



Executive Summary
CAREGIVING IN THE U.S.



conducted by



in collaboration with



funded by

MetLife Foundation



The National Alliance for Caregiving is dedicated to providing support to family caregivers and the professionals who help them and to increasing public awareness of issues facing family caregivers.

Established in 1996, The National Alliance for Caregiving is a non-profit coalition of national organizations focusing on issues of family caregiving. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, a government agency, and corporations.

The Alliance was created to conduct research, do policy analysis, develop national programs, increase public awareness of family caregiving issues, work to strengthen state and local caregiving coalitions, and represent the US caregiving community internationally. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, 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.

AARP is a nonprofit, nonpartisan membership organization that helps people 50+ have independence, choice and control in ways that are beneficial and affordable to them and society as a whole. AARP does not endorse candidates for public office or make contributions to either political campaigns or candidates. We produce *AARP The Magazine*, the definitive voice for 50+ Americans and the world's largest-circulation magazine with over 35.5 million readers; *AARP Bulletin*, the go-to news source for AARP's 40 million members and Americans 50+; *AARP Segunda Juventud*, the only bilingual U.S. publication dedicated exclusively to the 50+ Hispanic community; and our website, AARP.org. AARP Foundation is an affiliated charity that provides security, protection, and empowerment to older persons in need with support from thousands of volunteers, donors, and sponsors. We have staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.

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Caregiving in the U.S.

EXECUTIVE SUMMARY

National Alliance for Caregiving
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AARP

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This executive summary, along with the full report, is available at www.caregiving.org, www.aarp.org/caregivingus, and www.metlife.org

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I. Introduction

The purpose of this study is to present a portrait of family caregivers today, and to compare it to a portrait of caregivers in the past. A national profile of caregivers first emerged from the 1997 Caregiving in the U.S. study. A related study was conducted in 2004, and now, in 2009, we are presenting the results of the third wave of this important study. Each of the three studies has inquired about certain core elements of caregiving situations, while also exploring new areas.

The core areas that we examined include:

- The prevalence of caregivers in the U.S.
- Demographic characteristics of caregivers and care recipients
- The caregiving situation in terms of the nature of caregiving activities, the intensity and duration of care, the health conditions and living situation of the person to whom care is provided, and other unpaid and paid help provided
- How caregivers are affected by their role, at work, at home, and in their health situation
- Information needs and information sources

This year's unique areas of exploration were:

- Use of the Internet for information
- What public policies would support caregivers
- Use of technology

For the first time, this year's study also includes caregivers of children with special needs, in addition to the caregivers of adults age 50 or older included in the 1997 study and age 18 or older in 2004. In addition, this is the first Caregiving in the U.S. report to present trends from the prior study.

In addition to this executive summary report, other publications resulting from this study are:

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

II. Overview of Methodology

This report is based primarily on quantitative telephone interviews with 1,480 family caregivers age 18 or older. Caregivers are defined as those who provide unpaid care to an adult or a child with special needs, as described in the following two questions.

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.

The interviews include a random sample of 1,000 family caregivers and, to supplement the ethnic minority interviews achieved in that sample, 480 additional interviews with minorities. The interviews break out by race as follows: 858 White, non-Hispanic caregivers, 200 African-American caregivers, 201 Hispanic caregivers, 200 Asian-American caregivers, and 21 caregivers of another race. These results came from screening 6,806 adults.

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

All of the data gathered while screening potential respondents for caregivers were saved in order to estimate the proportion of households that include one or more caregivers. The screening data and survey results are weighted by household, based on the race/ethnicity and age of the householder, and type of household (family or non-family) reported by the initial respondent in each household.

In addition to the 1,480 caregiver interviews in the base study, an additional 288 interviews were conducted with caregivers of individuals age 50 or older. These interviews were weighted according to the weighted distribution of caregivers of individuals age 50+ in the base sample by race/ethnicity, age of householder, and type of household (family or non-family).

The questionnaire was designed to replicate many of the questions posed in 1997 and 2004 National Alliance for Caregiving/AARP national caregiving studies 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 input from a team of advisors listed in the acknowledgements.

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. The average length of the interview was 22.3 minutes. The survey was conducted between March 5 and June 17, 2009.

The margin of error for the overall 2009 results is plus or minus approximately 3.1 percentage points at the 95% confidence level. This means that 95 times out of 100, a difference of greater than three percentage points would not have occurred by chance. For subgroups of caregivers, the margin of error is larger.

Reading this Report

The main graphics and tables in this report present results for *all* 1,480 caregivers in the 2009 study. For any questions that were also asked in 2004, the trend among caregivers of adults age 18 or older is shown in mini-tables to the right of each graphic.

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

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

To signal *key* differences between 2004 and 2009 findings, the report uses an asterisk to highlight any percentage that is significantly higher than the comparison figure.

III. Key Findings

Prevalence of Caregiving

In the past 12 months, an estimated 65.7 million people in the U.S. have served as unpaid family caregivers to an adult or a child. About 28.5% of the respondents surveyed reported being caregivers. The percentage of people who are caregivers does not appear to have changed significantly since 2004.¹

Figure 1: Estimates of Individual Caregiving Prevalence by Age of Recipient

Type of Recipient	Prevalence	Estimated Number of Caregivers
Overall	28.5%	65.7 million
Only child recipients	1.7%	3.9 million
Only adult recipients	21.2%	48.9 million
Both adult and child recipients	5.6%	12.9 million

More than three in ten U.S. households (31.2%) report that at least one person has served as an unpaid family caregiver within the last twelve months, leading to an estimate of 36.5 million households with a caregiver present.

Basics of the Caregiving Situation

Caregivers are predominantly female (66%). They are 48 years of age, on average. One-third take care of two or more people (34%).

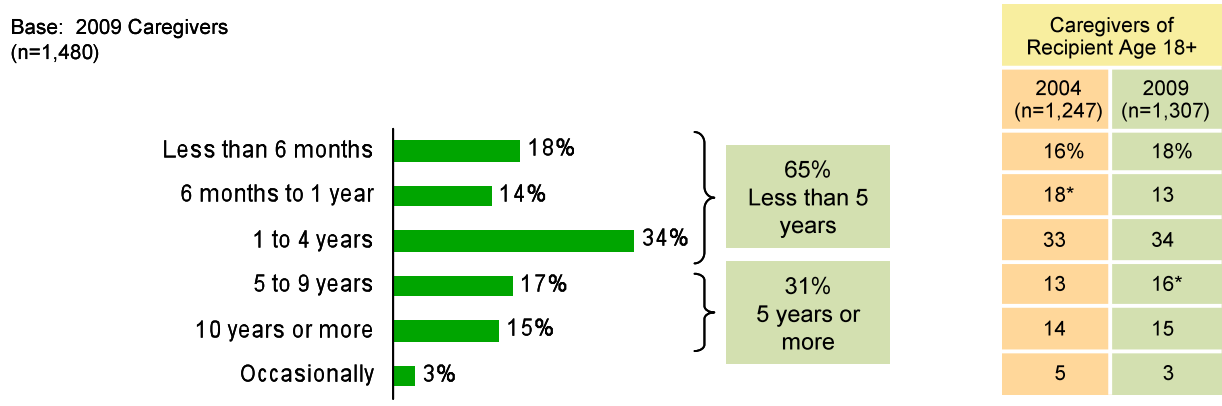
A large majority of caregivers provide care for a relative (86%), with over one-third taking care of a parent (36%). One in seven care for their own child (14%).

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.

Caregivers have been in their role for an average of 4.6 years, with three in ten having given care to their loved one for five years or more (31%).

Figure 2: Duration of Care for Recipient

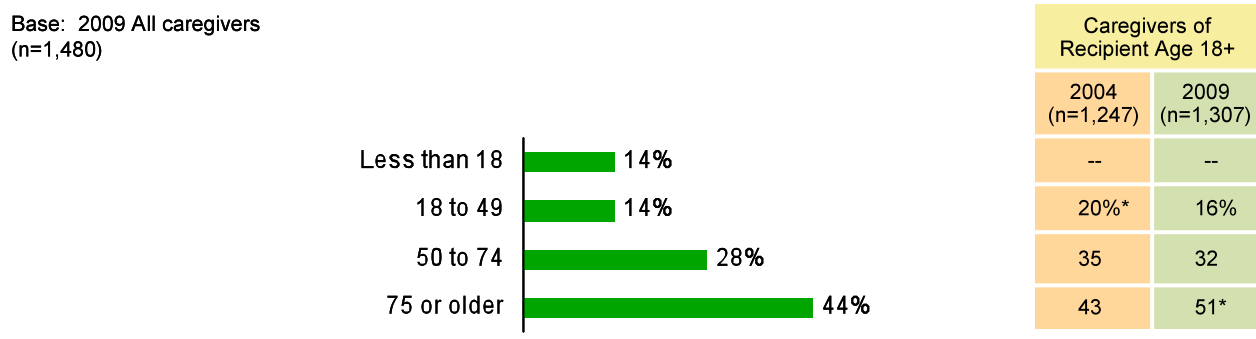
Q21. For how long have you been providing/did you provide care to your [relation]
[FOR CHILD RECIPIENT: for his/her condition?]



