CAREGIVING IN THE U.S.

A Focused Look at the Ethnicity of Those Caring for Someone Age 50 or Older

Executive Summary

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National Alliance for Caregiving

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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 the Ethnicity of 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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I. Introduction and Summary

The purpose of this analysis is to better understand caregivers from different ethnic backgrounds who care for someone age 50 or older. 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 does caregiving affect 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 who provide help to care recipients age 50 and older.

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

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

Readers who want a quick snapshot of the findings will find the next two pages helpful. Readers who want more information will find the balance of the report provides greater detail.

Hispanic caregivers are an average of 43 years old and are significantly younger than White and African-American caregivers. While they are less likely to be married than White caregivers (48% vs. 63%), they are more likely to say there are children or grandchildren currently living in their household who are under 18 (47% vs. 32% of all caregivers, 30% of White caregivers, and 30% of African-American caregivers). Hispanic caregivers are more like to be a primary caregiver (61% vs. 48% of White caregivers and 43% of Asian-American caregivers) and they are 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. Based on this information, it is not surprising that Hispanic caregivers are more likely to feel they need help balancing their work and family responsibilities (39% of Hispanic caregiver's vs. 27% of caregivers overall and 25% of White caregivers) and finding time for themselves (41% vs. 29% White caregivers). Although two-thirds rarely or never have gone to an Internet website in the past year to find information in any way 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 was identified as the most or second most helpful public policy option, followed by respite services.

African-American caregivers are significantly older (48 years old), on average, than Hispanic caregivers. They are more likely to be single-never married (28% vs. 15% of caregivers overall or 12% of White caregivers). Most African-American caregivers have an annual household income of less than $50,000 and they are more likely to be in this situation than other caregivers (59% vs. 39% of caregivers overall, 34% of White caregivers, or 31% of Asian-American caregivers. African-American caregivers (41%) are more likely to provide assistance with three or more ADLs (41% vs. 28% of White caregivers and 23% of Asian-American caregivers. Although 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, 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 Whites.

Asian-American caregivers are a study in contrast. They are almost equally likely to be male or female. Most Asian-American caregivers are married (58%). However, Asian-American caregivers are more likely to be single, never-married than other caregiver groups (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 group (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	Black (n=206) C	Hispanic (n=200) D	Asian-American (n=170) E
Gender					
Male	33%	33%	29%	33%	48%ABC
Female	67E	67E	71E	67	52
Age of Caregiver					
Mean age	*49.9D*	*51.1D*	*48.2D*	*43.1*	*45.1*
Marital Status					
Married	59%CD	63%CD	44%	48%	58%C
Living with a partner	5E	5E	4	12ABC	2
Single, never married	15	12	28AB	21B	29AB
Separated, divorced	14E	14E	16	15	10
Widowed	7E	7E	8	4	2
Children/Grandchildren <Age 18 in Household					
Yes	32%	30%	30%	47%ABC	37%
No	68D	70D	70D	53	62
Education					
Less than high school	4%	3%	5%	14%AB	6%
High school graduate	23E	24E	23E	20E	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	32BC
Household Income					
Less than $50,000 (net)	39%	34%	59%ABE	56%ABE	31%
$50,000 or more (net)	55CD	60CD	38	38	64CD
Current Employment Status					
Working full time	50%	51%	49%	43%	46%
Working part time	11	11	6	14	19C
Retired	17D	18D	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 see Caregiving in the U.S. A Focused Look at Those Caring for Someone Age 50 or Older (full report online).

II. Overview of Methodology

This study 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. This report focuses primarily on Hispanic, African-American and Asian-American caregivers who provide unpaid care to an older adult age 50 and older 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 an appendix of the full report which is available online at www.aarp.org.

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 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.

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 at the 95 percent level of confidence (occasionally we use capital letters in tables to signal significant differences). With a 95 percent confidence level as a threshold, one can expect that 95 percent of the time the differences identified as statistically significant would not have occurred by chance (i.e., one in twenty of the differences would be due to chance).[1] The margin of error at this level is +/-3.2 percent. In order to meaningfully manage subgroup differences, we report subgroup findings at the 99 percent level of confidence. 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 +/-4.2 percent at the 99 percent confidence level.[2]

Reading this Report

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.

