheimer's Caregiver Subgroups

- As one might expect, Alzheimer's caregivers whose recipient lives in assisted living or a nursing home take care of someone older (84.9 years, on average) than those whose recipient lives in his/her own home (80.3 years) or with their caregiver (78.0 years).
- As the caregiver's household income rises, so does the likelihood that he/she takes care of an older recipient. Among caregivers with less than \$50,000 in household income, the average care recipient age is 78.6 years, compared to 82.1 years for caregivers in households with at least \$50,000 in income.
- The care recipient's age tends to increase as the distance from the caregiver does. Caregivers who co-reside with their care recipient are 78.0 years of age, on average. Those living within an hour of their recipient care for someone who averages 81.4 years of age, while those who live farther away are providing care to a recipient averaging 83.5 years of age.

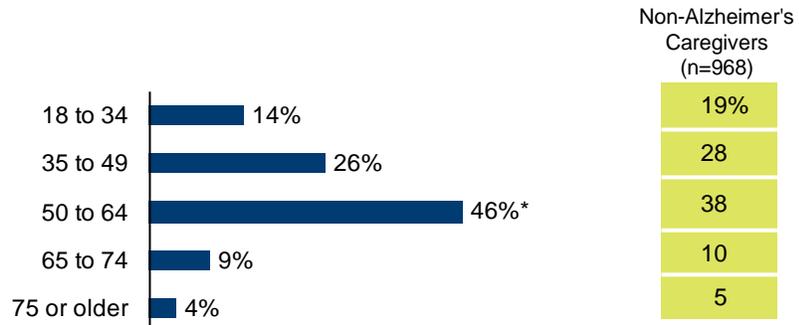
Age of Caregiver

The average age of Alzheimer's caregivers is 50.8, similar to the age of caregivers whose recipient does not have Alzheimer's or dementia (49.5 years old). Most of the Alzheimer's caregivers are age 50 or older (59%). Still, there is a sizeable proportion of younger caregivers, including 14% ages 18 to 34 and 26% ages 35 to 49.

Figure 5: Age of Caregiver

S2, S15. *How old were you on your last birthday?*

Base: 2009 All Alzheimer's caregivers
(n=423)



2009 Alzheimer's Caregiver Subgroups

- Primary caregivers of recipients with Alzheimer's or dementia are older than non-primary caregivers (54.5 vs. 47.6 years, on average).
- Similarly, caregivers in high burden situations are older (54.0 years, on average), than those who have a medium burden (48.7 years) or low burden (48.4 years).
- Those who feel they did not have a choice in becoming a caregiver are also older (53.6 vs. 48.0 years for those who did have a choice, on average).
- Caregivers who have been providing care longer tend to be older. Those who have been in their role for four years or more are 53.4 years of age, on average, whereas those providing care for less time are 49.2.
- Caregivers whose recipient lives in his or her own home are much younger (47.2 years of age) than those who live with their recipient (54.8 years) or those whose recipient is in a care facility (55.8 years).
- Caregivers who are racial/ethnic minorities tend to be younger (47.1 years) than White caregivers (51.7 years).

Care Recipient Relation to Caregiver

The vast majority of Alzheimer's caregivers take care of a relative (93%), an even larger share than the 86% of non-Alzheimer's caregivers who do. The remainder care for a friend, neighbor, or other non-relative.

More Alzheimer's caregivers provide care to a parent (51%) than any other relation. More specifically, 36% serve as caregivers for their mother and 15% care for their father. An additional 11% provide care to a parent-in-law. One in six are helping care for a grandparent or grandparent-in-law (17%), a larger share than the one in ten non-Alzheimer's caregivers who do (10%). Spousal caregiving accounts for 6% of Alzheimer's caregiving situations.

Figure 6: Care Recipient Relation to Caregiver

Q7. What is/was this person's relationship to you?

	Alzheimer's Caregivers (n=423)	Non-Alzheimer's Caregivers (n=968)
Relative	93%*	86%
Parent	51	49
Grandparent or grandparent-in-law	17*	10
Parent-in-law	11	10
Spouse or partner	6	6
Uncle, aunt	4	4
Sibling	2	4
Sibling-in-law	1	1
Child	1	1
Other relatives	1	1
Non-relative	6	14*

2009 Alzheimer's Caregiver Subgroups

- White caregivers of Alzheimer's loved ones are more apt than racial/ethnic minority caregivers to provide care to a parent (54% vs. 38%) or a parent-in-law (12% vs. 6%). By contrast, they are less likely to be caring for an aunt or uncle (2% vs. 14%) or a sibling or sibling-in-law (2% vs. 7%). Blacks are least likely to be caring for a relative (82% vs. 93% overall).
- Lack of choice in caregiving is associated with caring for a parent. Of the Alzheimer's caregivers who do not feel they had a choice in taking on their role, six in ten are caring for a parent (58%), compared to 45% of those who did have a choice. The reverse is true for caring for grandparents. Of those who feel they did not have a choice in becoming a caregiver, 9% care for a grandparent or grandparent-in-law, compared to 24% of those who did have a choice.
- The care recipient's relationship to the caregiver varies greatly depending on the caregiver's age. Alzheimer's caregivers who are 65 or older are more likely than younger caregivers to care for a spouse (37% vs. 1%) or a sibling (12% vs. 1%).
- By contrast, the 18- to 64-year-old caregivers are more likely than older caregivers to care for relatives of an older generation, such as their parent or parent-in-law (66% vs. 38%) or a grandparent or grandparent-in-law (19% vs. 0%).

- Those providing no more than 20 hours of care per week are twice as likely as those spending more time to care for their grandparent or grandparent-in-law (20% vs. 11%). Those giving more than 20 hours of care per week are far more likely to be a spousal caregiver (16%) than are those providing fewer hours of care (2%).
- Caregivers who have been in their role for 4 years or more are also more likely to be providing care to a spouse (11% vs. 3%).

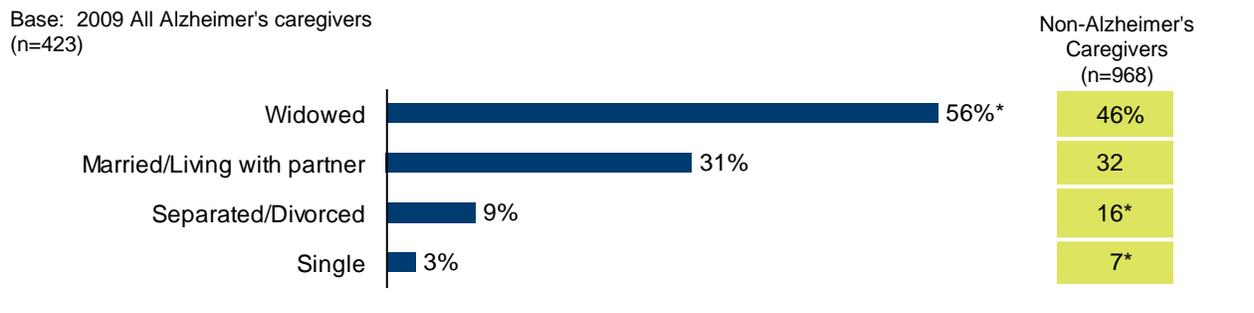
Marital Status of Care Recipient

More than half of Alzheimer's caregivers report that their care recipient is widowed (56%), and three in ten say their recipient is married or living with a partner (31%). About one in ten report a divorced or separated marital status (9%). Only 3% report that their care recipient is single.

Caregivers of people without Alzheimer's or mental confusion are less likely to report their loved one is widowed (46%) and more apt to say he or she is divorced or separated (16%) or single (7%).

Figure 7: Marital Status of Care Recipient

Q10. Is your [relation] currently/Was your [relation] widowed, married, living with a partner, separated, divorced, or single—that is, never been married?



2009 Alzheimer's Caregiver Subgroups

- White and Asian-American caregivers are more likely to report caring for a married person (30% and 48%, respectively) than are African-American caregivers (11%). African-Americans are more apt to say their care recipient is divorced (23% vs. 7% among Whites and 3% of Asians) or single (14% vs. 1% of Hispanics).
- Seven in ten care recipients living alone are reported to be widowed (73%), similar to the 76% of those living in a care facility.
- Of the care recipients who live with their caregiver, 50% are widowed and only 31% are married. Of those who live with someone else other than their caregiver—outside of a care facility, 41% are widowed and half are married (49%).

Duration of Care for Recipient

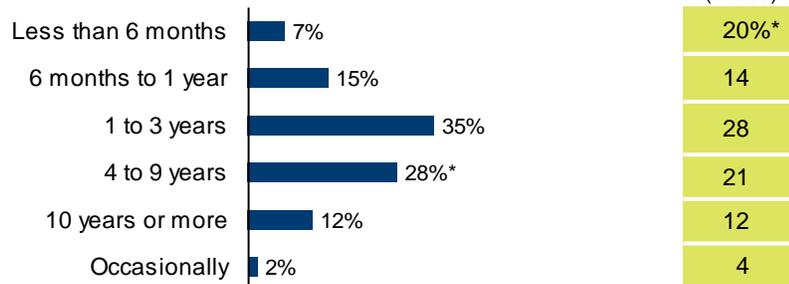
The average duration of caregiving reported by those who care for someone with Alzheimer's or mental confusion is four years, similar to the length of time other caregivers report. Roughly one in five Alzheimer's caregivers have provided care for less than one year (23%), 35% have been in their role for one to three years, and 40% have been caregivers for four or more years.

Figure 8: Duration of Care for Recipient

Q21. For how long have you been providing/did you provide care to your [relation]
[FOR CHILD RECIPIENT: for his/her condition]?

Base: 2009 All Alzheimer's caregivers
(n=423)

Non-Alzheimer's
Caregivers
(n=968)



2009 Alzheimer's Caregiver Subgroups

- One might imagine that caregivers of people with Alzheimer's or mental confusion often begin their role when their loved one still lives in his or her own home, but as the disease progresses, more may come to share a home with their care recipient. This may be part of what explains the finding that caregivers who live with their recipient have been providing care for 6.1 years, on average, far longer than the 3.6 years that caregivers of those who live in their own home have been in their role.
- Spousal caregivers of someone with Alzheimer's or mental confusion report having been caregivers for a very long time (8.7 years, on average). Nearly all spousal caregivers live with their recipient.[†]
- Primary caregivers have been in their role longer than non-primary caregivers (5.4 years vs. 3.4 years, on average).

Choice in Taking on Caregiver Role

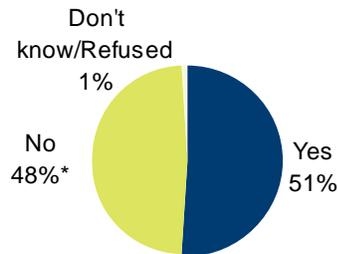
About half of Alzheimer's caregivers do not feel they had a choice in taking on their caregiving responsibility (48%). Caregivers of people without Alzheimer's or dementia are less likely to feel this lack of choice (41%).

[†] Caution, n=32 for spousal caregivers.

Figure 9: Choice in Taking on Caregiver Role

Q39. We have been talking about the help you provide/provided for your [relation].
Do you feel you had a choice in taking on this responsibility for caring for your [relation]?

Base: 2009 All Alzheimer's caregivers
(n=423)



Non-Alzheimer's
Caregivers
(n=968)

% No Choice
41%

2009 Alzheimer's Caregiver Subgroups

- Among those caring for a person with Alzheimer's or dementia, primary caregivers are more likely than non-primary caregivers to feel they did not have a choice (55% vs. 43%).
- Having a care recipient who lives in assisted living or a nursing home is also associated with lack of choice (64% vs. 43% when the recipient lives in his or her own home and 46% for caregivers who live with their recipient).

B. Caregiving Activities and Burden of Care

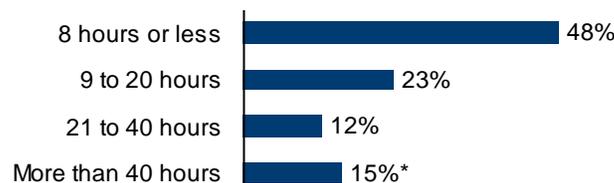
Hours of Care Provided

On average, Alzheimer's caregivers spend 21.9 hours per week providing care, revealing a more time intensive caregiving situation than that experienced by those who are providing care to a person with some other condition (17.4 hours per week, on average).³ Nearly half of Alzheimer's caregivers are in situations where their time commitment is modest, no more than eight hours each week (48%), but roughly one in six (15%) find themselves providing more than 40 hours of care per week.

Figure 10: Hours of Care Provided

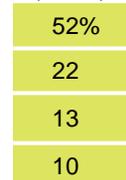
Q25. Thinking now of all the kinds of help you provide/provided for your [relation], about how many hours do/did you spend in an average week doing these things?

Base: 2009 All Alzheimer's caregivers
(n=423)



Average: 21.9 hours*

Non-Alzheimer's
Caregivers
(n=968)



17.4 hours

³ Any reports of constant care or caregiving in excess of 98 hours per week are capped at this level, equivalent to 14 hours per day.

2009 Alzheimer's Caregiver Subgroups

- Caregivers who live with their care recipient provide three times as many hours of care per week as those whose recipient lives in his/her own home (50.4 vs. 14.6 hours). Spousal caregivers, the vast majority of whom live with their loved one, are in particularly time-intensive caregiving situations (64.3 hours per week, on average).[†] Caregivers of those who live in assisted living or a nursing home spend an average of 10.5 hours per week giving care.
- Primary caregivers also spend considerably more hours giving care (32.7 per week, on average) than non-primary caregivers (13.0 hours).
- African-American and Hispanic caregivers spend much more time giving care (an average of 31.7 and 32.9 hours per week, respectively) than do White or Asian caregivers (19.8 and 15.8 hours).
- Caregivers age 65 or older provide care for notably more hours per week than do younger caregivers (39.1 vs. 19.3 hours).
- As one might expect, caregivers who are not employed tend to spend more time in their caregiving role (32.8 vs. 18.3 hours per week for employed caregivers).