The typical recipient of care is also female (62%) and averages 61 years of age. Seven in ten caregivers take care of someone 50 years of age or older, 14% take care of an adult age 18 to 49, while 14% take care of a child under the age of 18.

Figure 3: Age of Predominant Care Recipient

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



2004-2009 Trend for Caregivers of Recipient Age 18+

Both caregivers of adults and their care recipients are now older than their counterparts were five years ago. Among caregivers of adults (ages 18 or older), the average age of the caregiver rose from 46.4 to 49.2 years of age. This change is due to a decline among younger caregivers, those under the age of 50, and a shift upward among caregivers age 50 to 64.

The average care recipient's age increased from 66.5 to 69.3—among caregivers of adults—mainly because of an increase in the percentage age 75 or older (from 43% to 51%).

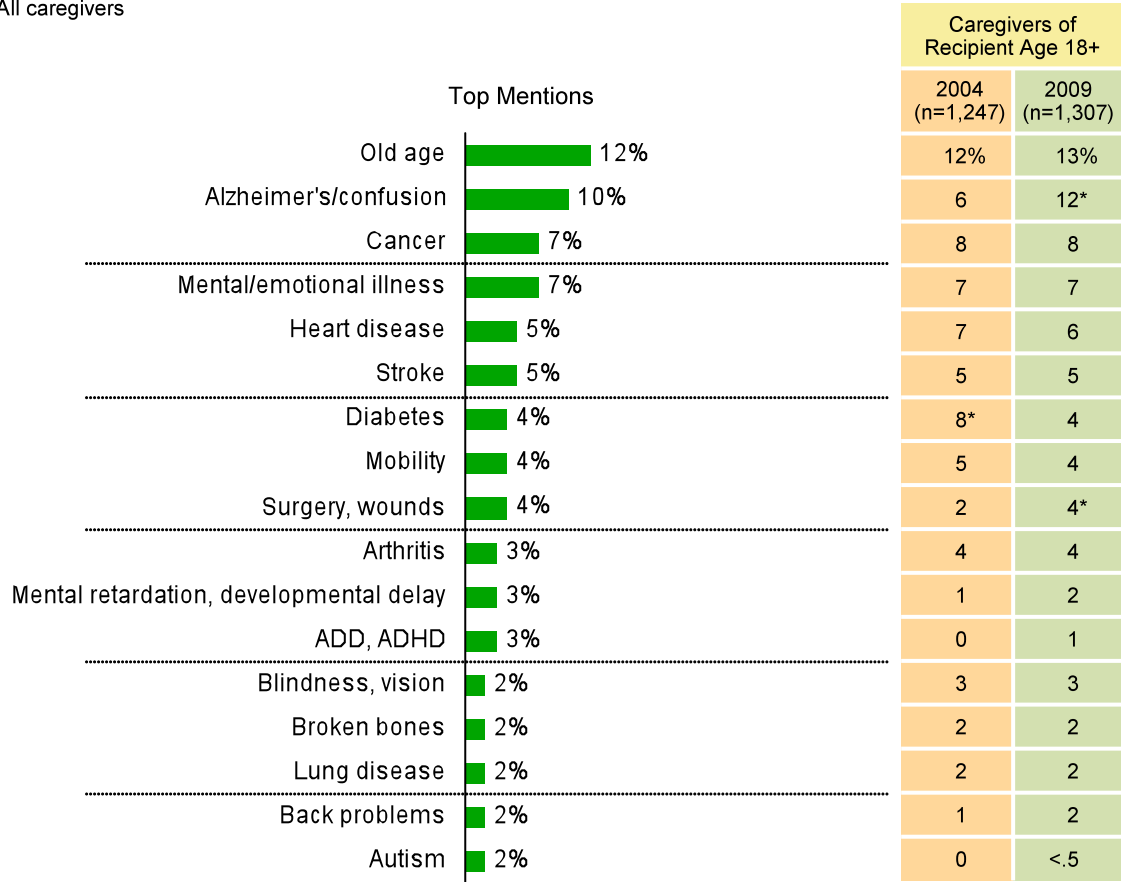
Care Recipient Condition

When caregivers are asked what they perceive to be the main reason their recipient needs care, the top two problems they report are old age (12%) and Alzheimer's or dementia (10%). Other frequent mentions are mental/emotional illness (7%), cancer (7%), heart disease (5%), and stroke (5%).

Figure 4: Main Problem or Illness of Care Recipient Identified by Caregiver

Q18. What would you say is/was the main problem or illness your [relation] has/had for which he/she needs/needed your care?

Base: 2009 All caregivers (n=1,480)



Given that care recipients are older in 2009 than were 2004 recipients, it is not surprising that a larger share of 2009 caregivers say Alzheimer's or dementia is the *main* problem for which their loved one needs care (6% 2004 vs. 12% 2009). Any caregivers who did not report Alzheimer's, dementia, or confusion as the main problem were asked whether their care recipient had this type of condition. Analysis shows that the overall prevalence of Alzheimer's or mental confusion has not changed significantly (23% 2004 vs. 26% 2009 among caregivers of adult recipients).

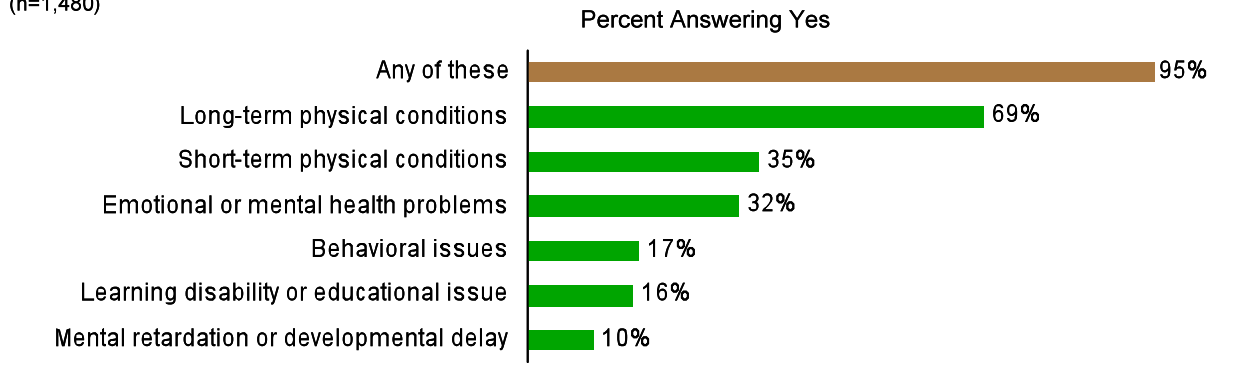
Long-term physical conditions are present in seven out of ten caregiving situations (69%) and 35% of caregivers say the person they care for has a short-term physical condition. There is some overlap between these two types of conditions; 17% say their recipient has

both. Three in ten say their care recipient has an emotional or mental health problem (32%), although a physical condition is also present in most of these cases (78%). The small percentage of caregivers who do not report any of these six conditions are typically caring for a recipient whose main problem is old age.

Figure 5: 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
 (n=1,480)



Seven in ten caregivers of children with special needs say their child care recipient is limited in his/her ability to do things that most children of the same age do (70%).

Nine in ten caregivers say their recipient takes prescription medications.

2004-2009 Trend for Caregivers of Recipient Age 18+

Caregivers of adults show an increase in the use of such medications, from 85% in 2004 to 93% in 2009. This change may also be related to the increase in the age of care recipients.

