

CAREGIVING IN THE U.S.

A Focused Look at Those Caring for the 50 +

FULL REPORT

November 2009

National Alliance for Caregiving
In Collaboration With
AARP

Funded by
MetLife Foundation

The **National Alliance for Caregiving** is a nonprofit coalition of more than 40 national organizations that focuses on issues of family caregiving across the life span. Established in 1996 by founding members AARP, the American Society on Aging, the National Association of Area Agencies on Aging, the National Council on Aging, and the U.S. Department of Veteran's Affairs, the Alliance was created to conduct research, do policy analysis, develop national programs, and increase public awareness of family caregiving issues. Recognizing that family caregivers make important societal and financial contributions toward maintaining the well-being of those for whom they care, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients. More information about The National Alliance for Caregiving is available at www.caregiving.org.

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Acknowledgements

The National Alliance for Caregiving in collaboration with AARP and with funding by MetLife Foundation is proud to present *Caregiving in the U.S. A Focused Look at Those Caring for Someone Age 50 or older*, a companion report partially based on findings from the *Caregiving in the U.S.* survey.

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Questionnaire revisions were made by a team representing the National Alliance for Caregiving, AARP and Mathew Greenwald & Associates. AARP funded Mathew Greenwald & Associates to conduct oversamples to match or exceed the numbers attained in 2004 to allow for a robust analysis and tracking of caregiving trends between 2004 and 2009. We would like to thank Linda Naiditch for her assistance. This report was written by Linda L. Barrett, Ph.D. It was reviewed by Teresa A. Keenan, Ph.D., Health Team Lead in AARP's Knowledge Management. Within AARP, we would also like to thank Liz Bradley, Elinor Ginzler, Robert Hodder, Susan Lutz, Kieun Oh, and Nancy Thompson for their insights and support as well as Jennifer Leslie for preparing the graphics for the ethnic subgroups. For additional information about this study, contact Linda Barrett at 202-434-6197 or lbarrett@aarp.org. This executive summary, along with the full report, is available at www.aarp.org/caregivingus, www.caregiving.org, and www.metlife.org.

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I. Introduction

The purpose of this analysis is to determine how many caregivers age 18 and over are providing assistance to someone age 50 years and older in the U.S. We want to know who they are, what they do for the person they assist, and how caregiving affects their lives.

The first national profile of caregivers was published in 1997 in *Caregiving in the U.S.* An updated version of the study was fielded in 2003 and reported in 2004. This report describes the findings from the third wave of this important study and begins to trend the findings. Each of these three studies has inquired about core elements of caregiving, and each has explored new areas.

The core areas include:

- How many caregivers there are in the U.S.?
- What are their demographic characteristics?
- What is the nature of their caregiving activities, the intensity and duration of care provided, the recipient's living situation and other sources of unpaid and paid help in the caregiving situation?
- How are caregivers affected by their role at work, at home, and in their social lives? Does caregiving affect their physical well-being, emotional stress, or create financial hardships?
- What are the information needs, and sources used by caregivers?

This year's unique areas of exploration include:

- Use of the Internet
- Perception of public policies designed to support caregivers
- Use of technology to assist them as caregivers

This is the first version of Caregiving in the U.S. to present trends for caregivers age 18 and over to care recipients age 50 and older.

II. Overview of Methodology

This report is based on telephone interviews with 1,397 caregivers who are 18 years of age and over who provide assistance to someone 50 years of age or older. The sample includes just over 800 Whites, approximately 200 African-Americans, 200 Hispanics, and 170 Asian-Americans. Caregivers are those who provide unpaid care to an older adult as described in the following question.

*At any time in the last 12 months, including now, have you provided unpaid care to a relative or friend 50 years or older to help them take care of themselves? Caregiving 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 does not need to live with you.*

Participants were recruited using a variety of appropriate sampling techniques. All of the White non-Hispanic participants were recruited using random digit dialing from the base study reported elsewhere. Most of the base study minority respondents were recruited using targeted samples. In addition, AARP commissioned the development of oversamples to allow us to better understand and compare caregivers assisting older adults. Geographic density samples were used to oversample African-Americans. The Hispanics and Asian-American oversamples required a combination of surname and density sampling. In addition, Knowledge Networks screened their Asian-American panel members to pre-identify Asian-American caregivers. Detailed information about the research methods appears in the appendix.

The screening results and survey results for the base study are weighted by household, based on the race/ethnicity and age of householder, and type of household (family or non-family) obtained from 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. The oversample of interviews of caregivers of recipients age 50 or older were weighted to the weighted distribution of caregivers age 50 and over in the base sample by householder race/ethnicity, age of the householder, and type of household (family or non-family).

The questionnaire was designed to replicate many of the questions posed in 1997 and 2004 as well as to explore new areas. It was designed by a team from the National Alliance for Caregiving, AARP, and Mathew Greenwald & Associates, and was also shaped by feedback from the advisory board.

Respondents were given the option of conducting the interview in Spanish or English, and 31% of the Hispanic respondents chose to conduct part, or all, of the interview in Spanish. The average length of the interview was 22.3 minutes. The survey data was collected between March 5 and June 17, 2009.

The margin of error for the sub-group reported in this section (caregivers 18 years of age and older caring for people age 50 and over) is +/- 3.2 percent at the 95 percent confidence level. This means that 95 times out of 100, a difference of greater than 3.2 percent would not have occurred by chance.

Reading this Report

The graphics in this report are designed to capture the descriptive information from the current wave of this study side-by-side with the new trend information. Consequently, readers should keep in mind that the graphic (pie chart or bar chart) on the left side of the page is the new data, and the table on the right side of the page represents a “mini” trend comparing the findings from 2004 with 2009. When the text describing the data is on the same page as the chart or table, the proportion is not repeated in the text. If they appear on different page, the proportion will appear in both places for easy reading and referencing.

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

To signal *key* differences between 2004 and 2009 findings, 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 refers solely to non-Hispanic Whites.

When presenting differences among age groups, younger groups refers to caregivers between the age of 18 to 49, middle aged caregivers refers to caregivers between the age of 50 to 64, and older caregivers refers to caregivers age 65 or older.

When talking about the reason the caregiver says the care recipient need assistance, the term Alzheimer’s disease or Alzheimer’s also includes care recipients the caregiver may have classified as having confusion, dementia, or forgetfulness.

III. Key Findings

This is the first version of *Caregiving in the U.S.* to present trends for caregivers age 18 and over who provide help to care recipients age 50 and older. In addition to this full report, other publications resulting from this study are:

- An Executive Summary of findings,
- A full report of findings, including appendices with the questionnaire and detailed methodology for caregivers of all ages
- Four companion reports that separately explore the experiences of caregivers (1) whose care recipient is under the age of 18, (2) whose caregiver is age 18 to 49, (3) whose caregiver is age 50 or older, or (4) caregivers from ethnic backgrounds (African-American, Hispanic, or Asian-American) who care for people age 50 or older.

We estimate there are at least 43.5 million caregivers age 18 and over, equivalent to 19 percent of all adults, who provide unpaid care to an adult family member or friend who is age 50 years or older. The percentage of people who are caregivers does not appear to have changed significantly since 2004.¹ Most caregivers assist other family members, most commonly their mother.

While caregivers and care recipients continue to be predominately female, both groups are approximately two years older now than their counterparts were five years ago. The average age of today's caregiver is 50, and the average age of today's care recipient is 77. While it is tempting to think the group of caregivers interviewed for this study are metaphorically the same caregivers from the last study, only older, the data shows that caregiving is a fluid role that people move into and out of over time. For example, on average, people are caregivers for four years.

When looking at the caregivers' age and the caregiver's relationship with the person they assist, one finds there are two distinctive types of caregivers. One group is composed of younger and middle aged caregivers who are providing care for a parent, parent-in-law, or grandparent (85% of all caregivers age 18 to 49 cares for one of these relatives and 75% of 50 to 64 year olds cares for one of these relatives). The second group is composed of older caregivers who are providing care for a spouse, sibling, or non-relative (58% of caregivers who are 65 or older care for these individuals).

Overall, there has been a decrease in the number of hours of care provided in an average week, yet a higher proportion of caregivers report helping their care recipient get into and out of beds and chairs, assisting with housework, and preparing meals.

¹ The 2009 study used a new method for measuring prevalence of caregiving. However, the methodology used in 2004 was applied to the 2009 findings to estimate if a change in prevalence has occurred. See the detailed findings and the detailed methodology appendix for more information. The estimate in 2004 was 16% vs. 18.9% in 2009, not a significant difference.

There is also an increase in the proportion of caregivers who say they need help or information. Specific areas of increased need include information on:

- Keeping their recipient safe at home,
- Finding easy activities to do with their care recipient,
- Choosing a home care agency, an assisted living facility, or a nursing home.

Caregivers also say they have increased their use of some services (such as outside transportation services for the person they help, and using a respite service or sitters).

Approximately three-fourths of caregivers have worked while caregiving. While this has remained consistent since our last study, there has been an increase in the proportion who says they have had to make a workplace accommodation due to caregiving. For example, there has been an increase in the most common workplace accommodation - having to go into work late, leave early, or take time off during the day to fulfill their caregiving responsibilities.

Time is an important issue for caregivers because this role takes time they could devote to other parts of their life. This situation can be further complicated when the caregiver does not feel she or he had a choice in taking on the role. Four in ten say they did not feel they had a choice in taking on this role. While caregiving is often a shared responsibility, it is not shared equally. Most caregivers say at least one other person has provided unpaid help to their care recipient in the past year. Among caregivers who say another unpaid caregiver provided help in the last twelve months, only one in ten say they split the care equally. One-third say they are the caregiver who provides most of the unpaid care.

Among caregivers who assist someone living in the community, the proportion of those who use paid services has decreased since our last study. However, among those who use paid services, there has been an increase in the proportion who says the paid caregiver provides more of the care recipient's care. We are more likely to see this higher reliance on paid help among caregivers with higher educational and income levels, along with those who have a low or medium level of burden and those who do not live with their care recipient.

Although most caregivers say they experience little physical strain, emotional stress, or financial hardship as a result of being a caregiver, there are indications that caregiving is becoming more emotionally stressful for some, and that some are experiencing more financial hardship fulfilling this role than five years ago.

While two-thirds of caregivers of those 50 and older say it is very or somewhat easy to coordinate their care recipient's health care professionals or service providers, one-quarter say they have a very or somewhat difficult time doing so. Caregivers who have a very or somewhat difficult time coordinating their care recipient's care are more likely to be caring for someone with Alzheimer's disease, to feel they had no choice in becoming a caregiver, have a high level of burden, and live one hour or more away from their care recipient.

Caregivers say they are likely to turn to health care providers, the Internet/print media, and family/friends/other caregivers for information. However, nearly half of caregivers say they have never gone to an Internet website in the past year to find information in any way related to being a caregiver. Nonetheless, caregivers are using technologies that help them meet their needs without having to go online. Nearly half report using one of six types of technology we asked about (such as electronic organizers or calendars, emergency response systems, electronic systems that send information to a doctor or care manager and electronic sensors to detect safety problems).^{2, 3}

Finally, caregivers tend to support the following caregiving-related policies: a tax credit of \$3,000, respite services, a voucher program which pays them a minimum wage to be a caregiver, and transportation services.

Since caregivers are a diverse and changing group, we need to continually reach out to them, over time, with information and services tailored to their needs in a variety of ways including providing information through intermediaries (such as doctors, nurses, case workers, disease-related organizations, friends and family). New technological devices and services that help caregivers and care recipients are likely to become more commonplace. While most caregivers say they are doing well, those who are vulnerable may need more than information.

When we take a closer look, we find there are many faces of caregiving. Three-fourths, are White. One in ten is Hispanic and another one in ten is African-American. Two percent are Asian-American. While there are similarities there are also important differences in these subgroups. We intentionally focused on each group separately so that their uniqueness can shine. The next two pages provide a summary of findings by ethnicity. For readers who want more information about ethnic caregivers who care for someone age 50 and over, see the companion report *A Focused Look at the Ethnicity of Those Caring for Someone Age 50 or Older*.

² Remote patient monitoring devices are projected to increase 77 percent over the next five years according to a study by ABI Research, Oyster Bay, NY.

³ Research shows a willingness to try new technologies they can help both caregiver and care recipient. See *Healthy @ Home Using Technology to Remain Independent*, AARP, 2008.

Hispanic caregivers are an average of 43 years old and are significantly younger than White and African-American caregivers. They are less likely to be married than White caregivers (48% vs. 63%) and more likely to say there are children or grandchildren under age 18 currently living in their household under age 18 (47% vs. 32% of all caregivers, 30% of White caregivers, and 30% of African-American caregivers). Hispanic caregivers are more likely to be a primary caregiver (61% vs. 48% of White caregivers and 43% of Asian-American caregivers) and more likely to say they have an annual income of under \$50,000 (56% vs. 39% of caregivers overall, 34% of White caregivers, and 31% of Asian-American caregivers). Therefore, it is not surprising that Hispanic caregivers are more likely to feel they need help balancing their work and family responsibilities (39% vs. 27% of caregivers overall and 25% of White caregivers) and finding time for themselves (41% vs. 29% White caregivers). While two-thirds have rarely/never gone to an Internet website in the past year to find information related to being a caregiver, more than half (53%) have used one of six technologies in caring for their care recipient. A caregiver tax credit ranked high on their list of desired public policies, yet they were more likely to support a voucher program where their care recipient could pay them a minimum wage for at least some of the hours they spend caregiving than White caregivers (37% vs. 24%).

African-American caregivers are significantly older (48 years old), on average, than Hispanic caregivers. They are more likely to be single-never married (28%) than caregivers overall (15%) or White caregivers (12%). Most African-American caregivers (59%) have an annual household income of less than \$50,000 and they are more likely to be in this situation than caregivers overall (39%), White caregivers (34%), or Asian-American caregivers (31%). African-American caregivers (41%) are more likely to provide assistance with three or more ADLs than White caregivers (28%) and Asian-American caregivers (23%). Seven in ten say they have rarely or never gone to Internet websites in the past year to find information in any way related to being a caregiver, yet about half (51%) report using one of six technologies in caring for their care recipient. African-American caregivers are more likely than Hispanic caregivers to support a three thousand dollar tax credit for caregivers. They are also more likely to support a voucher program than White caregivers.

Asian-American caregivers are almost equally likely to be male or female. While most are married (58%), significantly more than other caregiving groups are single, never-married (29% vs. 15% of all caregivers and 12% of White caregivers). Asian-Americans are highly educated. They are more likely to be college graduates than other caregiving groups (40% vs. 26% of caregivers overall, 26% of White caregivers, and 22% of Hispanic caregivers) and have a relatively high annual income.

Figure 1: Respondent Profile 18 + Caring for 50+

	Total (n=1,397) A	White (n=803) B	African- American (n=206) C	Hispanic (n=200) D	Asian- American (n=170) E
Gender					
Male	33%	33%	29%	33%	48% ^{ABC}
Female	67 ^E	67 ^E	71 ^E	67	52
Age of Caregiver					
Mean age	49.9 ^E	51.1 ^D	48.2 ^D	43.1	45.1
Marital Status					
Married	59% ^C	63 ^{CD}	44	48	58
Living with a partner	5 ^E	5	4	12 ^E	2
Single, never married	15	12	28 ^{AB}	21	29 ^{AB}
Separated, divorced	14 ^E	13	16	15	10
Widowed	7 ^E	7 ^E	8	4	2
Children/Grandchildren <Age 18 in Household					
Yes	32%	30	30	47 ^{ABC}	37
No	68 ^D	70 ^D	70 ^D	53	62
Education					
Less than high school	4%	3	5	14 ^{AB}	6
High school graduate	23 ^E	24 ^E	23 ^E	20 ^E	5
Some college	24	23	29	27	16
Technical school	2	2	3	3	1
College graduate	26	26	26	22	40 ^{ABD}
Graduate school	20	22	15	14	32 ^{CD}
Household Income					
Less than \$50,000 (net)	39%	34%	59% ^{ABE}	56% ^{ABE}	31%
\$50,000 or more (net)	55 ^{CD}	60 ^{CD}	38	38	64 ^{CD}
Current Employment Status					
Working full time	50%	51%	49%	43%	46%
Working part time	11	11	6	14	19 ^C
Retired	17 ^D	18 ^D	17	8	13

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated.

A full set of demographic tables appears at the end of this report detailing these and other characteristics. For additional information on Hispanic, African-American, and Asian-American caregivers, see *Caregiving in the U.S. 2009 Executive Summary: A Focused Look at Ethnicity and Caring for someone Age 50 or Older*.

IV. Detailed Findings

A. Prevalence of Caregiving

We estimate there are at least 43.5 million caregivers age 18 and over, equivalent to 19 percent of all adults, who provide unpaid care to an adult family member or friend who is age 50 years or older. We also estimate there are at least 54.1 million (24%) caregivers age 18 and over who provide unpaid care to an adult family member or friend who is age 18 and over.

Figure 2: Estimates of Individual Caregiving Prevalence by Age of Predominant Recipient⁴

Type of Predominant Recipient	Prevalence	Estimated Number of Caregivers
Predominant recipient age 50+	18.9%	43.5 million
Predominant recipient age 18+	23.5%	54.1 million

B. Basics of the Caregiving Situation

Current vs. Past Care

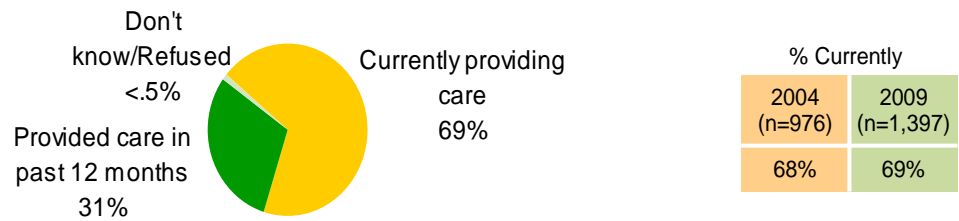
Over two-thirds of caregivers age 18 and over who provide assistance to someone age 50 and over say they are currently providing unpaid help to a relative or friend, while three in ten say they provided care in the past 12 months but are no longer doing so. This finding has remained consistent since our last caregiver study.

⁴ In order to estimate the prevalence of caregiving for a person age 50 or older, one must look at the *predominant* care recipient, since the questionnaire did not ask generally whether the caregiver provided care of *any* person age 50+. The magnitude of difference between prevalence of giving care to a predominant recipient vs. any recipient can be illustrated by looking at caregiving of adult's age 18+. The prevalence of providing care to a predominant recipient of this age is 23.5%, somewhat lower than the 26.8% known to be caring for any recipient age 18+.

Figure 3: Current vs. Past Care

Q1. Are you currently providing unpaid help to a relative, friend, or child, or was this something you did in the past 12 months but are no longer doing?

Base: 2009 All caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

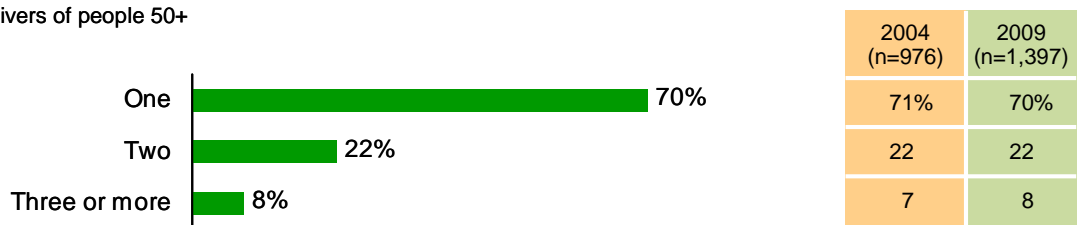
Number of Care Recipients

Most caregivers say they take care of one person, while about one in five say they care for two people. Less than one in ten report caring for three or more people.

Figure 4: Number of Care Recipients

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

Base: 2009 All caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Primary caregivers and older caregivers are more likely to report caring for one person.

- Primary caregivers are more likely than non-primary caregivers to report caring for only one person (76% vs. 62%).⁵ They are also more likely to say they are currently providing care rather than providing care in the past 12 months (73% vs. 64%).
- The likelihood of caring for just one recipient rises in relation to the age of the caregiver. Older caregivers are more likely to say they care for one person (82% among those 65 and older vs. 71% among those 50 to 64 and 65% among those 18 to 49). Similarly, middle aged caregivers and younger caregivers are more likely to say they are providing care to two people than older caregivers (25% among those 50 to 64 and 23% among those 18 to 49 vs. 12% among those 65 and older).

⁵ Primary caregivers are those that say no one else provides unpaid help in Q28, or respondent provides most of the help in Q29. A secondary caregiver is someone who says someone else provides most of the unpaid help or splits care in Q29.

However, the median number of people caregivers say they assist is one person, and this is consistent across the three age groups.

Caregiver Gender

Two-thirds of caregivers are female and one-third of caregivers are male.

Figure 5: Gender of Caregiver

Caregiver gender recorded by interviewer

Base: 2009 All caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

The profile of female caregivers shows they are more likely to:

- Identify themselves as the “sole caregiver” (31% vs. 23%).
- Have an annual household income of \$50,000 or less (43% vs. 31% of male caregivers),
- Have some college education (27% vs. 19% of male caregivers),
- Live in the same household as the care recipient or within 20 minutes of the care recipient (74% vs. 63%). When they say they do not live in the same household they visit their care recipient once a week or more (80% vs. 69%).
- Have to go from working full-time to part-time, or taken a less demanding job (12% vs. 5%) or experienced other impacts on their employment like losing benefits (4% vs. 1% and giving up work (8% vs. 2%).
- Be widowed (8% vs. 3% of male caregivers) or separated (3% vs. 1% of male caregivers).
- Male caregivers are more likely than female caregivers to say:
 - They help with arranging or supervising outside services from an agency (42% vs. 34%).
 - They were employed while being a caregiver (82% vs. 70%).

Care Recipient Gender

More than two-thirds of care recipients are female. Caregivers continue to be twice as likely to be caring for a female recipient as a male recipient.

Figure 6: Gender of Care Recipient

Q9. [IF NEEDED] Would you mind telling me if your [relation] is/was male or female?

Base: 2009 All caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

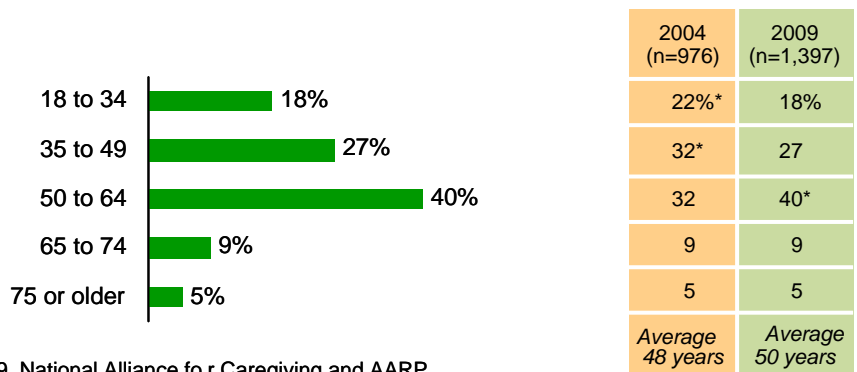
Age of Caregiver

The average age of caregivers 18 years of age and older who assist people age 50 or older is 50 years old. Over half (55%) of these caregivers say they are at least 50 years old including a small proportion (5%) age 75 or over (5%). More than one-quarter (27%) of caregivers are between 35 and 49 years of age and about one in five (18%) are 18 to 34 years old.

Figure 7: Age of Caregiver

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

Base: 2009 All caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

- About a quarter of young caregivers say they assist two people (25% of those 18 to 49 and 23% of those 50 to 64 vs. 12% of those 65 and older).
- One-quarter of older caregivers say they are assisting their spouse or partner and they are more likely to say this than their younger counterparts (25% of those 65 and older vs. to 4% of 50 to 64 year olds, 1% of 18 to 49 year olds).

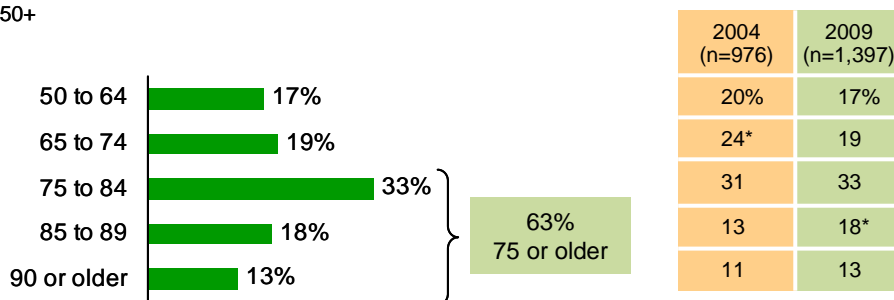
Age of Care Recipient

Six in ten caregivers say the people they assist are 75 or older, and one-third say the people they assist are between 75 and 84 years old. Fewer than one in five caregivers say the person they assist falls into any of the other age categories.

Figure 8: Age of 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 caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Upon examining the age of the caregivers and the people they assist, one finds some interesting patterns.

- Younger caregivers are more likely than their counterparts to be caring for people who are middle aged and older.
- Caregivers in their middle years are more likely than their younger or older counterparts to be caring for someone who is 75 years of age or older. This makes sense in light terms of the nature of the relationship between caregiver and care recipient which is discussed in the next section.