Help with Activities of Daily Living (ADLs)

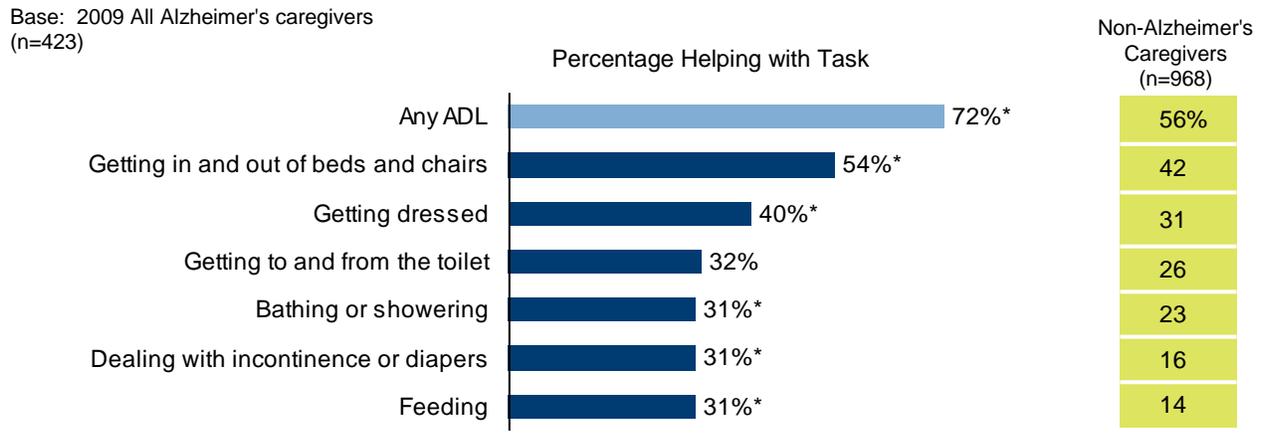
A majority of Alzheimer's caregivers (72%) help their care recipient with at least one Activity of Daily Living (ADL); that includes 38% who help with three or more. The most common ADL is helping their loved one get in and out of beds and chairs; 54% help with this. Four in ten help their care recipient get dressed (40%). Three in ten help with getting to and from the toilet (32%), bathing or showering (31%), dealing with incontinence or diapers (31%), or feeding their loved one (31%).

Caregivers whose loved one does not have Alzheimer's or dementia are far less likely to help with ADLs (56%), and they are less likely to help with each specific ADL except getting to or from the toilet.

[†] Caution, n=32 for spousal caregivers.

Figure 11: Help with Activities of Daily Living (ADLs)

Q22. 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. Do/Did you help your [relation] with [ADL] [IF CHILD RECIPIENT: because he/she is/was less able to do this task than children of the same age without his/her condition]?



2009 Alzheimer's Caregiver Subgroups

- Caregivers who live with their care recipient help with more ADLs (3.0, on average) than those whose recipient lives less than an hour away (2.0) or an hour or more away (1.8). Those who help someone living in assisted living or a nursing home are also helping with a larger number of ADLs (2.6).
- African-American caregivers assist with more ADLs than do Whites (3.2 vs. 2.0), and Hispanic caregivers also help with a similarly high number (2.9).
- Those who provide care to a spouse help with more ADLs, on average, than do those who care for some other relative or friend (3.2 vs. 2.1).[†]
- Female caregivers report helping their loved one with three specific tasks more commonly than male caregivers: getting dressed (47% vs. 28%), bathing (37% vs. 18%), and dealing with incontinence (36% vs. 23%).
- Those who live with their care recipient are also more likely than caregivers who live apart from their loved one to help with those same three ADLs.

Figure 12: Help with Selected ADLs Among Alzheimer's Caregivers

Distance from Care Recipient	Co-Reside (n=110)	Less Than 1 Hour Away (n=251)	1+ Hours Away (n=61)
Getting dressed	63%*	35%	27%
Bathing or showering	57%*	25%	18%
Dealing with incontinence or diapers	51%*	26%	23%

- African-American and Hispanic caregivers are more apt than White caregivers to help their care recipient get dressed (67% and 58% vs. 35%), bathe/shower (54%

[†] Caution, n=32 for spousal caregivers.

and 45% vs. 27%), or to feed him or her (49% and 53% vs. 25%). African-Americans are also more likely than Whites to help their loved one get in and out of beds and chairs (70% vs. 52%).

- Help with incontinence becomes more common as the duration of caregiving lengthens. Among those having given care for less than four years, 24% help with incontinence, compared to 41% of those who have given care for a longer period. As one might expect, this ADL is more apt to be performed by older caregivers (45% of those 65 or older) than younger ones (29%).

Help with Instrumental Activities of Daily Living (IADLs) and Other Supportive Activities

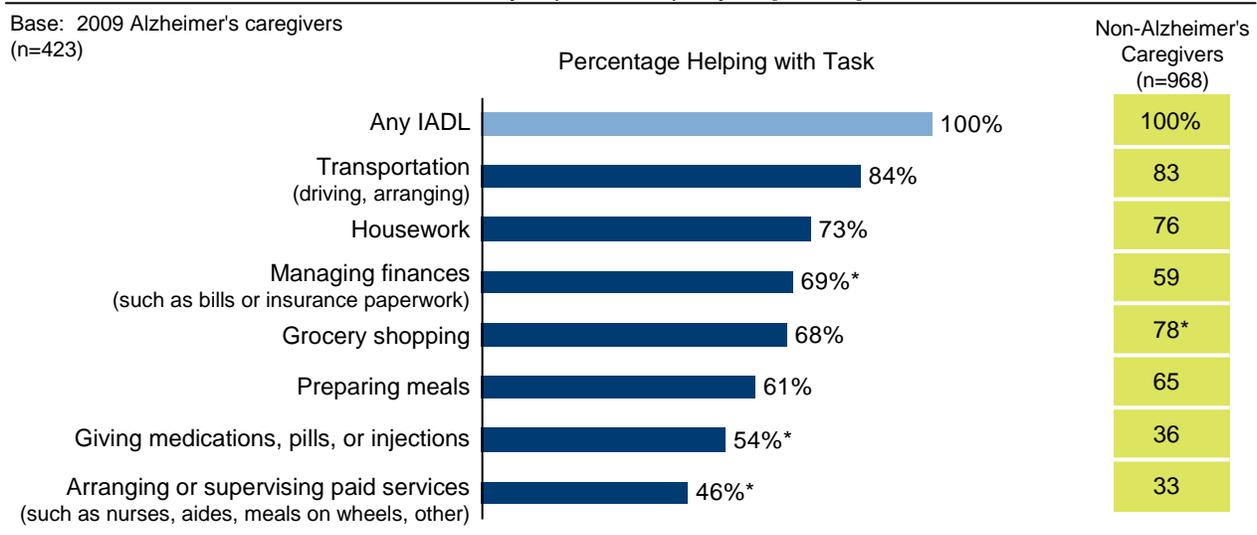
Caregivers of people with Alzheimer's or mental confusion help their loved one with 4.6 out of seven Instrumental Activities of Daily Living (IADLs) on average, not noticeably different from the 4.3 IADLs performed by other caregivers. Helping with transportation is most common for Alzheimer's caregivers (84%), followed by help with housework (73%), managing finances (69%), and grocery shopping (68%). Six in ten help their loved one prepare meals (61%), and slightly smaller shares help with medication (54%) or arranging services from an agency (46%).

The pattern of IADLs performed is different for those caring for someone who does not have Alzheimer's or mental confusion. A larger proportion of Alzheimer's caregivers give medicines (54% vs. 36%), manage finances (69% vs. 59%), or arrange or supervise services from an agency (46% vs. 33%). By contrast, they are less likely to help with grocery shopping (68% vs. 78%).

IADLs for Adult Recipients

Figure 13: Help with Instrumental Activities of Daily Living (IADLs)—for Adult Recipients

Q23. Do/Did you provide help to your [relation]...?



2009 Alzheimer's Caregiver Subgroups

- Not surprisingly, co-resident Alzheimer's caregivers help with more IADLs, on average (6.1 vs. 4.1 for those who live separately). They are much more likely than caregivers who live apart from their care recipient to help with each IADL except for arranging services from an agency. Roughly nine in ten co-resident caregivers help with each IADL except arranging services, which half help with.
- Help with grocery shopping is more common when the caregiver's loved one lives alone (82%) than when she or he shares a home with someone other than the caregiver (63%). Several other IADLs show a similar pattern: help with transportation (91% vs. 75%), managing finances (79% vs. 48%), and arranging services (51% vs. 32%). Presumably the person with whom the care recipient lives, typically a spouse but sometimes an adult child, fills in to help with these tasks.
- When a caregiver's recipient is in an assisted living facility or a nursing home, the mix of IADLs changes. Understandably, smaller shares of caregivers help with meal preparation (22%), giving medicines (26%), housework (33%), and grocery shopping (33%). But assistance with managing finances is still quite common (80%), more so than among caregivers whose loved one is in his or her own home (59%). Similarly, the need for arranging services is still evident (61%), more than it is when caregivers' loved one lives in his/her own home (40%).
- Primary caregivers help with more IADLs on average than non-primary caregivers (5.3 vs. 3.9). Further, they are more likely to help with each IADL except housework. The largest gaps between primary caregivers and non-primary caregivers are in managing finances (90% vs. 53%), giving medicines (70% vs. 41%), grocery shopping (80% vs. 57%), and preparing meals (70% vs. 53%).
- A larger share of African-American caregivers than White caregivers help with medication (72% vs. 51%), grocery shopping (80% vs. 65%), and preparing meals (75% vs. 57%). Hispanic caregivers are also more apt to help prepare meals (82%) relative to White caregivers (57%).
- A larger share of older caregivers, those at least 65 years of age, help their loved one by giving medicines (69% vs. 52% of younger caregivers) and managing finances (83% vs. 68%).
- Lower income caregivers, those in households with less than \$50,000 in income, are more apt to help their care recipient with housework (81% vs. 69% of higher income caregivers) and meal preparation (72% vs. 54%). One might hypothesize that a larger share of higher income caregivers use paid help in these areas. The data appear to support this possible explanation; although the two income groups are similarly likely to use at least some paid help, the higher income caregivers do indicate a greater reliance on the paid help. [See discussion pertaining to Figures 19 and 20.]

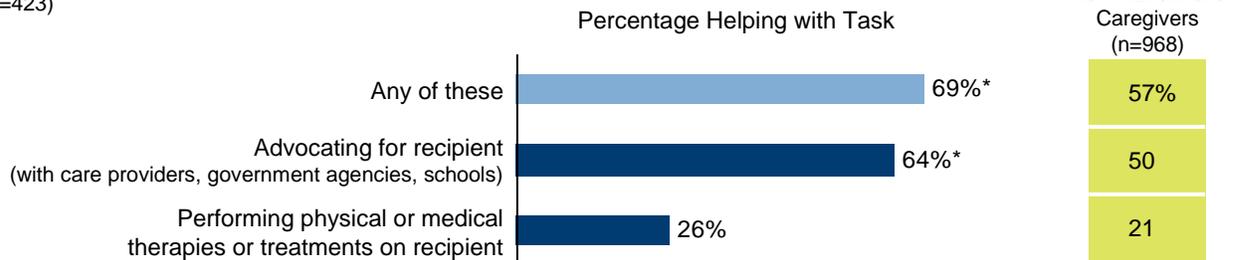
Other Supportive Activities for Adult Recipients

One role that a majority of Alzheimer's caregivers take on is that of advocating for their loved one, with care providers or government agencies. Six in ten report helping in this manner (64%), more than the half of non-Alzheimer's caregivers who do so (50%). Smaller shares of these two groups of caregivers perform physical or medical therapies or treatments on their loved one (26%, 21%).

Figure 14: Help with Other Supportive Activities—for Adult Recipients

Q23. Do/Did you provide help to your [relation]...?

Base: 2009 Alzheimer's caregivers
(n=423)



2009 Alzheimer's Caregiver Subgroups

- Advocacy for a loved one is more likely to be undertaken by Alzheimer's caregivers who are in more intensive caregiving situations, specifically:
 - Primary caregivers (76% vs. 55% of non-primary caregivers)
 - Those who spend more than 20 hours per week as a caregiver (73% vs. 61% of those spending less time)
 - Caregivers in households with at least \$50,000 in income (70% vs. 54% of lower income caregivers)
 - Caregivers who feel they had no choice in becoming a caregiver (79% vs. 50% of those who feel they had a choice)
 - Those who live with their care recipient (77%) and those whose loved one is in assisted living or a nursing home (77%), relative to those whose loved one lives in his or her own home (57%)
 - When the care recipient lives alone (74%), in contrast to when he or she lives with a person other than the caregiver (46%)
- As the caregiving burden rises, so does the likelihood that the caregiver will perform medical therapies or treatments on their loved one. Only 8% of low burden caregivers do so, compared to 22% of those with a medium burden and 49% of high burden caregivers.
- Similarly, co-resident caregivers are far more likely than those who live apart from their recipient to do medical treatments (53% vs. 19%).