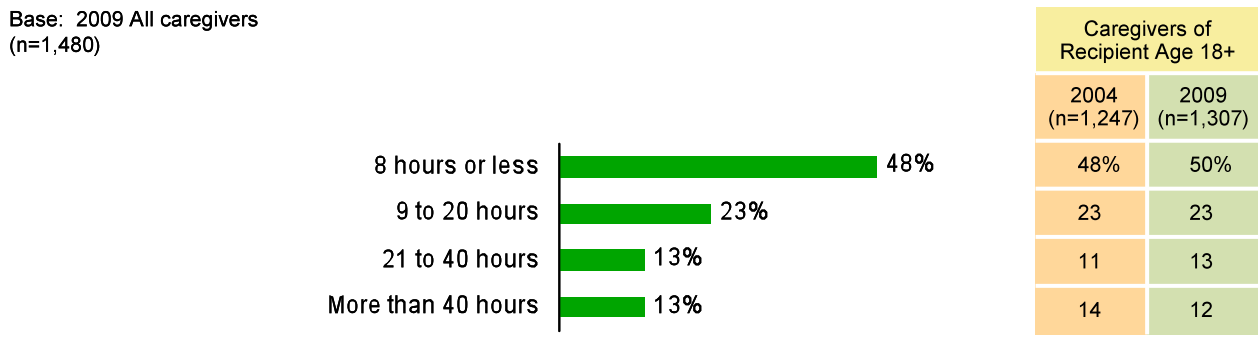
Caregiving Activities and Burden of Care

On average, caregivers spend 20.4 hours per week providing care.

Figure 6: 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
 (n=1,480)



Caregiving is particularly time-intensive for those who live with their care recipient (39.3 hours/week) and those caring for a child under the age of 18 (29.7 hours/week). Female caregivers spend more time providing care than men do, on average (21.9 vs. 17.4 hours/week).

2004-2009 Trend for Caregivers of Recipient Age 18+

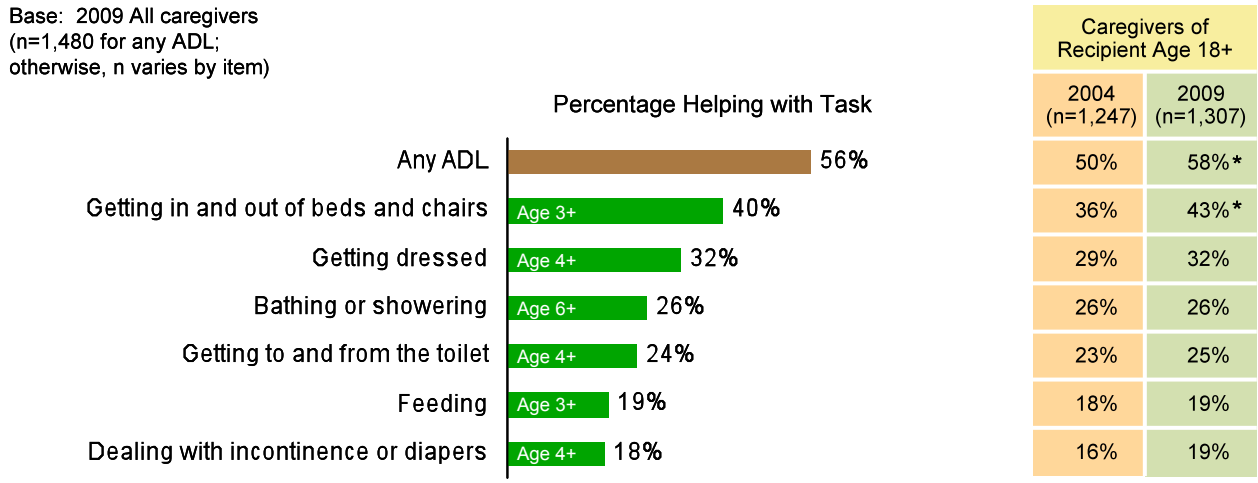
Since 2004, there have been changes in the amount of time caregivers of adult recipients spend taking care of their loved one, and in the way they use their caregiving time. The number of hours spent giving care declined by 2.6 hours, so now caregivers of adults spend an average of 18.9 hours per week in their helping role.

How is caregivers' time spent? A majority of caregivers help their loved one with at least one Activity of Daily Living (ADL) (56%). The most common of these is helping the care recipient get in and out of beds and chairs (40%). Personal care tasks are also fairly common—32% help their care recipient get dressed, 26% assist with bathing or showering, 24% help with getting to and from the toilet, and 18% help deal with incontinence. One in five help feed their loved one (19%).²

Figure 7: Help with Activities of Daily Living (ADLs)

Q22. I'm going to read a list of kinds of help which might be provided to a person if the person cannot do this by him or herself. Do/Did you help your [relation] with [ADL] [IF CHILD RECIPIENT: because he/she is/was less able to do this task than children of the same age without his/her condition]?

Base: 2009 All caregivers (n=1,480 for any ADL; otherwise, n varies by item)



Caregivers who were not employed while caregiving are more likely to help with each of the ADLs than employed caregivers are, except getting in and out of beds and chairs. Female caregivers are more likely than men to help with grooming—getting dressed (36% vs. 24%) and bathing (31% vs. 17%).

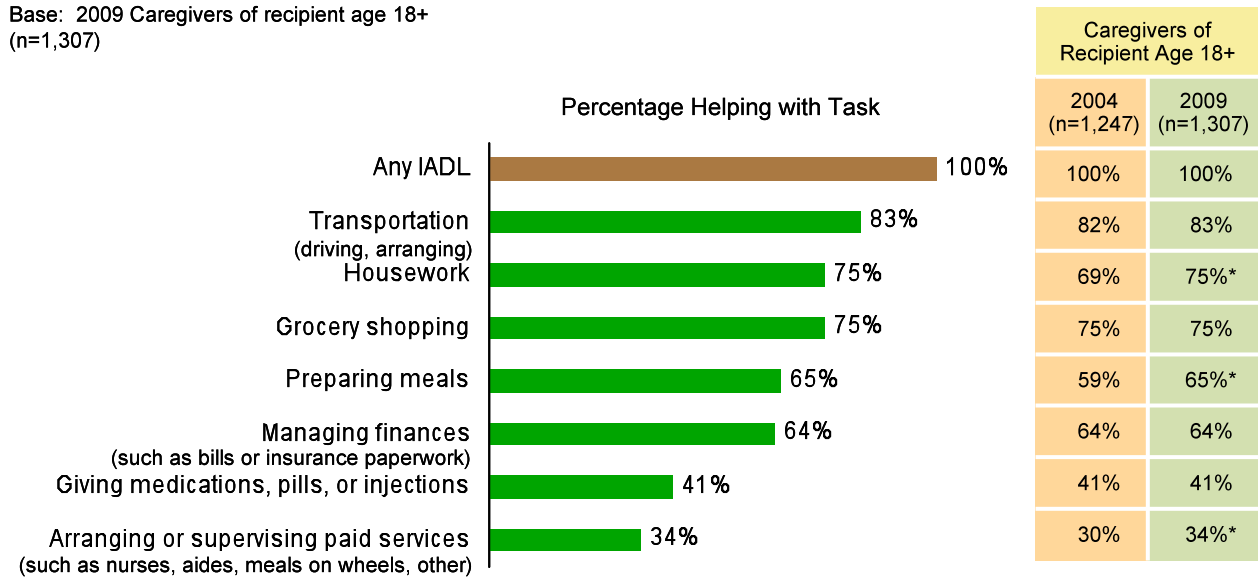
² To distinguish caregiving of children with special needs from typical parenting or child care, caregivers' help with each ADL was asked to be reported only if it was because the child was less able to do that task than other children of the same age without his/her condition. Further, ADLs performed for very young children—below the age thresholds shown in the chart—were not counted, since it would be expected that they would need assistance.

Caregivers of adults help on average with 4.4 out of seven Instrumental Activities of Daily Living (IADLs), including transportation (83%), housework (75%), grocery shopping (75%), meal preparation (65%), managing finances (64%), and arranging or supervising outside services (34%).

Figure 8: Help with Instrumental Activities of Daily Living (IADLs)—for Adult Recipients

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

Base: 2009 Caregivers of recipient age 18+ (n=1,307)



Other types of supportive activities carried out by caregivers of adults include advocating for their care recipient with care providers, government agencies, or schools (52%) and performing medical therapies or treatments (22%).

It is more common for co-resident caregivers and primary³ caregivers to help with these IADLs and the two supportive activities, compared to their counterparts.

2004-2009 Trend for Caregivers of Recipient Age 18+

In spite of a decline in the hours spent providing care by caregivers of adults, there was an increase in the proportion of caregivers who help with at least one Activity of Daily Living, from half in 2004 (50%) to 58% in 2009. In particular, the share who help their loved one get in and out of beds and chairs rose from 36% to 43%. This increase is apparent only among caregivers who do not have paid help. It is also fueled by a sharper increase among non-co-resident caregivers.