When presenting differences between different racial/ethnic groups, any mention of Whites refers solely to non-Hispanic Whites.

When presenting differences among age groups, "young caregivers” 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.

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[1] This takes Type I errors into account, that is the possibility of rejecting a true hypothesis.

[2] We conducted oversampling for the African-American and Hispanic subgroups to provide approximately 200 respondents from each ethnic group. The oversampling protocol used a combination of random digit dial telephone interviewing, surname and targeted random digit dial (RDD) techniques. This oversampling was implemented after the main RDD sample was finished so that we could determine how many interviews we needed to conduct to reach our target goal. Although we did not oversample Asian-American caregivers, there were 170 Asian-American caregivers in this study and we report the findings from those interviews in this section.

Data from the RDD, and oversamples of African-Americans, Hispanics, and Asian-American caregivers in the base study were weighted. Then, the extra interviews conducted among the 50+ (including White, African-Americans, and Hispanics) were weighted to the distribution of caregivers of the 50+ recipients in the base sample. Additional information about how the weights were developed can be founded in the detailed methodology as part of the full report.

III. Key Findings

Caregiver Ethnicity: Hispanic Caregivers

Most of the findings for ethnic subgroups are descriptive. Hispanic caregivers of people age 50 and over, as well as the people they assist, are not significantly different from other caregivers or care recipients unless specifically noted.

Basics of the Caregiving Situation

The Hispanic caregivers in this study are all 18 years of age and older and they provide help to someone age 50 and older. Like other caregivers, Hispanic caregivers are likely to be females (67% vs. 33% males). They are, however, younger and less likely to be married than some of their counterparts. They are also more likely to have children or grandchildren living in their household, to have lower educational levels and a lower annual household income. Specific information about these observations appears below.

- Hispanic caregivers are, on average, 43 years old. They are significantly younger than White caregivers, whose average age is 51, and African-American caregivers, whose average age is 48.
- Hispanic caregivers are less likely to be married (48% vs. 63% of White caregivers).
- Hispanic caregivers are also more likely to say there are children or grandchildren currently living in their own household who are under the age of 18 (47% vs. 32% of all caregivers, and 30% of White caregivers, and 30% of African-American caregivers).
- They are more likely to have an annual household income of under $50,000 (56% vs. 39% of caregivers overall, 34% of White caregivers, and 31% of Asian-American caregivers).
- Hispanic caregivers are more likely to say they have less than a high school education (14% vs. 4% of caregivers overall, and 3% of White caregivers).

Most Hispanic caregivers assist one person (68%). The majority provide care for a relative (89%), with more than half (52%) caring for a parent (40% care for their mother and 12% care for their father). Most of the Hispanic caregivers in this study are currently providing care (75%) and one-quarter (25%) provided care in the past twelve months. The average duration of care is 4 years.

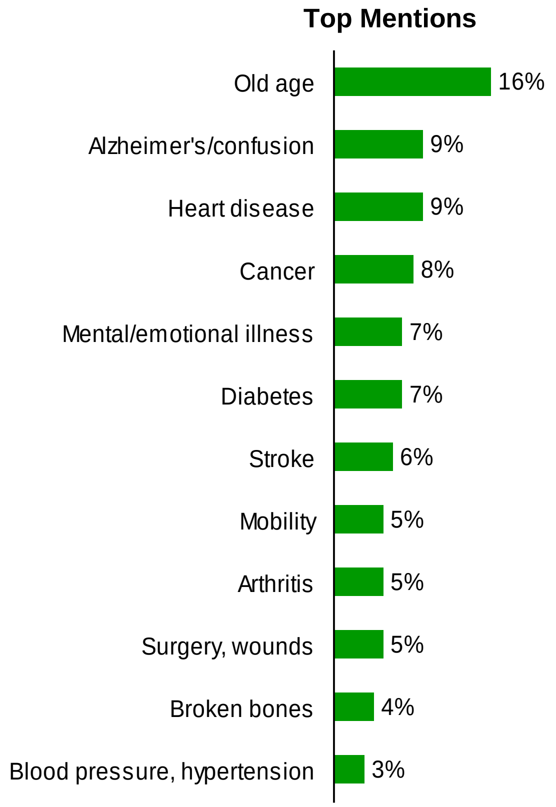
Care Recipient Condition

Most care recipients of Hispanic caregivers are female (71%). Their average age is 74, significantly lower than White care recipients (78 years).