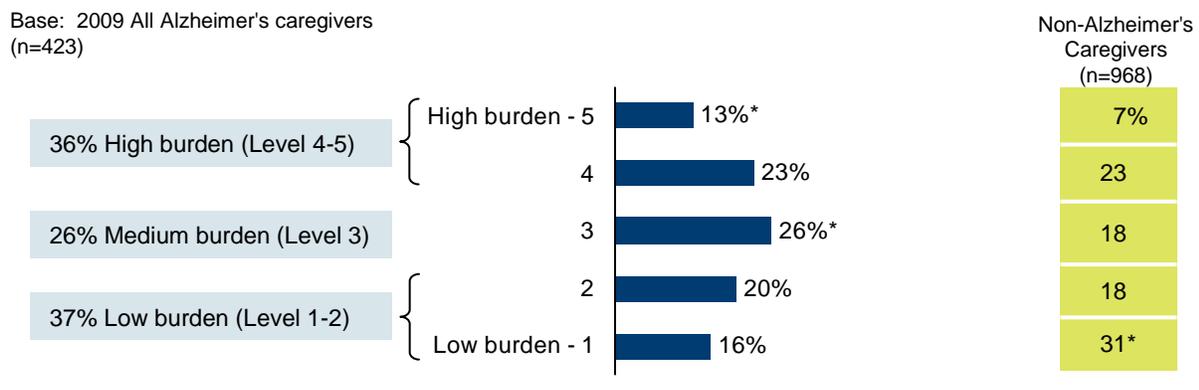
- Asian caregivers are more apt than White caregivers to report they perform such treatments (49% vs. 25%).

Burden of Care

Alzheimer's caregivers experience a greater burden of care than do caregivers whose loved one does not have Alzheimer's or dementia.⁴ They are half as likely to be in situations with the lowest level of care intensity (16% Level 1, compared to 31% of other caregivers. They are more likely to find themselves in situations with a medium to high level of burden (62% vs. 48%).

Overall, three in ten Alzheimer's caregivers are in high burden situations (36% with a level of care of 4 to 5), 26% have a medium burden, and 36% have a low burden (level 1 to 2).

Figure 15: Level of Care Index



For each level of care, the average number of hours of care provided, ADLs performed, and IADLs performed are as follows:

Figure 16: Components of Level of Care by Burden Category Among Alzheimer's Caregivers

Level of Care	Low Burden (n=140)	Medium Burden (n=104)	High Burden (n=171)
Hours of Care per Week	5.7	8.6	47.9
Number of ADLs – out of 6 total	0.3	2.6	3.8
Number of IADLs – out of 7 total	3.8	4.1	5.6

⁴ The measure of the burden experienced by caregivers is based on a Level of Care Index first developed in the 1997 study *Family Caregiving in the U.S.* and replicated in this study. The index is based on the number of hours of care given, as well as the number of ADLs and IADLs performed. The details of the index's construction are shown in Appendix B.

2009 Alzheimer's Caregiver Subgroups

- High burden situations are far more prevalent among caregivers who live with their recipient than among those who live separately (72% vs. 26%). Similarly, seven in ten of those caring for a spouse have a high caregiving burden (72%, compared to 34% of non-spousal caregivers who do).[†]
- A high burden is also more commonly reported by primary caregivers (48% vs. 26% of non-primary caregivers).
- Older Alzheimer's caregivers shoulder a greater caregiving burden than younger caregivers. Half of those ages 65 or older have a high caregiving burden (53% Levels 4 to 5), compared to 33% of younger caregivers.
- Caregivers who were not employed while caregiving are more likely to be in high burden situations (48% vs. 32% of employed caregivers).
- The burden of care is related to the length of time a person has been caregiving. Of those in their role less than four years, only 9% have a Level 5 burden, the highest on the scale, whereas twice as many longer-term caregivers do (20%).
- Caregivers in racial/ethnic minority groups bear greater burdens than do White caregivers (51% vs. 33% high burden). This difference is driven by the 57% of African-American caregivers and 45% of Hispanic caregivers in high burden situations. Asian caregivers (30% high burden) are more similar to Whites.

C. Presence of Other Caregivers

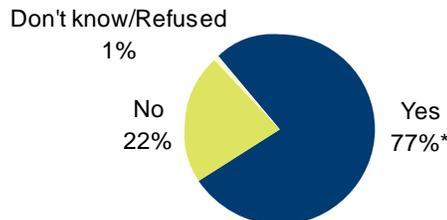
Presence of Other Unpaid Caregivers

Three-quarters of Alzheimer's caregivers (77%) report that someone else has also provided unpaid care to their relation within the past 12 months, notably more than the 66% of other caregivers who had this type of caregiving assistance.

Figure 17: Presence of Other Unpaid Caregivers

Q28. Has anyone else provided unpaid help to your [relation] during the last 12 months?

Base: 2009 All Alzheimer's caregivers (n=423)



Non-Alzheimer's Caregivers (n=968)

% Yes

66%

[†] Caution, n=32 for spousal caregivers.

2009 Alzheimer's Caregiver Subgroups

- Alzheimer's caregivers in high burden situations are least likely to say someone else provides unpaid help to their loved one (70% vs. 82% of those with medium or low burdens).
- Older caregivers—those age 65 or older—are less likely to have this kind of support (55% vs. 81% of younger caregivers).
- A related finding is that unpaid help is more common among employed caregivers (80%) than those who were not employed while caregiving (69%).
- As one might expect, caregivers who live with their recipient are least likely to say someone else also provides unpaid care (57%), and as distance away increases, so does the likelihood of this type of assistance. Among caregivers living within an hour of their recipient, 79% report other unpaid help, and 96% of those living even farther away do.
- The presence of other unpaid help is more widespread for recipients living with someone other than their caregiver (90%) than for those who live alone (78%) or those in a facility (73%).
- Only half of spousal caregivers (50%) report that someone else helps provide care, whereas 79% of those caring for some other relative or a friend do.[†]
- African-American caregivers are less likely than other ethnic groups to report the presence of other unpaid caregivers (55% vs. White 69%, Hispanic 80%, and Asian-American 82%).

Primary Caregiver Status

Just under half of Alzheimer's caregivers perceive themselves to be the primary unpaid caregiver (46%), meaning either that they are the sole caregiver (22%) or that there are other unpaid caregivers but they themselves provide the majority of unpaid care (24%). The 53% who are non-primary caregivers include 8% who share caregiving equally with someone else and 46% who say another caregiver provides most of the unpaid care.

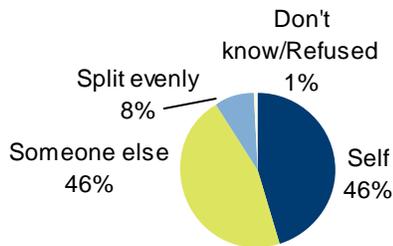
Interestingly, Alzheimer's caregivers are less likely than caregivers whose loved one has some other condition to consider themselves the primary caregiver (46% vs. 53%). This is true despite the fact that generally, caregivers in high burden and long duration situations—hallmarks of Alzheimer's disease—are *more* likely to be the primary caregivers. Perhaps when a relative suffers from Alzheimer's disease or mental confusion, a greater number of family members become involved in helping. The survey data bear this out; the decreased likelihood of being a *primary* caregiver is, in fact, driven by a lower likelihood of being the *sole* caregiver.

[†] Caution, n=32 for spousal caregivers.

Figure 18: Primary Caregiver Status

Q28. Has anyone else provided unpaid help to your [relation] during the last 12 months?
 Q29. Who would you consider to be the person who provides/provided most of the unpaid care for your [relation]—you yourself, or someone else?

Base: 2009 All Alzheimer's caregivers (n=423)



Non-Alzheimer's Caregivers (n=968)
 % Primary Caregiver
53%*

2009 Alzheimer's Caregiver Subgroups

- Older caregivers, those 65 and older, are much more likely than younger caregivers to be the primary caregiver (72% vs. 42%).
- A larger share of female caregivers than males consider themselves to be the primary caregiver (50% vs. 36%).
- The more intensive the caregiving situation, the more likely that the caregiver is the primary one. Specific groups more likely to be primary caregivers include:
 - High burden caregivers (60% primary vs. 37% of medium to low burden caregivers)
 - Those who had no choice about accepting their role (52% vs. 38% of those with choice)
 - Caregivers who live with their loved one (80%), compared to 40% of those who live less than an hour away and 17% of those who live an hour or more from their care recipient
 - Spousal caregivers, almost all who live with their care recipient (96% vs. 42% of non-spousal caregivers)[†]
 - Caregivers for four years or more (56% vs. 40% of those providing care for a shorter period of time)
- When caregivers' recipient lives in assisted living or a nursing home, about half say they are the primary caregiver (47%). A smaller share of those whose loved one lives in his/her own home say this is the case (32%).
- Of the caregivers whose recipient lives with someone else—typically a spouse or an adult child—only 22% consider themselves to be the primary caregiver. Presumably, the co-resident family member takes on that role. More than twice as many caregivers whose loved one lives alone say they are the primary caregiver (53%).

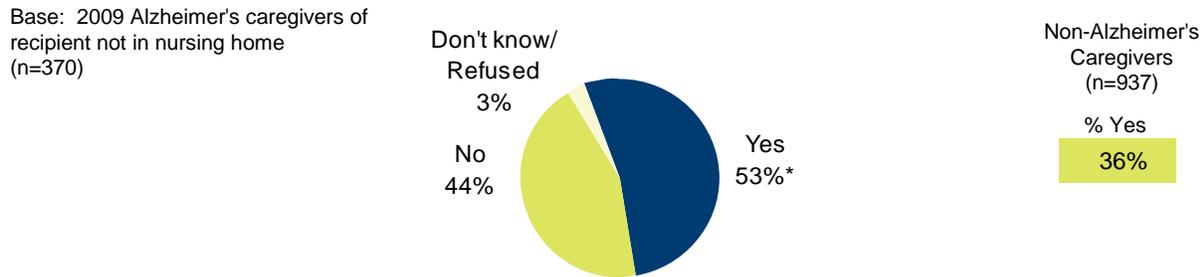
[†] Caution, n=32 for spousal caregivers.

Use of Paid Services

Among Alzheimer's caregivers whose recipient was not in a nursing home, half say their care recipient received paid help from aides, housekeepers or others during the last 12 months (53%). This compares to only 36% of non-Alzheimer's caregivers who report use of paid help.

Figure 19: Use of Paid Services

Q30. During the last 12 months, did your [relation] receive paid help from any aides, housekeepers, or other people who were paid to help him/her?



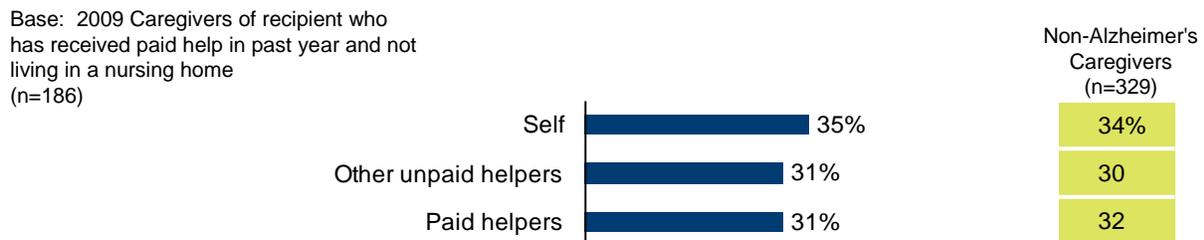
2009 Alzheimer's Caregiver Subgroups

- Two subgroups of Alzheimer's caregivers stand out as more likely to say their recipient used paid help—those who live at least one hour from their loved one (70%) and those whose loved one lives in an assisted living facility (85%).
- By comparison, 46% of those who live with their care recipient say she or he receives paid services, and 56% of those whose recipient lives in his/her own home do.
- Of note, caregivers who live in households with \$50,000 or more income are no more likely than those in households with lower incomes to report the use of paid services.

Three in ten of those whose care recipients receive paid help and do not live in a nursing home say the paid helpers provide most of the care for their loved one (31%). One-third say that they themselves provide more of the care (35%) and 31% say that other unpaid helpers do.

Figure 20: Predominant Caregiver Among Unpaid and Paid Helpers

Q31. Who would you say provides/provided more of your [relation's] care—you, other unpaid helpers, or paid helpers?



2009 Alzheimer's Caregiver Subgroups

- Among those whose care recipients have used paid help and do not live in a nursing home, caregivers with at least \$50,000 in household income are twice as likely as lower income caregivers to report that paid helpers provide the most care (39% vs. 14%), indicating that ability to afford the care influences how much it is used.
- Employed caregivers, who tend to have higher household incomes, are also more apt than those who are not employed to indicate that paid helpers are responsible for more of the care (35% vs. 17%).
- Only a small proportion of caregivers who live with their care recipient say paid helpers provide most of the care (7%). By comparison, 25% of caregivers whose recipient lives with someone else and 43% whose loved one lives alone report this is the case. This percentage predictably jumps for recipients who live in assisted living (96%).
- It is the lower and medium burden caregivers who are most likely to say that the paid help provides more care than others (38%, compared to 19% of high burden caregivers). It may be that reliance on the paid help is part of why their burden is lower, or it could be that the relative simplicity of a lower burden caregiving situation allows caregivers to feel more comfortable designating certain tasks to paid help.