Caregivers in 2009 are also more likely to help their loved one with several Instrumental Activities of Daily Living, including housework (from 69% to 75%), preparing meals (59% vs. 65%), and arranging or supervising outside services (30% vs. 34%). All of these increases occur regardless of the age of the care recipient, so they do not appear to be due to the higher average age of 2009 care

³ A primary caregiver is a person who provides all or the majority of the unpaid care for their care recipient.

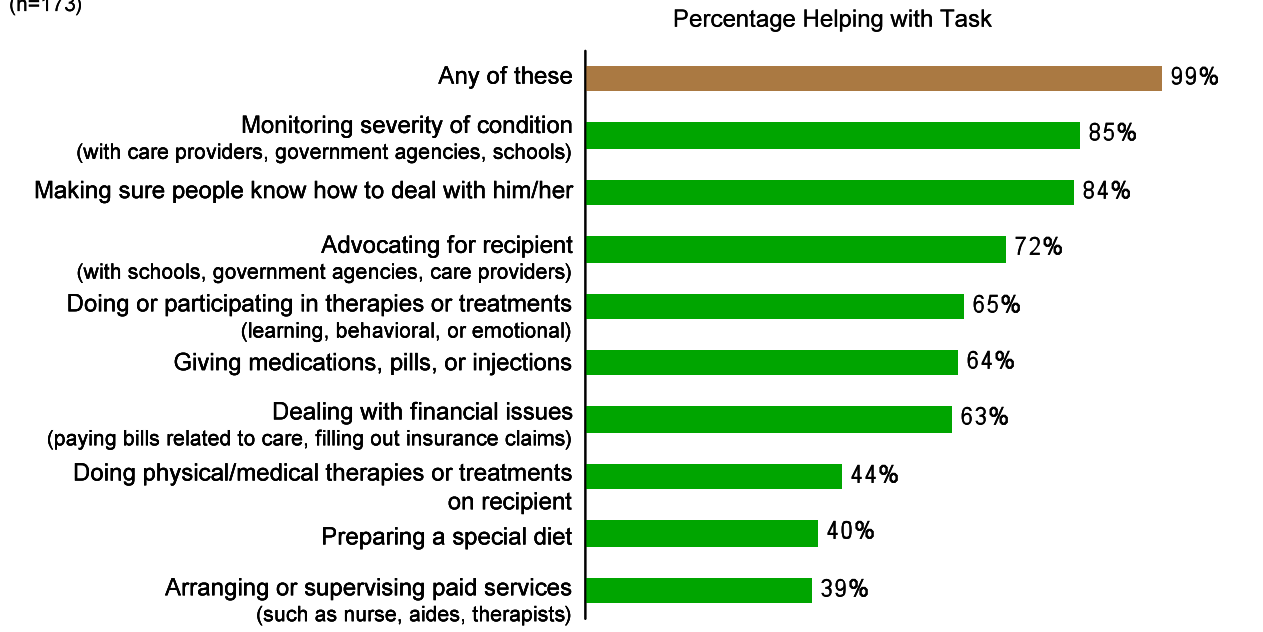
recipients. With the decline in hours of care counterbalanced by increases in selected ADLs and IADLs, the overall burden of care as measured by the Level of Care Index has not changed.

Caregivers of children with special needs help their care recipient with 5.6 out of nine Caregiving Support Activities (CSAs), on average. These include monitoring the child's condition (85%), ensuring that others know how to deal with him/her (84%), advocating on his/her behalf (72%), performing emotional or behavior treatments or therapies (65%), giving medicines or injections (64%), dealing with financial issues (63%), giving physical or medical therapies (44%), preparing a special diet (40%), or arranging/supervising outside services (39%). Male caregivers of children are more likely than female caregivers to help with financial issues (76% vs. 57%) and to advocate on behalf of the child (85% vs. 67%).

Figure 9: Help with Caregiving Support Activities (CSAs)—for Child Recipients

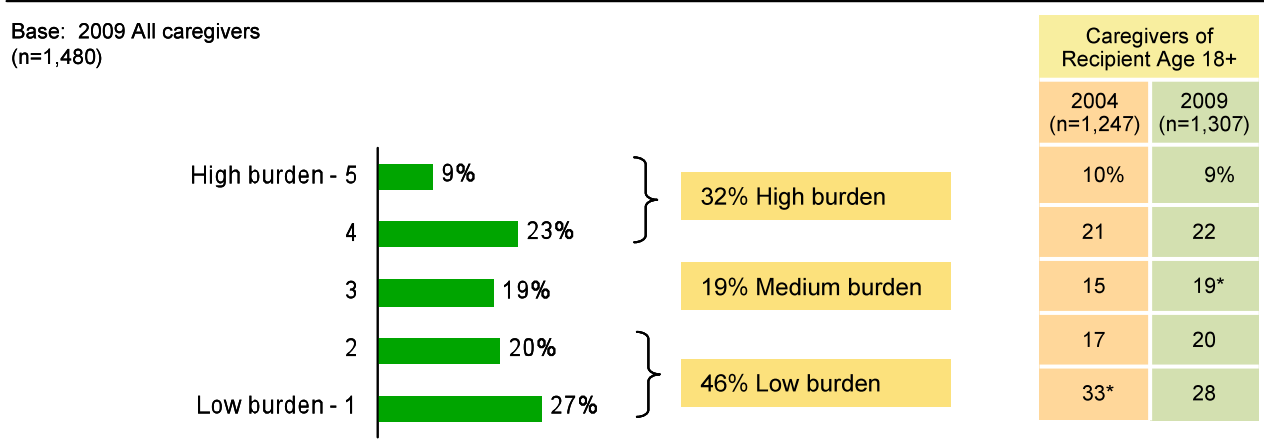
Q24. As a result of your [relation's] condition, do/did you provide help by...?

Base: 2009 Caregivers of recipient age 0 to 17 (n=173)



All of these activities add up to a burden of care that is high for 32% of caregivers, moderate for 19%, and relatively low for 46%.⁴

Figure 10: Level of Care Index



Most caregivers (66%) find it *very or somewhat* easy to coordinate care given by the various health professionals and service providers that help their loved one, but 25% indicate some difficulty with it.

Caregivers of children with special needs are especially likely to find this coordination at least somewhat difficult (40%). Caregivers who care for recipients with four or more of six types of conditions (e.g., short-term physical, long-term physical, mental health, developmental delay, learning/education, behavioral) are also highly likely to report such difficulty (43%). Those who help arrange or supervise paid services for their care recipient are twice as likely to find care coordination difficult (36% very or somewhat difficult vs. 20% not performing this ADL).

⁴ The "burden" of care is a simplified version of the Level of Care Index, the construction of which is detailed in Appendix B, Detailed Methodology.

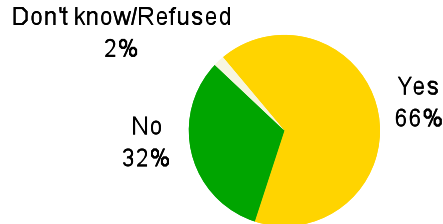
Presence of Other Caregivers

Most caregivers—among those whose recipient is not in a nursing home—say at least one other unpaid caregiver helps their care recipient (66%), while only 35% use paid help from aides, housekeepers, or other people paid to help their recipient.

Figure 11: Presence of Other Unpaid Caregivers

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

Base: 2009 All caregivers
(n=1,480)



% Yes	
Caregivers of Recipient Age 18+	
2004 (n=1,247)	2009 (n=1,307)
59%	68%*

Older caregivers, those age 65 or older, are most likely to be sole unpaid caregivers, without the support of other unpaid caregivers (47% vs. 30% of younger caregivers). Co-resident caregivers are also twice as likely to be sole caregivers (49% vs. 25% living separately).

The use of paid care is, of course, related to the caregiver's household income, such that 30% of those in households with less than \$50,000 in income use paid help, compared to 48% among those with \$100,000 or more of income.

2004-2009 Trend for Caregivers of Recipient Age 18+

There has been an increase in the share of caregivers of adults who say that their care recipient receives help from other unpaid caregivers, but a decrease in the share who receive paid help. Among caregivers of an adult recipient who is not in a nursing home, two-thirds now say there is at least one other unpaid caregiver helping their loved one (68%), up considerably from the 59% who reported this type of help in 2004.

The increase in unpaid help is driven by increases in those caring for recipients age 18 to 49 (38% in 2004 to 58% in 2009) and 65 to 74 (58% in 2004 to 74% in 2009). The change in unpaid help among 18- to 49-year olds may be because the 2009 caregivers of younger adults are in more intensive caregiving situations than in 2004 (with longer caregiving duration and greater needs for help selecting a nursing home or a home care agency). Increases in unpaid help were reported by all racial/ethnic groups of caregivers, with the exception of African-American caregivers.