Hispanic caregivers most frequently cite two problems as the main reason the person they assist needs care: 1) old age or aging (16%), and 2) Alzheimer's disease, confusion, dementia or forgetfulness (9%).

Figure 2: Main Problem or Illness Identified by Caregiver - Hispanics

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



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

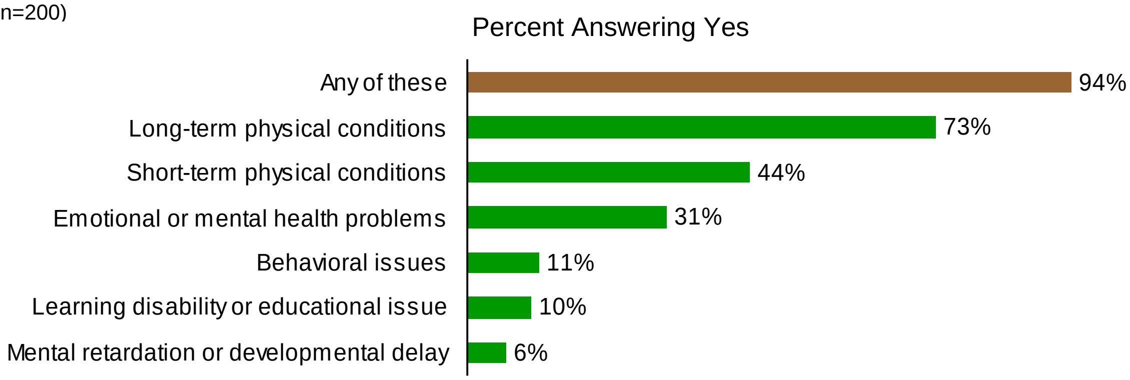
Most Hispanic caregivers say the person they help needs care because of a long-term physical condition (73%). Four in ten (44%) need care because of a short-term physical condition. Three in ten (31%) need care because of emotional/mental health issues.

Figure 3: Types of Care Recipient Conditions - Hispanics

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

[MULTIPLE RESPONSES ALLOWED]

Base: 2009 Hispanic caregivers 50+ (n=200)



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

Caregiving Activities and Burden of Care

Hours of Care Provided

While Hispanic caregivers spend an average of 25 hours in a typical week on caregiving activities, the largest proportion report spending between one to eight hours caregiving per week (36%).

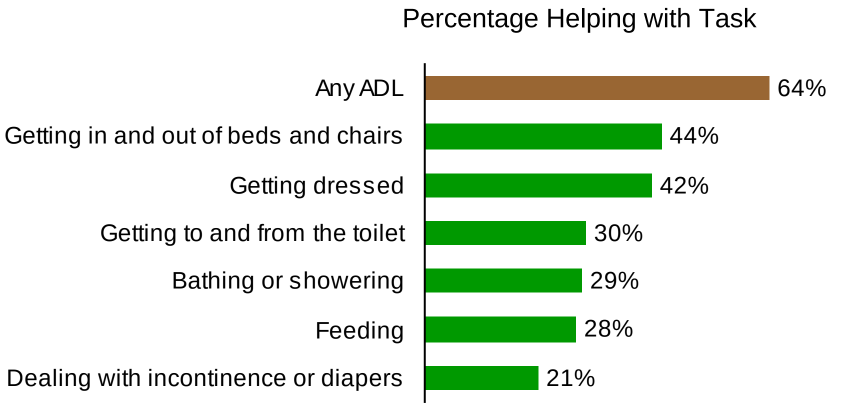
Activities of Daily Living

How do Hispanic caregivers spend their time? 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). On average, Hispanic caregivers provide care recipients help with two ADLs. More than one-third (36%) provide assistance with three or more ADLs. More than one-third (36%) do not provide assistance with any ADLs.