Figure 9: Age of Care Recipient by Age of Caregiver

	Caregiver Age		
	18 to 49 (n=483) A	50 to 64 (n=610) B	65 or older (n=291) C
Recipient 50 to 74 years	54% ^{BC}	20%	32% ^B
Recipient 50 to 64 years	24 ^{BC}	11	15
Recipient 65 to 74 years	30 ^{BC}	9	17 ^B
Recipient 75+ years	46	80 ^{AC}	68 ^A
Recipient 75 to 84 years	31	37 ^C	28
Recipient 85 to 89 years	9	28 ^{AC}	18 ^A
Recipient 90+ years	6	16 ^A	22 ^A

Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2004-2009 Trend of Caregivers of Recipients Age 50+

Both caregivers and care recipients are older now than their counterparts were five years ago. Among caregivers of the 50+ the average age has risen from 48 years to 50 years in 2009. This is largely because the proportion of younger caregivers 18 to 34 years has decreased (22% to 18%) and the proportion of caregivers 35 to 49 has decreased (32% to 27%), while the proportion of caregivers 50 to 64 has increased (32% to 40%). While it is tempting to think the group of caregivers interviewed for this study are metaphorically the same caregivers from the last study, only older, the data shows that caregiving is a fluid role that people move into and out of over time. On average, people are caregivers for four years.

Among care recipients the average age has increased from 75 years to 77 in 2009. This is largely because the proportion of care recipients 65 to 74 has decreased (24% to 19%), while the proportion of those 85 to 89 years has increased (13% to 18%). The subgroup age 85 and older is one of the fastest growing segments of our population.

Relationship of Caregiver and Care Recipient

Caregivers are more likely to say they care for a relative than a non-relative. More than one-third of caregivers say their mother is the person to whom they provide assistance. Less than half as many caregivers say their father is the person to whom they provide assistance.

Figure 10: Care Recipient Relation to Caregiver

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

	2004 (n=976)	2009 (n=1,397)
Relative	86%	89%
Mother	34	36
Father	10	14*
Grandmother	11*	8
Mother-in-law	8	8
Spouse	6	6
Grandfather	3	3
Father-in-law	2	3
Sister	2	2
Grandparent-in-law	1	2
Brother	1	2*
Aunt	1	2*
Uncle	4*	1
Daughter	<.5	1
Son	1	<.5
Brother-in-law	1	<.5
Aunt/Uncle (gender unknown)	1	0
Sister-in-law	<.5	<.5
Companion/partner	<.5	<.5
Other relative	1	1
Non-relative	14	11
Friend	NA	9
Neighbor	NA	2
Foster child	NA	1

Note: 2004 coding grouped friends and relatives, so trend data for non-relatives are not shown.

Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

When looking at the caregivers' age and the caregiver's relationship with the person they assist, one finds there are two distinctive types of caregivers.

- Those who are younger or middle aged providing care for a parent, parent-in-law, or grandparent (85% of all caregivers age 18 to 49 cares for one of these relatives and 75% of 50 to 64 year olds cares for one of these relatives).
- Those who are older providing care for a spouse, sibling, or non-relative (58% of caregivers who are 65 or older care for these individuals).

Caring for a parent is more common than caregiving for other relatives or friends.

Figure 11: Care Recipient Relation to Caregiver by Caregiver Age

	Caregiver Age		
	18 to 49 (n=483) A	50 to 64 (n=610) B	65 or older (n=291) C
Parent	48% ^C	62% ^{AC}	22%
Mother	30 ^C	48 ^{AC}	20
Father	18 ^C	14 ^C	2
Grandparent or grandparent-in-law	25 ^B	1	0
Spouse or partner	1	4 ^A	24 ^{AB}
Sibling	<.5	4 ^A	12 ^{AB}
Parent-in-law	12 ^C	11 ^C	6

Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

Marital Status of Caregiver

More than half of caregivers are married and almost one-third have a child or grandchild under the age of 18 currently living in their household.

Figure 12: Marital Status of Caregiver

D3. Are you currently...

	2004 (n=976)	2009 (n=1,397)
Married	57%	59%
Living with partner	6	5
Widowed	6	7
Separated	3	2
Divorced	11	12
Single, never married	17	15

Figure 13: Presence of Children

D6. Are there currently any children or grandchildren currently living in your household under 18 years of age

	2004 (n=976)	2009 (n=1,397)
Yes	36%	32%
No	64%	68%

Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Caregivers' marital status is related to their income and age.

- As caregivers' annual household income increases, so too does their likelihood of being married (80% of those with \$100,000 or more in annual income are married vs. 67% of those with \$50,000 to \$99,999 vs. 54% with \$30,000 to \$49,999 vs. 29% with less than \$30,000).
- In contrast, lower income caregivers are more likely to be divorced (21% of those with less than \$30,000 vs. 12% \$30,000 to \$49,999, 11% \$50,000 to \$99,999, and 3% with \$100,000 or more) or widowed (13% of those with less than \$30,000

and 10% with \$30,000 to \$49,999 vs. 3% \$50,000 to \$99,999 and 2% with \$100,000 or more).

- Nearly one in five (18%) caregivers between the age of 50 to 64 are divorced and this is a significantly higher proportion than caregivers between the age of 18 to 49 (7%) and 65 or older (8%) who say they are divorced.
- Caregivers who are 18 to 49 are more likely to say they are single-never married (21%) than caregivers who are 50 to 64 (11%) or 65 or older (5%).

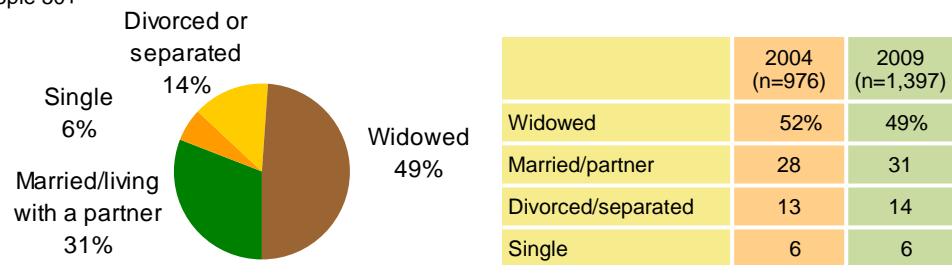
Marital Status of Care Recipient

Almost half of caregivers say their care recipient is widowed and about three in ten say he or she is married or living with a partner.

Figure 14: 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?

Base: 2009 All caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

- Younger caregivers are more likely to be caring for someone who is married than middle aged caregivers (36% of the 18 to 49 year olds vs. 24% of those 50 to 64).
- Middle aged caregivers are more likely to be caring for someone who is widowed than younger or older caregivers (63% of those 50 to 64 vs. 38% of those 18 to 49 and 45% of those 65 or older).

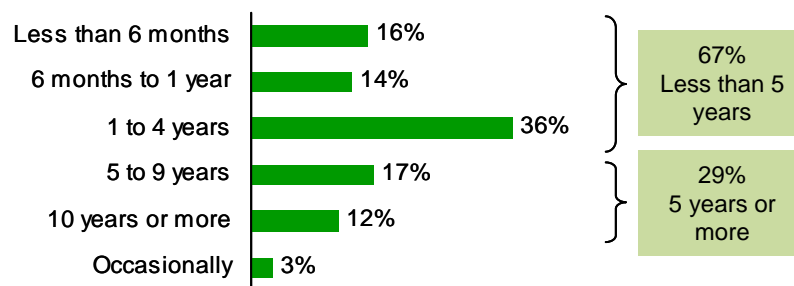
Duration of Care

The average length of time that caregivers age 18 and over say they spend assisting someone 50 or older is four years. Over one-third say they have spent one to four years assisting their care recipient, while about three in ten have been caregivers for a shorter period of time and another three in ten have provided care for five years or more.

Figure 15: 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 caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

The caregiver's age is associated with different lengths of care.

- Younger caregivers are more likely than older caregivers to say they have provided care for less than five years (73% of those 18 to 49 vs. 64% of those 50 to 64 and 58% of those 65 or older).
 - Younger caregivers are also more likely to say they have provided care for less than six months (20% of those 18 to 49 vs. 11% of those 65 or older).
- Middle aged and older caregivers are more likely than younger caregivers to say they provided care for 5 years or more (33% of those 50 to 64 and 39% of those age 65 or older vs. 23% of those 18 to 49).
 - Among the oldest caregivers, one in five (19%) have provided care for at least ten years, where as this is the case for smaller proportions of middle age (12%) and young caregivers (9%).

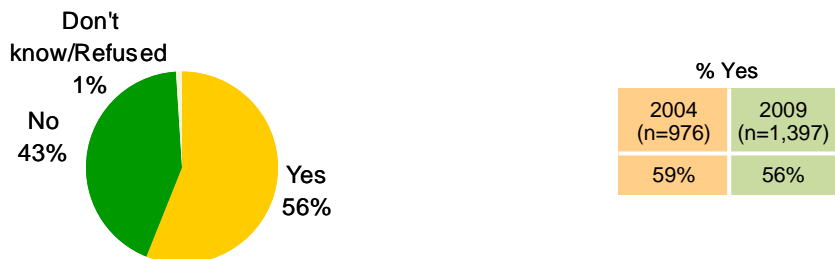
Choice in Taking on Caregiver Role

Four in ten caregivers caring for someone 50 or older say that he or she did not feel they had a choice in taking on this responsibility.

Figure 16: 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 caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Not having a choice to take on this role includes:

- A small majority (51%) of *primary caregivers* say they did not feel they had a choice to take on the caregiving role (among those who are *not* primary caregivers, 62% felt they had a choice about whether or not they took on the role).
- Middle aged caregivers are more likely than young caregivers they feel as though they did not have choice about taking on the caregiving role (49% of those 50 to 64 vs. 38% of those 18 to 49).
- Caregivers who describe their own health as fair/poor are more likely to say they feel as though they did not have a choice (53% vs. 36% of caregivers who describe their own health as excellent).

C. Caregiving Activities and Level of Care

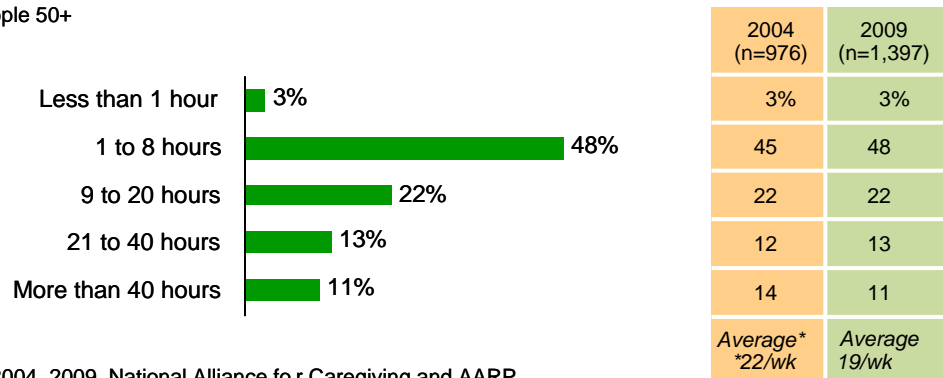
Hours of Care Provided

Almost half of caregivers of the 50 or older report they spend one to eight hours providing assistance in an average week. About one in five spend nine to 20 hours on caregiving activities, and roughly one in ten reports spending 21 to 40 hours or more than 40 hours in an average week doing these types of activities.

Figure 17: 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 caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Number of hours of care provided varies:

- As caregivers' age increases, the number of hours spent caregiving increases. Younger caregivers are more likely to spend 15 hours a week, on average, caring for the person they assist, compared to 19 hours a week for middle aged caregivers and 31 hours a week for older caregivers.
- By subgroups who are more likely to say they spend one to eight hours in an average week on caregiving activities include:
 - Those who were employed while caregiving (52% vs. 35% of those not employed while caregiving).
 - Those with higher annual incomes compared to those with lower annual incomes (53% of those who earn \$50,000 or more per year vs. 41% of those who earn less than \$50,000 per year).
 - Those who report their health is excellent (58%) or very good/good (49% vs. 30% in fair/poor health).
 - Those who are Asian-American (60% vs. 50% of White, 42% of African-American, and 36% of Hispanic caregivers).
 - Those who are more likely to be non-primary caregivers (61% vs. 36% of primary caregivers).
 - Those who have a low level of burden (76% vs. 65% with a medium level of burden).

- Those who do not live with their care recipient (56% vs. 14% who co-reside)
- By subgroups who are more likely to report spending 41 or more hours in an average on caregiving activities week include:
 - Those who report lower annual income than those who report higher annual income (15% of those earning less than \$50,000 per year vs. 8% of those earning \$50,000 or more per year).
 - Those who report having fair/poor health vs. 7% of those with excellent health and 10% of those with very good/good health).
 - Those who are more likely to be African-American (16%), Hispanic (17%) or caregivers overall caring for those 50 and older (11%) than Asian-American (5%).
 - Those who are more likely to be primary caregivers (19% vs. 4% non-primary caregivers).
 - Those who co-reside with the person they assist (35% vs. 6% who do not live in the same household).

Help with Activities of Daily Living (ADLs)

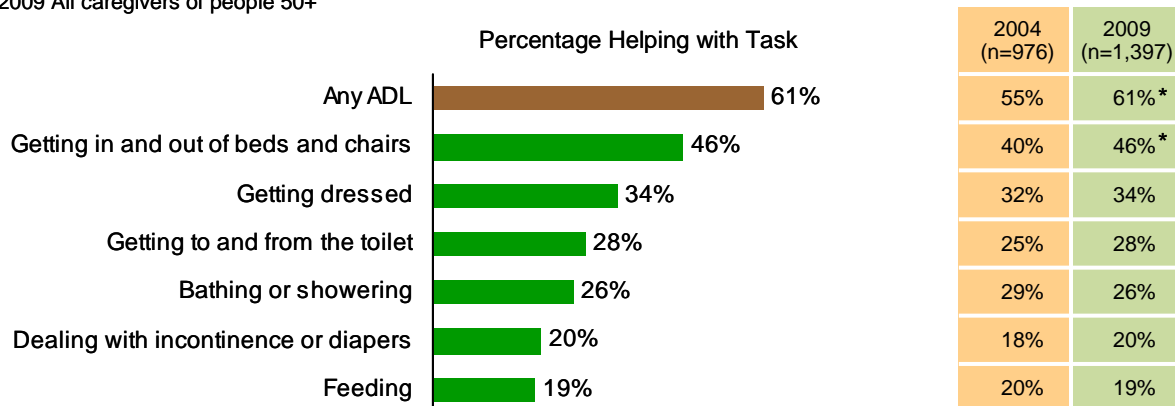
By definition, caregivers must assist the person they help with at least one activity of daily living (ADL) or instrumental activity of daily living (IADL). A majority of caregivers of the 50 or older assist the person they help with at least one ADL. The most common ADLs reported are helping someone get in and out of beds and chairs, to get dressed, and to get to and from the toilet.

On average caregivers provide care recipients help with two ADLs, and three in ten (30%) provide assistance with three or more ADLs.

Figure 18: 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]?

Base: 2009 All caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Caregivers more likely to help with ADLs are:

- Female caregivers are more likely than male caregivers to assist the person they help with personal care activities associated with ADLs such as:
 - Getting dressed (38% vs. 24% of males), and
 - Bathing or showering (30% vs. 16% of males).
- Older caregivers are more likely than younger caregivers to help the person they assist with bathing or showering (33% of those 65 or older vs. 22% of 18 to 49 year olds).
- Those who have not been employed while caregiving are more likely to have provided help to their care recipient with:
 - Getting dressed (43% vs. 30% who have been employed),
 - Getting to and from the toilet (34% vs. 26% who have been employed),
 - Bathing or showering (35% vs. 22% who have been employed), and
 - By dealing with incontinence or diapers (28% vs. 18% who have been employed).
- Short-term caregivers are more likely than long-term caregivers to assist with:⁶
 - Getting in and out of beds and chairs (54% vs. 39%),
 - Getting dressed (43% vs. 31%),
 - Getting to and from the toilet (35% vs. 26%), and
 - Bathing or showering (34% vs. 25%).
- Caregivers of people with Alzheimer's are more likely than other caregivers to help with at least one ADL (72% vs. 56%). Specifically, they are more likely to help with:
 - Getting in and out of beds and chairs (54% vs. 42%),
 - Getting dressed (40% vs. 31%),
 - By dealing with incontinence or diapers (31% vs. 16%),
 - By feeding him or her (31% vs. 14%).
- Caregivers who co-reside with their care recipient are more likely to assist with:
 - Any of the ADLs (75% vs. 57% not residing with their care recipient)
 - Getting in and out of beds and chairs (57% vs. 43%)
 - Getting dressed (53% vs. 29%).
- Caregivers who have a low level of burden are less likely to assist with:
 - Any ADLs (24% vs. 90% with a medium level of burden and 95% with a high level of burden,
 - Getting in and out of beds and chairs (14% vs. 74% with a medium or high level of burden),
 - Getting dressed (3% vs. 42% of those with a medium burden and 71% of those with a high burden),
 - Getting to and from the toilet (none of those with a low burden vs. 39% of those with a medium burden and 60% of those with a high burden),

⁶ Short-term caregivers are those who have been caregiving for less than one year and long-term caregivers are those who have been caregiving for five years or more.

- Bathing or showering (2% vs. 24% of those with a medium burden and 61% of those with a high burden),
- Dealing with incontinence or diapers (2% vs. 25% of those with a medium burden and 44% of those with a high burden), and
- Feeding her or him (3% vs. 27% of those with a medium burden, and 36% of those with a high burden).
- Asian-American caregivers are less likely to assist with getting dressed, getting to and from the toilet, bathing or showering than caregivers from other ethnic backgrounds. For more information, see the companion report on ethnicity.

Helping with Instrumental Activities of Daily Living (IADLs)

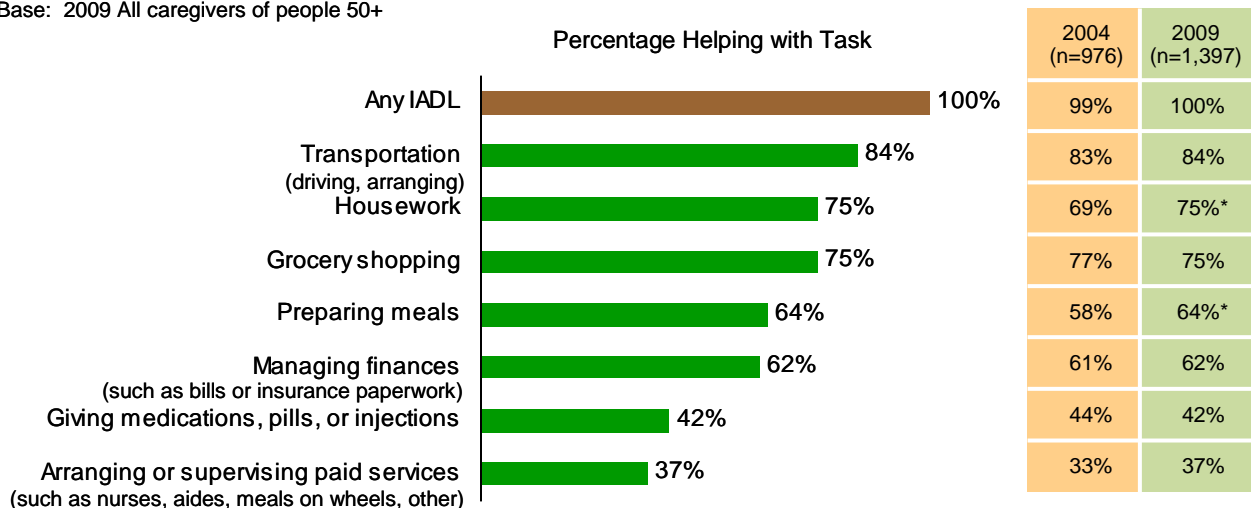
By definition, all caregivers in this study must assist the person they help with at least one ADL or IADL. The results show all caregivers help the person they assist with at least one IADL, and eight in ten (82%) report helping their care recipient with three or more IADLs. On average, they perform four IADLs and this has remained constant over time.

The most frequently reported IADLs performed are providing transportation such as driving or obtaining transportation for their care recipient (84%), followed by housework (75%) and grocery shopping (75%).

Figure 19: Help with Instrumental Activities of Daily Living (IADLs)

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

Base: 2009 All caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

The factors that appear to influence whether caregivers help with IADLs include the following:

- Caregivers' age.
 - Older and middle aged caregivers are more likely than younger caregivers to assist with:
 - Managing finances, such as paying bills or filling out insurance claims (68% of those 65 and older and 70% of those 50 to 64 vs. 54% of those 18 to 49)
 - Arranging or supervising services from an agency, such as nurses or aides (43% of those 65 and older and 42% of those 50 to 64 vs. 29% of those 18 to 49)
 - Middle aged caregivers are more likely than younger caregivers to assist with transportation, either by driving him/her or helping their care recipient get transportation (88% of those 50 to 64 vs. 79% of those 18 to 49)
 - Younger caregivers are more likely than middle aged or older caregivers to assist with housework, such as doing dishes, laundry or straightening up (82% of those 18 to 49 vs. 71% of those 50 to 64 and 65% of those 65 and older)
- Caregivers Health
 - As caregivers' health declines, the average number of IADLs they help with increases, such that those in excellent health help with four IADLs, on average, while caregivers in fair/poor health help with five IADLs, on average.
 - Caregivers who are in fair/poor health are more likely than those in excellent health to assist their care recipient by:
 - Grocery shopping (85% vs. 61%)
 - Preparing meals (80% vs. 57%)
 - Giving medicines, pills, or injections to the care recipient (51% vs. 36%)
 - Doing housework, such as doing dishes, laundry or straightening up (81% of those with fair/poor health vs. 70% with excellent health)
- Length of time as a caregiver:
 - Caregivers who have been providing assistance for longer periods of time are more likely to help with managing finances, such as paying bills, or filling out insurance claims (71% of those who have provided care for 5 or more years and 67% of those who have provided care for one to five years vs. 50% who have provided care for less than one year)
- Caregivers who assist someone who has Alzheimer's disease are more likely than those who assist other care recipients to help:
 - By giving medicines, pills, or injections for his/her condition (54% vs. 36%)

- With managing finances, such as paying bills, or filling out insurance claims (69% vs. 59%)
 - Arranging or supervising services from an agency, such as nurses or aides (46% vs. 33%)
- Caregivers who assist someone who has something other than Alzheimer's disease are more likely to assist with grocery shopping (78% vs. 68%).
- Caregivers Assisting Their Adult Child Age 50 or older
 - Caregivers who are assisting their adult child who is age 50 or older are more likely than other caregivers to assist with managing finances, such as paying bills, or filling out insurance claims (88% vs. 62%).
 - Caregivers who say that in caring for the person they help some form of technology was used are more likely than other caregivers to say they assist with managing finances, such as paying bills, or filling out insurance claims (69% vs. 56%).
- Caregivers who live with the people they assist are more likely to help with:
 - Giving medications, pills, or injections (70% vs. 35% who live separately),
 - Managing finances, such as paying bills, or filling out insurance claims (84% vs. 57%),
 - Grocery shopping (94% vs. 70%),
 - Housework, such as doing dishes, laundry or straightening up (93% vs. 71%),
 - Preparing meals 94% vs. 57%),
 - Transportation (92% vs. 81%) and
 - Arranging or supervising services from an agency, such as nurses or aides (45% vs. 35%).
- Caregivers with a high level of burden are more likely to help with every IADL, and those with a medium level are often more likely than those with a low level of burden as follows:
 - Giving medicines, pills, or injections (73% of those with a high burden, and 44% with a medium burden vs. 20% with a low burden),
 - Managing finances, such as paying bills, or filling out insurance claims (73% vs. 55% with a medium burden and 59% with a low burden),
 - Grocery shopping (89% vs. 73% with a medium burden and 67% with a low burden)
 - Housework, such as doing dishes, laundry or straightening up (92% vs. 74% with a medium burden and 65% with a low burden),
 - Transportation (90% with a high burden and 87% with a medium burden vs. 78% with a low burden) and
 - Arranging or supervising services from an agency, such as nurses or aides (54% with high burden and 38% with medium burden vs. 24% with low burden).

- Primary caregivers are more likely to provide assistance with:
 - Giving medicines, pills, or injections (48% vs. 36% non-primary caregivers),
 - Managing finances, such as paying bills, or filling out insurance claims (76% vs. 49%), and
 - Grocery shopping (80% vs. 69%)
- Caregivers who say they had no choice in taking on caregiving responsibilities say they are more likely to assist with managing finances than those caregivers who say they had a choice (75% vs. 53%).
- African-American and Hispanic caregivers are more likely to say they assist with grocery shopping (85% and 85% vs. 75% of all caregivers of people 50 and over and 72% of White caregivers). African-American caregivers are also more likely than White caregivers to say they help with managing finances (72% vs. 60%).

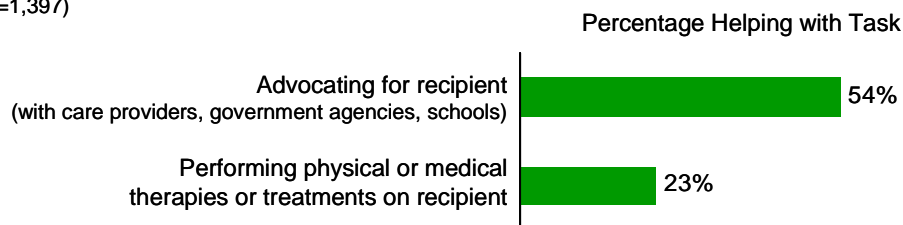
Other Supportive Activities

Approximately half of caregivers of the 50 or older say they have advocated for their care recipient with care providers, government agencies, or schools. One in four says they have performed physical or medical therapies or treatments on him or her.