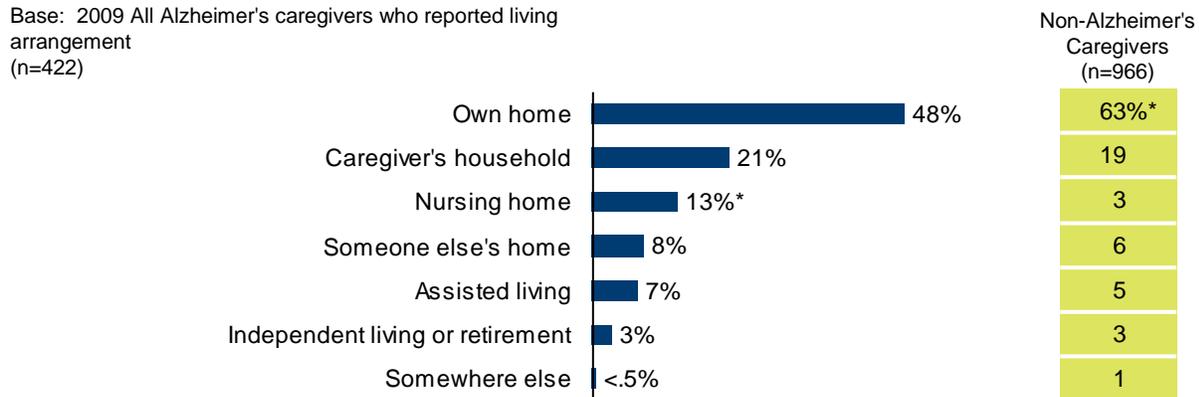
D. Care Recipient Living Situation

Where Care Recipient Lives

Half of Alzheimer's caregivers say their loved one lives in his or her own home (48%), but this living arrangement is more commonly reported by non-Alzheimer's caregivers (63%). By contrast, the Alzheimer's caregivers are more likely to indicate that the person to whom they provide care lives in a nursing home (13% vs. 3% of non-Alzheimer's caregivers). About one in five of both types of caregivers say they share a home with their care recipient (21%, 19%).

Figure 21: Where Care Recipient Lives

Q13. [IF NOT IN CAREGIVER'S HOUSEHOLD] Does/Did your [relation] live in his or her own home, someone else's home, an independent living or retirement community, an assisted living facility where some care may be provided, a nursing home or long-term care facility [IF CHILD RECIPIENT: a group home, foster care], or somewhere else? (Analyzed with Q11: Does/Did your [relation] live in your household, within twenty minutes of your home, etc?)



2009 Alzheimer's Caregiver Subgroups

- The likelihood of having a care recipient who lives in an assisted living facility is related to caregiver's household income. Only 2% of caregivers with less than \$50,000 in income have a care recipient in assisted living, compared to 9% of higher income caregivers. Perhaps the caregiver helps pay for this housing, or the caregiver's income is correlated with the care recipient's income.
- As the burden of care rises, so does the likelihood that the caregiver lives with his/her care recipient. Only 4% of low burden caregivers live with their loved one, compared to 15% of medium burden caregivers and 43% of those in high burden situations.
- Similarly, the proportion of primary caregivers who live with their care recipient is many times larger than the share of non-primary caregivers who do (38% vs. 8%).
- Caregivers who are 65 or older are more apt to live with the person to whom they provide care (43% vs. 18% of younger caregivers).
- Nine in ten spousal caregivers live with their loved one (92%), compared to only 17% of those caring for another relative or friend.[†]

[†] Caution, n=32 for spousal caregivers.

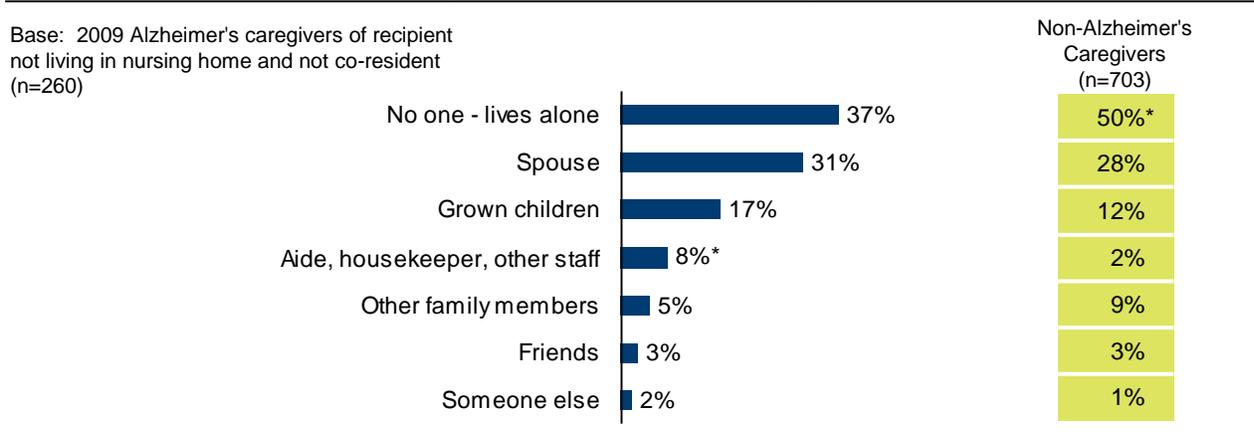
Who Care Recipient Lives With

Of the Alzheimer's care recipients who do not live with their caregiver or in a nursing home, more than one-third live alone (37%). Three in ten live with their spouse (31%), and about one in six live with grown children (17%). One in twelve (8%) live with paid staff.

Among non-Alzheimer's caregiving situations, a larger share of caregivers say their recipient lives alone (50%) and a smaller share say they live with paid staff (2%).

Figure 22: Who Care Recipient Lives With

Q14. Does/Did your [relation] live: [IF ADULT RECIPIENT: alone, with his/her spouse, with his/her grown children] [IF CHILD RECIPIENT: with his/her parents], with other family members, with friends, with an aide, housekeeper or other staff, or with someone else?
[MULTIPLE RESPONSES ALLOWED]



2009 Alzheimer's Caregiver Subgroups

- Among these non-co-resident caregivers whose loved one is not in a nursing home, those who are primary caregivers are twice as likely as non-primary caregivers to report that their loved one lives alone (59% vs. 26%), but half as likely to say their recipient lives with his or her spouse (18% vs. 39%).
- Older caregivers are more apt than younger ones to report that their loved one lives alone (61% of those 65+ vs. 35% of younger caregivers).

Caregiver Distance from Care Recipient

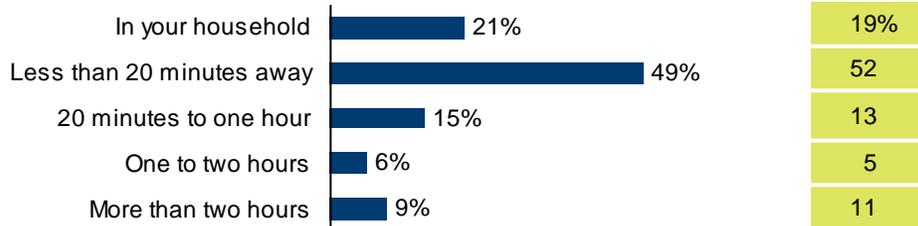
Seven in ten Alzheimer's caregivers live within twenty minutes of their care recipient (71%), including 21% who live together.

Figure 23: Caregiver Distance from Care Recipient

Q11. Does/Did your [relation] live in your household, within twenty minutes of your home, between twenty minutes and an hour from your home, a one to two hour drive from your home, or more than two hours away?

Base: 2009 All Alzheimer's caregivers (n=423)

Non-Alzheimer's Caregivers (n=968)



2009 Alzheimer's Caregiver Subgroups

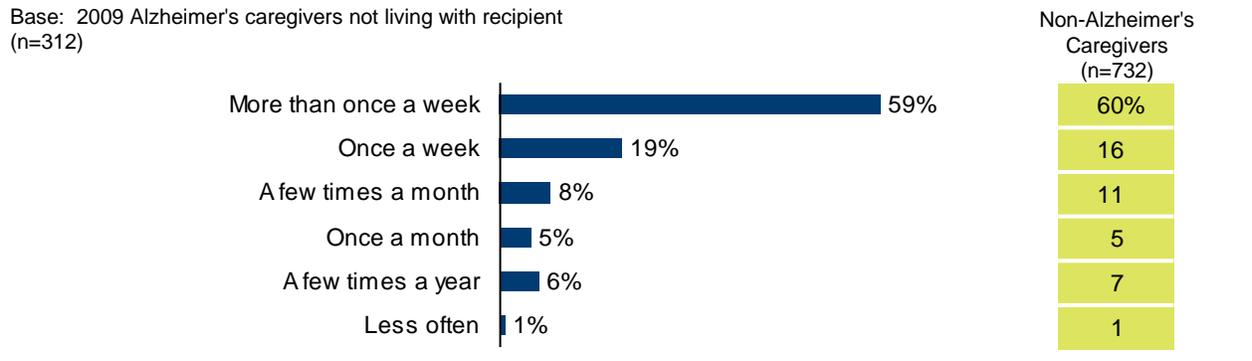
- Higher income Alzheimer's caregivers—those with at least \$50,000 in household income—are many times more likely to live an hour or more from their loved one than are lower income caregivers (20% vs. 4%). In particular, 12% live more than two hours away from their loved one vs. 1% of lower income caregivers. The greater reliance on paid caregiving that is seen among higher-income caregivers' recipients may be part of the reason. The added paid caregiving may fulfill enough of the recipients' needs that the caregivers feel they have more flexibility to live at a greater distance from their loved one. One might also posit that the higher-income caregivers are more apt to take on a caregiving role voluntarily since they have more money to travel to visit their loved one, but since they are no more likely than low income caregivers to feel they had a choice in taking on their role, this reasoning is not supported.

Frequency of Visits

Caregivers who do not live with their loved one were asked how often they visit their care recipient. A large majority visit at least once a week (78%), although at the other end of the scale, 8% visit less than once a month. Alzheimer's caregivers appear to visit their loved one with about the same frequency as non-Alzheimer's caregivers.

Figure 24: Frequency of Visits

Q12. On average, how often do/did you visit your [relation]?



2009 Alzheimer's Caregiver Subgroups

- Travel distance from the care recipient has a strong effect on the frequency of visits. Of the non-co-resident caregivers who live less than an hour from their loved one, 90% visit at least weekly, where as only 26% of those living farther away do.
- Still among non-co-resident caregivers, high burden caregivers are more apt than caregivers with a medium or low burden to visit once a week or more (86% vs. 75%). Likewise, a larger share of primary caregivers visit with this frequency (85% vs. 74% of non-primary).
- Those with less than \$50,000 in household income are more likely than higher income caregivers to say they visit more than once a week (73% vs. 52%). Part of this difference is due to the fact that higher income caregivers tend to live at a greater distance from their loved one. However, even among those who live within 20 minutes of their care recipient, the lower income caregivers are more likely to visit more than once a week (85% vs. 71%).

E. Care Recipient's Condition

Types of Care Recipient Conditions

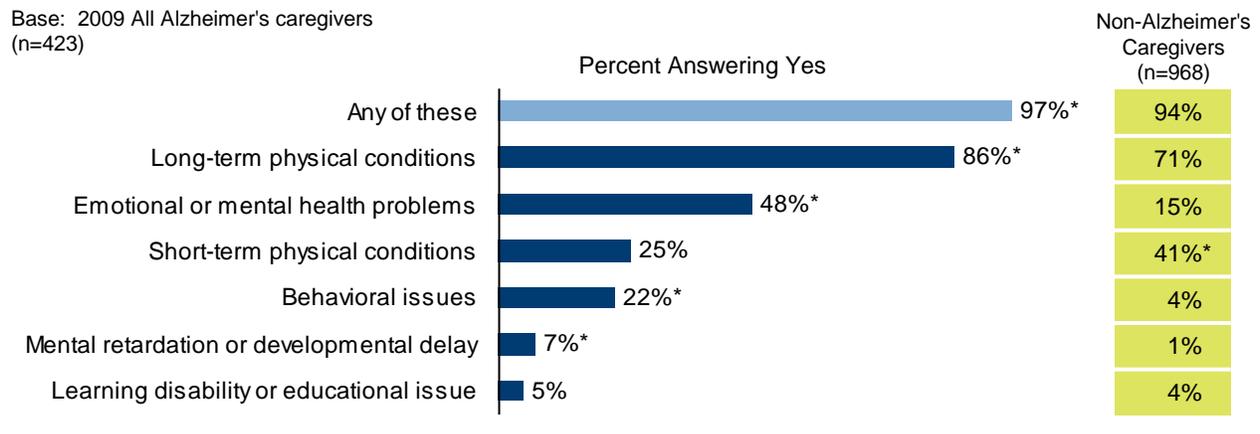
A large majority of those caring for someone with Alzheimer's disease, dementia, or mental confusion say their loved one needs care because of a long term condition (86%), and about half note that he or she has an emotional or mental health problem (48%). Non-Alzheimer's' caregivers are less likely to report these types of conditions (71% and 15%, respectively). Alzheimer's' caregivers are also many times more likely to say their loved one has behavioral issues (22% vs. 4%).

A small subset of Alzheimer's caregivers report mental retardation or developmental delay as a condition for which their loved one needs care (7%). Of note, even among those who volunteer that Alzheimer's or dementia is the *main* problem for which the recipient needs care [See Figure 1], the perception of developmental delay is just as prevalent (8%).

Only one in four Alzheimer's caregivers say their loved one has some sort of short-term physical condition (25%), compared to 41% of non-Alzheimer's caregivers who do.