Figure 4: Help with Activities of Daily Living (ADLs) - Hispanics

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 Hispanic caregivers of 50+ (n=200)



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

Among Hispanic caregivers, the most commonly reported ADLs are helping someone get in and out of beds and chairs (44%), get dressed (42%), and get to and from the toilet (30%).

Instrumental Activities of Daily Living

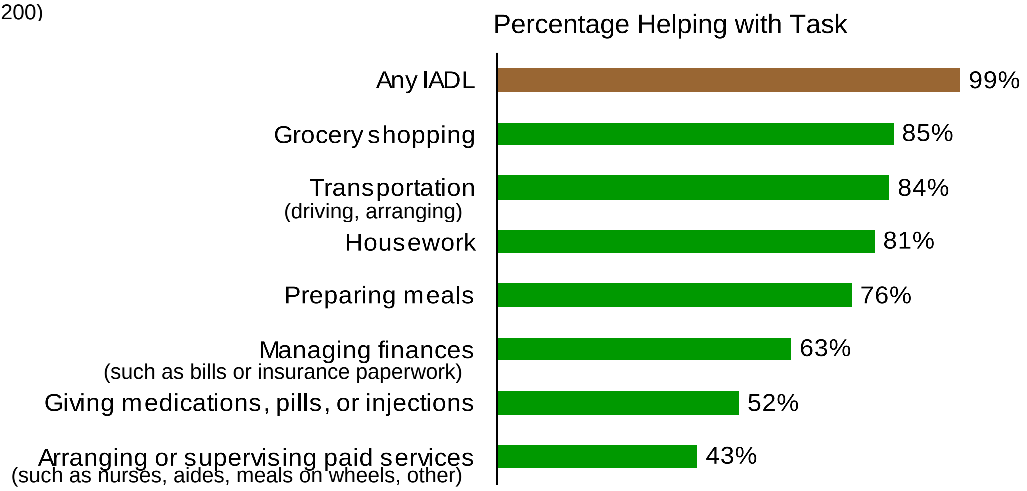
All caregivers perform at least one IADL. Nine in ten (93%) Hispanic caregivers help their care recipient with three or more IADLs. On average, Hispanic caregivers perform five IADLs, which is significantly more than White caregivers who, on average, perform four IADLs.

The most frequently reported IADLs performed by Hispanic caregivers are providing grocery shopping (85%) and transportation (84%). Hispanic caregivers are more likely to provide grocery shopping (85% vs. 72% of White caregivers). Hispanic caregivers are also more likely to report providing help with preparing meals than some other caregiver subgroups (76% vs. 64% of caregivers overall, 61% of White caregivers, and 60% of Asian-American caregivers).

Figure 5: Help with Instrumental Activities of Daily Living (IADLs) - Hispanics

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

Base: 2009 Hispanic caregivers of 50+
(n=200)



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

Among Hispanic caregivers, half (54%) say they have advocated for their care recipient with care providers, government agencies, or schools. One in three (29%) say they have performed physical or medical therapies or treatments on their care recipient.

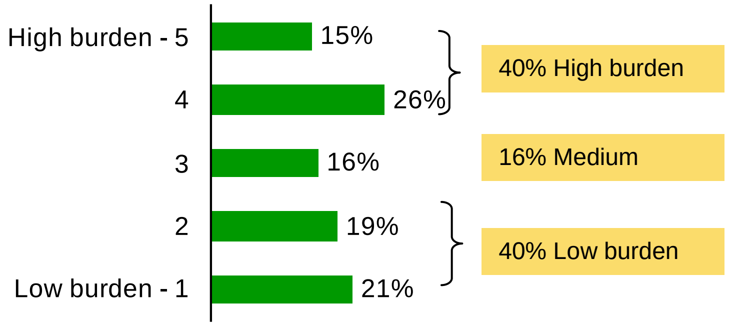
Level of Burden Index

A level of burden 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, with one being the lowest level of burden and five being the highest level of burden.

Two in five (40%) Hispanic caregivers are in a high burden situation, about one in six (16%) are in a medium burden situation and another two in five (40%) are in a low burden situation.

Figure 6: Level of Burden – Hispanics

Base: 2009 Hispanic caregivers 50+
(n=200)



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

Hispanic caregivers are more likely to experience a high level of burden than Asian-American caregivers (40% vs. 20%).