Figure 20: Help with Other Supportive Activities

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

Base: 2009 All caregivers of people 50+
(n=1,397)



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

The following subgroups of caregivers are more likely than their counterparts to have assisted by advocating for their care recipient with care providers, government agencies, or schools:

- Middle aged (64% of those 50 to 64 vs. 47% of those 18 to 49, and 52% of those 65 or older)
- College educated (61% vs. 44% with high school or less)
- Those with a higher annual income (62% with \$50,000 a year or more vs. 43% with less)
- Those who use technology to help them in their caregiving role (62% vs. 48% those who have not used technology in their caregiving role)

- Providing care for more than a year (44% who have assisted someone for less than one year vs. 58% who have assisted someone one to four years, and 64% who have assisted someone for five years or more)
- Providing care to an Alzheimer's patient (64% of caregivers vs. 50% assisting someone else)
- Those who co-reside with their care recipient (68% vs. 51%)
- Those who have a high level of burden (67% vs. 49% of those with a medium or low level of burden),
- Those who did not have a choice about taking on the caregiving role (66% vs. 46%), and
- Primary caregivers (62% vs. 48% of non-primary caregivers).
- Those caregivers who assist by doing physical or medical therapies or treatments for her/his care recipient are more likely to:
 - Have a high or medium level of burden (47% and 18% vs. 9% of those with a low level of burden) and
 - Those who co-reside with their care recipient (45% vs. 18%).

1997-2009 Trend of Caregivers of Recipients Age 50+

There has been an increase in the proportion of caregivers of those 50 and older who provide their care recipient help with any ADL (51% in 1997 to 61% in 2009).⁷ While most ADLs are characterized by substantial stability over time, there are a few exceptions. For example, there has been an increase in caregivers assisting their care recipients with:

- Getting in and out of beds and chairs (37% in 1997 to 46% in 2009),
- Dealing with incontinence or diapers (14% in 1997 to 18% in 2004 to 20% in 2009).

There has been a slight increase in the proportion of caregivers of those 50 and older who provide their care recipient help with any IADL (98% in 1997 to 100% in 2009). For example there has been an increase in the proportion of caregivers assisting with:

- Giving medications, pills, or injections (37% in 1997 to 42% in 2009),
- Managing finances, such as paying bills, or filling out insurance claims (56% in 1997 to 62% in 2009),
- Housework (69% in 2004 to 75% in 2009),
- Preparing meals (58% in 2004 to 64% in 2009),
- Transportation, either by driving or helping their care recipient to get transportation (79% in 1997 to 84% in 2009).

⁷ In most instances we cannot compare 1997 data with data from 2004 or 2009 because of methodological differences in the way the studies were implemented. However, we are able to compare 1997 behavioral data regarding ADLs and IADLS.

There has been a decrease in the proportion of caregivers assisting with arranging or supervising services from an agency, such as nurses or aides (54% in 1997 to 37% in 2009).

Level of Burden

A level of care index, first developed in the 1997 study *Family Caregiving in the U.S.* and used in the 2004 study, is replicated here to convey in a simple measure the level of “burden” experienced by the caregiver. The index is based on the number of hours of care the caregiver provides to the care recipient, along with the number of ADLs and IADLs the caregiver performs. Based on these two measures, we create an index of the level of burden with five levels, where one is the lowest level of burden and five is the highest level of burden.

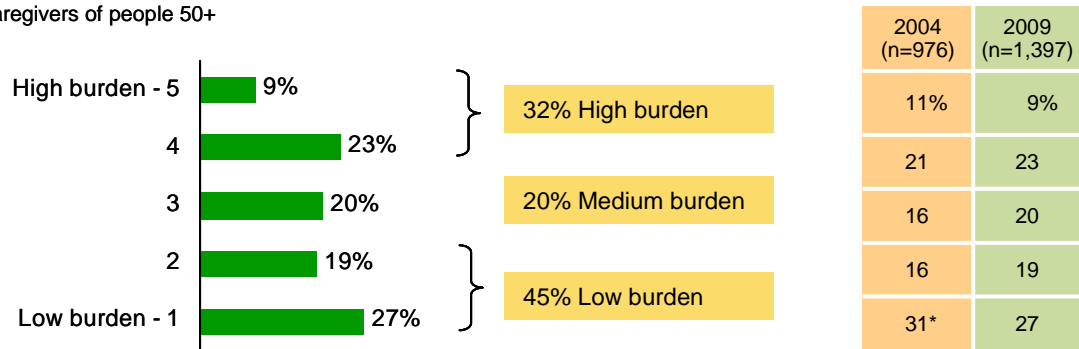
More than two in five (45%) caregivers are in a low burden situation, one in five (20%) are in a medium burden situation and one-third (32%) have a high burden.

Figure 21: Level of Burden Index

Q22 (number of ADLs and IADLs)

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 caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

The older the caregiver, the more likely she or he is to be in a high burden situation. Two in five (42%) caregivers age 65 and over have a high level of burden compared to only 27 percent of those between the ages of 18 to 49.

Figure 22: Level of Burden by Caregiver Age

	Caregiver Age		
	18 to 49 (n=483) A	50 to 64 (n=610) B	65 or older (n=291) C
Low burden	50% ^C	43%	36%
Medium burden	21	21	16
High burden	27	34	42 ^A

Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

High levels of caregiver burden are more common among the following caregivers:

- Those who are primary caregivers (42% vs. 22% of non-primary caregivers),
- Those whose care recipient lives with them in their household (65% vs. 24% not co-resident caregivers),
- Older caregivers (42% of those age 65 and older vs. 27% of those age 18 to 49),
- Lower income caregivers (38% of those with less than \$30,000 in household income vs. 24% of those with \$100,000 or more),
- Caregivers who have not been employed while caregiving (44% vs. 28% of those employed while caregiving), and
- Those in worse health (49% of those in fair/poor health vs. 31% of those in very good/good health vs. 22% of those in excellent health).

2004-2009 Trend of Caregivers of Recipients Age 50+

While fewer caregivers fall into the lowest burden of care level in 2009 compared to 2004 (27% vs. 31%), the other levels have been fairly consistent.

D. Presence of Other Caregivers

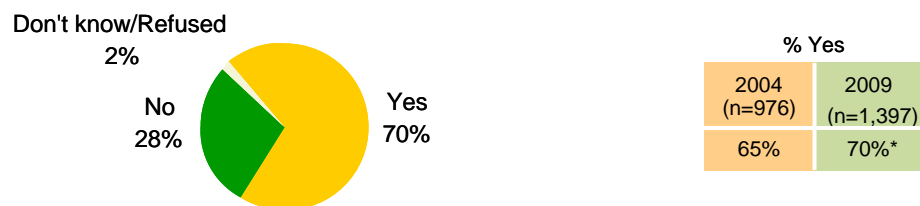
Presence of Other Unpaid Caregivers

Caregiving is often a shared responsibility. Seven in ten caregivers of care recipients 50 or older say at least one other person has provided unpaid help to their care recipient in the past 12 months. However, caregiving responsibilities are rarely shared equally. Among caregivers who say another unpaid caregiver provided help in the last 12 months, only one in ten (9%) say they split care equally.

Figure 23: Presence of Other Unpaid Caregivers

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

Base: 2009 All caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Those more likely to report having help from other unpaid caregivers include:

- Younger and middle aged caregivers (73% of caregivers 18 to 49 and 72% of caregivers 50 to 64 vs. 52% of caregivers age 65 or older),
- Caregivers with a higher education (78% of caregivers with a college degree vs. 68% of those with some college and 58% of those with a high school diploma or less).
- Those with higher incomes (76% those whose annual income is greater than \$50,000) than those with less income (60%).
- Employed caregivers (74% vs. 58% of unemployed caregivers).

2004-2009 Trend of Caregivers of Recipients Age 50+

Overall, there has also been a decrease in the use of paid caregivers (46% to 41% in 2009). However, among those who do use paid services the proportion who say paid helpers provided their care recipient the most care has increased substantially (18% to 37%).

Among caregivers who say the person they assist received paid help in the past twelve months, there has been a decrease in the proportion who says they provide most of their care recipient's help (44% to 32%).

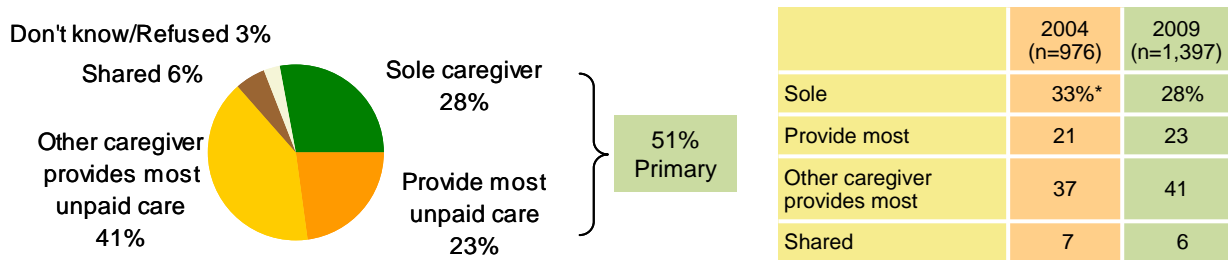
Primary Caregiver Status

Primary caregivers represent half of all caregivers (51%). They are defined as those who say they are the “sole” caregiver (28%) or the one who provides the most unpaid care among the unpaid caregivers (23%).

Figure 24: 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 caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Those caregivers of care recipients age 50 and older that are more likely to be the primary caregiver are:

- Hispanic caregivers (61% primary caregivers vs. 48% of Whites and 43% of Asian Americans),
- Those who feel they did not have a choice in taking on their caregiving role (59% vs. 44% of those who feel they had a choice),
- High burden caregivers (66% are primary vs. 47% of low burden and 35% of medium burden),
- Those spending more time each week providing care (72% of those caring 21 or more hours a week vs. 43% of those spending less time providing care),
- Co-resident caregivers (84% vs. 42% of those not living with their care recipient),
- Older (70% of those 65 and older vs. 45% of those 18 to 49 and 51% of those 50 to 64),
- Less educated (59% of those with a high school diploma or less vs. 45% of those with a college degree or more),
- Those who have not been employed while caregiving (63% vs. 46% of those who have been employed),
- Those in fair or poor health (61% vs. 49% of those in very good/good health and 47% of those in excellent health), and
- Those who have been providing care for 5 years or longer (58% vs. 44% of those caring for less than 1 year).

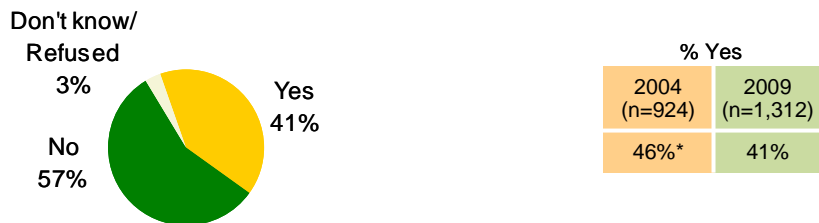
Use of Paid Services

Four in ten caregivers of care recipients age 50 and older who do not live in nursing homes say the person they assist has received paid help from providers such as aides, housekeepers, or others who were paid to help.

Figure 25: 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?

Base: 2009 All caregivers of people 50+ not in nursing home



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Demographic factors which seem to be related to the use of paid help are age, education, and ethnicity.

- More middle aged (46%) and older caregivers (46%) use paid help than younger caregivers (34%).
- Caregivers who have at least a college degree are more likely than those with less education to use paid help (47% vs. 36% of those with some college and 34% with a high school diploma or less).
- White caregivers are more likely to report using paid help (43% vs. 29% of African-American caregivers.⁸

2004-2009 Trend of Caregivers of Recipients Age 50+

The proportion of caregivers who use paid services has decreased from 46 percent in 2004 to 41 percent in 2009, perhaps reflecting the economy in general.

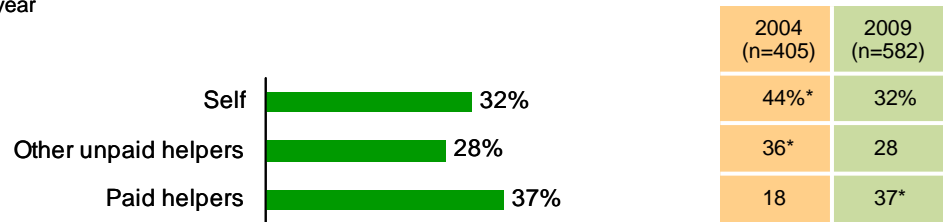
Among caregivers who say their care recipient received paid help almost one-third (32%) say they, themselves, are the predominant caregiver. However, more than one-third (37%) say the paid helper provided more of their care recipient's help than unpaid caregivers.

⁸ For more information about differences by ethnicity, see the companion report entitled *Caregiving in the U.S. A Focused Look at the Ethnicity of Those Caring for someone Age 50 or Older*.

Figure 26: 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?

Base: 2009 Caregivers of people 50+ who received paid help in past year



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

- Caregivers with a high level of burden are more likely to say they provide more care than the paid helpers (56% vs. 17% of those with a medium level of burden and 17% of those with a low level of burden)
- More than three-fourths (77%) of caregivers who co-reside with their care recipient say they are predominant caregivers compared to one in five (22%) who do not live with the care recipient. However, among those who do not live with the care recipient, one-fourth (25%) live less than an hour away.

2004-2009 Trend of Caregivers of Recipients Age 50+

There has been a significant decrease in the proportion of caregivers who use paid services from 46 percent to 41 percent. However, among those who use paid services, there has been an increase in the proportion who says the paid helper is the predominant caregiver (18% in 2004 to 37% in 2009).

E. Care Recipient Living Situation

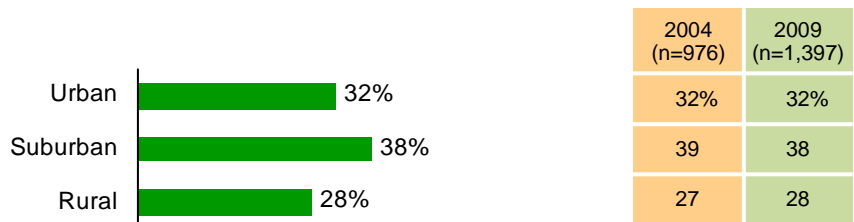
Where Care Recipients' Live

Care recipients are fairly evenly split by suburban, urban and rural areas, and this pattern has not changed since 2004. Almost two in five caregivers say the person they assist lives in a suburban area, while about one-third say the care recipient lives in an urban area and slightly less than three in ten say the care recipient lives in a rural area.

Figure 27: Geographic Area Where Care Recipient Lives

Q15. Does your [relation] live in an urban, suburban, or rural area?

Base: 2009 All caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

White caregivers are less likely to say their care recipient lives in an urban area and are more likely to say their care recipient lives in a rural or suburban area than any ethnic minority (for more information please refer to the section on ethnicity).

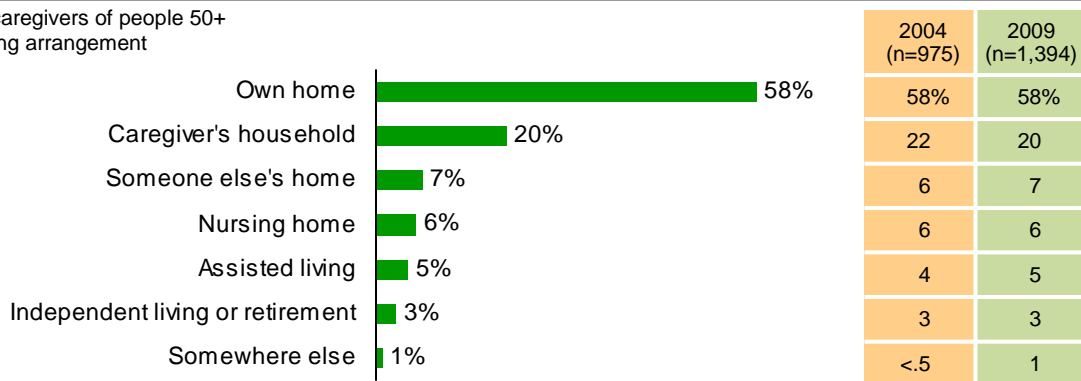
- Female caregivers are more likely to care for someone who lives in a rural area (31% vs. 23% of male caregivers).

Most care recipients live in their own home and one in five live in the caregiver's home. Few live in other settings.

Figure 28: 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, or somewhere else?
 (Analyzed with Q11: Does/Did your [relation] live in your household, within twenty minutes of your home, etc?)

Base: 2009 All caregivers of people 50+ who reported living arrangement



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Caregivers who say their recipient lives in his/her own home include those who are:

- Younger (70% are 18 to 49, 53% are 50-65 vs. 38% of those 65 or older).
- Short-term caregivers of less than one year (66% vs. 50% of long-term caregivers of 5+ years,
- Less likely to be caring for Alzheimer's patients (63% vs. 48% caring for someone with Alzheimer's disease),
- Be a non-primary caregiver (68% vs. 47%),
- Have a low level of burden (71% vs. 54% of those with a medium burden, and 44% of those with a high level of burden).

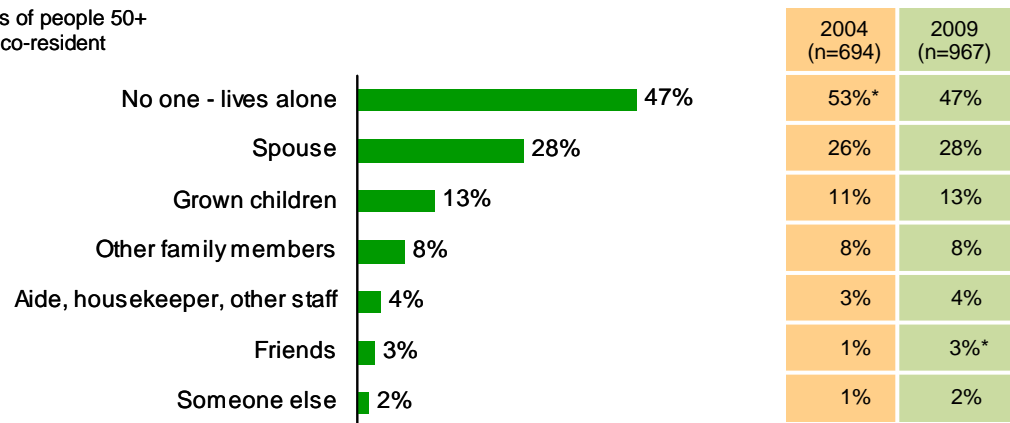
Who Care Recipient Lives With

Almost half of caregivers say the person they assist lives alone, while more than one-quarter say they live with a spouse. Roughly one in eight say the care recipient lives with one of their adult children.

Figure 29: Who Care Recipient Lives With

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

Base: 2009 All caregivers of people 50+ not living in facility or not co-resident



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Caregivers who are more likely to report the person they assist lives alone include:

- Older caregivers (68% vs. 51% of middle age and 40% of young caregivers)
- Middle age caregivers (51% vs. 40% young caregivers)
- Those caring for non-Alzheimer’s patients (50% vs. 37% Alzheimer’s patients)
- Primary caregivers are more likely to say their care recipient lives alone (64% vs. 35% of non-primary caregivers).
- Half of caregivers with a low level of burden say their care recipient lives alone (51% vs. 37% of those with a medium level of burden).
- Those that live less than an hour away from their care recipient (50% vs. 34% of those who live an hour or more from their care recipient).

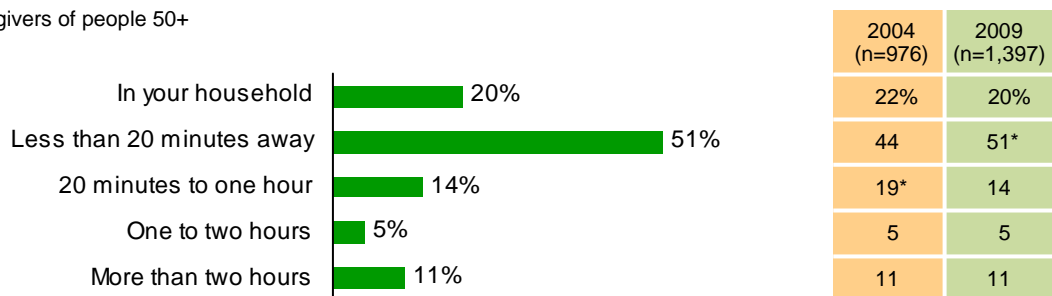
Caregiver Distance from Care Recipient

Among caregivers who do not live with their care recipient, more than half (50%) live within twenty minutes of their care recipient’s home. One in five (20%) say the person they assist lives in their home and fewer say the person lives 20 minutes or more from their home.

Figure 30: 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 caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

- As caregiver age increases, they are more likely to report living with their recipient. More than one-third (37%) of older caregivers live with their recipient, compared to one in five (20%) of middle aged caregivers and about one in six (14%) of younger caregivers. Older caregivers are more likely to be caring for a spouse or partner than middle aged or younger caregivers (25% vs. 4% and 1% respectively).
- Younger caregivers are more likely to live within 20 minutes of their care recipient (57% of those 18 to 49 vs. 41% of those 65 or older).

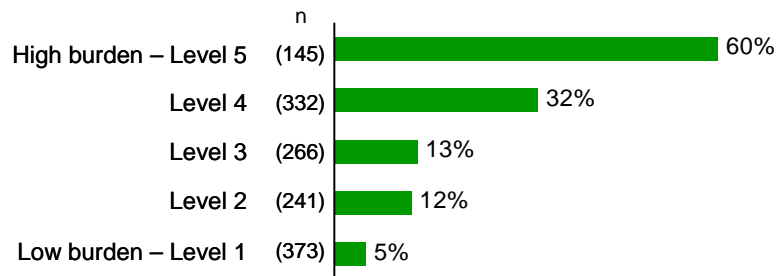
More than half (59%) of the caregivers who do not live with the person they assist say they visit with their care recipient more than once a week and nearly another one in six (17%) visit once a week. One in ten (10%) visit a few times a month and one in twenty (5%) visit once a month. A minority visit a few times a year (7%) and only one percent say they visit less often.

As burden increases, so too does the likelihood that the care recipient lives in the caregiver’s household.

Figure 31: Co-Residence by Level of Burden

Base: 2009 All caregivers of people 50+

Percentage of Caregivers Who Say Recipient Lives with Them



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2004-2009 Trend of Caregivers of Recipients Age 50+

The proportion of caregivers who say they live less than 20 minutes from the home of the person they provide care has increased during the past five years (44% to 51% in 2009), and the proportion of caregivers who say they live within 20 minutes to one hour from their care recipient has decreased (19% to 14% in 2009). There has also been a decline in the proportion of care recipients who live alone (down from 53% to 47% in 2009).

Frequency of Visits

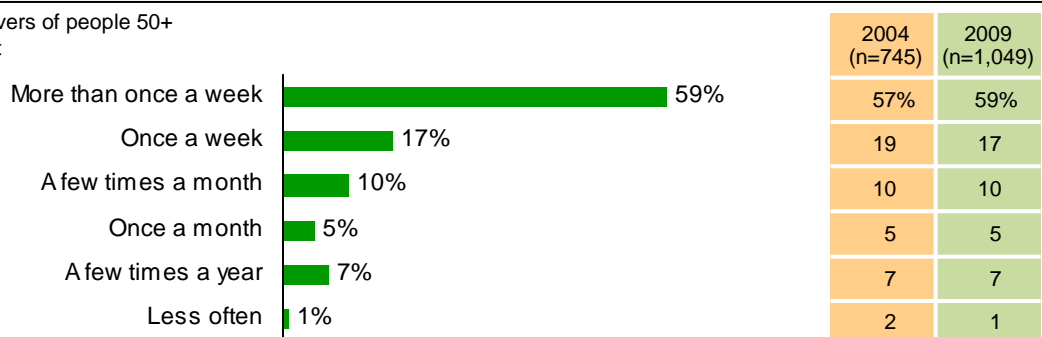
About six in ten caregivers who do not live in the same household with their care recipient, say they visit more than once a week. Approximately one in six visits weekly and one in ten say they visit once a month.

Figure 32: Frequency of Visits

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

More than once a week, once a week, a few times a month, once a month, a few times a year, or less often?

Base: 2009 All caregivers of people 50+ not living with recipient



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Caregivers who are more likely to say they visit their care recipient more than once a week include those who:

- Have less than a college degree (67% vs. 51% of those with a college degree or more),
- Have under \$100,000 in household income (64% vs. 45% of those with \$100,000 or more),
- Report worse health (65% in fair/poor health and 63% in very good/good health vs. 47% of those in excellent health).