On the other hand, use of paid aides, housekeepers, or other staff declined from 41% in 2004 to 35% in 2009. These shifts could be due to tight budgets resulting from the 2008 recession and the financial crisis late that year. Analyses show that

the use of paid help went down among non-primary caregivers (47% in 2004 to 41% in 2009), as well as among primary caregivers who live with their care recipient (35% to 27%). Declines in paid help occurred among those caring for someone age 18 to 64 (27% in 2004 to 18% in 2009), but not among those caring for someone age 65 and older. Finally, declines in the use of paid help occurred among those caring for someone *without* Alzheimer’s or dementia (37% to 33%), while those caring for someone with Alzheimer’s or dementia showed no decline.

Of the caregivers of adults whose recipients do use paid help, there has been a sharp increase in the share of caregivers who say this paid help provides more care than they or other unpaid caregivers do, from 19% in 2004 to 37% in 2009. There has not been an increase in the burden of care experienced by those who use paid help, or an increase in employment while caregiving, either of which might motivate caregivers to shift more responsibilities to paid caregivers. Nor is the change a result of care recipients being older in 2009; the increase is evident in all care recipient age groups.

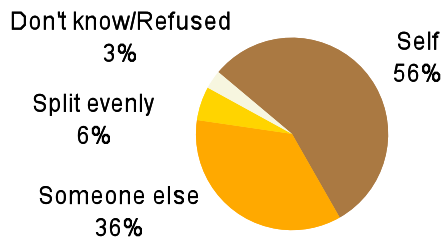
It is possible that the rise in reliance on paid care is driven by additional disposable income among those using paid services. Six in ten (63%) 2009 users of paid services have \$50,000 or more in household income, compared to only 47% in 2004.

In spite of these changes in the use of paid and unpaid help, the proportion of caregivers who consider themselves the primary caregiver has remained unchanged. Just over half of all caregivers say they provide all or most of the unpaid care (56%).

Figure 12: 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 (n=1,480)



% Primary Caregiver	
Caregivers of Recipient Age 18+	
2004 (n=1,247)	2009 (n=1,307)
57%	53%

Nearly three in ten caregivers have used an outside transportation service for their loved one (29%), while 12% have used a respite service.

2004-2009 Trend for Caregivers of Recipient Age 18+

Caregivers of adults in 2009 are more likely than 2004 caregivers to avail themselves of two types of supportive services—transportation services (from 18% in 2004 to 29% in 2009) and respite services (5% vs. 11%).

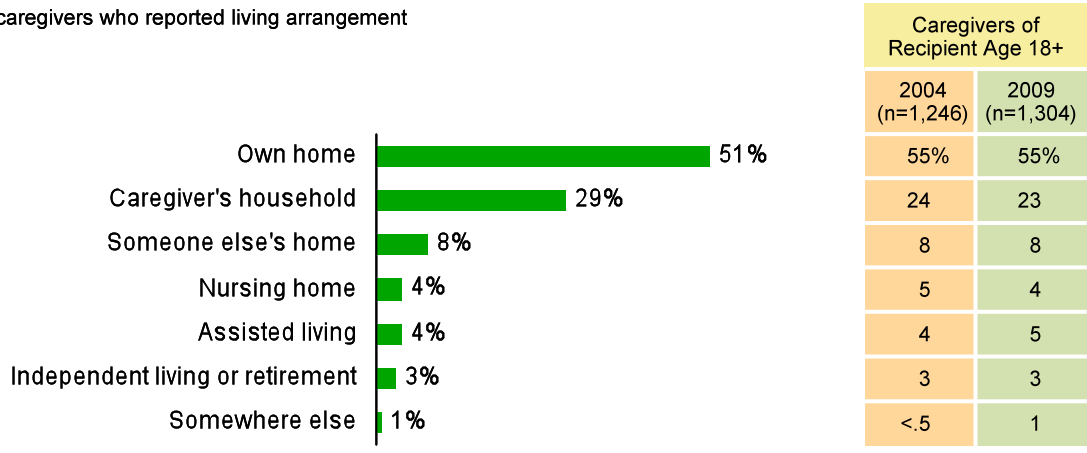
Care Recipient Living Situation

Half of caregivers say their loved one lives in his or her own home (51%), while 29% live together with their care recipient. Only 4% of caregivers say that their care recipient lives in a nursing home and the same percentage say their recipient's home is an assisted living facility.

Figure 13: Where Care Recipient Lives

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

Base: 2009 All caregivers who reported living arrangement (n=1,477)



Co-residence is found more frequently when the caregiver's household income is less than \$50,000 (38% vs. 23% of those in higher income households), suggesting that co-residence arises from necessity. The likelihood of sharing a home with the care recipient declines as the recipient's age rises, from 65% of those caring for a child recipient to 20% of those caring for someone age 50 or older. Note that nearly all caregivers who are parents caring for their own child age 0 to 17 live with their child (96%).

Three-quarters of caregivers live either together or within twenty minutes of their care recipient (74%). Of the caregivers who do not live with their care recipient, three-quarters visit him/her at least once a week (76%).

2004-2009 Trend for Caregivers of Recipient Age 18+

Caregivers of adults now live slightly closer to their care recipients than they did in 2004. The proportion living either together or within 20 minutes of their care recipient rose from 66% to 72%, with a complementary decline in the proportion living 20 minutes to one hour away (from 19% to 13%).

Strain and Stress of Caregiving

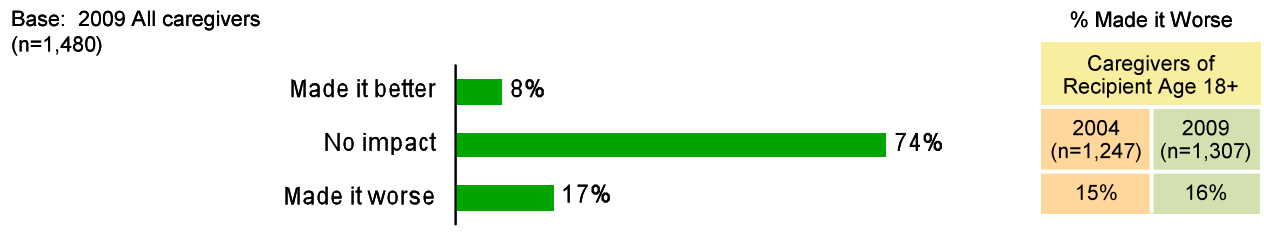
Most caregivers feel their health is *excellent* or *very good* (57%), while 17% say it is *fair* or *poor*. By comparison, 13% of the general adult population describe their health as *fair* or

poor.⁵ The longer a caregiver has been providing care, the more likely she or he is to report *fair* or *poor* health. Specifically, 23% of those who have been providing care for five years or more report their health is *fair* or *poor*.

In fact, 17% of caregivers feel their health has gotten worse as a result of caregiving.

Figure 14: 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?

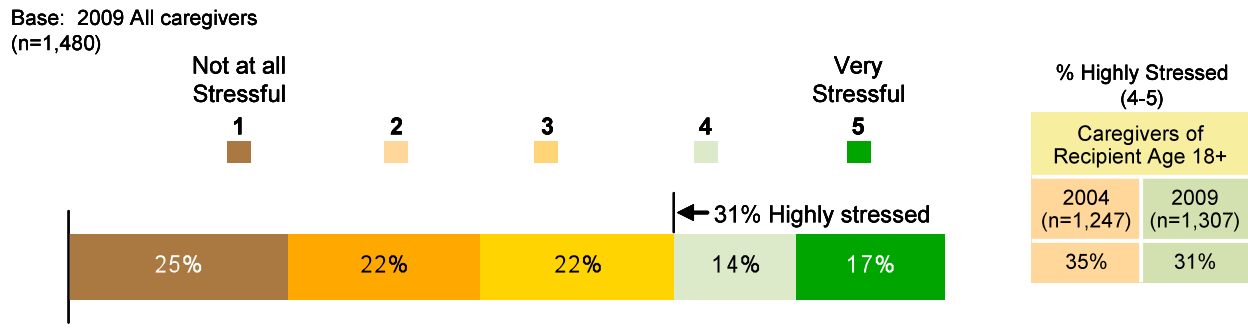


Those who have been providing care for five years or more are nearly twice as likely as shorter-term caregivers to report this decline in their health (24% vs. 14%). Other caregivers who are more likely to report worsening health include high burden caregivers (28% vs. 12% for medium to low burden caregivers), co-resident caregivers (28% vs. 13%), women (20% vs. 12% men), and those providing 21 or more hours of care per week (29% vs. 13% caring 0 to 20 hours).