Figure 25: Types of Care Recipient Conditions

Q17. *Would you say that your [relation] needs/needed care because of any...?*
[MULTIPLE RESPONSES ALLOWED]



2009 Alzheimer's Caregiver Subgroups

- Caregivers who volunteer that Alzheimer's disease or dementia is their loved one's main condition are more likely than Alzheimer's caregivers in general to say their loved one has emotional or mental health problems (62% vs. 48%).
- Alzheimer's caregivers who live at least one hour from their loved one are also more apt to believe their loved one has an emotional or mental health problem (62% vs. 46% for those who live closer or live together).
- The vast majority of African-American and Hispanic caregivers report that their care recipient has a long-term physical condition (95% each), more so than do White (85%) or Asian (72%) caregivers.
- The caregiver perception of lack of choice in taking on the caregiver role is associated with recipients who have mental health or behavioral conditions. In particular, Alzheimer's caregivers who feel they had no choice in taking on their caregiving role are more apt than those who did have a choice to say their loved one has emotional or mental health problems (60% vs. 39%) or behavioral issues (28% vs. 17%).

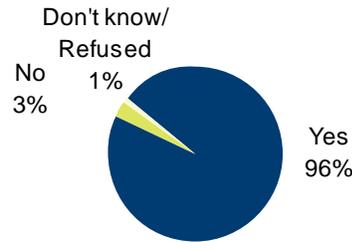
Medication Management

Nearly all Alzheimer's caregivers say their care recipient takes prescription medications (96%), virtually identical to the share of non-Alzheimer's caregivers who do.

Figure 26: Use of Prescription Medicine

Q26. Does/Did your [relation] take any prescription medicine?

Base: 2009 All Alzheimer's caregivers (n=423)



Non-Alzheimer's Caregivers (n=968)

% Yes

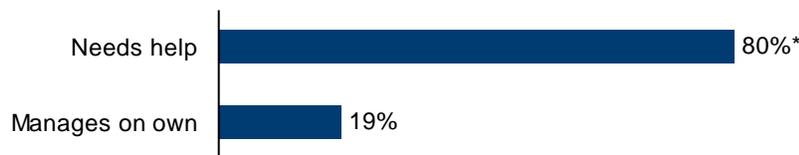
95%

Given the mental clarity needed to take medications properly, it is not surprising that medication issues are highly prevalent for recipients who have Alzheimer's or dementia—80% need someone to oversee his or her medication so that it is taken in the right amount and on time. The caregivers who name Alzheimer's or mental confusion as the main condition are especially likely to say their recipient needs help with medications (92%). By contrast, only one-third of caregivers whose loved one has some other condition indicate that medication management is an issue (34%).

Figure 27: Medication Management

Q27. Would you say your [relation] needs/needed someone to oversee giving him/her medicine in the right amount and on time or that he/she manages/managed this well on his/her own?

Base: 2009 Caregivers whose recipient takes prescription medication (n=410)



Non-Alzheimer's Caregivers (n=921)

34%

65*

2009 Alzheimer's Caregiver Subgroups

- The need for oversight in taking medicines properly is more common among high burden Alzheimer's caregivers than those with a low burden (87% vs. 69%).
- Nearly all of the care recipients living in assisted living or a nursing home are reported to need someone to oversee their medication (97%). Even among the care recipients living alone, 67% need this type of help.
- 93% of spousal caregivers of Alzheimer's recipients say their loved one needs someone to oversee the taking of their medications.[†]

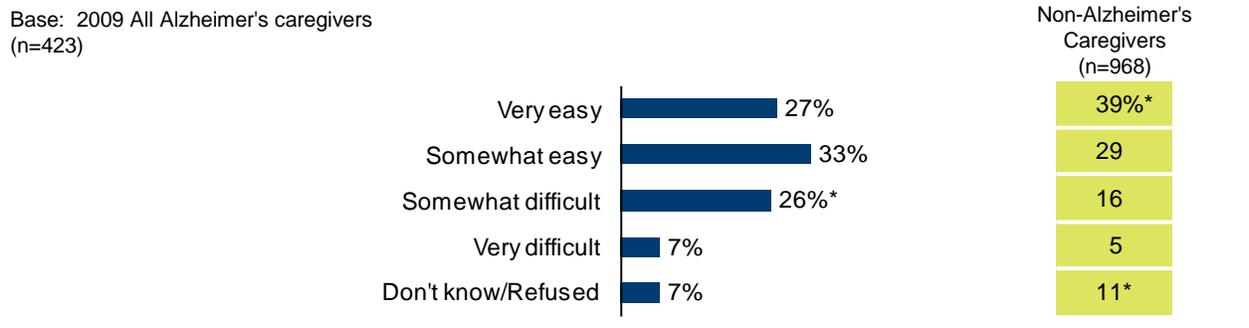
[†] Caution, n=32 for spousal caregivers.

Ease of Coordinating Care

One in three Alzheimer's caregivers finds it difficult to coordinate between the various health care and service providers who treat or help their care recipient (33%). A smaller share of non-Alzheimer's caregivers feel this degree of difficulty (21%), perhaps because of fewer care providers or less complex needs.

Figure 28: Ease of Coordinating Care

Q38. Please think about all of the health care professionals or service providers who give/gave care or treatment to your [relation]. How easy or difficult is/was it for you to coordinate care between these providers?



2009 Alzheimer's Caregiver Subgroups

- High burden Alzheimer's caregivers are more apt to note difficulty with coordination of services (43% vs. 26% of low burden caregivers).
- Younger caregivers are also more likely to consider this coordination difficult (35% of 18- to 64-year olds vs. 18% of older caregivers), even when controlling for the burden and duration of care.

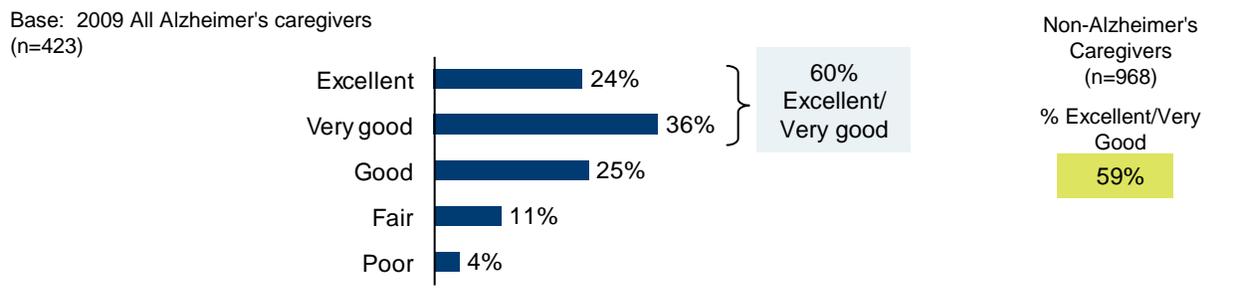
F. Strain and Stress of Caregiving

Caregiver Health

Six in ten Alzheimer's caregivers consider themselves to be in *excellent* or *very good* health (60%), about the same as caregivers of recipients without Alzheimer's or dementia.

Figure 29: Caregiver Health

D1. How would you describe your own health?



2009 Alzheimer's Caregiver Subgroups

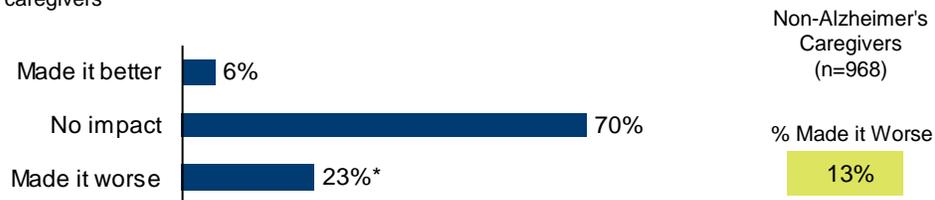
- Caregiving appears to tax one's health over time. Two-thirds of those in their role for less than four years report their health to be *excellent* or *very good* (67%), whereas only half of those who have been providing care for four years or more rate their health as highly (48%).
- White caregivers rate their health more highly than minorities do, with 62% of Whites saying they are in *excellent* or *very good* health, compared to 48% of Hispanics and Asians, and 49% of African-Americans.
- The caregiver's health declines as the burden of care rises; 74% of low burden caregivers rate their health as at least *very good*, while 41% of high burden caregivers do. Primary caregivers, who as a group tend to have a greater burden of care, also tend to be less healthy (50% *excellent/very good* vs. 69% of non-primary caregivers).
- Co-resident caregivers are less likely to rate their health as *very good* or better (43%) than those who live separately (64%).
- Not surprisingly, younger caregivers—those ages 18 to 64—rate their health more highly than older caregivers do (63% vs. 41% *excellent/very good*), even at low and medium burden levels.
- Caregivers who had a choice about taking on their role rate their health more highly (67% vs. 51%).
- Spousal caregivers are among the least likely to rate their health highly (24% *excellent/very good*).[†]

Although most Alzheimer's caregivers believe that taking care of their loved one has not had any effect on their health (70%), more than one in five feel it has had a negative impact (23%). This negative outcome is less widespread for non-Alzheimer's caregivers (13%).

Figure 30: Impact of Caregiving on Caregiver's Health

D2. How would you say taking care of your [relation] has affected your health?
Has it made it better, not affected it, or made it worse?

Base: 2009 All Alzheimer's caregivers (n=423)



2009 Alzheimer's Caregiver Subgroups

- Again, the duration of care seems to create or exacerbate the health decline. Of those who have provided care for fewer than four years, 17% note a downturn in

[†] Caution, n=32 for spousal caregivers.

their health, but 31% of those who have been caregivers for four years or more discern a negative impact on their health.

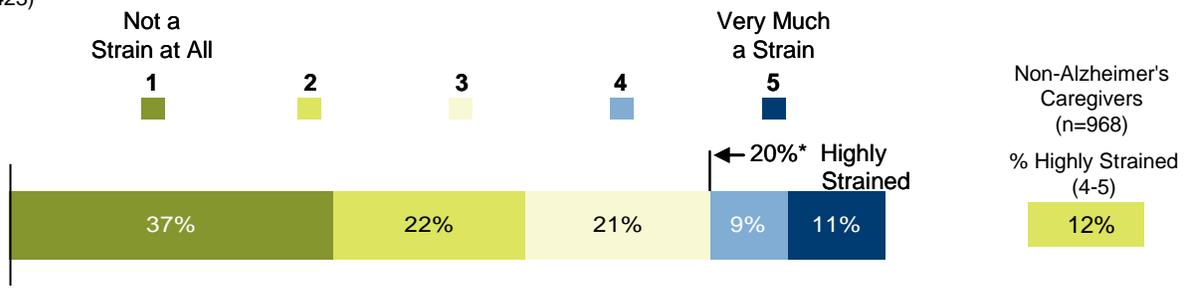
- A larger share of female caregivers than males report that caregiving has made their health worse (27% vs. 15%).
- Other subgroups of Alzheimer's caregivers who are more likely to report worsening health include:
 - High burden caregivers (37% vs. 16% of those in low to medium burden situations)
 - Primary caregivers (36% vs. 12% of non-primary)
 - Spousal caregivers (43% vs. 22%)[†]
 - Those who felt they had no choice in accepting their role (33% vs. 13% of those who had a choice)
 - Those who live with their loved one (34% vs. 20% of those living separately)

Providing care for a person with Alzheimer's, dementia, or mental confusion appears to cause a greater physical strain than caring for a person without this type of condition. One in five Alzheimer's caregivers say their role creates a high level of strain (20% rating it 4 to 5 on a 5-point scale), compared to 12% for non-Alzheimer's caregivers. Six in ten Alzheimer's caregivers rate their physical strain as low (59% rating it 1 to 2), and 21% report moderate strain (3 on the scale).

Figure 31: Physical Strain of Caregiving

Q35. Think of a scale from 1 to 5, where 1 is not a strain at all and 5 is very much a strain. How much of a physical strain would you say that caring for your [relation] is/was for you?

Base: 2009 All Alzheimer's caregivers (n=423)



2009 Alzheimer's Caregiver Subgroups

- Subgroups that are more likely to report a high degree of physical strain (4 to 5 on a 5-point scale) include:
 - Primary caregivers (30% vs. 11% of non-primary)
 - Those who did not have a choice in taking on their caregiving role (28% vs. 12% of those who did)

[†] Caution, n=32 for spousal caregivers.

- Those in high burden caregiving situations (38% vs. 13% for medium and 7% for low burdens)
- Co-resident caregivers (34% vs. 16% of those who live separately)
- Women (24% vs. 12% of men)
- Caregivers who were not employed (29% vs. 17% of employed caregivers)
- African-Americans (35%) relative to White (19%) and Hispanic (13%) caregivers

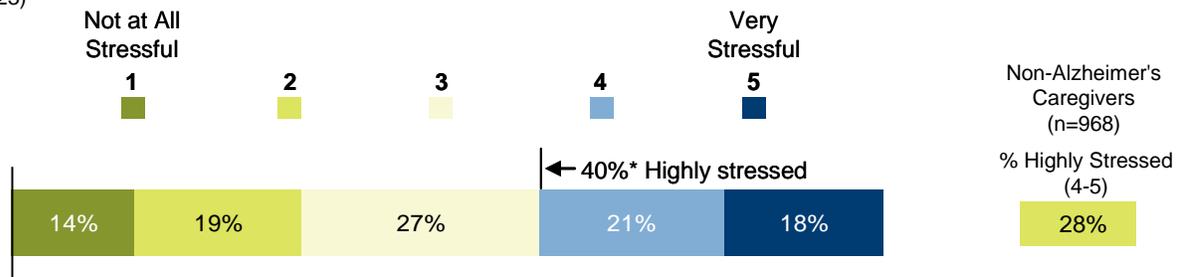
Emotional Stress of Caregiving

The experience of providing care to a person with Alzheimer's or dementia is associated with a fair degree of emotional stress. In fact, four in ten Alzheimer's caregivers rate their stress highly (40% rating stress 4 to 5 on a 5-point scale), and 27% consider their stress moderate (with a rating of 3). Three in ten report little to no emotional stress (33% giving a rating of 1 to 2), while non-Alzheimer's caregivers are much more likely to (52%).