In addition, female caregivers are more likely to report visiting their care recipient once a week or more often (80% vs. 69% of male caregivers)

F. Care Recipient's Condition

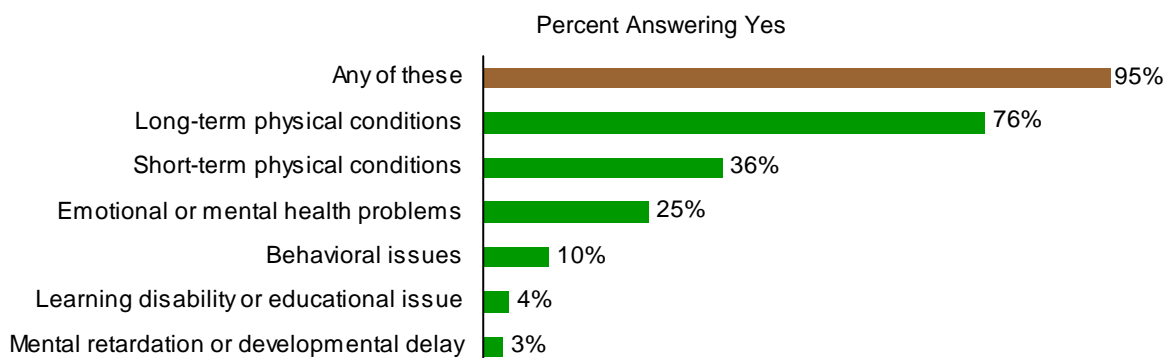
Types of Care Recipient Conditions

Three-fourths of caregivers say the person they help needs care because of long-term physical conditions and over a third needs care because of a short-term physical condition. One in four people needs care because of emotional/mental health issues.

Figure 33: Types of Care Recipient Conditions

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

Base: 2009 All caregivers of people 50+



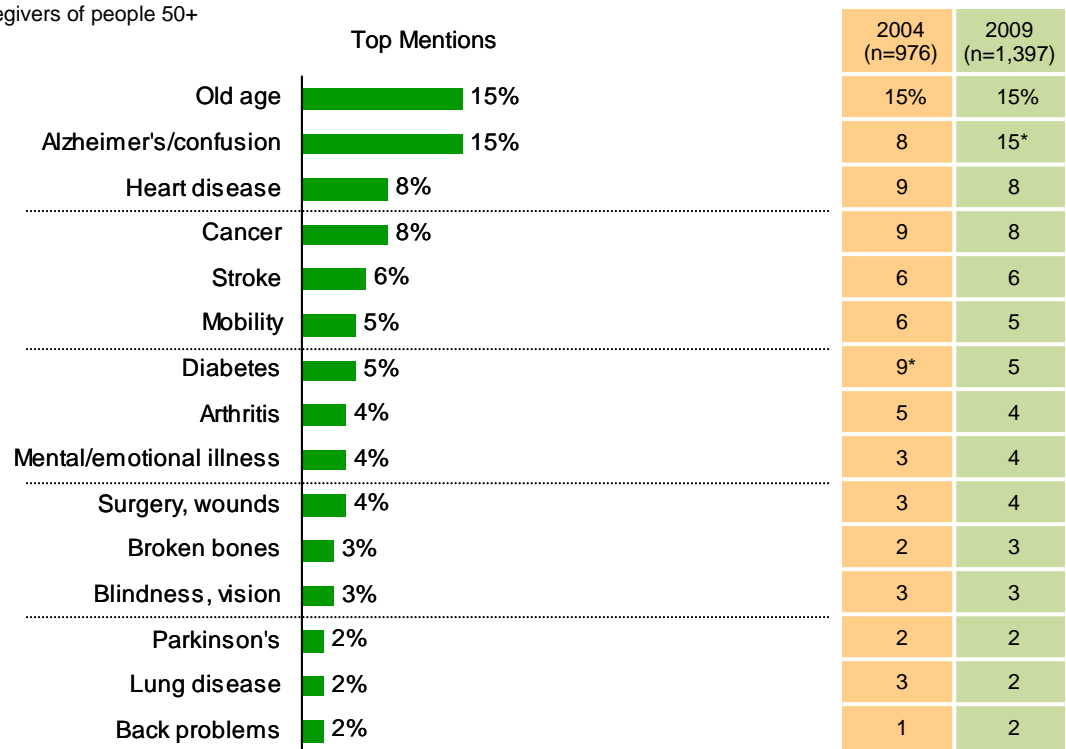
Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

Care Recipient’s Main Problem or Illness

When we asked caregivers an open-ended question about the main problem or illness the person they care for has, the two most frequently cited problems or illnesses caregivers report among their care recipients were 1) old age, aging or 2) Alzheimer’s disease, confusion, dementia or forgetfulness. These are followed about almost one in twelve who report heart disease or cancer.

Figure 34: Main Problem or Illness of Care Recipient
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 caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

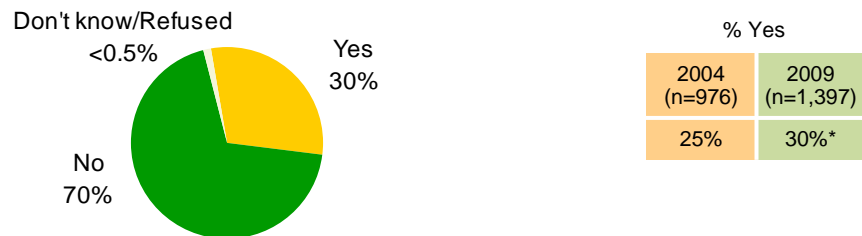
- Caregivers who have been providing care for 5 or more years are more likely to be caring for someone whose main problem is associated with the aging process (22%), than are those who have been caring for less than 1 year (9%).
- Caregivers who are more likely to say their care recipients main problem is Alzheimer’s, confusion, dementia, or forgetfulness include those in their middle years (19% of caregivers age 50 to 64 vs. 11% of those 18 to 49) and those who have been caring for 1 to 4 years (19% vs. 10% of those who have cared for less than 1 year).

When we asked caregivers who did not identify Alzheimer’s disease or dementia as the main problem or illness a follow-up question that specifically asked about Alzheimer’s or other mental confusion, three in ten said yes.

Figure 35: Presence of Alzheimer's or Mental Confusion

Q20/Q18. Does/Did your [relation] suffer from Alzheimer's or other mental confusion?

Base: 2009 All caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2004-2009 Trend of Caregivers of Recipients Age 50+

Given that care recipients are older in 2009 than care recipients were in 2004, it is not surprising that a larger proportion of caregivers in 2009 say Alzheimer’s or dementia is the main reason their care recipient needs care (8% in 2004 vs. 15% in 2009). In addition, the overall prevalence of Alzheimer’s or mental confusion among care recipients has increased (22% in 1997 to 25% in 2004 to 30% in 2009).

This finding is consistent with the World Alzheimer Report that estimates more than 35 million people around the world report living with Alzheimer’s disease or other types of dementia. This is approximately a ten percent increase over previous estimates. The Alzheimer’s Association of the U.S. uses a less conservative count when they estimate more than five million people in this country are affected by the disease.⁹ Given current trends in the incidence of these health problems, it is likely the proportion of people reporting them will continue to increase and will affect caregivers in their middle and later years.

⁹ The Associated Press, September 21, 2009 Dementia toll climbs to 35 million worldwide – Estimate of Alzheimer’s, other ills, is 20 percent higher than predictions.

Medication Management

Nearly all caregivers report the person they assist takes prescription medicine (96%).

Figure 36: Use of Prescription Medicine
Q26. Does/Did your [relation] take any prescription medicine?

Base: 2009 All caregivers of people 50+



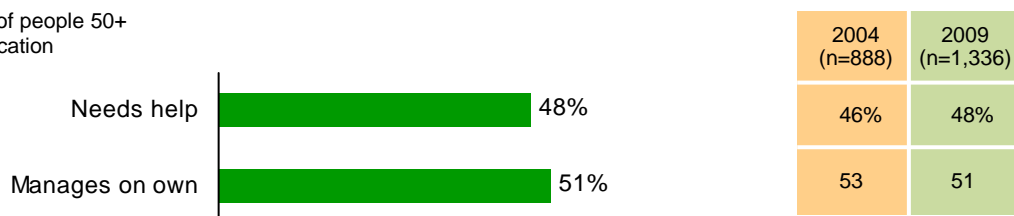
Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

Nearly half of all caregivers whose recipient takes medication (48%) report that the person they assist needs help managing their medication.

Figure 37: 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 manage/managed this well on his/her own?

Base: 2009 caregivers of people 50+ taking prescription medication



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

While there are no differences by caregiver characteristics in whether or not care recipients take prescription medication, certain groups of caregivers are more likely to report that their care recipient needs help taking their medication. These groups include:

- Caregivers in medium and high burden situations (55% and 66% respectively vs. 33% of low burden caregivers),
- Those providing 21 or more hours of care per week (67% vs. 42% of those providing fewer hours of care),
- Co-resident caregivers (61% vs. 45% of those not living with their care recipient),
- Middle aged and older caregivers (54% and 55% respectively vs. 41% of younger caregivers), and
- Those caring for someone with Alzheimer's or dementia (80% need help vs. 34% of those caring for someone without these conditions).

2004-2009 Trend of Caregivers of Recipients Age 50+

The proportion of caregivers who report their care recipient takes prescription medication has increased from 92 percent in 2004 to 96 percent in 2009. However, the proportion needing assistance taking their medication has not changed significantly

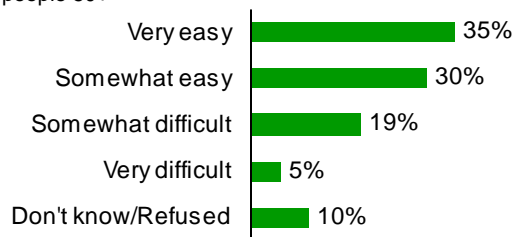
Ease of Coordinating Care

Two-thirds (66%) of caregivers say coordinating the care of the person they help is very or somewhat easy, yet a quarter (24%) say it is somewhat or very difficult to coordinate the care between various health care professionals or service providers.

Figure 38: 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?

Base: 2009 All caregivers of people 50+ (n=1,397)



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

- Caregivers who are more likely to say it is somewhat or very difficult to coordinate care are those caring for someone with Alzheimer's disease or related conditions (33% vs. 21% of caregivers assisting recipients with other conditions), those experiencing a high level of burden (36% vs. 16% of those with a low level of burden), those who feel as though they had no choice to take on the caregiving role (31% vs. 19% of those who feel they had a choice), and those who live more than one hour from their care recipient (34% vs. 20% who do not co-reside with their recipient but live less than one hour away from them).

G. Stress and Strain of Caregiving

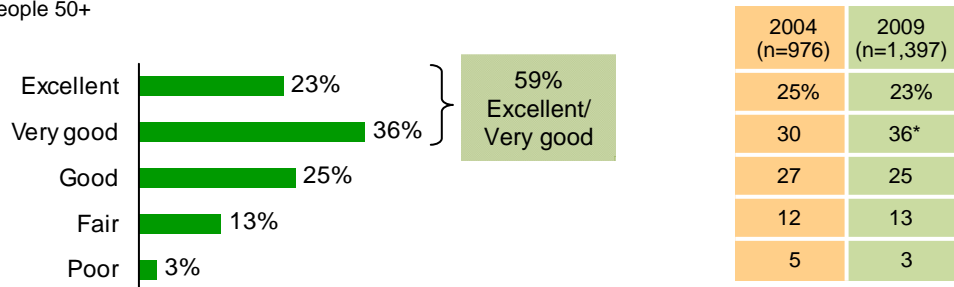
Caregiver Health

Six in ten (59%) caregivers describe their own health as excellent or very good. About one in six (16%) caregivers describes their health as fair or poor.

Figure 39: Caregiver Health

DI. How would you describe your own health?

Base: 2009 All caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Caregivers who describe their health as excellent or good are characterized by:

- Youth. Two-thirds (68%) of caregivers age 18 to 49 say their health is excellent or very good compared to just over half of the middle aged caregivers (55%) and fewer older caregivers (40%),
- Educational achievement. Almost three-fourths (72%) of caregivers with at least a college degree say their health is excellent or good compared to about half of caregivers with some college (49%) or a high school diploma or less (47%),
- Higher income. More than eight in ten (83%) of those earning \$100,000 a year or more say their health is excellent or good compared to less than two-thirds (63%) of those who earn between \$50,000-99,000 and half (51%) of those who earn \$30,000-49,000 and fewer of those who earn less than \$30,000 annually (37%),
- Employed. Caregivers who say they were employed at some time while they were caregiving are more likely to say their health is excellent or very good (65% vs. 42% who were not employed while caregiving),
- Short-term caregivers. Caregivers who provided help for less than one year (64%) are more likely to be in excellent or very good health than those who were long-term caregivers of 5 or more years (51%), and
- Ethnicity. More likely to be White (62% vs. 48% of those who are Hispanic),
- Being non-primary caregivers (64% vs. 54% Primary caregivers),
- Having a choice in taking on the caregiving role (63% vs. 54%),
- By having a low or medium level of burden (64% and 66% vs. 49% with a high burden), and

- Not residing with the person they assist (64% vs. 41% who live with the person they assist).

2004-2009 Trend of Caregivers of Recipients Age 50+

The proportion of caregivers who described their health as very good has increased since 2004 from 30 percent to 36 percent.

Impact of Caregiving on Caregiver’s Health

Three-fourths of caregivers of the 50 or older say caregiving has not affected their health. About one in six say caregiving has made their health worse.

Figure 40: 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 caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Those who say caregiving has not affected their health are:

- Male caregivers are more to say this (80% vs. 72% female caregivers)
- Those with an annual income of more than \$50,000 or more (78% vs. 69% who earn less than \$50,000). This is especially the case for those who report annual incomes of over \$100,000 (84%) compared to those who report incomes of less than \$30,000 (68%) or \$30,000-\$49,999 (68%),
- Caregivers who perceive their own health to be excellent are more likely to say caregiving has not affected their health (85% vs. 75% who say their own health is very good/good or 75% who say their own health is fair/poor. In addition those who say their health is very good or good are more likely to say caregiving has not affected their health (75% vs. 59% who rate their health as fair/poor,
- Likely to be non-primary caregivers (81% vs. 69%),
- More likely to say they had a choice about taking on the caregiving role (79% vs. 70% who did not have a choice),
- More likely to be at a low or medium level of burden rather than high burden (81%, 78% vs. 64% respectively), and
- More likely to live apart from their care recipient (77% vs. 66% who live in the same household).

Caregiving who are more likely to say has made their health worse are:

- Female caregivers (19% vs. 11% of male caregivers).
- Middle aged caregivers (21% of those 50 to 64 years old) are more likely to say caregiving has made their health worse than young caregivers (12% of the 18 to 49 year olds).
- Caregivers who report their health as fair or poor (34% vs. 6% of those who say their health is excellent). Those who say they are in very good/good health are also more likely to say caregiving has made their health worse (15% s. 6% who say they are in excellent health).
- Caregiver’s of Alzheimer’s patients (23% vs. 13% who do not care for Alzheimer’s patients).
- Caregivers who do not have children under 18 in the home (19% vs. 10% who do have children in the home).
- Those who are more likely to be White (17% vs. 9% African-American).
- Those who say they had not choice in taking on this role (25% vs. 9% having a choice),
- Those who are at a high level of burden (29% vs. 12% of those at a medium level and 9% at a low level of burden),
- Those who are living in the same household as the care recipient (27% vs. 14% not living in the same household).

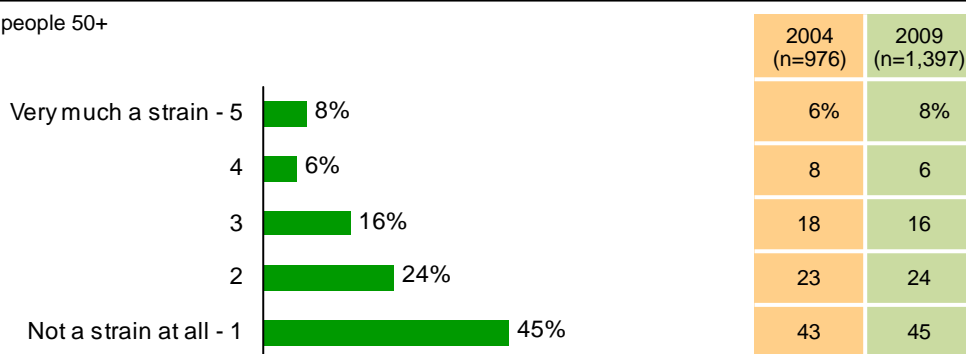
Physical Strain of Caregiving

We asked caregivers to use a five-point scale to rate how much physical strain they thought they experienced as a result of caring for the person they assist. Almost seven in ten (69%) rate the physical strain of caregiving low (rating of one or two). Less than one in six (14%) caregivers rate the physical strain of caregiving high (rating of four or five).

Figure 41: 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 caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Those who are more likely to rate the physical strain of caregiving high (four or five) are female, older, have lower incomes, a higher level of burden, and live with their care recipient:

- Females (17% vs. 10% of males),
- Older caregivers (21% of caregivers age 65 and older vs. 11% of caregivers 18 to 49),
- Those with lower annual income (19% with less than \$50,000 vs. 11% of those with an annual income of \$50,000 or more),
- Those in fair or poor health (32% vs. 12% of those with good or very good health and 8% of those with excellent health),
- Those with a high level of burden (31% vs. 9% of those with a moderate level of burden and 5% of those with a low level of burden), and
- Those living with the care recipient (29% vs. 11% who do not live with the care recipient).

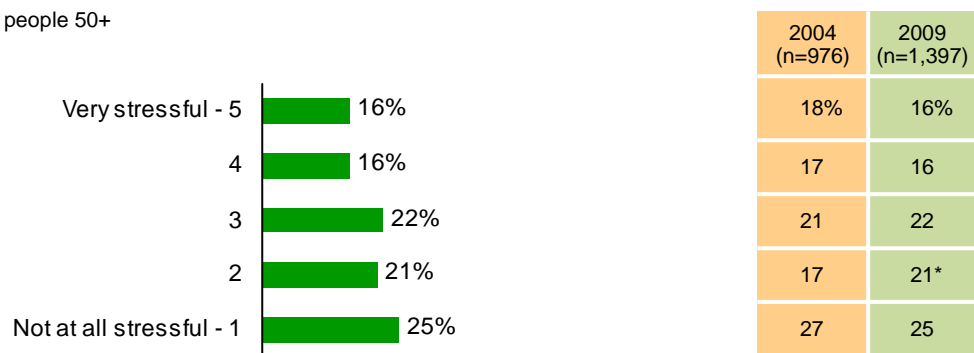
Emotional Stress of Caregiving

More than two in five (46%) rate the emotional stress of caregiving low (one or two on a five-point scale). One in five (22%) indicate they have moderate stress, and about one-third (31%) rate the emotional stress of caregiving high (a four or five).

Figure 42: 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 caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Subgroups that are more likely to rate the emotional stress associated with caregiving as high (level four or five) includes:

- Female caregivers (36% vs. 23% of males),

- Those who say their own health is fair or poor (47% vs. 31% of caregivers who rate their health very good or good, and 22% of caregivers who rate their health as excellent),
- Those who report a high level of burden (51% vs. 29% of those with a moderate level of burden and 19% of those with a low level of burden),
- Those who live with the care recipient (46% vs. 28% who do not live with the care recipient),
- Those who care for Alzheimer’s patients (40% vs. 28% of those with other conditions).

About half (53%) of all caregivers say that as a result of caregiving, they have less time for friends or other family members. Three in ten (31%) feel they need help or information finding time for themselves.

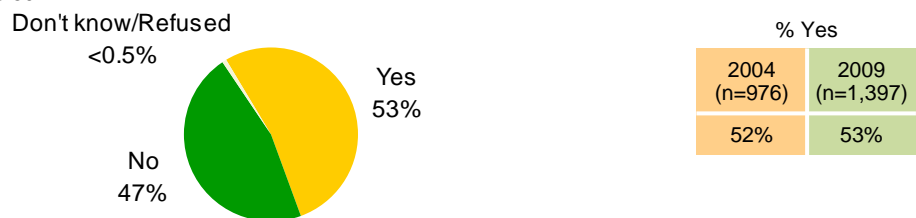
Time for Family and Friends

Just over half of all caregivers say that as a result of caregiving, they have less time for friends or other family members.

Figure 43: 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 caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Caregivers who say they have less time for friends or family members are:

- Are those who have fair or poor health (61% vs. 47% of those who have excellent health),
- Caring for those with Alzheimer’s disease (63% vs. 49% of caregivers who assist care recipients who do not have Alzheimer’s disease),
- Those with a high level of burden (74% vs. 56% of those with a medium level of burden and 37% of those with a low level of burden).
- Those who are primary caregivers (59% vs. 49%).
- Those who say they did not have a choice to take on this role (64% vs. 45%)
- Those with high (77% vs. 56% with a medium level of burden and 37% with low burden)
- Those with a medium level of burden (56% vs. 37% with a low level of burden), and
- Those who co-reside with their care recipient (71% vs. 49%).

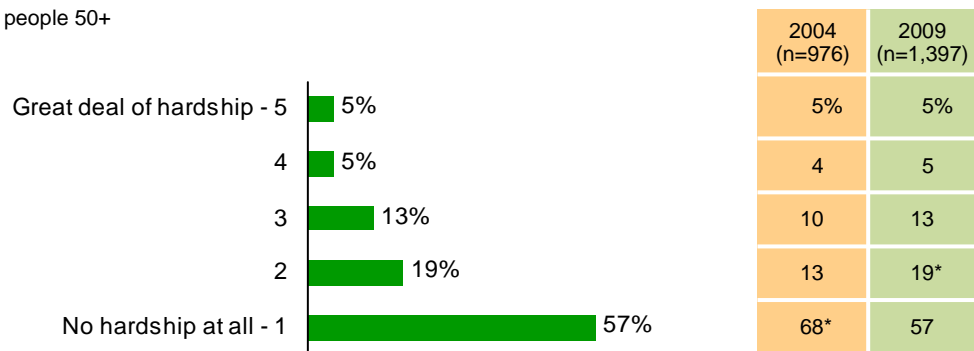
Financial Hardship of Caregiving

Most caregivers (77%) rate the financial hardship of caring for their care recipient low (one or two on a five-point scale). Slightly more than one in ten (13%) rate the financial hardship as moderate, and one in ten rate the financial hardship of caregiving high.

Figure 44: 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 caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Caregivers more likely to experience financial hardship (rating of four or five) from caregiving are similar to those who experience physical strain and emotional stress. These subgroups are based on caregivers' health, income, perceived choice, level of burden, and living with the care recipient.

2004-2009 Trend of Caregivers of Recipients Age 50+

While there has been stability in the level of physical strain caregivers experience from caregiving, there is a slight increase in the proportion of caregivers who say they are experiencing emotional stress at level 2 (17% to 21%), and financial hardship, also at level two (13% to 19%). At the same time, there has been a decrease in the proportion of caregivers who rate financial hardship at level one, no hardship at all.

These findings suggest a minority of caregivers are experiencing higher levels of stress and strain associated with their caregiving experiences. The results also identify specific subgroups likely to experience these problems and good target audiences for caregiver service interventions.

H. Impact of Caregiving on Work

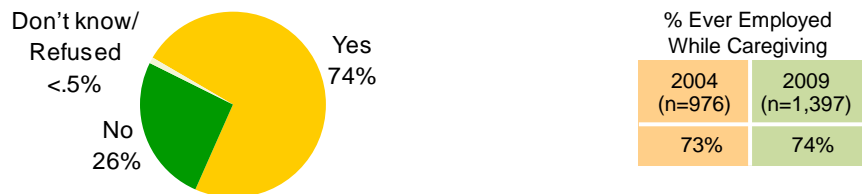
Concurrence of Employment and Caregiving

Almost three-quarters of caregivers have been employed while they were assisting another person.

Figure 45: 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 caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Caregivers ever employed while caregiving include:

- Male caregivers (82% vs. 70% females),
- Younger caregivers (83% of younger caregivers, and 78% of those middle aged caregivers vs. 34% of older caregivers).
- Those with an annual income of \$50,000 (81% vs. 65% with an annual income under \$50,000).
- Those with a college degree (83% vs. 66% of those with less education).
- Those who are in excellent or very good/good health (80% and 78% vs. 50% in fair or poor health).
- Those who are not primary caregivers (81% vs. 67% of primary caregivers),
- Those with a low or medium level of burden (80% and 77% vs. 64% with a high level of burden),
- Those who do not co-reside with the person they assist (76% vs. 64% of those living with the person they help).

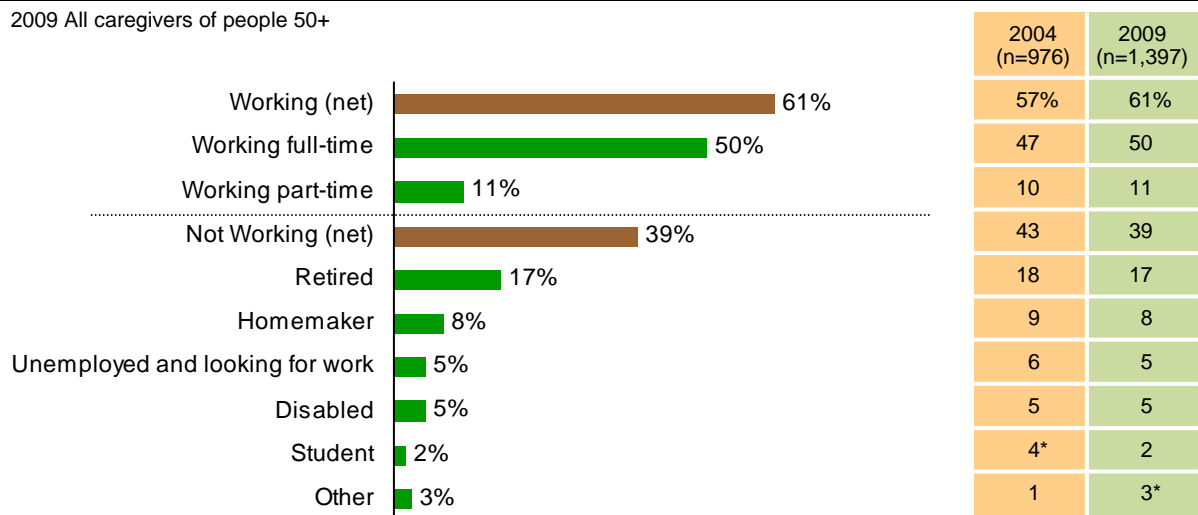
Current Employment Status

Half of caregivers say they are currently working full time and one in ten are working part time.