Three in ten caregivers consider their caregiving situation to be emotionally stressful (31% rating their stress as 4 to 5 on a 5-point scale), and co-residence and burden of care are again factors related to stress. Women are also more likely than men to feel high stress (35% vs. 25%).

Figure 15: 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?



⁵ Source: Provisional Summary Health Statistics for U.S. Adults, National Health Interview Survey, 2008, dated August 2009.

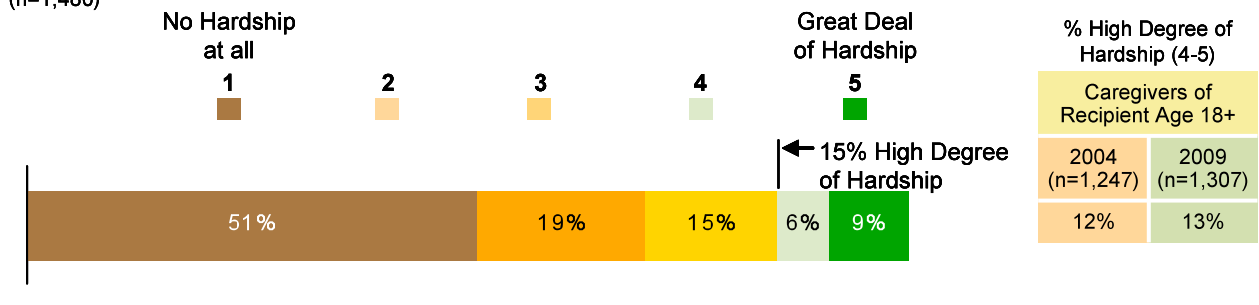
Half of caregivers (53%) say that their caregiving takes time away from friends and other family members. Those who have sacrificed this time with family and friends are far more likely to feel high emotional stress (47%) than are those who have been able to maintain the time they spend with family and friends (14%).

Even after the economy tumbled in late 2008 and during the ongoing recession, only 15% of caregivers report feeling a strong financial hardship—defined as a rating of 4 to 5 on a 5-point scale—as a result of caring for their loved one.

Figure 16: 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
(n=1,480)



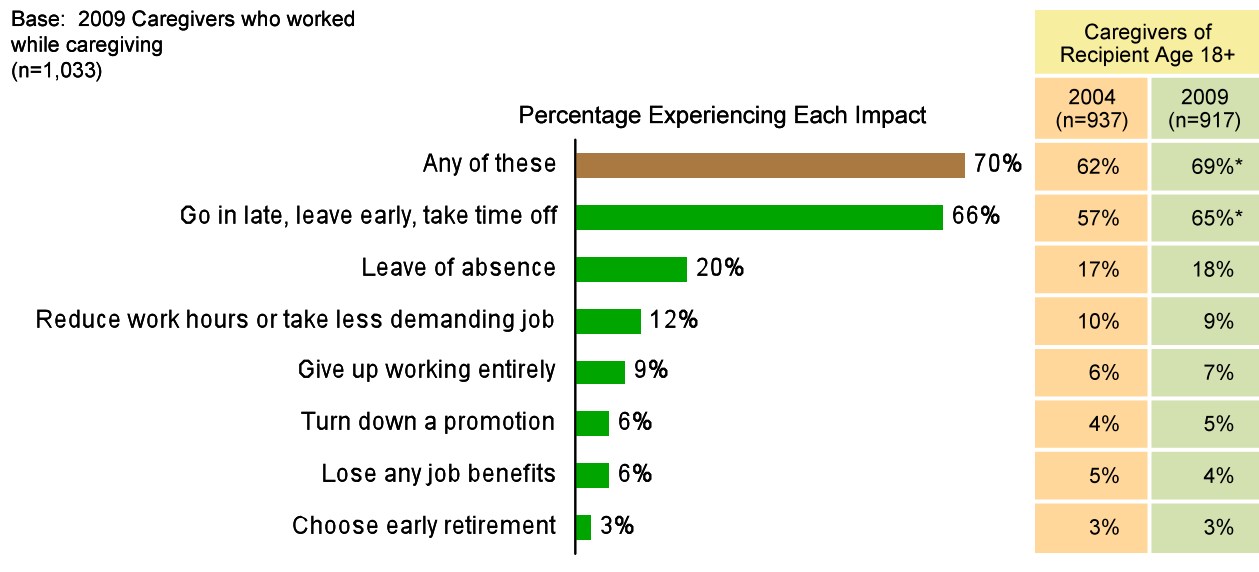
However, this hardship is far more prevalent among those caring for their own child (37% vs. 11% of those caring for some other family member or friend), and those in households with less than \$50,000 in income (21% vs. 10% in higher income households). High burden situations are also correlated with financial challenge. In high burden situations, 23% report a strong financial hardship compared to 10% of low burden caregivers who do.

Impact of Caregiving on Work

Over seven in ten caregivers were employed at some time when they were caregiving (73%). Among them, two-thirds have gone in late, left early, or taken time off during the day to deal with caregiving issues (66%). One in five took a leave of absence (20%).

Figure 17: Work Accommodations Due to Caregiving

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



2004-2009 Trend for Caregivers of Recipient Age 18+

Caregivers in 2009 more commonly report that they shift their arrival or departure times or take time off to provide care than did 2004 caregivers (57% 2004 vs. 65% 2009). This increase is apparent only among caregivers providing less than 40 hours of care a week, and is especially prominent among those providing 0 to 8 hours or 9 to 20 hours per week. Coming during a recession when feelings of job security would be expected to be low, these findings are somewhat surprising. They could be a result of broadened employer tolerance of informal flextime behavior on the part of their employees.

Information Sources and Needs

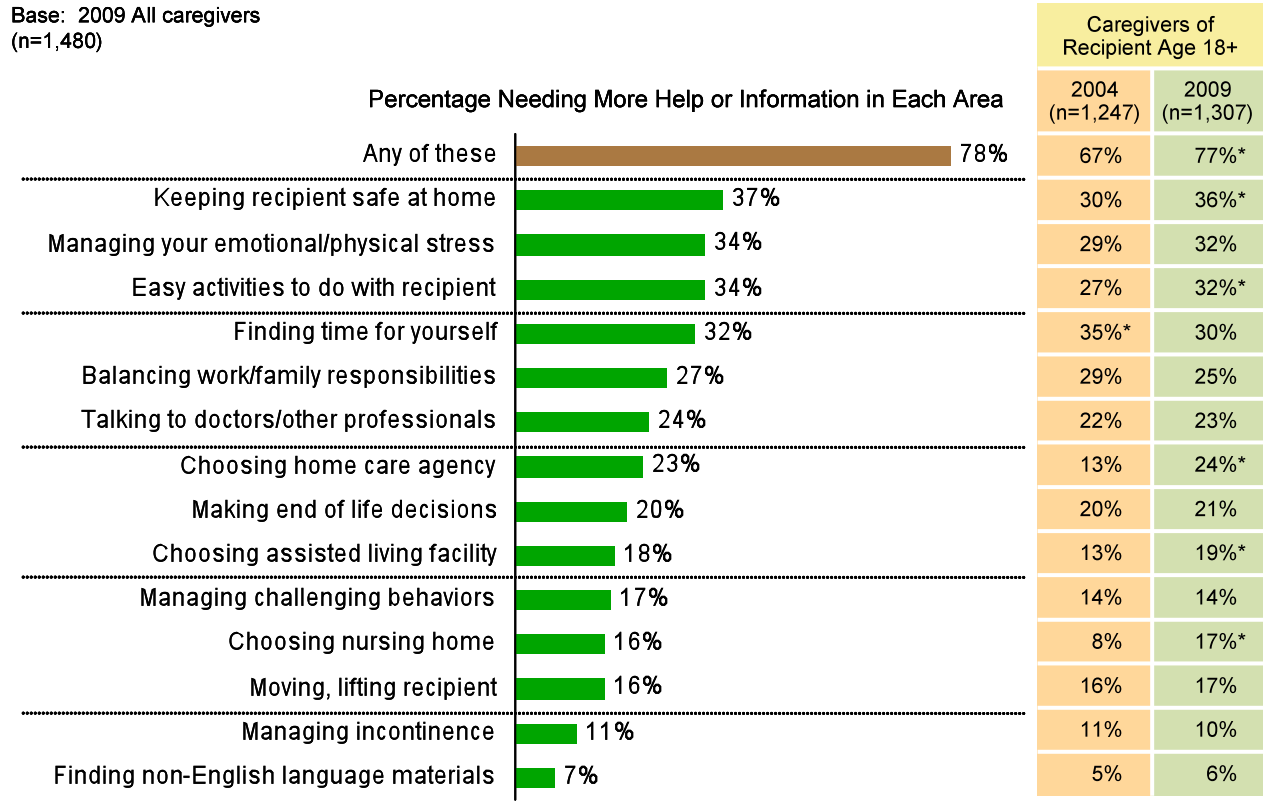
One in five caregivers say they have obtained formal caregiver training (19%), but caregivers are hungry for more help or information. In fact, three-quarters (78%) feel they need more help or information about at least one of 14 specific topics related to caregiving. Caregivers in high burden situations are particularly likely to want help or information (83% vs. 73% of low burden caregivers).