Figure 32: Emotional Stress of Caregiving

Q36. 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 [relation] is/was for you?

Base: 2009 All Alzheimer's caregivers (n=423)



2009 Alzheimer's Caregiver Subgroups

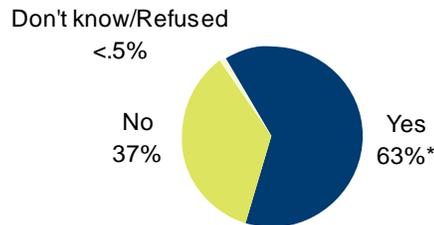
- Emotional stress, like physical stress, is more pronounced among Alzheimer's caregivers who have a high burden (58% indicating high emotional stress with a rating of 4 to 5 vs. 25% among low burden caregivers).
- Primary caregivers, who tend to have a higher burden, also rate their emotional stress more highly than non-primary caregivers (49% vs. 33% high stress).
- Lack of choice in taking on their caregiver role is associated with higher emotional stress as well (54% vs. 26% high stress).
- Female caregivers are more likely than male caregivers to rate their emotional stress highly (44% vs. 32%).
- Even when their loved one is in assisted living or a nursing home, the emotional stress of supporting them can still be prevalent (51%). High stress is more common in that situation than it is when the care recipient lives in someone else's home (27%).

In addition to experiencing emotional stress, a majority of caregivers contend that providing care to a person with Alzheimer's or mental confusion means they now spend less time with friends and family (63%). Loss of this time to re-energize and receive the support of family and friends must increase the personal toll felt by caregivers. A smaller share of those caring for someone without Alzheimer's or mental confusion report this loss of time with friends and family (49%).

Figure 33: Time for Family and Friends

Q40. As a caregiver, do/did you have less time for friends or other family members than before?

Base: 2009 All Alzheimer's caregivers (n=423)



Non-Alzheimer's Caregivers (n=968)

% Yes

49%

2009 Alzheimer's Caregiver Subgroups

- Alzheimer's caregivers who are particularly likely to report less time for family and friends include those with a high burden (82%) and primary caregivers (76%). By contrast, only half of low burden caregivers (50%) or non-primary caregivers (52%) have experienced this change.
- Living with the care recipient seems to exacerbate this problem of losing touch with friends and family (81% vs. 58% for those living separately). This may be why a very high proportion of spousal caregivers have noticed a loss of time with family and friends (85% vs. 62% non-spousal caregivers).[†]
- Those who feel they had no choice in becoming a caregiver are more apt than those who took on their role voluntarily to spend less time with friends and family (72% vs. 54%).
- Women are more likely than men to be distanced from friends and family as a result of caregiving (68% vs. 53%).

Financial Hardship of Caregiving

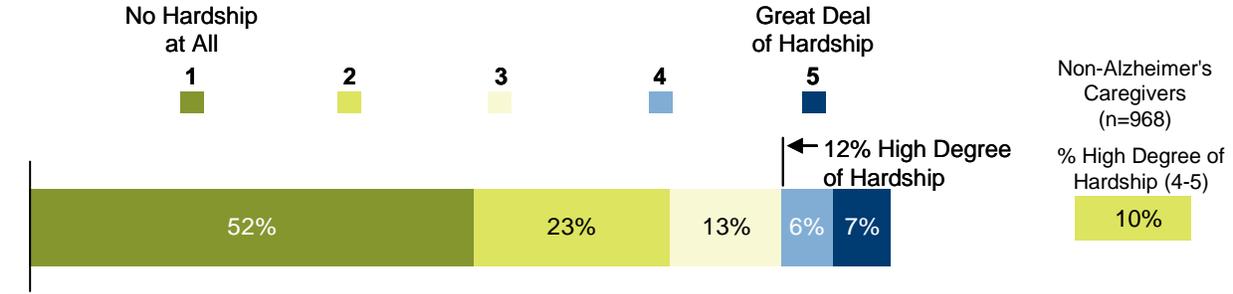
Most Alzheimer's caregivers feel little or no financial hardship as a result of caring for their loved one (74%). Only 12% report a high degree of financial hardship (4 to 5 on a 5-point scale). Still, these caregivers are more likely to feel at least a small amount of financial stress (a rating of 2 or higher) than are non-Alzheimer's caregivers (48% vs. 40%).

[†] Caution, n=32 for spousal caregivers.

Figure 34: Financial Hardship of Caregiving

Q37. 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 [relation] is/was for you?

Base: 2009 All Alzheimer's caregivers (n=423)



2009 Alzheimer's Caregiver Subgroups

- Serious hardship is more than twice as prevalent for caregivers who live with their loved one (26% vs. 9% of those living separately rating hardship 4 to 5) and four times as common among those who are caring for their spouse (46% vs. 10%).[†]
- Also more likely to cite serious financial hardship are caregivers who carry a high burden (23% vs. 10% for medium burden and 4% for low burden) and primary caregivers (22% vs. 5% for non-primary).
- Lack of choice in taking on one's caregiving role is also associated with a greater likelihood of serious financial hardship (20% vs. 6% of those who had a choice).
- Of those who were not employed while providing care, 21% rate their financial hardship as serious (4 to 5), compared to half as many employed caregivers (10%).

G. Impact of Caregiving on Work

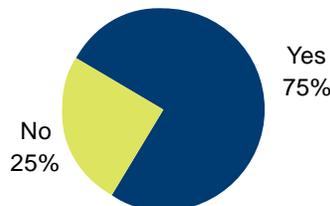
Employment Status and Caregiving

Three-quarters of Alzheimer's caregivers indicate they were employed at some time while they were caregiving (75%).

Figure 35: Concurrence of Employment and Caregiving

Q33. Have you been/Were you employed at any time since you began helping your [relation]? Analyzed with Q32 current employment status and Q1 whether current or past caregiver

Base: 2009 All Alzheimer's caregivers (n=423)



Non-Alzheimer's Caregivers (n=968)
% Ever Employed While Caregiving

73%

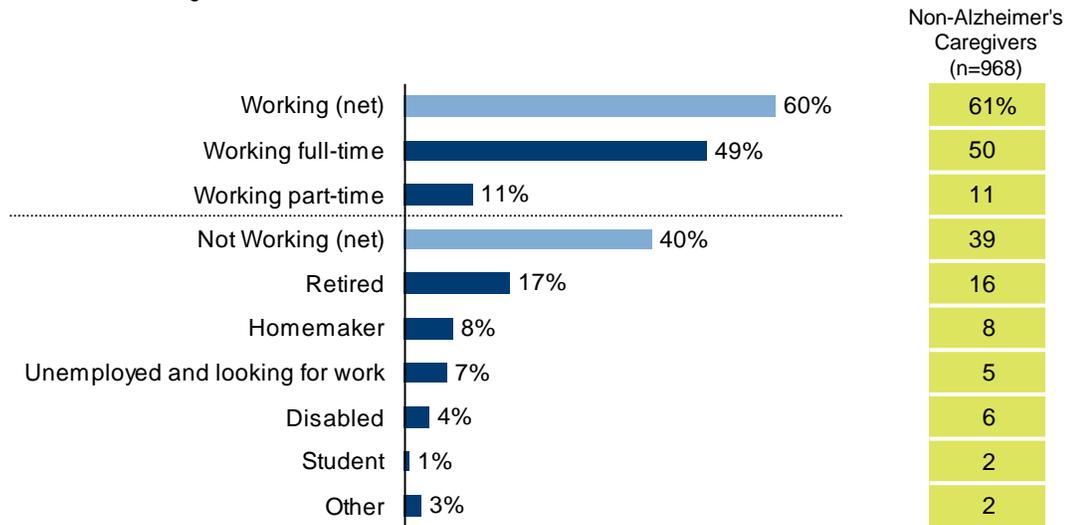
[†] Caution, n=32 for spousal caregivers.

Six in ten of those who were Alzheimer's caregivers in the past 12 months are currently employed (60%), with 49% working full time and 11% working part time. 17% are retired.

Figure 36: Current Employment Status of Caregiver

Q32. Are you currently working full time, working part time, a student, disabled, retired, a homemaker, unemployed and looking for work, or something else?

Base: 2009 All Alzheimer's caregivers (n=423)



2009 Alzheimer's Caregiver Subgroups

- Most caregivers age 65 or older have not been employed while serving as a caregiver, perhaps because 75% of them are currently retired. Only 35% report having been employed, compared to 81% of younger caregivers.
- Caregivers with a low burden are more likely to have been employed at some point while caregiving (84% vs. 66% of high burden caregivers).
- The same holds true of non-primary caregivers (82% vs. 67% of primary caregivers), and caregivers who live separately from their loved one (78% vs. 65% of those living together).
- A smaller proportion of African-American caregivers are currently employed (41%) relative to caregivers who are White, Hispanic, or Asian (61%, 64%, 69% respectively).

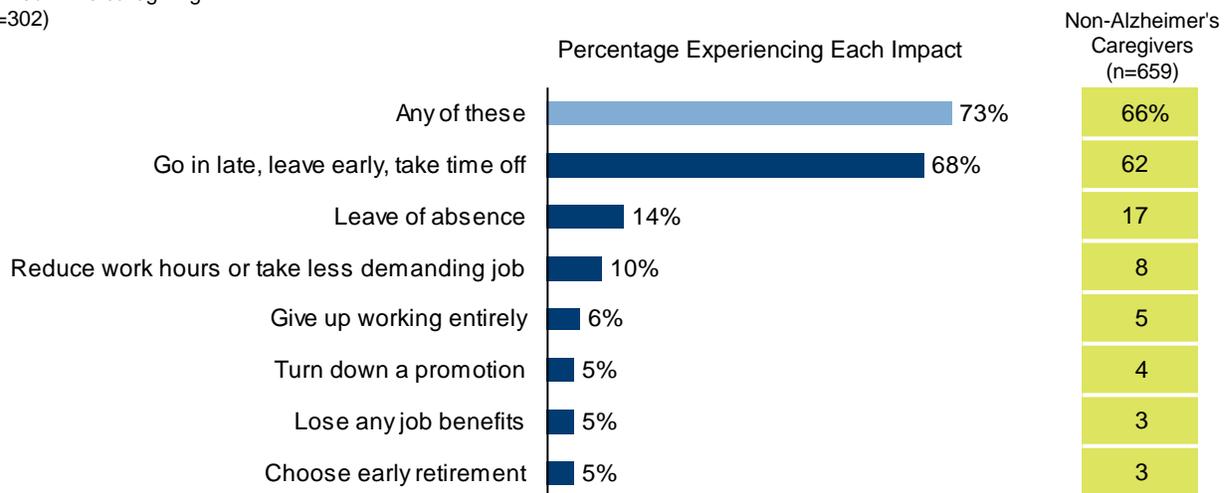
Work Accommodations Due to Caregiving

Given the challenge that many working individuals face in trying to achieve a good work/life balance, it is no surprise that becoming a caregiver results in employment changes or adjustments. Seven in ten Alzheimer's caregivers who worked while caregiving report making changes such as cutting back their working hours, changing jobs, stopping work entirely, taking a leave of absence, or other such changes as a result of their caregiving role (73%). The change seen most often is flexing work hours or taking time off to provide care (68%), but one in ten (10%) go so far as to stop work entirely, either leaving their job or taking early retirement.

Figure 37: Work Accommodations Due to Caregiving

Q34. *In your experience as both a worker and a caregiver, did you ever...?*

Base: 2009 Alzheimer's caregivers who worked while caregiving (n=302)



2009 Alzheimer's Caregiver Subgroups

- Caregivers with a higher burden of care, primary caregivers, and those who live with their care recipient make these employment changes at a much higher rate than their counterparts. For example, 83% of primary caregivers who worked while caregiving have gone in late or early, or taken time off to provide care, compared to 58% of non-primary caregivers.
- Stopping work entirely, including early retirement, is also twice as frequent among primary caregivers (14% vs. 6% non-primary) and three times as prevalent among caregivers who live with their loved one (22% vs. 7% of those living separately).
- Those who feel they had no choice in becoming a caregiver are more apt to flexing their work hours or taking time off to provide care (76% vs. 60%).

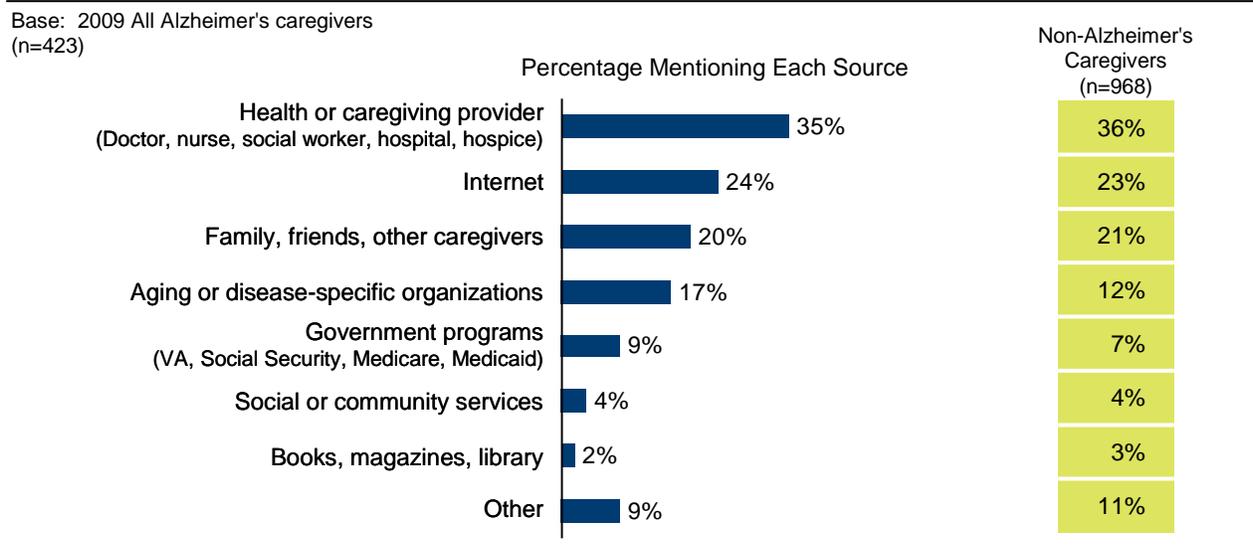
H. Information Sources and Needs

Sources of Information

When asked where they would turn for information related to caregiving, one in three Alzheimer's caregivers would seek out a health or caregiving provider (35%). These include doctors (20%), nurses (9%), as well as hospitals, residential facilities, social workers, and others. Another one in four would refer to the internet (24%), while two in ten would turn to family, friends, or other caregivers (20%). Only 6% cite a disease-specific organization, although this distinguishes them from non-Alzheimer's caregivers (1%).