Figure 46: 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 caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Caregivers who are more likely to report they are currently working full-time include:

- Males (59% vs. 45% are females),
- Younger (61% of those 18 to 49) or middle aged (52% of those 50 to 64) than older (7% of those 65+),
- College graduates (60% vs. 42% some college or 40% with a high school education or less),
- Those who earn \$50,000 or more (61% vs. 37% who earn less than \$50,000 per year), and especially likely to earn \$100,000 or more (69% vs. 56% of those with an annual income of \$50,000-\$99,999 and 49% of those with an annual income of \$30,000-\$49,999),
- Those employed while caregiving (66% vs. 3% unemployed)
- Those in better health (57% of those who report their health as excellent and 54% of those who report their health as very good/good vs. 23% of those who report their health as fair/poor,
- Those who do not co-reside with the person they assist (54% vs. 33%)
- Those with lower levels of burden (58% of those with a low level of burden and 54% of those with a medium level of burden vs. 38% with a high level of burden), and
- Those that are not primary caregivers (57% vs. 43%).

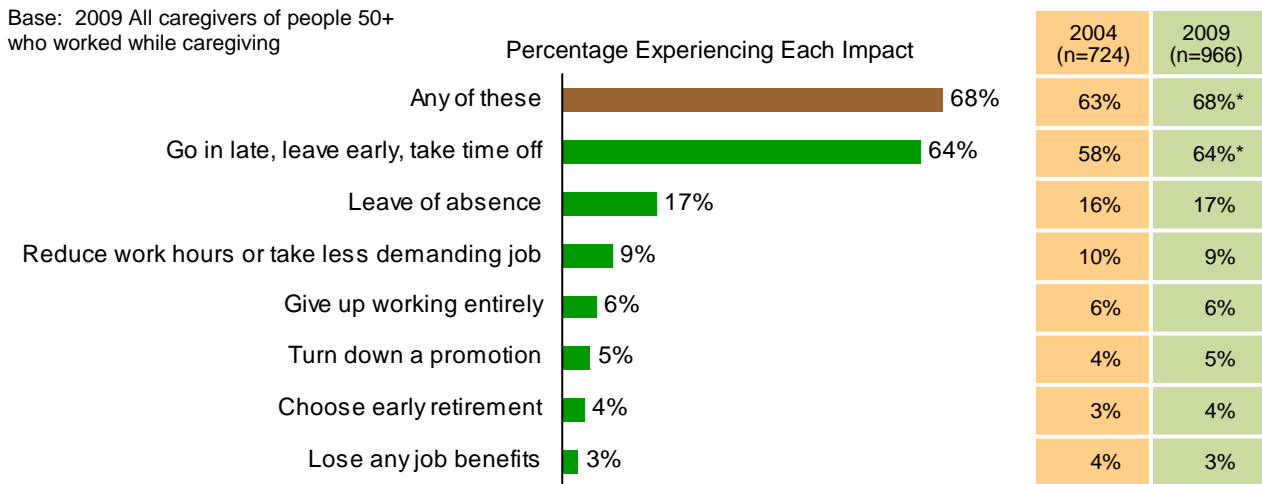
Work Accommodations Due to Caregiving

Among people who were employed while caregiving, most have had to make a work place accommodation due to caregiving (68%). The most common work place accommodation is going in late, leaving early, or taking time off during the day (64%). This work place accommodation has increased since the last study (58% in 2004 to 64% in 2009).

Figure 47: Work Accommodations Due to Caregiving

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

Base: 2009 All caregivers of people 50+ who worked while caregiving



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Caregivers, who are more likely to say they go in late, leave early, or take time off during the day as a result of caregiving include:

- Younger caregivers (63% of those 18 to 49, or 67% of those 50 to 64 vs. 47% of those 65 or older),
- Those with annual incomes of \$50,000 or more per year (69% vs. 56% whose annual income is less than \$50,000),
- Those in fair/poor health (79% vs. 63% of those with very good/good health or 60% of those with excellent health),
- Those who live with the care recipient (74% vs. 62% not living in the same household),
- Those with a high level of burden (78% vs. 56% of those with a low level of burden and 65% of those with a medium level of burden), and
- Those who say they had no choice in taking on the caregiving role (75% vs. 55%).

2004-2009 Trend of Caregivers of Recipients Age 50+

There has been an increase in the proportion of employed caregivers who say they have made any workplace accommodation (63% in 2004 to 68% in 2009). There has also been an increase in the most frequently reported workplace accommodation, going in late, leaving early, or taking time off (58% in 2004 to 64% in 2009).

I. Caregiving Information

Sources of Information

More than one-third (36%) of caregivers, say that if they were looking for information about some aspect of helping their care recipient, they would turn to a health or other caregiving provider (such as a doctor, nurse, caregiving provider, hospital, social worker, hospice or mental health provider). One in four (25%) say they would turn to the Internet and print media while about one in five caregivers (21%) say they would turn to family, friends or other caregivers. Fewer (14%) would turn to the government (8%) aging or disease specific organizations, social or community services (4%), or some other source (10%).

Figure 48: 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 (n=1,397)
Health or caregiving provider	36%
Doctor	20%
Nurse, other health professional	11%
Caregiving provider (such as a nursing home, assisted living facility, home care, senior day care)	4%
Hospital, clinic	3%
Social worker, case worker	2%
Hospice	1%
Mental health provider	<.5%
Internet and print media	25%
Internet	23%
Books, magazines, library	3%
Government programs	8%
Government	5%
Veteran's administration	2%
Social Security, Medicaid, Medicare	2%
Family, friends, caregivers	21%
Family, friends, colleagues, word of mouth	20%
Family caregivers, support groups, people with similar experience	1%
Aging or disease specific organizations	14%
Senior citizen's center, aging organization	12%
Disease-specific organization	3%
Social services, community services	4%
Other	10%
Church, minister	2%
Employer	1%
Insurance company	1%
School	<.5%
Other	7%

2009 Caregiver Subgroup Differences

Subgroups that are more likely to turn to a health or caregiving provider for information include:

- Those with more education (38% of those with a college degree or more and 40% of those with some college vs. 28% of those with a high school diploma or less)

- Those who have cared for their loved one for a shorter length of time (43% of those who have been providing care for less than one year vs. 33% of those who have been caregiving for 1 to 4 years or 32% of those who have caring for 5 or more years)

Subgroups that are more likely to turn to the Internet or print media for information include:

- Those who were employed while caregiving (27% vs. 18% of those unemployed)
- Younger and middle aged caregivers (28% of those 18 to 49 and 25% of those 50 to 64 vs. 11% of those age 65+)
- Caregivers with annual incomes of \$100,000 or more (32% vs. 17% of those earning incomes under \$30,000)
- Asian-American caregivers (39% vs. 25% of caregivers of 50+ overall, 24% of Caucasian caregivers and 19% of African-American caregivers)
- Non-primary caregivers (30% vs. 20% of primary caregivers)
- Those with a low or medium burden (26% of low and 33% with a medium burden vs. 18% of high burden caregivers)

Caregivers who feel they did not have a choice in taking on their caregiving role are more likely to say they would turn to government programs for information (11% vs. 5% among those who felt they had a choice).

Conversely, those who felt they had a choice in taking on their role are more likely to turn to family, friends, or colleagues for information (26% vs. 14% of those who felt they had no choice).

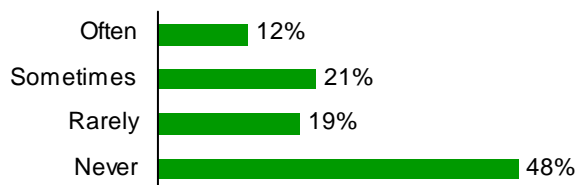
Internet Usage

Given that caregiver's average age is 50, it is somewhat surprising that two-thirds (67%) have rarely or never gone to Internet websites in the past year to find information in any way related to being a caregiver (among this group, 48% say they have never done this).

Figure 49: 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]?

Base: 2009 All caregivers of people 50+
(n=1,397)



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Approximately one-third (33%) of caregivers of the 50+ have often or sometimes gone on to Internet websites in the past year to find information in any way related to being a caregiver. These caregivers are more likely to be:

- Young or middle age caregivers (33% of those 18 to 49 and 37% of those 50 to 64 vs. 16% of those 65+).
- Caregivers with more education (42% of those with a college degree or more vs. 30% of those with some college, and 19% of those with a high school education or less).
- Caregivers with higher annual income (46% of those with an annual income of \$100,000 vs. 34% of those with \$50,000 to \$99,999, 28% of those with \$30,000 to 49,999, and 20% of those who earn less than \$30,000 annually).
- Caring for someone with Alzheimer’s disease (41% vs. 29% caring someone who does not have Alzheimer’s disease).

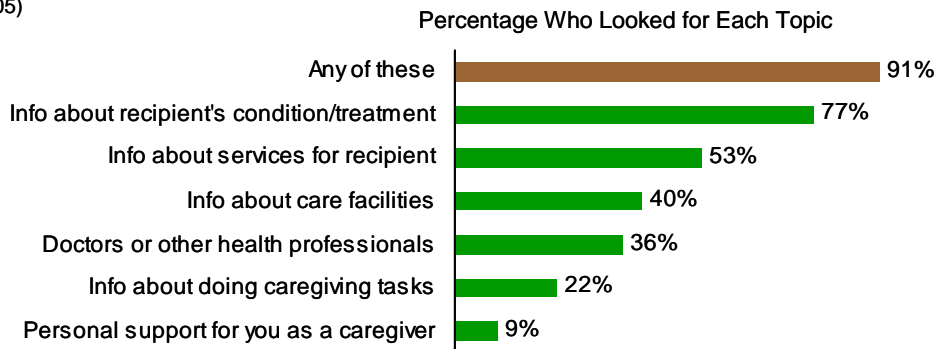
These caregivers are more likely to be long-distance caregivers (45% of those who live one hour or more from the care recipient vs. 30% of those who live within an hour of their care recipient. Be Internet website users are also more likely to say they feel they had no choice in becoming a caregiver (38% vs. 29% of those who feel they had a choice). The Internet website users are also more likely to be employed while caregiving (35% vs. 24% not employed while caregiving).

Among those caregivers who have used the Internet for a caregiving-related purpose, three-fourths (77%) say they looked for information about their care recipient’s condition or treatment and about half (53%) looked for information about services for care recipients.

Figure 50: Caregiving Information Sought Online

Q43. Did you look online for...?

Base: 2009 All caregivers of people 50+ who used the internet for a caregiving-related purpose (n=705)



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Among caregivers who have gone online for a caregiving purpose, those who are more likely to have sought any of the mentioned types of information include:

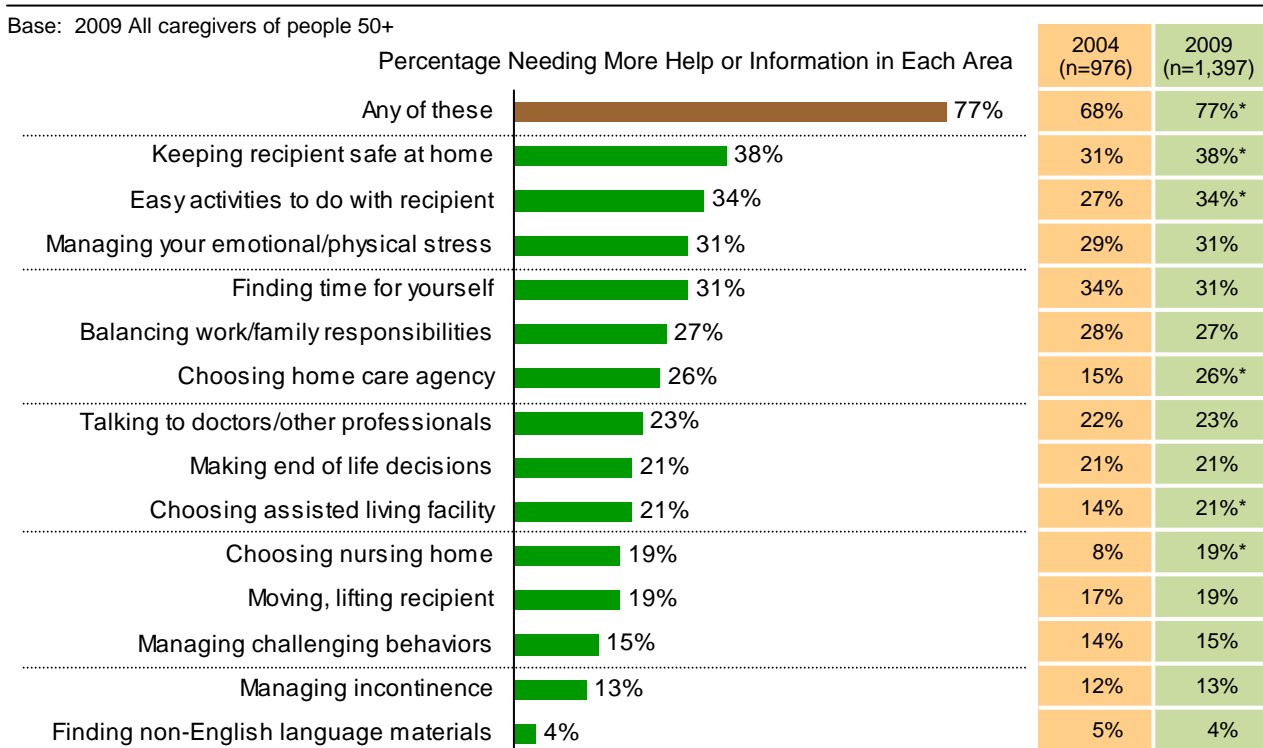
- Younger or middle aged caregivers (50% of those 18 to 49, 52% of those 50 to 64 vs. 23 of those 65+),
- Caregivers of Alzheimer’s patients (95% vs. 89% of those not caring for an Alzheimer’s patient).

Information Needs

More than three-fourths (77%) of caregivers say they feel they need/needed more help or information on at least one of the fourteen categories we asked about. Almost four in ten caregivers (38%) say they need information about keeping the person they care for safe at home and one-third (34%) need information about finding easy activities to do with the person they care for. A similar share needs information or help on managing emotional stress or physical strain. This represents the first time caregivers selected one of their own needs.

Figure 51: Caregiving Information Needs

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



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Those who want more information or help include:

- Caregivers in more intensive caregiving situations are most likely to want more information. Over eight in ten caregivers with a medium to high burden of care desire more information on at least one topic (84%), compared to just 71% of low burden caregivers.
- Caregivers co-residing with the person for whom they provide care are more likely to need more information (85% vs. 76% not co-resident), as are those providing care for 9 or more hours each week (84% vs. 72% of those giving care 0 to 8 hours a week).
- The need for more help or information also varies by the care recipient's age. Younger and middle aged caregivers are more likely to want more help or information on at least one topic mentioned (80% vs. 64% of caregivers age 65+).
- Hispanic and Asian-American caregivers are also more likely to want information than White caregivers (87% Hispanic and 87% Asian-American vs. 75% White).
- Those who felt they had no choice in taking on their caregiving role are more likely to need more information or help on at least one topic (85% vs. 72% of those who felt they had a choice).
- Caregivers providing care to a loved one with Alzheimer's are more likely to need more information (86% vs. 74% of those caring for someone without Alzheimer's). They are more likely to want help or information on managing challenging behaviors (33% vs. 8% of those not caring for someone with Alzheimer's), easy activities they can do with their loved one (43% vs. 29%), managing incontinence (18% vs. 10%), finding time for themselves (40% vs. 27%), choosing an assisted living facility (26% vs. 18%), and choosing a nursing home (28% vs. 15%).
- Women are more likely than men to need more help or information on at least one topic (80% vs. 72% of males). In particular, they are more likely to want help or information on moving or lifting the person they care for (21% vs. 14%) and on managing their emotional and physical stress (36% vs. 22%).

2004-2009 Trend of Caregivers of Recipients Age 50+

Caregivers' information needs have increased during the past five years from two-thirds (68%) to three-quarters (77%) who say they need information about at least one of fourteen types of information we asked about. Caregivers express a significant increase in the need for specific types of information such as, keeping recipients safe at home (31% to 38% in 2009), easy activities to do with their care recipient (27% to 34% in 2009), choosing a home care agency (15% to 26% in 2009), choosing an assisted living facility (14% to 21% in 2009), and choosing

a nursing home (8% to 19% in 2009). These findings suggest good targets for caregiver interventions.

J. Support for Caregivers

Supportive Services and Practices

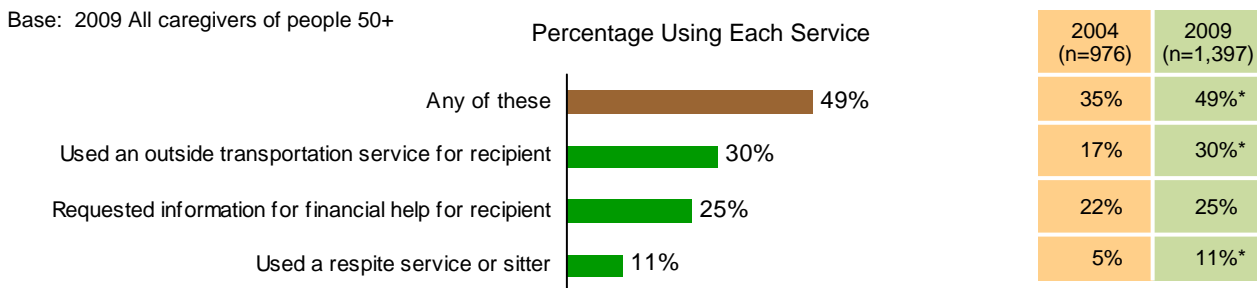
Two-thirds (66%) of caregivers say coordinating the care of the person they help is very or somewhat easy, yet a quarter (24%) say it is somewhat or very difficult to coordinate the care between various health care professionals or service providers. Caregivers who say it is somewhat or very difficult to coordinate the care are more likely to be caring for someone with Alzheimer’s disease or related conditions (33% vs. 21% of caregivers assisting recipients with other conditions), experiencing a high level of burden (36% vs. 16% of those with a low level of burden), feel as though they had no choice to take on the caregiving role (31% vs. 19% of those who feel they had a choice), and those who live more than one hour from their care recipient (34% vs. 20% who do not co-reside with their recipient but live less than one hour away from them).

Almost half (49%) report using any of the three services we asked them about. Three in ten (30%) say they have used an outside transportation service for their care recipient and one-quarter (25%) say they have requested information for financial help for their care recipient. Fewer caregivers report using respite services (11%).

Figure 52: Use of Services

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

Base: 2009 All caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Those who report using more services include:

- Male caregivers are more likely to have used an outside transportation service for their loved one (37% vs. 27% of females)
- Middle age or older caregivers are more likely to have utilized a respite service (14% of those age 50+ vs. 8% of younger caregivers 18 to 49) or arranged for an outside service to provide transportation for their loved one (35% of those age 50+ vs. 25% of younger caregivers)
- Those who have been in their caregiving role for a longer amount of time are more likely to have utilized one of the three services we asked about (53% of those who have been caring for their loved one for 1 year or more vs. 40% of those who have providing care for less than 1 year)
- Those who feel they did not have a choice in taking on their caregiving role are more likely to have used one of the services mentioned (56% vs. 43% of those who feel they had a choice)

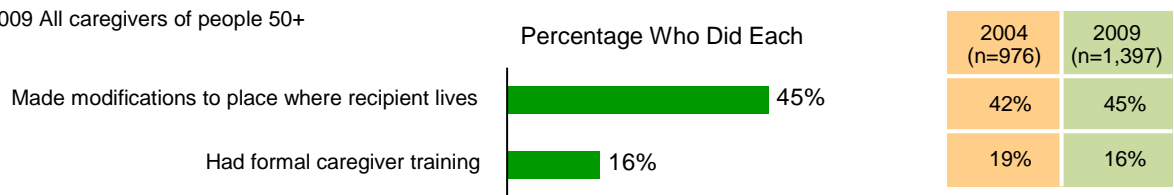
2004-2009 Trend of Caregivers of Recipients Age 50+

The proportion of caregivers who say they have used any of the services asked about has increased (35% to 49% in 2009). More specifically, the use of transportation services for their care recipient has increased (17% to 30% in 2009). While still a small proportion, caregivers' use of respite services has doubled (5% to 11% in 2009).

Figure 53: Use of Services to Ease Care

Q46. Have you done or obtained any of these types of things to make it easier to care for your [relation]?

Base: 2009 All caregivers of people 50+



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Caregivers who are more likely to have made modifications to the place where the care recipient lives are:

- Those with high or medium levels of burden (59%, 47% vs. 34% of caregivers with low burden).
- Those who live in the same household as the care recipient (54% vs. 42% who do not live with their care recipient)
- Longer term caregivers (49% of those who have been caregivers for 5 or more years and 48% of those who have been caregivers for one to four years vs. 37% of those who have been a caregiver for less than one year.

Caregivers who have had formal caregiver training are more likely to:

- Be African-American (29% vs. 16% of caregivers of the 50+ overall, 14% of White caregivers or 15% of Asian-American caregivers.
- Those with a high level of burden ((24% vs. 10% at the low level of burden).
- Those living with their care recipient (23% co-reside vs. 14% who do not live in the same household)
- Caregivers who live less than one hour from the care recipient (16% vs. 8% who live one hour or more away from the care recipient.

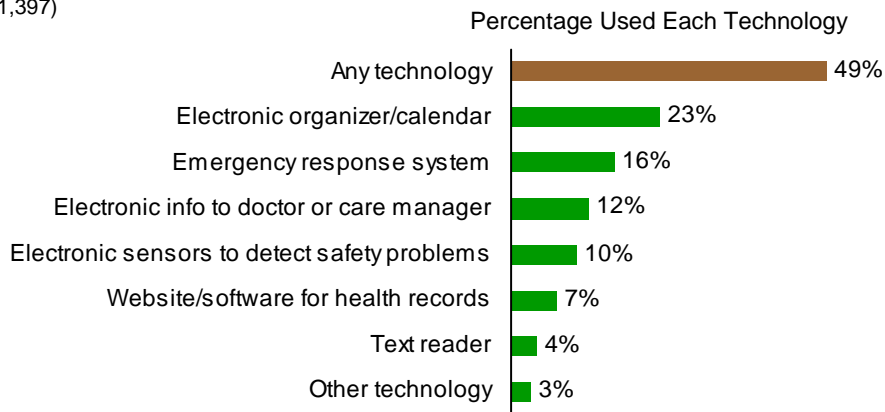
Use of Technology

Despite the numbers on Internet use, today the use of other technology is widespread. We found that nearly half (49%) of caregivers say they have ever used one of the six technologies or some other technology in caring for their care recipient. Almost one-quarter (23%) say they have used an electronic organizer or calendar for caregiving, about one in six (16%) have used an emergency response system. Approximately one in ten says they have used any device that electronically sends information to a doctor or other care manager (12%), or has electronic sensors that detect safety problems in the care recipient’s environment (10%).

Figure 54: Use of Technology in Caregiving

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

Base: 2009 All caregivers of people 50+ (n=1,397)



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

2009 Caregiver Subgroup Differences

Caregivers of female recipients are more likely to say technology was used in their caregiving activities (54% vs. 39% of those caring for male recipients).

Caregivers who are more likely to say they have used any of these devices are those who:

- Long-term caregivers of five years or more (55% vs. 43% of those caregiving for less than one year), and
- Those at a high level of burden (55%) or medium level of burden (54%) compared to those at a low level of burden (43%).

Caregivers who are more likely to use an electronic organizer or calendar are those who are:

- Younger and middle aged caregivers (26% of those 18 to 49, 22% of those 50 to 64 vs. 14% of those 65 or older).
- In fair/poor health (32% vs. 21% who are in very good/good health, 21% excellent health).
- Experiencing moderate to high levels of burden (55% of level 3 and 4 caregivers vs. 41% of level 1).

Caregivers who are more likely to use a device that electronically sends information to a doctor or care manager to help manage the person they assist include:

- Those at higher levels of burden (15% with a high burden and 16% with a medium level of burden vs. 8% with a low burden).
- Those who live separately and provide 21 hours of care per week or more (20% vs. 8% those who provide the same amount of care but live with their care recipient).

Caregivers who are more likely to say they use a personal emergency (PERS) system, such as Lifeline, are:

- Older or middle aged rather than younger caregivers (20% of those 65 or older and 21% of those 50 to 64 vs. 10% of those 18 to 49).