The most popular aspects of caregiving for which caregivers would like help or information are keeping their loved one safe at home (37%), managing their own stress (34%), easy activities to do with their care recipient (34%), and finding time for themselves (32%).

Figure 18: Caregiving Information Needs

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

Base: 2009 All caregivers
(n=1,480)



2004-2009 Trend for Caregivers of Recipient Age 18+

In general, the demand for caregiving information seems to have increased over the past five years. A greater proportion desire information on at least one topic (77% vs. 67% in 2004), with 2009 caregivers showing increased interest in care recipient safety at home (36% vs. 30% in 2004), easy activities (32% vs. 27%), and choosing either a home care agency (24% vs. 13%), an assisted living facility (19% vs. 13%), or a nursing home (17% vs. 8%).

The desire for information or help on finding easy activities becomes more marked as the recipient age increases, and is most prominent among caregivers whose recipient is 65 or older. This may relate to increasing media coverage on keeping active in one's older years.

There are no apparent patterns explaining the increase in a desire for help in finding assisted living, a home care agency, or a nursing home appears. However, the increased demand for information on choosing an assisted living facility is found only among those who live separately from their care recipient.

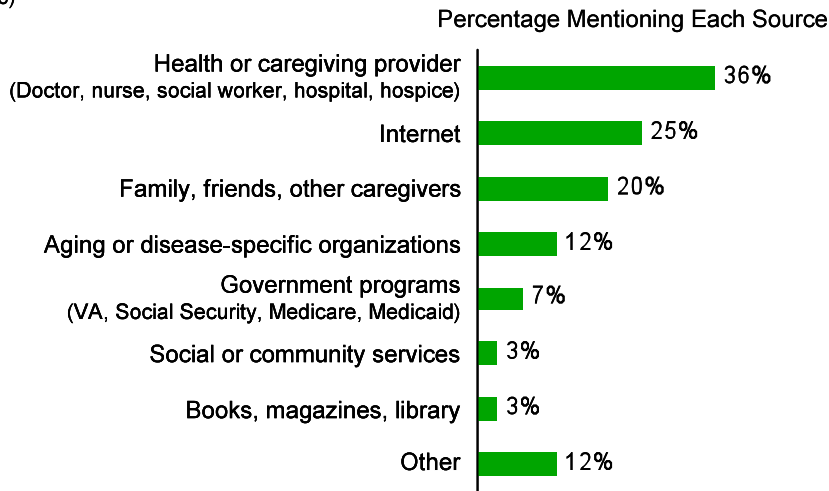
2009 caregivers express less desire for information about finding time for themselves (30% vs. 35% in 2004). Of note, this decline is not apparent among co-resident caregivers.

It is important that any groups who wish to support caregivers know where they turn for information related to caregiving. If caregivers were to look for information to help them take care of their loved one, their top source of information would be a health or caregiving provider (36%)—including a doctor (22%), nurse or other health professional (11%), or a hospital, caregiving provider, social worker, etc.

Figure 19: 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?

Base: 2009 All caregivers
(n=1,480)



The Internet is also a popular resource, named top of mind as a potential resource by 25% of caregivers. However, half of all caregivers say they have used the Internet in the past year to find caregiving information (53%).

Use of this resource rises in relation to household income, from 36% of caregivers with less than \$30,000 in income to 66% of those with \$100,000 or more. As one might expect, older caregivers are far less likely than younger ones to use the Internet for a caregiving-related purpose. Specifically, only 30% of those who are 65 or older used it, compared to 56% of younger caregivers. There are racial/ethnic differences in Internet usage as well. Two-thirds of Asian-American caregivers have gone online for caregiving information (66%), more so than Whites, African-Americans, or Hispanics (54%, 44%, and 50%, respectively).

Among those who used the Internet for a caregiving-related purpose, three in four looked for information about their loved one’s condition or treatment (78%), while a smaller majority (58%) sought information about caregiving services. Other goals of their online research include finding doctors or other health professionals (36%), finding information about care facilities (34%), or learning about how to do caregiving tasks (26%). Relatively few (13%) looked for support for themselves as caregivers.

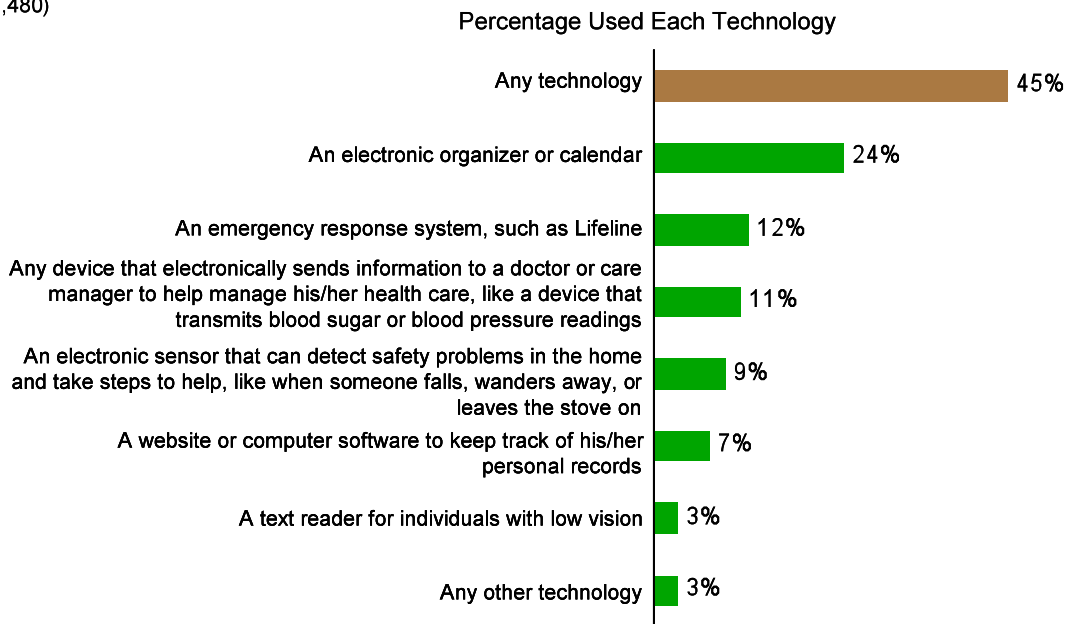
Other sources of information that caregivers would consult include family, friends, and other caregivers (20%), aging or disease-specific organizations (12%), and government programs (7%).

Support for Caregivers

Technology offers great promise for facilitating some of the responsibilities that caregivers' shoulder and more generally to improve the care of their recipients. Nearly half of caregivers say some sort of technology has been used in the care of their recipient. The most prevalent technology used is an electronic organizer or calendar (24%). Half as many say their care recipient has used an emergency response system like Lifeline (12%) or that the care recipient uses a device that sends information electronically to a doctor or a care manager (11%). Nearly one in ten report use of a sensor that detects problems in the home, like when someone falls, wanders away, or leaves the stove on (9%), and 7% report use of a website or computer software to keep track of personal health records.