Figure 38: Sources Used for Caregiving Information

Q41. If you were looking for information about some aspect of helping take care of your [relation], where would you turn?
[MULTIPLE RESPONSES ALLOWED]



2009 Alzheimer's Caregiver Subgroups

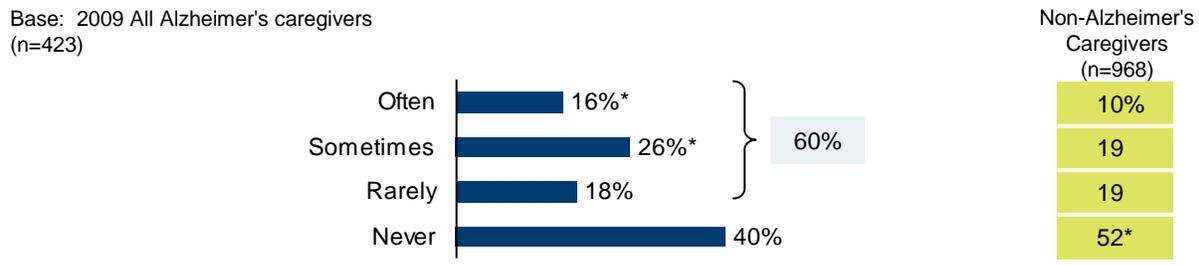
- Younger caregivers, those 18 to 64 years of age, are more than twice as likely as those who are older to use the internet for caregiving information (27% vs. 8%). Men are also more likely than women to use it (31% vs. 20%).
- Those in low burden situations are also more likely to say they would turn to the internet (29% vs. 16% of those in high burden situations).
- Higher caregiver household incomes (\$50,000 or more per year) are associated with a greater likelihood of contacting a health or caregiving professional for information (41% vs. 26% of lower income caregivers).
- Caregivers who feel they had a choice in taking on the responsibility of caring for their loved one turn to friends and family for advice more often than those who feel they had no choice (25% vs. 14%). They are less likely to turn to government programs (4% vs. 13%).

Internet Usage

The internet is a caregiving resource for Alzheimer's caregivers more than for those who care for someone without any kind of dementia or mental confusion. Six in ten Alzheimer's caregivers (60%) have been to an internet site to find caregiving related information within the past year, compared to 48% of non-Alzheimer's caregivers.

Figure 39: Internet Usage for Caregiving Information

Q42. How often, if at all, have you gone to internet websites in the past year to find information in any way related to being a caregiver for your [relation]?



2009 Alzheimer's Caregiver Subgroups

- Usage of the internet for caregiving information is higher among caregivers with greater household incomes. 70% of Alzheimer's caregivers in households with incomes of \$50,000 or more went online for caregiving information during the past year, whereas only 43% of those with less income did.
- As one might expect, younger caregivers are far more likely than older ones to use the internet. Specifically, 63% of those age 18 to 64 used it for a caregiving-related purpose, compared to 36% of older caregivers.
- Low burden caregivers are more likely than high burden caregivers to use the internet for caregiving information (67% vs. 51%); this difference is seen among younger as well as older caregivers.
- Alzheimer's caregivers whose recipient receives paid help are also more apt to use the internet (66% vs. 52%).

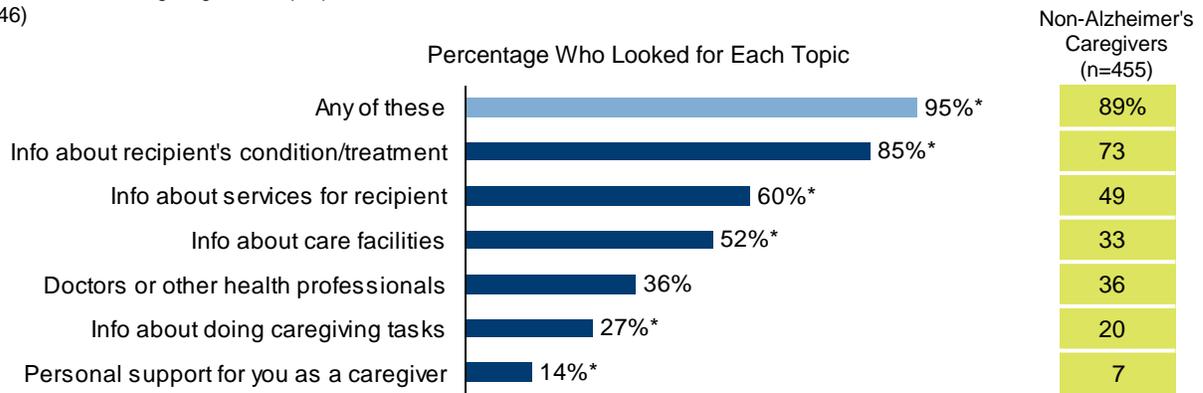
Among the Alzheimer's caregivers who used the internet for a caregiving-related purpose, more than eight in ten report they have looked online for information about their loved one's condition or treatment (85%). Six in ten (60%) sought out information about services for their recipient, and half (52%) looked for information about care facilities. Relatively few (14%) searched online for information about support for themselves as a caregiver.

For nearly every information topic asked about in the survey, Alzheimer's caregivers are more likely than non-Alzheimer's caregivers to have sought out information online.

Figure 40: Caregiving Information Sought Online

Q43. Did you look online for...?

Base: 2009 Alzheimer's caregivers who used the internet for a caregiving-related purpose (n=246)



2009 Alzheimer's Caregiver Subgroups

- A larger share of caregivers age 18 to 64 seek out information about services available for their loved one (63% vs. 23% of caregivers age 65+) and about doctors or other health professionals (38% vs. 18%).
- African-American caregivers are particularly inclined to look for information about available services (80%), relative to White caregivers (59%) and Asian caregivers (48%).

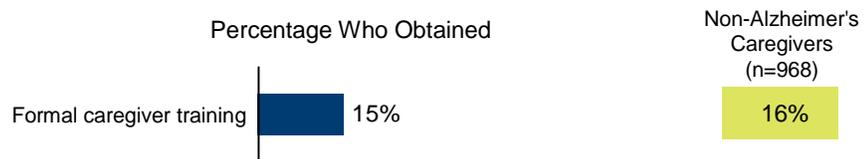
Caregiver Training and Information Needs

Only 15% of Alzheimer's caregivers have had any formal caregiver training about how to care for someone with their loved one's needs.

Figure 41: Caregiving Training

Q46. Have you done or obtained any of these types of things to make it easier to care for your [relation]? Have you obtained formal training of some sort about how to care for a person with your [relation's] needs?

Base: 2009 All Alzheimer's caregivers (n=423)



2009 Alzheimer's Caregiver Subgroups

- The chances of having participated in this training decline as distance from the caregiver increases. Specifically, 23% of those who live with their loved one have had such training, compared to 15% of those living within an hour and only 2% of those living farther away.
- Formal caregiver training is more widespread among high burden caregivers than it is among those with a low burden (20% vs. 10%).

- Three in ten African-American caregivers say they have had this type of training (32%), more than twice the proportion of White or Hispanic caregivers (13% each).

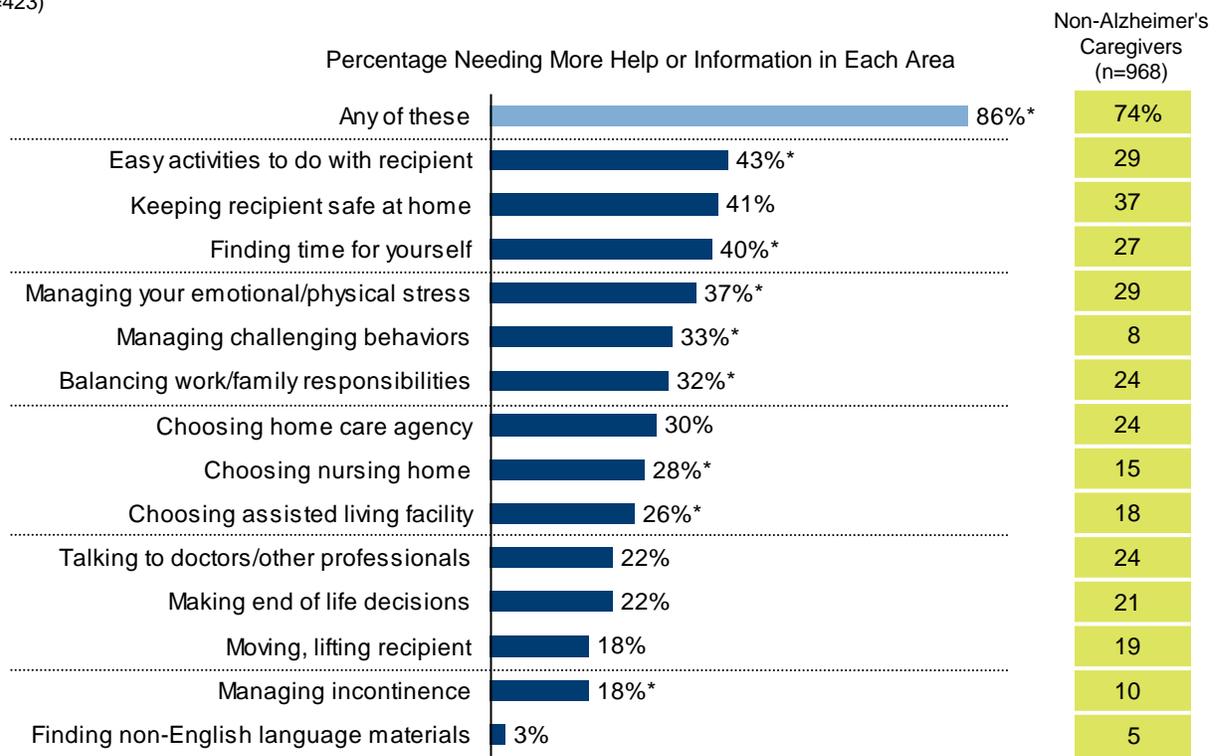
Regardless of whether they have had any formal training, a large majority of Alzheimer's caregivers feel they need more help or information about at least one of fourteen topics related to caregiving (86%); they surpass the 74% of non-Alzheimer's caregivers who feel this way. In fact, for 8 of the 14 topics asked about, a larger share of Alzheimer's caregivers express a need.

Alzheimer's caregivers' top information needs include finding easy activities to do together (43%), keeping their loved one safe (41%), and finding time for themselves (40%). The need for information about easy activities and finding time for themselves is more prevalent for them than it is for non-Alzheimer's caregivers (29% and 27%, respectively). Alzheimer's caregivers are also several times as likely as non-Alzheimer's caregivers to need help or information about managing challenging behaviors (33% vs. 8%).

Figure 42: Caregiving Information Needs

Q48. As a caregiver, on which of the following do you feel you need/needed more help or information?

Base: 2009 All Alzheimer's caregivers (n=423)



2009 Alzheimer's Caregiver Subgroups

- Certain information needs are more prominent during the earlier caregiving years and decline as the duration of caregiving increases. For example, the need for help managing challenging behaviors is cited by 41% of those providing care for less than four years, whereas 20% of longer-term caregivers do so. A similar contrast exists in selecting an assisted living facility (32% vs. 18%) or nursing home (33% vs. 19%), presumably because the care recipients are entering these types of care facilities over time.
- Caregivers' perception of choice on taking on their role appears to have an impact on the need for help managing emotional and mental stress. Nearly half of those who feel they had no choice need help or information about stress (47%), compared to 27% of those who felt they did have a choice.
- Greater burden is associated with a greater need for help or information. Specifically, the needs of high burden caregivers stand in contrast to those of low burden caregivers for:
 - Seeking easy activities to do with the care recipient (47% vs. 33%)
 - Finding time for oneself (60% vs. 25%)
 - Managing emotional and physical stress (49% vs. 29%)
 - Managing end-of-life decisions (27% vs. 14%)
 - Moving or lifting (28% vs. 6%)
 - Managing incontinence or toileting problems (29% vs. 7%)
- The types of help needed also differ between men and women. Female caregivers are more likely than men to want help with keeping their loved one safe at home (46% vs. 32%), finding time for themselves (45% vs. 32%), and managing emotional and physical stress (41% vs. 28%).