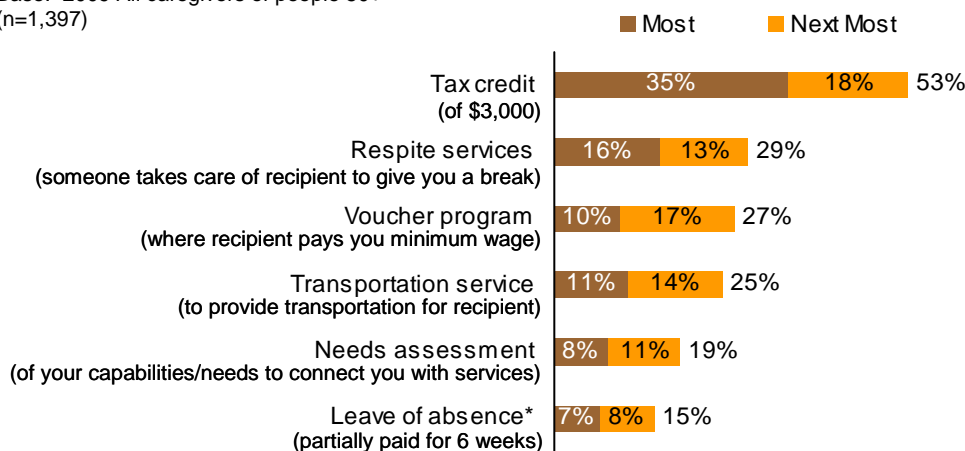
Reaction to Caregiving-Related Policy

Caregivers were asked about six potential caregiving-related policies. Over half (53%) say their first or second choice would be a caregiver tax credit of three thousand dollars. Almost three in ten (29%) selected respite services as their first or second choice. More than a quarter (27%) selected a voucher program, where their care recipient could pay them a minimum wage for at least some of the hours they spent caregiving as their first or second choice. One-quarter (25%) selected an outside service to provide transportation for their care recipient as their first or second choice, while one in five (19%) said a needs assessment and fewer said a leave of absence.

Figure 55: 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?

Base: 2009 All caregivers of people 50+ (n=1,397)



Source: Caregiving in the U.S. 2004, 2009, National Alliance for Caregiving and AARP

*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 Caregiver Subgroup Differences

Subgroups who are more likely are more likely to choose a caregiver tax credit of three thousand dollars as most helpful include:

- Younger and middle aged caregivers are more likely to choose a caregiver tax credit of three thousand dollars as their first choice (42% of those 18 to 49 and 32% of those 50 to 64 vs. 21% of those 65+)
- Caregivers with a college degree or more (38% vs. 28% of those with a high school education or less)
- Caregivers who earn \$50,000 or more per year (41% vs. 29% of those who earn less than \$50,000 per year)

- Those employed while caregiving (38% vs. 26% who were not employed while providing care).

The second policy option selected by most caregivers was a tax credit (21%).

V. Summary and Conclusions

Caregivers are still a diverse group with a variety of experiences. There are caregivers who are minimally involved in providing care, they report having a relatively easy experience managing their care recipient's needs and little negative impact on their own emotional, physical or financial lives. On the other hand, a smaller proportion of caregivers carry a heavy burden which takes a toll on them by increasing their vulnerability to physical strain, emotional stress, and financial hardships.

As the baby boom continues to age over the next 25 years, the proportion of people needing care may increase while the availability of family members to fill the caregiving role may decrease. This study shows caregivers are already using some types of technology that provide them greater freedom while helping to maintain the health and safety of their care recipients in the home. They are also using transportation services to navigate the community.

In the future, new policies may help support caregivers or expand services to assist both themselves and their care recipient. This study has given a voice to the preferences of today's caregivers regarding policy options. In the meantime, we need to provide specific information and supports identified in this study such as how to provide safe and stimulating home environments, meet their transportation needs, and help them choose home care agencies, assisted living facilities, or nursing homes when the time is right for them. We can also identify functional benchmarks which can assist families to decide when a variety of technologies may be helpful to both the caregiver and the care recipient.

Figure 56: 2009 Respondent Demographic Profile 18 + Caring for 50+

	Total (n=1,397) A	White (n=803) B	African- American (n=206) C	Hispanic (n=200) D	Asian- American (n=170) E
Gender					
Male	33%	33%	29%	33%	48% ^{ABCD}
Female	67 ^E	65 ^E	71 ^E	67	52
Age of Caregiver					
18 to 34	18%	15%	22%	30% ^{AB}	28% ^B
35 to 49	27	27	25	34	27
50 to 64	40	42 ^D	39	30	36
65 to 74	9	10	8	6	7
75 or older	5 ^D	5 ^D	5	1	2
<i>Mean age</i>	<i>49.9^D</i>	<i>51.1^D</i>	<i>48.2^D</i>	<i>43.1</i>	<i>45.1</i>
Race/Ethnicity of Caregiver					
White	76%	100%	0%	0%	0%
African-American	11	0	100	0	0
Hispanic	10	0	0	100	0
Asian-American	2	0	0	0	100
Other	2	0	0	0	0
Marital Status					
Married	59% ^C	63% ^{CD}	44%	48%	58%
Living with a partner	5 ^E	5	4	12 ^E	2
Single, never married	15	12	28 ^{AB}	21	29 ^{AB}
Separated, divorced	14	13	16	15	8
Widowed	7 ^E	7 ^E	8	4	2
Children/Grandchildren <Age 18 in Household					
Yes	32%	30	30	47 ^{ABC}	37
No	68 ^D	70 ^D	70 ^D	53	62

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated at 99% level.

Caregiving in the U.S – A Focused Look at Those Caring for Someone Age 50 or Older

2009 Respondent Demographic Profile 18+ Caring for 50+ (Continued)

	Total (n=1,397) A	White (n=803) B	African- American (n=206) C	Hispanic (n=200) D	Asian- American (n=170) E
Education					
Less than high school	4%	3	5	14 ^{AB}	6
High school graduate	23 ^E	24 ^E	23 ^E	20 ^E	5
Some college	24	23	29	27	16
Technical school	2	2	3	3	1
College graduate	26	26	26	22	40 ^{ABD}
Graduate school	20	22	15	14	32 ^{CD}
Household Income					
Less than \$50,000 (net)	39%	34%	59% ^{ABE}	56% ^{ABE}	31%
Less than \$15,000	7	6	9	15 ^B	8
\$15,000 to \$29,999	12	11	19	16	9
\$30,000 to \$49,999	19	17	31 ^{ABE}	22	14
Less than \$50,000, not fully specified	1	1	1	2	-
\$50,000 or more (net)	55% ^{CD}	60% ^{CD}	38%	38%	64% ^{CD}
\$50,000 to \$74,999	20	21	16	18	17
\$75,000 to \$99,999	13 ^C	14 ^C	7	9	14
\$100,000 or more	20 ^D	22 ^D	15	10	30 ^{CD}
\$50,000+, not fully specified	3	3	1	1	3
Current Employment Status					
Working full time	50%	51%	49%	43%	46%
Working part time	11	11	6	14	19 ^C
Retired	17 ^D	18 ^D	17	8	13
Homemaker	8 ^C	8 ^C	2	10	8
Unemployed and looking for work	5	4	11	9	8
Disabled	5 ^E	5 ^E	8 ^E	6	1
Student	2	1	3	6	3
Other	3	2	3	5	2

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated.

2009 Respondent Demographic Profile 18+ Caring for 50+ (Continued)

	Total (n=1,397) A	White (n=803) B	African- American (n=206) C	Hispanic (n=200) D	Asian- American (n=170) E
Caregiver Living Location					
Urban	29% ^B	22%	49% ^{AB}	54% ^{AB}	43% ^{AB}
Suburban	39 ^D	41 ^D	36	25	46 ^D
Rural	31 ^{CDE}	35 ^{CDE}	13	19	10
Care Recipient Living Location					
Urban	32% ^B	26%	49% ^{AB}	58% ^{AB}	46% ^{AB}
Suburban	38 ^D	40 ^D	34	22	45 ^D
Rural	28 ^{CDE}	32 ^{CDE}	15	18	9

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated.

**Figure 57: Respondent Profile
Trend in Caregivers 18+ Caring for 50+**

	Caregivers of Recipient Age 50+	
	2004 (n=976)	2009 (n=1,397)
Gender of caregiver		
Male	37%	33%
Female	63	67
Age of Caregiver		
18 to 34	22%	18%
35 to 49	32	27
50 to 64	32	40*
65 to 74	9	9
75 or older	5	5
<i>Mean age</i>	<i>47.7</i>	<i>49.9*</i>

Respondent Profile Trend in Caregivers 18+ Caring for 50+ (Continued)

	Caregivers of Recipient Age 50+	
	2004 (n=976)	2009 (n=1,397)
Race/Ethnicity of Caregiver		
White	74%	76%
African-American	11	11
Hispanic	10	10
Asian-American	4*	2
Other	<.05	2
Marital Status		
Married	57%	59%
Living with a partner	6	5
Single, never married	17	15
Separated, divorced	14	14
Widowed	6	7
Children/Grandchildren <Age 18 in Household		
Yes	36%	32%
No	64	68
Education		
Less than high school	5%	4%
High school graduate	28	23
Some college	26	24
Technical school	3	2
College graduate	23	26
Graduate school	14	20*
Household Income		
Less than \$50,000 (net)	48%*	39%
Less than \$15,000	7	7
\$15,000 to \$29,999	15	12
\$30,000 to \$49,999	25*	19
Less than \$50,000, not fully specified	0	1
\$50,000 or more (net)	43	55*
\$50,000 to \$74,999	18	20
\$75,000 to \$99,999	9	13*
\$100,000 or more	17	20
\$50,000+, not fully specified	0	3

Respondent Profile Trend in Caregivers 18+ Caring for 50+ (Continued)

	Caregivers of Recipient Age 50+	
	2004 (n=976)	2009 (n=1,397)
Current Employment Status		
Working full time	47%	50%
Working part time	10	11
Retired	18	17
Homemaker	9	8
Unemployed and looking for work	6	5
Student	4*	2
Disabled	5	5
Other	1	3*
Caregiver Living Location		
Urban	28%	29%
Suburban	40	39
Rural	29	31
Care Recipient Living Location		
Urban	32%	32%
Suburban	39	38
Rural	27	28

Appendix A

Caregiving in the U.S. 2009 Posted Questionnaire Caregivers of Recipients Age 50+

A. INTRO

Hello. My name is _____ and I am an interviewer with National Research. We are conducting a public opinion survey about important issues facing us today. We are not selling anything or raising money. The survey is completely confidential.

May I please speak to the person 18 years old or older in your household who had a birthday most recently?

[IF NECESSARY ARRANGE FOR A CALL BACK AND RECORD DATE AND TIME. REPEAT INTRO. AS NECESSARY]

[IF NEEDED REASSURE RESPONDENT: This research company will never try to sell you anything]

[IF ASK: The survey takes about 20 minutes]

B. SCREEN

SC1a. 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.

[IF YES: Is that you or someone else?]

[IF R. IS UNSURE, RE-READ QUESTION]

[IF R. ASKS “DOES GIVING MONEY COUNT?,” ASK: Aside from giving money, do you provide any other type of unpaid care to help them take care of themselves, such as help with personal needs, household chores, arranging for outside services, or other things? **[IF NOTHING OTHER THAN MONEY, CODE “NO”]**

	<u>1997</u> (n=--)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Yes -- Person On Phone Is Caregiver	--	97%	95%
Yes -- Another Person In Household	--	3	5
No.....	--	--	--
(VOL) Don't know.....	--	--	--

[TERMINATE IF (SC1a=3, 4 or 5).]

This is an important study and to be sure we talk to a variety of people, I need to ask you some basic questions.

SC2. First, how old were you on your last birthday? **[RECORD AGE]**

_____ **[SKIP TO SC3. TERMINATE IF <18.]**

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
18 to 34	22%	22%	18%
35 to 49	39	32	27
50 to 74	35	42	49
75 or older	3	4	5
(VOL) Don't know/Refused	--	1	1

SC2b. **[IF DON'T KNOW/REFUSED (SC2=98 or 99)]** Well are you... **[READ LIST]**

	<u>1997</u> (n=--)	<u>2004</u> (n=4)	<u>2009</u> (n=12)
35 to 44	--	84%	2%
45 to 54	--	--	57
55 to 64	--	16	23
65 to 74, or	--	--	14
75 or older?	--	--	5

SC3. Are you of Hispanic origin or background?

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Yes	5%	10%	10%
No	95	90	90
(VOL) Don't know	--	--	*
(VOL) Refused	*	--	--

SC4. Would you say you are White, Black or African American, Asian-American or Pacific Islander, or something else? **[ALLOW MULTIPLE RESPONSE]**

[IF HISPANIC, PROMPT:] I've recorded your Hispanic ethnicity. This question asks your race. **[REPEAT QUESTION]**

	<u>1997</u> (n=1202)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
White	86%	79%	82%
Black	11%	12%	11%
Asian-American	2%	4%	2%
Hispanic	--	2%	--
Other [SPECIFY _____]	1%	3%	6%
(VOL) Don't know/Refused [TERMINATE]	--	*	--

SC5. **RECORD GENDER, DO NOT ASK**

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Male	27%	38%	34%
Female	73	62	66

SC6. How many people, including children, live in the household?

[INTERVIEWER NOTE: Count should include the respondent.]

_____ [RECORD NUMBER]

	<u>1997</u> (n=--)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Lives alone [SKIP TO CHECKPOINT]	--	17%	19%
Two	--	36	37
Three to five	--	43	39
Six or more	--	4	5
(VOL) Don't know/Refused [TERMINATE]	--	--	--

SC7. Are you the person in the household who owns or rents the residence?

[WE WANT THE PERSON WHO PAYS THE MORTGAGE OR WHOSE NAME IS ON THE LEASE]

	<u>1997</u> (n=--)	<u>2004</u> (n=819)	<u>2009</u> (n=1141)
Yes	--	84%	93%
No [SKIP TO SC9]	--	16	7
(VOL) Don't know/Refused [TERMINATE]	--	--	--

SC8. [IF HOUSEHOLDER (SC7=1)] Are you related by marriage, blood, or adoption to anyone in the household?

	<u>1997</u> (n=--)	<u>2004</u> (n=684)	<u>2009</u> (n=1026)
Yes [SKIP TO CHECKPOINT]	--	92%	92%
No [SKIP TO CHECKPOINT]	--	8	8
(VOL) Don't know/Refused [TERMINATE]	--	1	--

SC9. Thinking about the person who owns or rents the house, please tell me, is that person related to anyone in the household by marriage, blood, or adoption?

[IF MORE THAN ONE PERSON OWNS/RENDS, WE WANT THE PERSON WHO PAYS THE MORTGAGE OR WHOSE NAME IS ON THE LEASE]

	<u>1997</u> (n=--)	<u>2004</u> (n=135)	<u>2009</u> (n=115)
Yes	--	86%	86%
No	--	14	14

SC10. Thinking about the person who owns or rents the house, please tell me how old they are? [PROMPT: Your best estimate is fine]

_____ [RECORD AGE; ALLOW ANY AGE]

	<u>1997</u> (n=--)	<u>2004</u> (n=135)	<u>2009</u> (n=115)
18 to 30	--	5%	9%
31 to 50	--	37	36
51 to 70	--	24	27
71 or older	--	32	28
(VOL) Don't know/Refused [TERMINATE]	--	2	--

SC11. As far as you know, is the person of Hispanic origin or background?

	<u>1997</u> (n=--)	<u>2004</u> (n=135)	<u>2009</u> (n=115)
Yes	--	8%	21%
No.....	--	91	79
(VOL) Don't know/Refused	--	1	--

SC12. Would you say they are White, Black or African American, Asian-American or Pacific Islander, or something else? **[ALLOW MULTIPLE RESPONSE]**

[IF HISPANIC, PROMPT:] I've recorded their Hispanic ethnicity. This question asks their race. **[REPEAT QUESTION]**

	<u>1997</u> (n=--)	<u>2004</u> (n=135)	<u>2009</u> (n=115)
White	--	75%	66%
Black	--	15	17
Asian-American.....	--	4	4
Other [SPECIFY _____]	--	4	14
(VOL) Don't know/Refused/Not specified [TERMINATE]	--	2	--

CHECKPOINT:

IF HISPANIC SAMPLE AND:

IF R IS HH & NOT HISPANIC ((SC6=1 OR SC7=1) AND SC3=2,3,4) OR HH IS NOT HISP (SC11=2,3,4): TERMINATE AS "NON-HISP HH".

IF AFRICAN-AMERICAN SAMPLE AND:

IF R IS HH & NOT AA (((SC6=1 OR SC7=1) AND (SC4m1#2 AND SC4m2#2 AND SC4m3#2..etc)) OR HH IS NOT AA (SC12m1#2 AND SC12m2#2 AND SC12m3#2...etc): TERMINATE AS "NON-BLACK HH".

IF INITIAL RESPONDENT CAREGIVER (SC1a=1): GO TO TEXT BEFORE Q1.

IF INITIAL RESPONDENT NOT CAREGIVER, BUT CAREGIVER IN HH (SC1a=2 AND SC1b#1): CONTINUE TO SC13.

SC13. May I please speak to the person in your household who is providing unpaid care to a relative or friend 50 years or older?

[IF MORE THAN ONE CAREGIVER, ASK TO SPEAK TO THE ONE WITH THE LAST BIRTHDAY]

Yes

Not available **[DO NOT GO TO SC14a; THANK & ARRANGE CALLBACK]**

No/Don't know/Refused **[DO NOT GO TO SC14a; THANK & CALL BACK TO CONVERT]**

CALLBACK SCREENS:

CB: When would be a good time to call back? **[RECORD DATE AND TIME]**

CONF: Your appointment is set for **[DATE]** at **[TIME]**. Is that correct? **[CONFIRM OR CHANGE DATE AND TIME IF NEEDED]**

INTRO FOR CALLBACK (WHEN CALL BACK SCHEDULED AT SC13)

Hello. My name is _____ and I am an interviewer with National Research. We called you recently and we were told that someone in your household is providing unpaid care to a relative or friend. **[GO TO SC13 AND ASK FOR THE CAREGIVER. USE THE CAREGIVER'S NAME IF KNOWN.]**

[IF NEEDED]:

We are conducting a survey about caregiving. We are not selling anything or raising money. The survey is completely confidential.

This research company will never try to sell you anything.

The survey takes about 20 minutes.

CAREGIVER ON PHONE (after having been handed the phone by initial respondent):

SC14a. **[IF SC1a=2]** Hello. We are conducting a survey about caregiving. Just to confirm...

At any time in the last 12 months, including now, have you provided unpaid care to a relative or friend 50 years or older to help them take care of themselves?

Caregiving 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 does not need to live with you.

	<u>1997</u> (n=--)	<u>2004</u> (n=23)	<u>2009</u> (n=60)
Yes	--	100%	100%

SC14c. Is there someone else in your household who is a caregiver for a relative or friend 50 years or older?

	<u>1997</u> (n=--)	<u>2004</u> (n=--)	<u>2009</u> (n=--)
Yes [SKIP BACK TO SC13]	--	--	--

SC15. Just to be sure I speak to people of all ages, how old were you on your last birthday?

_____ **[RECORD AGE; SKIP TO SC17. TERMINATE IF <18 YEARS OLD.]**

SC16. **[IF DON'T KNOW/REFUSED (SC15=98 or 99)]** Well are you... **[READ LIST]**

	<u>1997</u> (n=)	<u>2004</u> (n=)	<u>2009</u> (n=)
18 to 24			
25 to 34			
35 to 44			
45 to 54			
55 to 64			
65 to 74, or			
75 or older?			
(VOL) Don't know [TERMINATE]			
(VOL) Refused [TERMINATE]			

CAREGIVER AGE

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
18 to 34	22%	22%	18%
35 to 49	39	32	27
50 to 64	26	32	40
65 to 74	9	9	9
75 or older	3	5	5
(VOL) Don't know/Refused/Other age category	--	--	1
Mean	46.1	47.7	49.9

SC17. Are you of Hispanic origin or background?

	<u>1997</u> (n=)	<u>2004</u> (n=)	<u>2009</u> (n=)
Yes			
No			
(VOL) Don't know			
(VOL) Refused			

SC18. Would you say you are White, Black or African American, Asian-American or Pacific Islander, or something else? **[ALLOW MULTIPLE RESPONSE]**

[IF HISPANIC, PROMPT:] I've recorded your Hispanic ethnicity. This question asks your race. **[REPEAT QUESTION]**

	<u>1997</u> (n=)	<u>2004</u> (n=)	<u>2009</u> (n=)
White			
Black			
Asian-American			
Other [SPECIFY _____]			
(VOL) Don't know [TERMINATE]			
(VOL) Refused [TERMINATE]			

CAREGIVER RACE

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
White	82%	74%	76%
Black	11	11	11
Asian-American	2	4	2
Hispanic	5	10	10
Other	1	*	2

CAREGIVER GENDER

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Male	27%	37%	33%
Female	73	63	67

ALL CAREGIVERS:

C. CHARACTERISTICS OF THE RELATIONSHIP

This survey is part of an important national study conducted by the National Alliance for Caregiving and A-A-R-P. We really appreciate your participation.

[IF HELPFUL, INTERVIEWER MAY TELL RESPONDENT] This is a national survey, and although individual answers are confidential, the results from the overall survey will be published.

- Are you currently providing unpaid help to a relative or friend, or, was this something you did in the past 12 months but are no longer doing?

[IF BOTH CURRENT AND PAST, CODE “CURRENTLY” AND SAY:] Let’s talk about whomever you are currently providing care for.

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Currently.....	77%	68%	69%
Past 12 months	23	32	31
(VOL) Don't know/Refused	--	*	*

WORDING NOTE 1:

IF CURRENTLY (Q1=1): USE PRESENT TENSE, first verb in {BRACKETS}

IF PAST 12 MONTHS (Q2=2, 3, or 4): USE PAST TENSE, second verb in {BRACKETS}

- How many people age 50 or older {do you provide this care for? / did you provide this care for in the past 12 months?} **[RECORD NUMBER]**

_____ **[ALLOW 0-97; TERMINATE IF 0]**

FOR THE FEW RESPONDENTS WHO SAY THEY ARE CAREGIVERS TO 5+ PEOPLE, WE WILL DOUBLE CHECK THAT THEY ARE TRULY CAREGIVERS – THEY CAN'T BE IN AN INSTITUTIONAL SETTING AND THEY MUST BE CARING FOR RECIPIENTS WHO DO HAVE SPECIAL NEEDS.

- [IF Q2 >= 5]** {Are/were} all of these people together in an institutional or group setting like nursing care or day care or a school where you work or volunteer?

Yes **[TERMINATE]**.....

No.....

(VOL) Don't know **[TERMINATE]**

- [IF Q2 >= 5]** I need to understand whether this {is/was} care for some kind of special needs, or whether this {is/was} normal care one would expect for average, healthy people. How many of the people you help care for {have/had} some sort of special need that {is/was} the reason for their care? All of them, some of them, or none of them?

All **[SKIP TO TEXT AFTER Q2B]**

Some **[GO TO Q2B]**

None **[TERMINATE]**

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(VOL) Don't know [TERMINATE]

2b. How many people age 50 or older {do you provide this care for? / did you provide this care for in the past 12 months?} [RECORD NUMBER]

_____ [ALLOW 0-97; TERMINATE IF 0]

(VOL) Don't know [TERMINATE].....

(VOL) Refused [TERMINATE].....

FINAL NUMBER OF CARE RECIPIENTS

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
One	69%	71%	70%
Two	23	22	22
Three or more	8	7	8
(VOL) Don't know/Refused [TERMINATE]	*	*	--

[IF ONE PERSON (Q2=1): Now, I'd like to ask you some questions about the person for whom you {provide/provided} care.]

[IF MORE THAN ONE (Q2=2 thru 97): Let's focus on the person for whom you {provide/provided} the most assistance.]

5. **CARE RECIPIENT AGE:** How old {is/was} that person? [PROMPT: Your best estimate is fine]

_____ [RECORD AGE IN YEARS, SKIP TO C1. TERMINATE IF <50]

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
50 to 64	12%	20%	17%
65 to 74	23	24	19
75 to 84	40	31	33
85 to 89	14	13	18
90 or older	10	11	13
(VOL) Don't know/Refused	1	--	*

6. [IF DK/REF (Q5=998 or 999), ASK]: Well, {is/was} that person 50 years or older?

Yes

No

(VOL) Don't know TERMINATE.....

(VOL) Refused TERMINATE.....

7. What {is/was} this person’s relationship to you? **[PRE-CODED OPEN END. DO NOT READ LIST]**

[AS NEEDED: She/He is your _____?]

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
RELATIVE:	85%	86%	89%
Father	9	10	14
Mother	31	34	36
Grandfather	3	3	3
Grandmother	12	11	8
Grandparent-In-Law	1	1	2
Spouse	5	6	6
Companion/Partner	*	*	*
Father-In-Law	3	2	3
Mother-In-Law	9	8	8
Son	--	1	*
Daughter	*	*	1
Brother	1	1	2
Sister	1	2	2
Aunt	--	1	2
Uncle	--	4	1
Aunt/Uncle (gender unknown 2004)	6	1	--
Brother-In-Law	*	1	*
Sister-In-Law	1	*	*
Nephew	--	--	*
Niece	--	--	*
Other Relative [SPECIFY _____]	1	1	1
NON-RELATIVE:	15	14	11
Friend	15	14	9
Neighbor	--	--	2
Other non-relative	*	--	1
(VOL) Don't know/Refused	*	1	*

[IF Q7 = 1, 2, 3, 5, 6, 7, 8, 9, 10, 12, 13, 14, 15, 16, 17, 18, 19, 22 → SKIP TO COMMAND BEFORE Q10]

[IF Q7 = 4, 22, 23, 24, 25, 26, 27, 28, or 29 → SKIP TO Q9]

[IF Q7 = 11 or 20 → CONTINUE TO Q8]

8. **[IF Q7 = 11 or 20]: RECORD GENDER OF THE RESPONDENT’S [Q7 CODE]. DO NOT ASK UNLESS NEEDED.**

9. **[IF Q7 = 4, 22, 23, 24, 25, 26, 27, 28, OR 29] Would you mind telling me if your [Q7 CODE] {is/was} male or female? RECORD GENDER OF THE RESPONDENT’S [Q7 CODE]. DO NOT ASK UNLESS NEEDED.**

CARE RECIPIENT GENDER

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Male	20%	28%	32%
Female	56	68	68
(VOL) Don't know/Refused	*	4	*
Unknown	24	--	--

[IF CURRENTLY CARE FOR SPOUSE (Q1=1 AND Q7=20), AUTOCODE Q10=2 AND SKIP TO Q11.]