Presence of Other Caregivers

Unpaid Caregivers

Caregiving is often a shared responsibility. Almost two-thirds (64%) of Hispanic caregivers 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 Hispanic caregivers who say another unpaid caregiver provided help in the last 12 months, only a small minority (4%) say they split care equally.

Six in ten (61%) Hispanic caregivers say they are the “sole” caregiver (33%) or the caregiver who provides the most unpaid care among the unpaid caregivers (28%). Collectively, we call these two groups primary caregivers. Hispanic caregivers are more likely to be primary caregivers (61% vs. 48% of White caregivers or 43% of Asian-American caregivers).

Paid Caregivers

Among Hispanic caregivers of people who do not live in nursing homes, four in ten (38%) say that during the past 12 months the person they assist received paid help from aides, housekeepers, or other people. Among this subgroup of Hispanic caregivers four in ten (39%) say the paid helper provided their care recipient the most help, while one in three (32%) say they provided the most help and less than one in five (17%) say another unpaid caregiver provided the most help to the care recipient.

Care Recipient Living Situation

Where Care Recipients Live

Hispanic caregivers are more likely to say the person they assist lives in an urban area (58% vs. 32% of caregivers overall and 26% of White caregivers). This is partly an artifact of the density sampling used to reach Hispanic caregivers. About one in five (22%) Hispanic caregivers say the person they assist lives in a suburban area, and less than one in five (18%) Hispanic caregivers say the person they assist lives in a rural area.

Most Hispanic caregivers say their care recipient continues to live in their own home (55%) and more than one in four (28%) lives in the caregiver's home. Few live in other settings.

About one-third (34%) of Hispanic caregivers say the person they assist lives alone, while one in five say she or he lives with a spouse (22%) or with his or her adult children (21%).

Almost half (49%) of caregivers say they live within twenty minutes of the home of their care recipient.

Among Hispanic caregivers who do not live with the person they assist, six in ten (63%) say they visit their care recipient more than once a week, and about one in ten visit once a week (13%) or a few times a month (13%). One in ten (9%) visit less than once a month.

Stress and Strain of Caregiving

Among Hispanic caregivers, almost half (48%) describe their health as excellent or very good. Three in ten (29%) rate their health as good, and one-quarter (23%) rate their health as fair or poor. Seven in ten (70%) Hispanic caregivers say caregiving has not affected their health. About one in five (18%) say caregiving has made their health worse.

More than half (58%) of Hispanic caregivers rate the physical strain of caregiving low (rating of one or two on a five-point scale) and one in five rate the physical strain of caregiving high (21% give a rating of four or five).

Almost half (47%) of Hispanic caregivers, rate the emotional stress of caregiving low (one or two on a five-point scale). One in five (19%) indicate they have moderate stress, and about one-third (33%) rate the emotional stress of caregiving high (a four or five).

Most Hispanic caregivers (67%) rate the financial hardship of caring for their care recipient low (one or two on a five-point scale). About one in six rate the financial hardship as moderate (17%) or high (15%).

Time is an important issue for caregiver(s) because it can take time they would otherwise devote to other parts of their lives. This situation can be further complicated when the caregiver does not feel she or he had a choice in taking on the caregiving role. More than one-third (36%) of Hispanic caregivers did not feel they had a choice in taking on the caregiving role, and more than half (54%) of Hispanic caregivers say that as caregivers, they have less time for friends or other family members than before becoming a caregiver. Furthermore, among Hispanic caregivers more than four in ten (41%) say they need help finding time for themselves, which is more than White caregivers (29%).

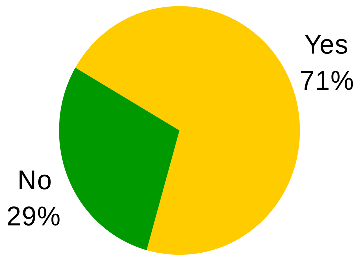
Impact of Caregiving on Work

Most (71%) of Hispanic caregivers have been employed while they were providing care.