Figure 20: Use of Technology in Caregiving
Q44. *In caring for your [relation], was the following ever used?*

Base: 2009 All caregivers
(n=1,480)

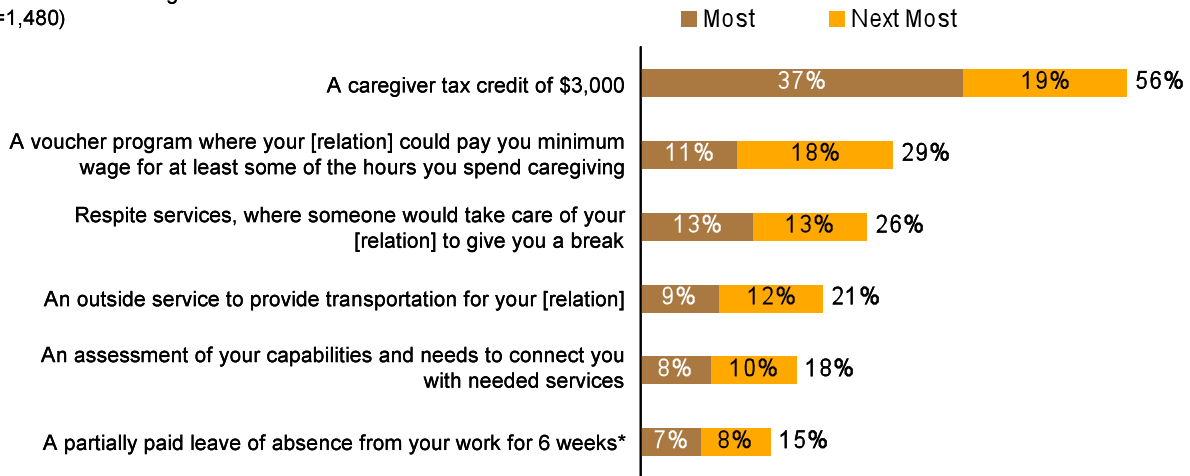


Of six potential national policies or programs that could be offered to help caregivers, by far the most popular is a caregiver tax credit of \$3,000. Half of caregivers rate it as the first or second most preferred policy. About three in ten prefer a voucher program where their care recipient could pay them minimum wage for at least some of their caregiving hours (29% first or second choice), and a similar proportion prefer respite services (26%).

Figure 21: 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
(n=1,480)



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

Interestingly, preference for the tax credit *rises* in relation to household income. Among caregivers with less than \$30,000 in household income, 52% choose the tax credit as their first or second choice, compared to 62% of those with \$100,000 or more in income.

However, the voucher program where the care recipient can pay the caregiver minimum wage for at least a portion of their caregiving hours is much more popular among the low income caregivers. Four in ten (42%) of those with less than \$30,000 in household income prefer the voucher program as their first or second choice, and this percentage declines to 17% of the highest income caregivers—those with \$100,000 or more in household income.

Demographics

Seven in ten caregivers are non-Hispanic White (72%), 13% are African-American, and 2% each are Hispanic or Asian-American. Six in ten caregivers are married (58%). More than one-third (37%) have children or grandchildren under the age of 18 in the household.

Four in ten have completed college (43%), although three in ten have had a high school education or less (29%). Four in ten have less than \$50,000 in household income (42%).

Figure 22: Profile of Respondents

	Total (n=1,480)	Caregivers of Children 0 to 17 (n=173) A	Caregivers of Younger Adults 18 to 49 (n=187) B	Caregivers of Older Adults 50+ (n=1,397) C
Gender				
Male	34%	28%	40% ^A	33%
Female	66	72 ^B	59	67
Age of Caregiver				
18 to 34	22%	35% ^C	30% ^C	18%
35 to 49	29	41 ^{BC}	26	27
50 to 64	35	17	31 ^A	40 ^{AB}
65 to 74	9	5	10	9 ^A
75 or older	4	1	2	5 ^{AB}
<i>Mean age</i>	<i>48.0</i>	<i>40.6</i>	<i>45.8^A</i>	<i>49.9^{AB}</i>
Race/Ethnicity of Caregiver				
White	72%	60%	61%	76% ^{AB}
African-American	13	17	17	11
Hispanic	12	19 ^C	20 ^C	10
Asian-American	2	2	1	2
Other	2	1	1	2
Marital Status				
Married	58%	53%	56%	59%
Living with a partner	5	6	4	5
Single, never married	16	21	19	15
Separated, divorced	14	16	15	14
Widowed	6	4	6	7
Children/Grandchildren <Age 18 in Household				
Yes	37%	79% ^{BC}	30%	32%
No	63	21	70 ^A	68 ^A

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

Three in ten caregivers have no more than a high school education, while more than four in ten caregivers have completed college. Caregivers' median household income is \$57,200, compared to \$52,029 for the U.S. overall.⁶ Nearly six in ten are currently employed.

2004-2009 Trend for Caregivers of Recipient Age 18+

Caregivers of adults in 2009 have higher educational levels than seen in 2004. Specifically, 45% now have completed college, up from 36% in 2004.

Profile of Respondents (continued)

	Total (n=1,480)	Caregivers of Children 0 to 17 (n=173) A	Caregivers of Younger Adults 18 to 49 (n=187) B	Caregivers of Older Adults 50+ (n=1,397) C
Education				
Less than high school	6%	13% ^C	8%	4%
High school graduate	23	21	29	23
Some college	25	28	28	24
Technical school	2	4	2	2
College graduate	25	17	18	26 ^{AB}
Graduate school	18	15	15	20
Household Income				
Less than \$50,000 (net)	42%	59% ^{BC}	44%	39%
Less than \$15,000	8	15 ^{BC}	6	7
\$15,000 to \$29,999	14	18	21 ^C	12
\$30,000 to \$49,999	18	24	16	19
Less than \$50,000, not fully specified	1	1	1	1
\$50,000 or more (net)	53	37	49 ^A	55 ^A
\$50,000 to \$74,999	19	11	22 ^A	20 ^A
\$75,000 to \$99,999	13	10	13	13
\$100,000 or more	19	15	13	20 ^B
\$50,000+, not fully specified	2	1	1	3 ^A
<i>Median Household Income</i>	<i>\$57,200</i>	<i>\$41,700</i>	<i>\$53,100</i>	<i>\$60,300</i>
Current Employment Status				
Working full time	46%	35%	44%	50% ^A
Working part time	11	18 ^{BC}	5	11 ^B
Retired	15	7	14	17 ^A
Homemaker	10	14 ^C	15 ^C	8
Unemployed and looking for work	7	12 ^C	10	5
Disabled	6	8	7	5
Student	2	4 ^B	<.5	2 ^B
Other	3	2	5	3

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

⁶ Source: U.S. Census Bureau, American Community Survey, 2008.

A plurality of caregivers live in a suburban setting, but three in ten each live in urban or rural areas. A similar distribution is seen for care recipients. Eleven percent of caregivers have served in the armed forces, and 17% of their adult care recipients have.

Profile of Respondents (continued)

	Total (n=1,480)	Caregivers of Children 0 to 17 (n=173) A	Caregivers of Younger Adults 18 to 49 (n=187) B	Caregivers of Older Adults 50+ (n=1,397) C
Caregiver Living Location				
Urban	29%	30%	27%	29%
Suburban	39	40	35	39
Rural	31	26	36	31
Care Recipient Living Location				
Urban	33%	31%	34%	32%
Suburban	37	39	32	38
Rural	28	26	31	28
Caregiver Service in Armed Forces				
Served on active duty	11%	7%	14%	11%
Did not ever serve	89	92	86	89
Care Recipient Service in Armed Forces (among those with adult recipients)	(n=1,307)		(n=187)	(n=1,397)
Served on active duty	17%	--	5%	20% ^B
Did not ever serve	82	--	95 ^C	79

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

IV. Summary and Conclusions

Caregivers are a diverse group. Their caregiving experiences range from those that are relatively easy to manage, to those that are burdensome. We know that most caregivers today are able to fulfill this role without experiencing overwhelmingly negative physical, emotional, or financial consequences. On the other hand, caregivers with the heaviest responsibilities are vulnerable to risks such as a decline in health, emotional stress, and economic hardship.

As the baby boom generation ages over the next 25 years, the numbers of people needing care will swell. The numbers of younger people available to provide care are likely to dwindle. This suggests that in the future, caregivers will be older, on average, than today's caregivers and may have greater infirmity of their own. In addition, the younger people who step into a caregiving role in the future may perceive they have less choice about becoming a caregiver. A greater share of caregivers may provide care to two or more care recipients.

The future may bring some positive changes as well. In particular, we are likely to see an expansion of the use of technologies that are already available to caregivers and recipients, as well as the development of new technologies.

It is important to recognize that the nearly 66 million caregivers are a critical extension of our formal health care system. Without their efforts, there would be a shift of recipients into public programs such as Medicaid, and the quality of life and the health status of many who need care would decline. It is important to do all we can to support caregivers so they can continue in their roles. Specifically, it is important to:

- 1) Identify and help caregivers who are most at risk for deteriorating health, financial security, and quality of life so that they can continue to provide care while maintaining their own well being
- 2) Identify and advocate for programs that make a real difference in caregivers' well being and in their ability to continue providing care
- 3) Identify and promote the use of technologies that can facilitate caregiving
- 4) Extend the reach of caregiver programs to all caregivers regardless of the age of their care recipient
- 5) Encourage families to plan proactively for aging and potential health/disability issue



Executive Summary
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