10. {Is your [Q7 CODE] currently/Was your [Q7 CODE]} widowed, married, living with a partner, separated, divorced, or single – that is never been married?

	<u>1997</u> (n=--)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Widowed	--	52%	49%
Married	--	27	30
Living with a partner	--	1	1
Separated	--	2	1
Divorced	--	11	12
Single	--	6	6
(VOL) Don't know/Refused	--	*	*

11. {Does/Did} your [Q7 CODE] live.... [READ LIST]

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
In your household [SKIP TO Q16]	21%	22%	20%
Within twenty minutes of your home	55	44	51
Between twenty minutes and an hour from your home.....	13	19	14
A one to two hour drive from your home, or.....	5	5	5
More than two hours away?	6	11	11
(VOL) Don't know/Refused [SKIP TO Q14]	*	*	*

12. [IF NOT IN HOUSEHOLD (Q11=2 thru 5)] On average, how often {do/did} you visit your [Q7 CODE].....more than once a week, once a week, few times a month, once a month, few times a year, or less often?

	<u>1997</u> (n=--)	<u>2004</u> (n=745)	<u>2009</u> (n=1049)
More than once a week.....	--	57%	59%
Once a week	--	19	17
Few times a month	--	10	10
Once a month	--	5	5
Few times a year	--	7	7
Less often	--	2	1
(VOL) Don't know/Refused	--	1	1

13. [ASKED IF NOT IN HOUSEHOLD (Q11=2 thru 5), BUT SHOWN BASED ON ALL RESPONDENTS] {Does/Did} your [Q7 CODE] live in...[READ ENTIRE LIST]

	<u>1997</u> (n=--)	<u>2004</u> (n=975)	<u>2009</u> (n=1394)
His or her own home	--	58%	58%
Someone else's home.....	--	6	7
[SHOW IF ADULT RECIPIENT (C1=1)] An independent living or retirement community.....	--	3	3
[SHOW IF ADULT RECIPIENT (C1=1)] In an assisted living facility where some care may be provided	--	4	5
(edited) A nursing care or long-term care facility [SKIP TO Q15]	--	6	6
Lives in caregiver's household	--	22	20

	Or somewhere else? [SPECIFY _____]	--	*	1
	(VOL) Don't know/Refused	--	--	*
14.	[IF ADULT RECIPIENT (C1=1), ASK]: {Does/Did} your [Q7 CODE] live... [READ ENTIRE LIST UNLESS "LIVES ALONE"] [MULTIPLE PUNCH]			
		<u>1997</u> (n=1509)	<u>2004</u> (n=694)	<u>2009</u> (n=967)
	Alone	43%	53%	47%
	With her/his spouse.....	--	26%	28%
	With her/his grown children	--	11%	13%
	With other family members	--	8%	8%
	With friends	--	1%	3%
	With an aide, housekeeper, or other staff	--	3%	4%
	With his/her parents	--	--	*
	Or with someone else? [SPECIFY _____]	--	1%	2%
	Does not live alone (1997)	57%	--	--
	(VOL) Don't know/Refused	*	*	*

15.	{Does/Did} your [Q7 CODE] live in an urban, suburban, or rural area?			
		<u>1997</u> (n=--)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
	Urban	--	32%	32%
	Suburban.....	--	39	38
	Rural area	--	27	28
	(VOL) Don't know/Refused	--	3	2

16.	And do you live in an urban, suburban, or rural area?			
		<u>1997</u> (n=--)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
	Urban	--	28%	29%
	Suburban	--	40	39
	Rural area	--	29	31
	(VOL) Don't know	--	2	2

D. CHARACTERISTICS OF RECIPIENT

17. Would you say that your [Q7 CODE] {needs/needed} care because of any...[READ ITEMS A-F IN ORDER]

	% Yes	1997 (n=--)	2004 (n=--)	2009 (n=1397)
a.	Short-term physical conditions?	--	--	36%
b.	Long-term physical conditions?	--	--	76%
c.	Emotional or mental health problems?	--	--	25%
d.	Mental retardation or developmental delay?	--	--	3%
e.	Learning disability or educational issue?	--	--	4%
f.	Behavioral issues?	--	--	10%
	None of these	--	--	5%

18. What would you say {is/was} the main problem or illness your [Q7 CODE] {has/had}, for which he/she {needs/needed} your care? [PRECODED OPEN END: ACCEPT ONE ANSWER.]

[IF “DISABLED”, PROBE: “What kind of disability would that be?”]

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
ADD, ADHD, Attention deficit disorder	--	--	*
AIDS	*	--	*
Alzheimer’s, confusion, dementia, forgetfulness	10%	8%	15%
Amputee	*	1	1
Arthritis	6	5	4
Asthma, breathing problems	--	--	1
Back problems	1	1	2
Blindness, vision loss, can’t see well	3	3	3
Blood pressure, hypertension	2	1	1
Brain damage or injury	*	--	1
Broken bones	3	2	3
Cancer	9	9	8
Deafness, hearing loss	*	1	*
Diabetes	5	9	5
Epilepsy, seizures	--	1	*
Feeble, unsteady, falling	--	1	1
Heart disease	10	9	8
Lung disease, emphysema	3	3	2
Mental retardation, developmental delay, Down syndrome .	--	*	*
Mental illness, emotional illness, depression	3	3	4
Mobility, can’t get around	10	6	5
Old age, just old, Aging	15	15	15
Osteoporosis	1	1	*
Paraplegia	1	1	1
Parkinson’s	--	2	2
Speaking, can’t speak	--	*	*
Stroke	8	6	6
Substance/drug/alcohol abuse	*	*	1
Surgery, wounds	2	3	4
Other [SPECIFY _____]	6	9	7
(VOL) Don't know	2	2	*
(VOL) Refused	*	*	*
None (1997)	*	--	--

20. [ASKED OF THOSE CARING FOR ADULTS AND ALZHEIMER’S NOT MENTIONED IN Q18. RESULTS BASED ON ALL RESPONDENTS] {Does/Did} your [Q7 CODE] suffer from Alzheimer’s or other mental confusion?

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Yes	22%	25%	30%
No	78	74	70
(VOL) Don't know/Refused	--	1	*

21. For how long {have you been providing/did you provide} care to your [Q7 CODE]??
[RECORD YEARS]

[PROMPT: Your best estimate is fine]

[IF MORE THAN ONE CONDITION, PROMPT:] Think about your caregiving for the main problem or illness you mentioned earlier.

_____ [ALLOW 1-93, or PRE-CODED OPEN END]

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Occasionally, on and off	4%	5%	3%
Less than six months	11	15	16
Six months to one year	7	17	14
One to four years	42	35	36
Five to nine years.....	21	14	17
Ten years or more.....	15	13	12
(VOL) Don't know/Refused	1	1	1

22. I'm going to read a list of kinds of help, which might be provided to a person, if the person cannot do this by him or herself. For each, just tell me if you {provide/provided} this kind of help.

{Do/Did} you help your [Q7 CODE]...[RANDOMIZE & READ LIST]

	% Yes	1997 (n=1509)	2004 (n=976)	2009 (n=1397)
a.	Get in and out of beds and chairs	37%	40%	46%
b.	Get dressed	31%	32%	34%
c.	Get to and from the toilet	26%	25%	28%
d.	Bathe or shower	27%	29%	26%
e.	By dealing with incontinence or diapers	14%	18%	20%
f.	By feeding him or her	19%	20%	19%
	None of these	49%	45%	39%

NUMBER OF ADLs

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
None	49%	45%	39%
One	14	15	19
Two	9	11	11
Three.....	8	7	9
Four.....	9	8	9
Five	6	7	6
Six.....	5	6	6

23. {Do/Did} you provide help to your [Q7 CODE] ...[RANDOMIZE ITEMS A-F, KEEP G-H LAST]

	% Yes	1997 (n=1509)	2004 (n=976)	2009 (n=1397)
Q22g.	By giving medicines, pills, or injections for his/her condition	37%	44%	42%
a.	With managing finances, such as paying bills, or filling out insurance claims	56%	61%	62%
b.	With grocery shopping	77%	77%	75%
c.	With housework, such as doing dishes, laundry, or straightening up	74%	69%	75%
d.	With preparing meals	60%	58%	64%
e.	With transportation, either by driving him/her, or helping your [Q7 CODE] get transportation	79%	83%	84%
f.	With arranging or supervising services from an agency, such as nurses or aides	54%	33%	37%
	None of these	2%	1	*

	% Yes	1997 (n=1509)	2004 (n=976)	2009 (n=1397)
g.	By advocating for him/her with care providers, government agencies, or schools	--	--	54%
h.	By doing physical or medical therapies or treatments on him/her	--	--	23%

NUMBER OF IADLS

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
None	2%	1%	*
One	5	9	7%
Two	12	9	10
Three.....	14	16	14
Four.....	17	18	18
Five	17	19	16
Six.....	18	17	21
Seven.....	15	12	14

[IF ADULT RECIPIENT (C1=1) AND NO/DK/REF TO (Q22a thru g AND Q23a thru f = 2, 3, or 4), THEN TERMINATE – TREAT AS NON CAREGIVER HOUSEHOLD.]

25. Thinking now of all the kinds of help you {provide/provided} for your **[Q7 CODE]**, about how many hours {do/did} you spend in an average week, doing these things? **[RECORD HOURS PER WEEK]**

_____ **[ALLOW 1-168]**

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Less than 1 hour per week	--	3%	3%
One to eight hours.....	48%	45	48
Nine to twenty hours	21	22	22
Twenty-one to forty hours	9	12	13
Forty-one or more hours	17	14	11
(VOL) Don't know /Refused	6	4	2
<i>Mean</i>	23.2	22.0	18.8

E. MEDICATIONS

26. {Does/Did} your **[Q7 CODE]** take any prescription medicine?

	<u>1997</u> (n=--)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Yes	--	92%	96%
No [SKIP TO Q28]	--	6	3
(VOL) Don't know/Refused [SKIP TO Q28]	--	2	2

27. Would you say your **[Q7 CODE]** {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?

	<u>1997</u> (n=1423)	<u>2004</u> (n=888)	<u>2009</u> (n=1336)
Needs help	24%	46%	48%
Manages on own	74	53	51
(VOL) Don't know/Refused	2	1	1

F. OTHER CAREGIVER SUPPORT

28. Has anyone else provided unpaid help to your **[Q7 CODE]** during the last 12 months?

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Yes	81%	65%	70%
No [SKIP TO Q30]	19	33	28
(VOL) Don't know/Refused [SKIP TO Q30]	--	2	2

29. Who would you consider to be the person who {provides/provided} most of the unpaid care for your [Q7 CODE] – you yourself, or someone else?

	<u>1997</u> (n=1238)	<u>2004</u> (n=631)	<u>2009</u> (n=923)
Self	27%	33%	32%
Someone else	51	56	58
(VOL) We split it evenly	21	10	9
(VOL) Don't know/Refused	1	1	1

PRIMARY CAREGIVER STATUS

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Sole caregiver	19%	33%	28%
Provides most unpaid care.....	22	21	23
Other caregiver provides most unpaid care	41	37	41
Caregiving shared equally.....	17	7	6
Don't know/Refused	1	3	3

30. During the last 12 months, did your [Q7 CODE] receive paid help from any aides, housekeepers, or other people who were paid to help him/her?

	<u>1997</u> (n=--)	<u>2004</u> (n=924)	<u>2009</u> (n=1312)
Yes	--	46%	41%
No [SKIP TO Q32]	--	54	57
(VOL) Don't know/Refused [SKIP TO Q32]	--	--	3

31. **[IF YES (Q30=1), ASK]:** Who would you say {provides/provided} more of your [Q7 CODE]'s care – you, other UNPAID helpers, or PAID helpers?

	<u>1997</u> (n=--)	<u>2004</u> (n=405)	<u>2009</u> (n=582)
You [THE RESPONDENT].....	--	44%	32%
Other unpaid helpers.....	--	36	28
Paid helpers	--	18	37
(VOL) Don't know/Refused	--	3	3

G. STRESS ON WORKING CAREGIVERS

32. Now I have a few questions about you. Are you currently...[READ LIST]

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Working full-time [SKIP TO Q34 IF CURRENT CG (Q1 = 1)]....	52%	47%	50%
Working part-time [SKIP TO Q34 IF CURRENT CG (Q1 = 1)] ..	12	10	11
A student	--	4	2
Disabled	--	5	5
Retired.....	16	18	17
A homemaker.....	--	9	8
Unemployed and looking for work.....	--	6	5
Unemployed	20	--	--
Something else [SPECIFY _____]	--	1	3

(VOL) Don't know/Refused * * *

33. {Have you been employed at any time since you began helping your [Q7 CODE]? / Were you employed at any time while you were helping your [Q7 CODE]}?

	<u>1997</u> (n=501)	<u>2004</u> (n=600)	<u>2009</u> (n=854)
Yes	35%	56%	55%
No [SKIP TO Q35]	65	43	45
(VOL) Don't know/Refused [SKIP TO Q35]	--	*	*

34. In your experience as both a worker and a caregiver, did you ever...[READ LIST]

	% Yes	<u>1997</u> (n=1193)	<u>2004</u> (n=724)	<u>2009</u> (n=966)
a.	Have to go in late, leave early, or take time off during the day to provide care	49%	58%	64%
b.	Have to take a leave of absence	11%	16%	17%
c.	Have to go from working full-time to part-time, or taken a less demanding job	7%	10%	9%
d.	Have to turn down a promotion	3%	4%	5%
e.	Lose any of your job benefits?	4%	4%	3%
f.	Have to give up working entirely	6%	6%	6%
g.	Choose early retirement	4%	3%	4%
	None of these	46%	37%	32%

H. PHYSICAL, EMOTIONAL AND FINANCIAL STRESS OF CAREGIVING

35. 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 [Q7 CODE] {is/was} for you?

	<u>1997</u> (n=1502)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
1 – Not a strain at all	56%	43%	45%
2	18	23	24
3	15	18	16
4	5	8	6
5 – Very much a strain	6	6	8
(VOL) Don't know/Refused	--	*	*

36. 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 [Q7 CODE] {is/was} for you?

	<u>1997</u> (n=1500)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
1 – Not at all stressful.....	35%	27%	25%
2	21	17	21
3	19	21	22
4	11	17	16
5 – Very stressful	14	18	16
(VOL) Don't know/Refused	--	*	*

37. 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 [Q7 CODE] {is/was} for you?

	<u>1997</u> (n=1501)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
1 – No hardship at all	77%	68%	57%
2	10	13	19
3	7	10	13
4	3	4	5
5 – Great deal of hardship.....	4	5	5
(VOL) Don't know/Refused	--	*	*

38. Please think about all of the health care professionals or service providers who {give/gave} care or treatment to your [Q7 CODE]. How easy or difficult {is/was} it for you to coordinate care between these providers? Would you say...[READ LIST]? [ROTATE 1-4/4-1]

	<u>1997</u> (n=--)	<u>2004</u> (n=--)	<u>2009</u> (n=1397)
Very easy	--	--	35%
Somewhat easy.....	--	--	30
Somewhat difficult	--	--	19
Very difficult.....	--	--	5
(VOL) Don't know/Refused	--	--	10

39. We have been talking about the help you {provide/provided} for your [Q7 CODE]. Do you feel you had a choice in taking on this responsibility for caring for your [Q7 CODE]?

	<u>1997</u> (n=--)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Yes	--	59%	56%
No	--	40	43
(VOL) Don't know/Refused	--	1	1

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

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Yes	43%	52%	53%
No	56	47	47
(VOL) Don't know/Refused	*	1	*

I. USE OF INTERNET AND OTHER TECHNOLOGIES

41. If you were looking for information about some aspect of helping take care of your **[Q7 CODE]**, where would you turn? **[DO NOT READ CODES, MULTIPLE PUNCH IF THEY VOLUNTEER MORE THAN ONE]**

	<u>1997</u> (n=--)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Doctor	--	31%	20%
Nurse, other health professionals	--	11%	11%
Social worker, case worker	--	--	2%
Hospital, clinic	--	1%	3%
Caregiving provider (such as nursing home, assisted living facility, home care, senior daycare).....	--	--	4%
Hospice	--	--	1%
Mental health provider.....	--	--	*
Internet	--	30%	23%
Books, magazines, library	--	8%	3%
Government	--	6%	5%
Veteran's administration.....	--	--	2%
Social Security, Medicaid, Medicare	--	--	2%
Family, friends, colleagues, word of mouth	--	13%	20%
Family caregivers, support groups, people with similar experience	--	1%	1%
Senior citizen's center, aging organization.....	--	7%	12%
Disease-specific group or organization	--	--	3%
Social/human/family/community services	--	--	4%
Employer	--	1%	1%
School	--	--	*
Church, minister	--	3%	2%
Insurance company	--	--	1%
Other [SPECIFY _____]	--	1%	7%
(VOL) Don't know/Refused/None	--	8%	14%

42. 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 [Q7 CODE]? [READ LIST] [ROTATE 1-4/4-1]

	1997 (n=--)	2004 (n=--)	2009 (n=1397)
Often.....	--	--	12%
Sometimes	--	--	21
Rarely	--	--	19
Never [SKIP TO Q44]	--	--	48
(VOL) Don't know/Refused [SKIP TO Q44]	--	--	--

43. Did you look online for...?

(Based on all respondents)

	% Yes	1997 (n=--)	2004 (n=976)	2009 (n=1397)
a.	Information about your [Q7 CODE]'s condition or treatment?	--	30%	40%
b.	Information about services available for people like your [Q7 CODE]?	--	18%	27%
c.	Support for you personally as a caregiver?	--	13%	5%
d.	Information about how to do specific caregiving tasks?	--	--	12%
e.	Doctors or other health professionals?	--	--	18%
f.	Information about care facilities?	--	--	21%
	None of these	--	68%	53%

(Based on those using the internet for caregiving-related purpose)

	% Yes	1997 (n=--)	2004 (n=--)	2009 (n=705)
a.	Information about your [Q7 CODE]'s condition or treatment?	--	--	77%
b.	Information about services available for people like your [Q7 CODE]?	--	--	53%
c.	Support for you personally as a caregiver?	--	--	9%
d.	Information about how to do specific caregiving tasks?	--	--	22%
e.	Doctors or other health professionals?	--	--	36%
f.	Information about care facilities?	--	--	40%
	None of these	--	--	9%

44. In caring for your [Q7 CODE], was [READ ITEM] ever used? [REPEAT STEM EVERY 3 ITEMS OR AS NEEDED.]

	% Yes	1997 (n=--)	2004 (n=--)	2009 (n=1397)
	Used Technology (net)	--	--	49%
a.	An electronic organizer or calendar?	--	--	23%
b.	Any device that electronically sends information to a doctor or care manager to help manage his/her health care, like a device that transmits blood sugar or blood pressure readings?	--	--	12%
c.	A text reader for individuals with low vision?	--	--	4%
d.	An emergency response system, such as Lifeline?	--	--	16%
e.	A website or computer software to keep track of his/her personal health records?	--	--	7%
f.	An electronic sensor that can detect safety problems in the home and take steps to help, like when someone falls, wanders away, or leaves the stove on?	--	--	10%
	Net – Any other technology	--	--	3%
	Video/audio monitoring	--	--	1%
	Enhanced telephones (for visual or hearing impaired or immobile people)	--	--	1%
	Other technology that is on-point (locator bracelets/GPS, speech/hearing technology, sensors on bed or chair to signal if someone is getting up unsafely, low vision aids)	--	--	1%
	Named standard communications, security, monitoring or treatment devices without any special technology in "other" category	--	--	9%
	Emails, texting, fax	--	--	1%
	Cell phone, telephone, intercom (no mention of enhancement)	--	--	2%
	Mobility aids like lifts, electric wheelchairs, etc.	--	--	2%
	Security or alarm system	--	--	1%
	Smoke or carbon monoxide detectors	--	--	1%
	Symptom/condition monitors such as monitors for blood pressure, heart, glucose, oxygen, temperature, apnea	--	--	2%
	Treatment machines or devices (oxygen machine, nerve stimulator, feeding pump, pacemaker, defibrillator, muscle stimulating suit, washing aid)	--	--	2%
	Computer (no mention of any special usage or functioning), standard software	--	--	1%
	Miscellaneous mentions that are not really technology (teaching materials, some information available on the computer; visual aids, calculator, CD player)	--	--	*

J. INFORMATION/SERVICES/POLICY

45. In your experience as a caregiver, have you ever.... **[READ LIST; PROGRAM SO THAT ITEMS A AND B COME LAST IN THE SERIES]**

	% Yes	1997 (n=1509)	2004 (n=976)	2009 (n=1397)
a.	Requested information about how to get financial help for your [Q7 CODE] ?	15%	22%	25%
b.	Used a respite [RESS – PIT] service or a sitter to take care of your [Q7 CODE] to free up your time?	14%	5%	11%
c.	Had an outside service provide transportation for your [Q7 CODE] instead of you providing the transportation?	15%	17%	30%
	None of these	66%	65%	51%

46. Have you done or obtained any of these types of things to make it easier to care for your **[Q7 CODE]**?

Have you...**[READ LIST]**?

	% Yes	1997 (n=1194)	2004 (n=976)	2009 (n=1397)
a.	Had modifications made in the house or apartment where your [Q7 CODE] {lives/lived} to make things easier for him/her?	28%	42%	45%
b.	Obtained formal training of some sort about how to care for a person with your [Q7 CODE] 's needs?	--	19%	16%

47a. 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 helpful, regardless of whether or not you used it already. **[ROTATE ITEMS; READ LIST]** Which one you would {find/have found} most helpful?

47b. Which one would you {find/have found} the next most helpful, regardless of whether or not you used it already? **[ROTATE ITEMS; READ LIST IF NEEDED, EXCLUDING IF SELECTED IN Q47a]**

% Selected as Most or Next Most Helpful	1997 (n=--)	2004 (n=--)	2009 (n=1397)
An assessment of your caregiving capabilities and needs to connect you with needed services	--	--	19%
A caregiver tax credit of three thousand dollars	--	--	53%
[IF EVER EMPLOYED WHILE CAREGIVING] A partially paid leave of absence from your work for 6 weeks	--	--	15%
A voucher program where your [Q7 CODE] could pay you minimum wage for at least some of the hours you spend caregiving	--	--	27%
Respite services, where someone would take care of your [Q7 CODE] to give you a break	--	--	29%
An outside service to provide transportation for your [Q7 CODE]	--	--	25%

Don't Know/Refused	--	--	20%
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48. As a caregiver, on which of the following do you feel you [need/needed] more help or information?

[RANDOMIZE AND READ LIST] [REPEAT EVERY 4-5 ITEMS: Do you feel you {need/needed} more help or information on...]

	% Yes	1997 (n=--)	2004 (n=976)	2009 (n=1397)
a.	Keeping the person you care for safe at home	--	31%	38%
b.	Managing challenging behaviors, such as wandering	--	14%	15%
c.	Easy activities you can do with the person you care for	--	27%	34%
d.	Managing incontinence or toileting problems	--	12%	13%
e.	Moving or lifting the person you care for	--	17%	19%
f.	Balancing your work and family responsibilities	--	28%	27%
g.	Finding time for yourself	--	34%	31%
h.	Choosing an assisted living facility	--	14%	21%
i.	Choosing a nursing home	--	8%	19%
j.	Choosing a home care agency	--	15%	26%
k.	How to talk with doctors and other healthcare professionals	--	22%	23%
l.	Managing your emotional and physical stress	--	29%	31%
m.	Making end-of-life decisions	--	21%	21%
n.	Finding non-English language educational materials	--	5%	4%
	None of these	--	32%	23%

K. DEMOGRAPHICS

And finally, just a few questions for classification purposes only....

D1. How would you describe your own health? Is it excellent, very good, good, fair, or poor?

	<u>1997</u> (n=--)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Excellent	--	25%	23%
Very good	--	30	36
Good	--	27	25
Fair	--	12	13
Poor	--	5	3
(VOL) Don't know/Refused	--	*	*

D2. How would you say taking care of your **[Q7 CODE]** has affected your health? Has it made it better, not affected it, or made it worse?

	<u>1997</u> (n=--)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Made it better	--	8%	8%
Not affected it	--	76	75
Made it worse	--	14	16
(VOL) Don't know/Refused	--	2	1

D3. Are you currently... **[READ LIST]**

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Married	62%	57%	59%
Living with a partner	4	6	5
Widowed.....	8	6	7
Separated.....	2	3	2
Divorced	11	11	12
Single, never married	13	17	15
(VOL) Don't know/Refused	1	*	*

D4. Did you ever serve on active duty in the US Armed Forces? **[PROBE: Army, Navy, Air Force, Marines, Coast Guard or Women's Armed Forces]**

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Yes	11%	14%	11%
No.....	88	85	89
(VOL) Don't know/Refused	1	*	*

D5. Did your **[Q7 CODE]** serve in the US Armed Forces?