Figure 7: Concurrence of Employment and Caregiving - Hispanics

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 Hispanic caregivers 50+ who worked while caregiving (n=121)



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

Among those who have been employed while caregiving, most have had to make a work place accommodation due to caregiving (70%). Furthermore, among Hispanic caregivers, four in ten say that as a caregiver they feel they need more help or information on balancing their work and family responsibilities, and they are more likely to feel this way than some other caregivers (39% of Hispanic caregivers vs. 27% of caregivers overall and 25% of White caregivers).[3]

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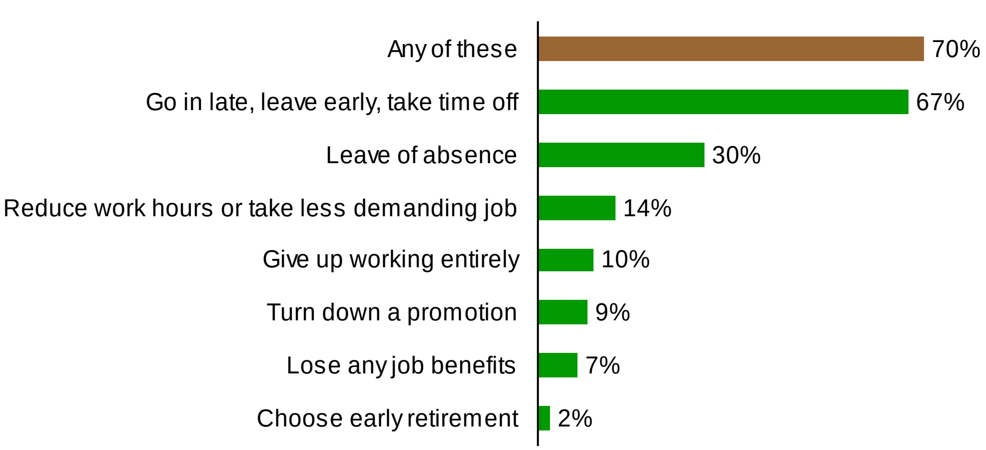
[3] "Caregivers overall" refers to all caregivers 18 and over providing care to someone age 50 and over.

Figure 8: Work Accommodations Due to Caregiving - Hispanics

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

Base: 2009 Hispanic caregivers of 50+ who worked while caregiving (121)



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

The most common workplace accommodation is going in late, leaving early, or taking time-off during the day (67%). Hispanic caregivers are more likely to say they had to take a leave of absence than other caregivers (30% vs. 17% of caregivers overall and 15% of White caregivers).

Information Sources and Needs

Sources of Information

More than one-third (36%) of Hispanic 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-third (33%) say they would turn to the Internet and print media, while about one in five caregivers (19%) say they would turn to family, friends or other caregivers. Fewer would turn to aging or disease specific organizations (7%), government programs (4%), social or community services (1%).

Figure 9: Sources Used for Caregiving Information - Hispanics

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

[MULTIPLE RESPONSES ALLOWED]

Base: 2009 Hispanic caregivers 50+

	2009
Health or caregiving provider	36%
Doctor	25%
Nurse, other health professional	9%
Caregiving provider (such as a nursing home, assisted living facility, home care, senior day care)	4%
Hospital, clinic	1%
Social worker, case worker	1%
Hospice	1%
Mental health provider	0%
Internet and print media	33%
Internet	32%
Books, magazines, library	1%
Government programs	4%
Government	3%
Social Security, Medicaid, Medicare	1%
Veteran’s administration	0%
Family, friends, caregivers	19%
Family, friends, colleagues, word of mouth	18%
Family caregivers, support groups, people with similar experience	1%
Aging or disease specific organizations	7%
Senior citizen's center, aging organization	6%
Disease-specific organization	2%
Social services, community services	1%
Other	5%
Insurance company	1%
Church, minister	0%
Employer	0%
School	0%
Other	4%

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

Internet Usage

Among Hispanic caregivers, two-thirds (68%) 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, including many who have never done this (49%). About one-third (32%) say they have sometimes or often gone to Internet websites in the past year for such information.

Among those Hispanic caregivers who have used the Internet for a caregiving-related purpose, eight in ten (77%) say they looked for information about their care recipient's condition or treatment while about half (55%) looked for information about services for recipients.