I. Support for Caregivers

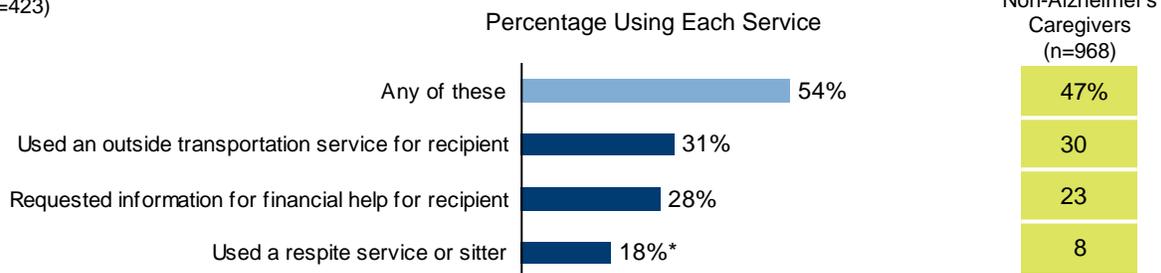
Supportive Services and Practices

About half of all Alzheimer's caregivers (54%) have sought at least one of three specific types of help on behalf of their care recipient. Transportation services and information about financial help for their loved one are equally common (31% and 28%, respectively). A smaller proportion have used a respite service or a sitter (18%), with Alzheimer's caregivers more likely than other caregivers (8%) to have done so.

Figure 43: Use of Services

Q45. In your experience as a caregiver, have you ever...?

Base: 2009 All Alzheimer's caregivers (n=423)



2009 Alzheimer's Caregiver Subgroups

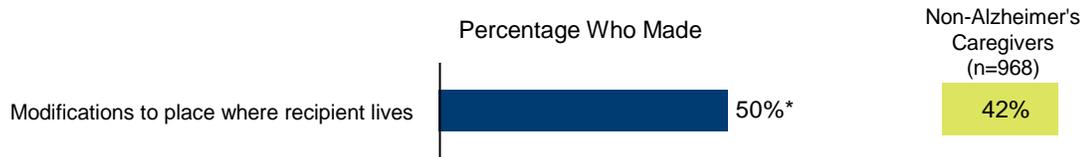
- The likelihood of using a respite service is greater among high burden caregivers (28% vs. 11% of low burden caregivers) and among those in their role for four years or more (25% vs. 14% of shorter-term caregivers).
- African-American caregivers are less likely than White caregivers to have used respite services (7% vs. 20%).
- The need for financial help is more apparent among Alzheimer's caregivers whose loved one is in assisted living or a nursing home (45%) than those living in their own home or the caregiver's (24%). Use of an outside transportation service follows a similar pattern (50% vs. 28%).

Half of Alzheimer's caregivers report having made home modifications to make things easier for their care recipient (50%), slightly more than the 42% of non-Alzheimer's caregivers who have.

Figure 44: Home Modifications

Q46. Have you done or obtained any of these types of things to make it easier to care for your [relation]? Have you had modifications made in the house or apartment where your [relation] lives to make things easier for him/her?

Base: 2009 All Alzheimer's caregivers (n=423)



2009 Alzheimer's Caregiver Subgroups

- Caregivers who have been in their role for at least four years are more apt to have made home modifications (61% vs. 44% of shorter-term caregivers).

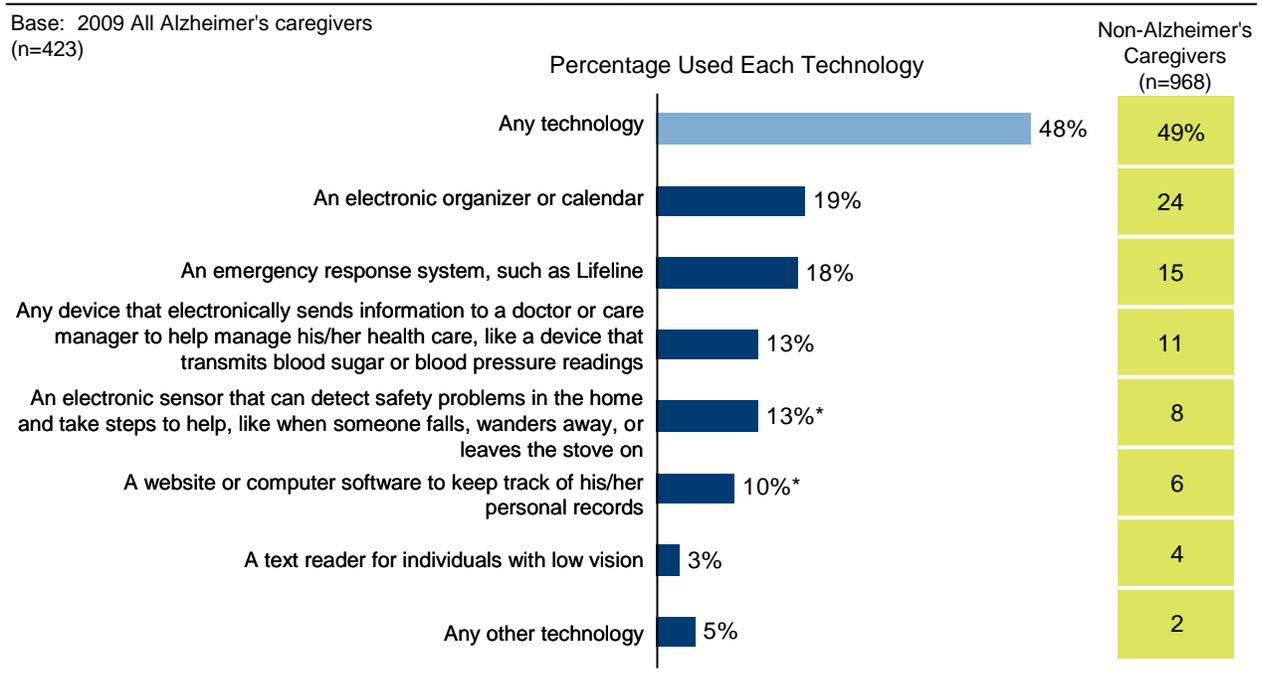
Use of Technology

In caring for their loved one, half of Alzheimer's caregivers have used some sort of technological device (48%). One in five have used an electronic organizer or calendar (19%) or an emergency response system such as Lifeline (18%). One in eight have used a device that electronically sends information to a doctor or care manager to help manage the recipient's care (13%) or an electronic sensor that can detect safety problems in the home and take steps to help (13%). Other uses of technology include a website or software for personal health records (10%), a text reader for people with low vision (3%), or some other technology (5%).

Use of an electronic sensor to detect safety problems is more common among Alzheimer's caregivers than non-Alzheimer's caregivers (13% vs. 8%), as is use of systems to keep track of health records (10% vs. 6%).

Figure 45: Use of Technology in Caregiving

Q44. In caring for your [relation], was the following ever used?



2009 Alzheimer's Caregiver Subgroups

- As one might imagine, use of a system like Lifeline is more widespread for recipients who live alone (25%) compared to those who live with either the caregiver or someone else (13%).
- Asian caregivers are far more likely than White or African-American caregivers to use a website or software to track health records (28% vs. 9% each).
- Minority caregivers, in general, are more apt than White caregivers to report use of an electronic organizer or calendar (30% vs. 17%).

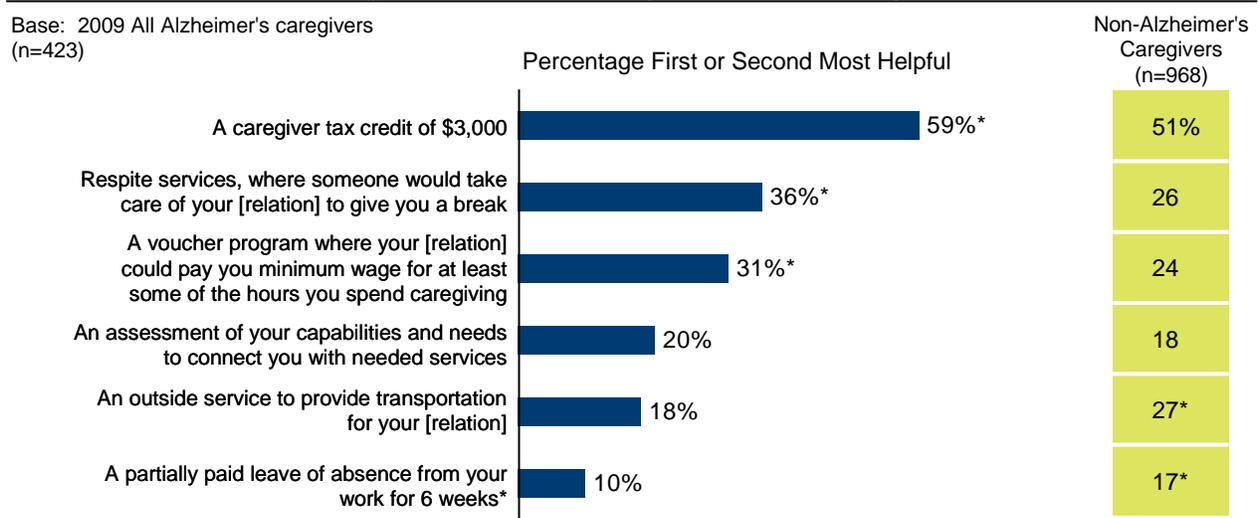
Reaction to Caregiving-Related Policies

Of six national policies or programs presented to caregivers as potential ways to help them, the most popular by far is a caregiver tax credit of \$3,000 (59% rate it as their first or second most preferred policy). Roughly one in three prefer respite services (36% first or second choice) or a voucher program where they could be paid minimum wage for at least some of their caregiving hours (31%).

The preferences of Alzheimer's caregivers differ from those of caregivers whose recipient has some other condition. The former are more apt to prefer the tax credit, voucher, or respite, whereas non-Alzheimer's caregivers are more inclined to choose an outside transportation service or a partially paid leave of absence from work.

Figure 46: Reaction to Caregiving-Related Policies

Q47. I am going to read you a list of things that policymakers are proposing to help caregivers like yourself. Please tell me which one you would find/have found most/second most helpful, regardless of whether or not you have used it already?



*Asked only of caregivers who were employed while caregiving, but percentages shown are based on all caregivers to be comparable with other policy items.

2009 Alzheimer's Caregiver Subgroups

- The voucher program that would pay caregivers for at least some of their time is more popular among caregivers with less than \$50,000 in household income (42% vs. 25% of higher income caregivers) and those in their role for at least four years (39% vs. 25% of shorter-term caregivers). Also particularly likely to prefer this program are women (37% vs. 21% of men) and African-American caregivers (47% vs. 30% of Whites and 20% of Asians).
- The tax credit is more commonly preferred by higher income caregivers (65% of those with \$50,000+ in household income) than lower income caregivers (48%).
- Caregiver expectations about the helpfulness of respite services rise in relation to burden of care. Only 23% of low burden caregivers prefer such a program, whereas 46% of high burden caregivers do.

J. Respondent Profile

Most caregivers of individuals with Alzheimer's, dementia, or mental confusion are women. Their average age is 51. Six in ten are married. Three in ten of these caregivers have children under the age of 18 living in their home.

Figure 47: Profile of Respondents

	Alzheimer's Caregivers (n=423)	Non-Alzheimer's Caregivers (n=968)
Gender		
Male	34%	32%
Female	66	68
Age of Caregiver		
18 to 34	14%	19%
35 to 49	26	28
50 to 64	46*	38
65 to 74	9	10
75 or older	4	5
<i>Mean age</i>	<i>50.8</i>	<i>49.5</i>
Race/Ethnicity of Caregiver		
White	81%*	74%
African-American	8	12*
Hispanic	7	11
Asian-American	2	2
Other	2	1
Marital Status		
Married	60%	59%
Living with a partner	3	6*
Single, never married	16	14
Separated, divorced	15	13
Widowed	6	7
Children/Grandchildren <Age 18 in Household		
Yes	30%	33%
No	70	67

Half of the respondents who care for someone with Alzheimer's, dementia, or mental confusion have a college degree. Their average household income is \$67,200.

Six in ten are employed, and 17% are retired.

	Alzheimer's Caregivers (n=423)	Non-Alzheimer's Caregivers (n=968)
Education		
Less than high school	3%	5%
High school graduate	22	24
Some college	23	24
Technical school	2	2
College graduate	26	26
Graduate school	23	19
Household Income		
Less than \$50,000 (net)	36%	41%
Less than \$15,000	8	7
\$15,000 to \$29,999	12	13
\$30,000 to \$49,999	15	20
Less than \$50,000, not fully specified	1	1
\$50,000 or more (net)	60	54
\$50,000 to \$74,999	17	20
\$75,000 to \$99,999	16	11
\$100,000 or more	22	20
\$50,000+, not fully specified	4	2
<i>Median Household Income</i>	<i>\$67,200</i>	<i>\$57,700</i>
Current Employment Status		
Working full time	49%	50%
Working part time	11	11
Retired	17	16
Homemaker	8	8
Unemployed and looking for work	7	5
Disabled	4	6
Student	1	2
Other	3	2

Four in ten Alzheimer's caregivers live in suburban areas, as do their care recipients. Roughly three in ten live in urban areas and an equal share live in rural areas. One in five care recipients have served in the armed forces.

	Alzheimer's Caregivers (n=423)	Non-Alzheimer's Caregivers (n=968)
Caregiver Living Location		
Urban	28%	30%
Suburban	40	38
Rural	31	31
Care Recipient Living Location		
Urban	29%	34%
Suburban	40	37
Rural	28	28
Caregiver Service in Armed Forces		
Served on active duty	12%	10%
Did not ever serve	88	90
Care Recipient Service in Armed Forces		
Served on active duty	23%	19%
Did not ever serve	76	80