	<u>1997</u> (n=--)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Yes	--	19%	20%
No.....	--	80	79
(VOL) Don't know/Refused	--	1	1

D6. Are there any children or grandchildren currently living in your household under 18 years of age?

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Yes	41%	36%	32%
No.....	58	64	68
(VOL) Don't know/Refused	1	*	*

D7. What is the last grade of school you completed? **[IF NEEDED, READ LIST]**

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Less than high school.....	9%	5%	4%
High school grad/GED.....	35	28	23
Some college.....	22	26	24
Technical school.....	4	3	2
College grad	20	23	26
Graduate school/Grad work	9	14	20
(VOL) Don't know/Refused	1	*	*

D8a. Last year, what was your total annual household income from all sources?

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
Under \$15,000.....	14%	7%	7%
\$15,000 to \$29,000	26	15	12
\$30,000 to \$49,000	24	25	19
\$50,000 to \$74,000	14	18	20
\$75,000 to \$99,000	6	9	13
\$100,000 or more.....	5	17	20
Less than \$25,000, not fully specified	1	--	--
More than \$25,000, not fully specified.....	2	--	--
Less than \$50,000, not fully specified	--	--	1
More than \$50,000, not fully specified.....	--	--	3
(VOL) Don't know/Refused	8	10	5

D10. (none) If the situation arose, would you be interested in participating in future research on caregivers?

Yes

No.....

D11. (none) Also, the results of this survey are totally confidential. However if a reporter writing a story about the results of the overall survey wanted to ask you more questions or get a quote from you for a news story, would you like to get a call back or not? It is completely optional.

- Yes
- No [SKIP TO THANK YOU]
- (VOL) Don't know [SKIP TO THANK YOU]
- (VOL) Refused [SKIP TO THANK YOU]

[IF D10=1 OR D11=1, ASK:] What is the best number call you on [IF D10=1: for future research]?

- [] _____
- The number we called
- (VOL) Refused

[ALL]: Finally, for verification purposes only, what is your name?

- _____
- (VOL) Refused

D12. RECORD LANGUAGE OF THE INTERVIEW

- ENTIRELY SPANISH.....
- Mainly Spanish.....
- HALF AND HALF
- Mainly English.....
- ENTIRELY ENGLISH.....

BURDEN

	<u>1997</u> (n=1509)	<u>2004</u> (n=976)	<u>2009</u> (n=1397)
1-Low.....	32%	31%	27%
2	15	16	19
3	16	16	20
4	20	21	23
5-High.....	12	11	9

[THANK YOU]: Thank you very much for your time. Your responses have been very helpful to this research.

Appendix B: Detailed Methodology

The national study contains the results of 6,806 interviews among adults in the U.S., of whom 1,480 were caregivers who completed interviews. A total of approximately 200 caregiver interviews each of African American, Hispanic, and Asian caregivers were obtained.

In order to strengthen the analysis of caregivers of recipients ages 50 or older, additional interviews were conducted among this subgroup to reach 806 non-minority White caregivers, 200 Hispanics, and 206 African Americans.

The sections below describe the basic research and sample designs for the study, the research procedures used to implement the project, the methodology used for estimating caregivers, weighting specifics, and the response rate is included at the end of this section.

A. Research Design

The research design of this study is based on achieving several goals for NAC and AARP. One driving goal of the project is to estimate the number of caregivers in the U.S. population, as well as the number of caregiving households. For the first time, this number is to include individuals who are caregivers for children under the age of 18. Other aims include exploring caregiver characteristics, roles, and needs, as well as how these have changed since related surveys conducted in 1997 and 2004. New areas of exploration in this year's study are caregiver use of the internet for information, use of technology for the care recipient, and public policies that would help caregivers.

Because of the importance of achieving accurate trend data, the project design closely mirrored that developed for the 2004 Caregiving in the U.S. study.

B. Questionnaire Design

The questionnaire was drafted by Mathew Greenwald & Associates, drawing from the 2004 NAC/AARP study, Family Caregiving in the U.S. The questionnaire, shown in Appendix A, has two components. The first is a screener used to identify a caregiver in the household and to obtain selected demographic information from a randomly-selected respondent in all households contacted—regardless of the presence of caregiving in the household. These data are used to estimate the prevalence of caregiving. The second part of the questionnaire reflects the questions about caregiving administered to all caregivers.

The questionnaire was programmed into a computer aided telephone interviewing system and Greenwald & Associates fully briefed the interviewers on the purpose of the study and how to conduct the interview. Interviews were monitored periodically and interviewers were given refresher briefings.

The questionnaire was professionally translated into Spanish, building from the translation of the 2004 questionnaire.

C. Sample

The research design for the national study called for completing 1,000 interviews with a national random sample of caregivers. Random digit dial (RDD) sample, stratified by geography to generate a set of telephone numbers proportionate to the population, was used for those interviews. In addition, the design called for using oversamples to reach a total of 200 African American caregivers, 200 Hispanic caregivers, and 200 Asian caregivers.

To achieve these targets in the most cost-effective way, targeted samples were used. For African Americans, geographic density samples were used in which RDD samples are drawn from telephone exchanges with a concentration of at least 30% African Americans. For Hispanics, interviews came from a surname sample and a 40% or greater geographic density sample. For Asian Americans, the study relied primarily on an Asian surname sample, as well as a surname sample within a 10% or greater density area, and pre-screened Asian members of Knowledge Networks' RDD-recruited panel. All samples, except the Knowledge Networks Asian sample, came from Survey Sampling, Inc.

The various samples produced the following number of completed interviews and screened respondents:

Sample	Completed Interviews	Additional Screened Respondents
Random digit dial	1,000	3203
African American targeted	127	422
Asian targeted	136	844
Knowledge Networks (Asian)	54	412
Hispanic targeted	163	445
Total	1,480	5,326

From all of these interviews, we obtained interviews with 858 White, non-Hispanic caregivers, 200 African-American caregivers, 201 Hispanic caregivers, 200 Asian American caregivers, and 21 caregivers of another race.

In addition to the 1,480 caregiver interviews in the base study, an additional 288 interviews were conducted among caregivers of individuals age 50 or older, to bring the total among this caregiving subset to 1,397 caregivers, including 803 Whites, 206 African Americans, and 200 Hispanics, as well as 170 Asians and a small number of other minorities from the base study. The Whites and some of the minorities were reached through random digit dialing. The remaining minorities were reached through targeted samples like those described above.

D. Field Methodology

In order to get the most nationally representative sample of adults and households, a randomly selected respondent was selected to interview in each household. Specifically, when contact was established, the interviewer asked to speak with the person in the household aged 18 or older with the most recent birthday. This procedure was initiated in the 2004 study. In the case of the racial/ethnic over-samples, to be eligible, the householder had to be of the targeted race/ethnicity. The interviewer continued with the screener among all randomly-selected respondents, and proceeded to the substantive portion of the questionnaire if a caregiver was identified and agreed to participate.

Pertinent demographic data were collected on all of these initial, randomly-selected respondents (age, race, and gender). Furthermore, data on the household were gathered for the national study (family or non-family status of household members, age of householder, and race of householder).

The screening questions used to identify the presence of a caregiver in the household are as follows:

In the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 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.

In the last 12 months, has anyone in your household given unpaid care to any child under the age of 18 because of a medical, behavioral, or other condition or disability? This could include care for ongoing medical conditions or serious short-term ones, emotional or behavioral problems, or developmental problems, including mental retardation.

If the randomly-selected respondent reported no caregiver in the household, the interview ended after obtaining the demographic data for the individual and the household. If the randomly-selected respondent was a caregiver, interviewers proceeded to administer the full questionnaire. If the randomly-selected respondent was not a caregiver, but he/she identified someone in the household as a caregiver, the interviewer asked to speak with the caregiver after obtaining necessary demographic data from the randomly-selected respondent. Only one caregiver per household was interviewed.

For the oversample among caregivers of recipients ages 50 and older, only the first caregiving question above was asked, with the age of the recipient changed from 18 to 50. If the initial respondent reported that there was no caregiver present in the household, the interview was ended and no household screening data was collected.

In order to be validated as a caregiver and complete the full interview, all self-identified caregivers of an adult also had to report providing help with at least one activity of daily living or instrumental activity of daily living.

For the Knowledge Networks panel, the screener portion of the questionnaire was administered to all of the Asian households on their panel. If a caregiver in the household was identified, the name, phone number, and a convenient time to call were obtained. If more than one caregiver was identified, Knowledge Networks randomly selected one to participate in the telephone interview. Those data were then forwarded to the field service to complete the caregiver interviews by telephone. All caregiver interviews were conducted by telephone instead of online to eliminate the chance of error due to mode effects.

All interviewing was conducted by National Research. A five-call design was used for interviewing so that every number was dialed at least five times in an attempt to establish contact. Every soft refusal was followed by another attempt to convert the refusal into a completed interview.

Respondents were given the option of conducting the interview in Spanish or English, and 31% of Hispanic respondents chose to conduct part or all of the interview in Spanish.

Interviews from the main RDD national sample and the African American and Hispanic oversamples were conducted date through May 23, 2009. The Asian oversample continued through June 6, 2009 and the oversample of caregivers ages 50+ continued through June 17, 2009.

The completed interviews averaged 22.3 minutes in length.

See Appendix A for the full CATI-formatted questionnaire with all instructions.

E. Weighting

Data from all samples in the base study—except those used to reach the additional 288 caregivers of adults age 50 or older—were combined and weighted. The oversample interviews of caregivers of older recipients were also combined later for analyses specific to caregivers of recipients ages 50 or older, in a manner described below.

The household weight was used to weight the base study results in order to estimate the prevalence of caregiving household in the U.S. and to analyze the substantive results from the full interviews. Separately, a population weight was derived to estimate the prevalence of caregiving among the U.S. adult population.

Household Weights

Household weights involved a multi-stage weighting procedure. In the first stage, all base study data were weighted by householder race/ethnicity, and in the second stage, by householder age and household type (family or non-family). The weighting was based on all respondents who were fully screened in the base study, and who did not terminate during the screening process. The dataset included screened respondents who reported no caregivers in the household, caregivers who completed the interview, and respondents who reported the presence of caregivers who chose not to participate in the full interview

or who only partially completed it. Weighting targets came from the Current Population Survey, 2008 Annual Social and Economic Supplement, conducted by the U.S. Census Bureau and released in January 2009.

The 288 oversample interviews among caregivers of recipients ages 50 or older were weighted to the weighted distribution of caregivers of 50+ recipients in the base sample by race/ethnicity, age of householder, and type of household (family or non-family).

Population Weights

Population weights were based on the subset of fully screened respondents in the base study who were the initial randomly selected individuals. They were weighted using a single-stage weighting procedure by age, sex, and race/ethnicity to the 2008 population estimates released by the Population Division of the U.S. Census Bureau on May 14, 2009.

F. Estimating Prevalence of Caregiving

Household Prevalence

There were 6,806 total screened households. Using household weighted figures, 1,711 of these households had caregivers, as validated through a complete survey (n=1,618) or through a partial survey (n=93). In addition, there were 446 households who reported presence of a caregiver, but who did not continue the interview through to validate the caregiver.

However, among the respondents who initially reported a caregiver in the household and continued far enough in the survey to validate their presence, a very large proportion (92.8%) were ultimately validated. Accordingly, we also count as caregivers 92.8% of the 446 households (resulting n=414) who reported a caregiver but did not continue with the full survey. Thus 1,711 validated caregivers plus an estimated 414 additional caregivers, on a base of 6,806 total screened caregivers, leads to a household prevalence rate of 31.2%.

	Prevalence	Number of Households in the U.S.	Estimated Number of Caregiving Households
Overall	31.2%	116,783,000	36.5 million
White (Non-Hispanic)	30.5%	82,765,000	25.2 million
Black	33.6%	14,111,000	4.7 million
Asian	20.0%	4,409,000	0.9 million
Hispanic	36.1%	13,339,000	4.8 million

The study also examined prevalence of households in which the caregiver's principal recipient is a person who is at least 50 years of age. This prevalence was found to be 21.1% based on the following figures. Of the 6,806 screened households, there were 1,204 interviews among validated caregivers of recipients age 50+. An additional 57 were among non-validated caregivers of 50+ recipients; these were multiplied by 92.8%—the proportion of the *households* with reported caregivers who went far enough in the survey to verify their status and who were validated—resulting in 53 additional caregivers. There were 246 non-validated caregivers whose recipient age was unknown; they were multiplied by 92.8% and then by 71.8%, the proportion of caregivers who care for someone age 50 or older (resulting in n=171 additional caregivers). Finally, there were 10 validated caregivers whose recipient age was unknown, and they were multiplied by 71.8% (resulting in n=7 additional caregivers). A total of 1,435 caregivers divided by 6,806 screened caregivers leads to the 21.1% prevalence estimate.

	Prevalence	Number of Households in the U.S.	Estimated Number of Caregiving Households
Caregivers of Recipients Age 50+	21.1%	116,783,000	24.6 million

Population Prevalence

Using the 6,806 randomly selected initial respondents weighted with population weights, we find that 1,633 are caregivers, as validated through a complete or partial survey. In addition, 350 reported they were caregivers but did not continue the interview to validate that. However, among the *initial* respondents who initially reported being a caregiver and continued far enough in the survey to validate their status, 88.5% were ultimately validated. Applying this percentage to the 350 non-validated caregivers results in n=310 additional caregivers. The 1,633 plus 310 caregivers, on a base of 6,806 total screened caregivers, leads to a population prevalence rate of 28.5% and an estimate of 65.7 million individual caregivers in the U.S. The prevalence for each race/ethnicity is shown in the following table.

	Prevalence	Number of Adults Age 18+ in the U.S.	Estimated Number of Adult Caregivers in the U.S.
Overall	28.5%	230,087,100	65.7 million
White (Non-Hispanic)	27.6%	157,927,600	43.6 million
Black	32.4%	26,377,500	8.5 million
Asian	17.6%	10,287,000	1.8 million
Hispanic	32.3%	30,851,100	10.0 million

The population prevalence of caregivers whose principal recipient is at least 50 years of age is 18.9%, based on a total of 1,286 caregivers out of 6,806 screened individuals. The 1,286 caregivers were identified as follows. First, 1,133 of the initial respondents were validated caregivers of an older recipient. An additional 58 were non-validated caregivers of age 50+ recipients; these were multiplied by 88.5%—the proportion of initially-reported caregivers who were asked validating questions and ultimately were confirmed to be caregivers. This results in 51 additional caregivers. There were 152 non-validated caregivers whose recipient age was unknown; they were multiplied by 88.5% and then by 71.4%, the proportion of initial caregivers who care for someone age 50 or older (resulting in n=96 additional caregivers). Finally, there were 8 validated caregivers whose recipient age was unknown, and they were multiplied by 71.4% (resulting in n=6 additional caregivers).

	Prevalence	Number of Adults Age 18+ in the U.S.	Estimated Number of Adult Caregivers in the U.S.
Caregivers of Recipients Age 50+	18.9%	230,087,100	43.5 million

G. Weighting Substantive Results

As described above, a population weight and a household weight were created to estimate the incidence of caregiving among the population and in households in the U.S. For reporting the results of the national survey in this report among the 1,480 caregivers interviewed, the data weighted by households was used, as it was in 2004. The main reason is that the final caregiver sample was derived from identifying caregivers in the household even if they were not the initial, randomly-selected respondent. Hence, the sample is representative of caregivers in U.S. households. In addition, it gave the most valid comparisons to the 1997 NAC/AARP caregiving study which reported household-level data.

H. Calculation of the Level of Care Index

The calculation of the level of burden index begins by assigning points for the number of hours of care, as follows:

Hours of Care	
0 to 8 hours	1 point
9 to 20 hours	2 points
21 to 40 hours	3 points
41 or more hours	4 points

In addition, points are assigned for the number of ADLs and IADLs performed, as follows. Note that for caregivers of children, "Caregiving Support Activities" (CSAs) are substituted for IADLs in the calculations.

Types of Care Provided	
0 ADLs, 1 IADL/CSAs	1 point
0 ADLs, 2+ IADLS/CSAs	2 points
1 ADL, any number of IADLS/CSAs	3 points
2+ ADLs, any number of IADLS/CSAs	4 points

Then, the total number of points is consolidated into five levels of care. In this report, analysis often further collapses the five levels into three categories of burden, with "high burden" equating to Levels 4 to 5, "medium burden" corresponding to Level 3, and "low burden" equating to Levels 1 and 2.

Consolidating Points into Five Levels of Care and Three Burden Categories		
2 to 3 points	Level 1	Low burden
4 points	Level 2	
5 points	Level 3	Medium burden
6 to 7 points	Level 4	High burden
8 points	Level 5	

I. Margin of Error and Response Rate

The margin of sampling error, at the 95% confidence level, for the overall sample and for the three age-specific subsets, which are the focus of separate companion reports, are shown in the following table. The margin of error will be larger for subgroups within each sample.

Sample (with unweighted n's)	Margin or error
Overall prevalence estimates Based on 6,806 screened interviews	1.5 percentage points
Results of entire substantive base study Based on 1,480 completed interviews	3.1 percentage points
Results for caregivers of children ages 0 to 17 Based on 173 completed interviews	8.5 percentage points
Results for caregivers of 18- to 49-year olds Based on 187 completed interviews	8.9 percentage points
Results for caregivers of recipients ages 50 or older Based on 1,397 completed interviews	3.2 percentage points

The response rate of each sample is shown in the following table. The response rates are based upon a standard method provided by the American Association for Public Opinion Research (AAPOR).¹⁰

Sample	Response Rate
Random digit dial	9.9%
African American targeted	9.3%
Asian targeted	3.5%
Hispanic targeted	4.6%

¹⁰ The American Association for Public Opinion Research. 2000. *Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys*. Ann Arbor, Michigan: AAPOR. Response rate formula #2. Knowledge Networks' pre-screening interviews are not included in the response rate calculation because dispositions from online screening are not comparable.

J. Banner Definitions

The banners used in the analysis of the main report are defined as follows:

BANNER #1			
1	2009 Total	2009 Total	Year=2009 and status=1 and smpl le 4
2	TREND CR 18+	2004	Year=2004, status=1, and selc1=1 (after Q5 and Q6)
3		2009	Year=2009, status=1, and selc1=1
4	Care recipient age	0-17	Selc1=1
5		18-49	Agecr 18-49
6		50+	CG50=1 (Includes base sample and oversample)
7	Caregiver race/ethnicity	White	Racecg=1
8		Black	Racecg=2
9		Hispanic	Racecg=5
10		Asian	Racecg=3
11	Primary Caregiver Status	Primary	Q28=2 or Q29=1
12		Not	Q28=1 and Q29=2-3
13	Did caregiver have choice	Choice	Q39=1
14		No Choice	Q39=2
15	Burden of care	Low	Burden=1-2
16		Medium	Burden=3
17		High	Burden=4-5
18	Hours Spent Caregiving	0-8	Q25=0-8, 169
19		9-20	Q25=9-20
20		21+	Q25=21-168, 170
21	Hours Spent Caregiving	0-20	Q25=0-20, 169
22		21+	Q25=21-168, 170
23	Where recipient lives	In caregiver's household	Q11=1
24		Not in household	Q11=2-7
25	Distance from recipient	< 1 hr, but not in household	Q11=2-3
26		1 hr+	Q11=4-5
27	Where recipient lives by hours of care provided	In household, 0-20 hours	Q11=1, Q25=0-20, 169
28		In household, 21+ hours	Q11=1, Q25=21-168, 170
29		Not in household, 0-20 hours	Q11=2-5, Q25=0-20, 169
30		Not in Household, 21+ hours	Q11=2-5, Q25=21-168, 170

Notes: Columns 3, 4, 5, and 7 thru 30 are all subsets of Column 1. That is, they are based on year=2009, status=1 (completed questionnaires only), and smpl le 4 (base study, no oversample for recipients 50+). Column 6 also includes smpl ge 5 (oversample of recipients ages 50+).

BANNER #2			
1	2009 Total		Year=2009 and status=1 and smpl le 4
2	Caregiver Gender	Male	Sexcrg=1
3		Female	Sexcrg=2
4	Caregiver age	18-49	Agecrg=18-49
5		50-64	Agecrg=50-64
6		65+	Agecrg=65-100
7	Education	<=HS	Educ (D7)=1-2
8		Some College or technical school	Educ=3-4
9		College grad or higher	Educ=5-6
10	Household income	<\$50K	Income (D8)= 1-3, 9, 11
11		\$50K+	Income=4 -6, 10
12	Household income	<\$30K	Income=1,2,11
13		\$30-\$49K	Income=3
14		\$50-\$99K	Income=4-5
15		\$100K+	Income=6
16	Employed while caregiving	Empl	(Q1=1 and (Q32=1-2 or q33=1)) or (Q1>= 2 and Q33=1)
17		Not empl	(Q1=1 and Q32 ge 3 and Q33=2) or (Q1>= 2 and Q33=2)
18	Is caregiver a parent caring for his/her own child	Yes	Q7=5 or 19
19		No	Q7 not = 5 or 19
20	Presence of Physical Conditions	Any long term physical condition	Q17b=1
21		Short-term physical condition but no long-term condition	Q17b=2 and Q17a=1
22		No physical condition	Q17a=2 and Q17b=2
23	Presence of a mental/emotional condition	Mental/emotional condition	Q17c=1
24		No mental/emotional cond.	Q17c=2
26	Duration of caregiving	<1 year	Q21x=95-96
26		1 to 4 years	Q21x=1-4
27		5+ years	Q21x=5-93
28	Presence of Alzheimer's or dementia	Yes	Alzdem=1
29		No	Alzdem=2

Notes: Columns 2 thru 29 are all subsets of Column 1. That is, all columns are for year=2009, status=1 (completed questionnaires only), and smpl le 4 (base study, no oversample for recipients 50+).

The banners used in the analysis of caregivers of recipients age 50 or older are defined as follows:

RECIPIENT 50+ BANNER #1			
1	1997	1997 50+	Year=1997 and status=1 and CR50=1
2	2004	2004 50+	Year=2004 and status=1 and CR50=1
3	2009	2009 50+	Year=2009 and status=1 and CR50=1
4	Caregiver race/ethnicity	White	Racecg=1
5		Black	Racecg=2
6		Hispanic	Racecg=5
7		Asian	Racecg=3
8	Primary Caregiver Status	Primary	Q28=2 or Q29=1
9		Not	Q28=1 and Q29=2-3
10	Did caregiver have choice	Choice	Q39=1
11		No Choice	Q39=2
12	Burden of care	Level 1	Burden=1
13		Level 2	Burden=2
14		Level 3	Burden=3
15		Level 4	Burden=4
16		Level 5	Burden=5
17	Hours Spent Caregiving	0-8	Q25=0-8, 169
18		9-20	Q25=9-20
19		21+	Q25=21-168, 170
20	Hours Spent Caregiving	0-20	Q25=0-20, 169
21		21+	Q25=21-168, 170
22	Where recipient lives	In caregiver's household	Q11=1
23		Not in household	Q11=2-7
24	Distance from recipient	< 1 hr, but not in household	Q11=2-3
25		1 hr+	Q11=4-5
26	Where recipient lives by hours of care provided	In household, 0-20 hours	Q11=1, Q25=0-20, 169
27		In household, 21+ hours	Q11=1, Q25=21-168, 170
28		Not in household, 0-20 hours	Q11=2-5, Q25=0-20, 169
29		Not in Household, 21+ hours	Q11=2-5, Q25=21-168, 170

Notes: Columns 4 through 29 are all subsets of Column 3. That is, they are based on year=2009, status=1 (completed questionnaires only), and CG50 (recipient age 50 or older, including base sample and oversample).

RECIPIENT 50+ BANNER #2			
1	2009 Total		Year=2009 and status=1 and CR50=1
2	Caregiver Gender	Male	Sexcg=1
3		Female	Sexcg=2
4	Caregiver age	18-49	Agecg=18-49
5		50-64	Agecg=50-64
6		65+	Agecg=65-100
7	Education	<=HS	Educ (D7)=1-2
8		Some College or technical school	Educ=3-4
9		College grad or higher	Educ=5-6
10	Household income	<\$50K	Income (D8)= 1-3, 9, 11
11		\$50K+	Income=4 -6, 10
12	Household income	<\$30K	Income=1,2,11
13		\$30-\$49K	Income=3
14		\$50-\$99K	Income=4-5
15		\$100K+	Income=6
16	Employed while caregiving	Empl	(Q1=1 and (Q32=1-2 or q33=1)) or (Q1>= 2 and Q33=1)
17		Not empl	(Q1=1 and Q32 ge 3 and Q33=2) or (Q1>= 2 and Q33=2)
18	Is caregiver a parent caring for his/her own child	Yes	Q7=5 or 19
19		No	Q7 not = 5 or 19
20	Caregiver Health	Excellent	D1=5
21		Very good or good	D1=3 or 4
22		Fair/poor	D1=1 or 2
23	Use of technology	Used technology	Q44ct >=1
24		Did not use technology	Q44ct=0
26	Duration of caregiving	<1 year	Q21x=95-96
26		1 to 4 years	Q21x=1-4
27		5+ years	Q21x=5-93
28	Presence of Alzheimer's or dementia	Yes	Alzdem=1
29		No	Alzdem=2

Notes: All columns are for year=2009, status=1 (completed questionnaires only) and CG50 (recipient age 50 or older, including base sample and oversample)