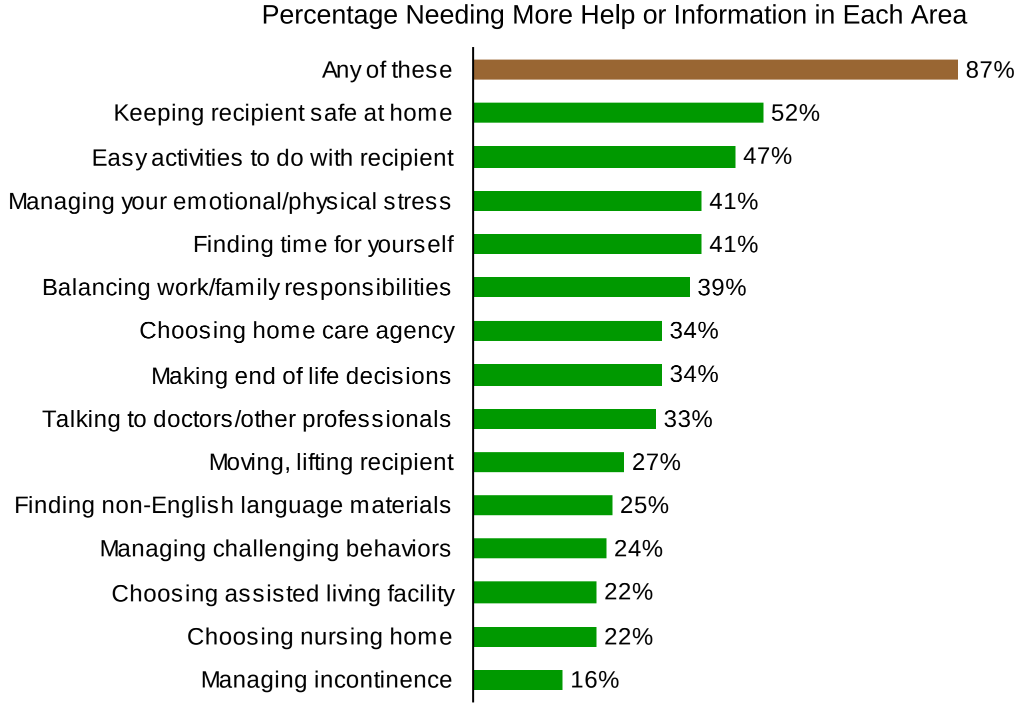
Information Needs

Almost nine in ten (87%) Hispanic caregivers say they need more help or information on at least one of the fourteen categories we asked about. They were significantly more likely to say this than caregivers overall (77%), and White caregivers (75%).

Figure 10: Caregiving Information Needs - Hispanics

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

Base: 2009 Hispanic caregivers of 50+ (n=200)



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

Hispanic caregivers generally have the same information needs as other caregivers, but a greater proportion want help or information on certain items. For example, Hispanic caregivers are more likely to say they need information:

- About keeping their recipient safe at home (52% vs. 38% of all caregivers, and 36% of White caregivers),
- Having easy activities to do with recipient (47% vs. 34% of all caregivers and 31% of White caregivers),

- Finding time for themselves (41% vs. 29% of White caregivers),
- Balancing work and family responsibilities (39% vs. 27% of all caregivers, and 25% of White caregivers),
- Making end-of-life decisions (34% vs. 21% of all caregivers and, 19% of White caregivers), and
- Finding non-English language educational materials (25% vs. 4% of all caregivers, 1% of White caregivers, and 4% of African-American caregivers).

Support for Caregivers

Supportive Services and Practices

Six in ten (61%) Hispanic caregivers say coordinating the care of the person they help is very or somewhat easy, while one-third (32%) say it is somewhat or very difficult.

There are a variety of services that could support Hispanic caregivers and almost half (49%) report using any of the three services we asked them about. More than one-quarter (26%) have requested information for financial help for their care recipient, and about one-quarter (24%) have used an outside transportation service for their care recipient. Fewer Hispanic caregivers report having used respite services (13%).

About one-third (36%) of Hispanic caregivers say they have had some modification made in the house or apartment where their care recipient lives, while few have taken formal caregiving training (18%).

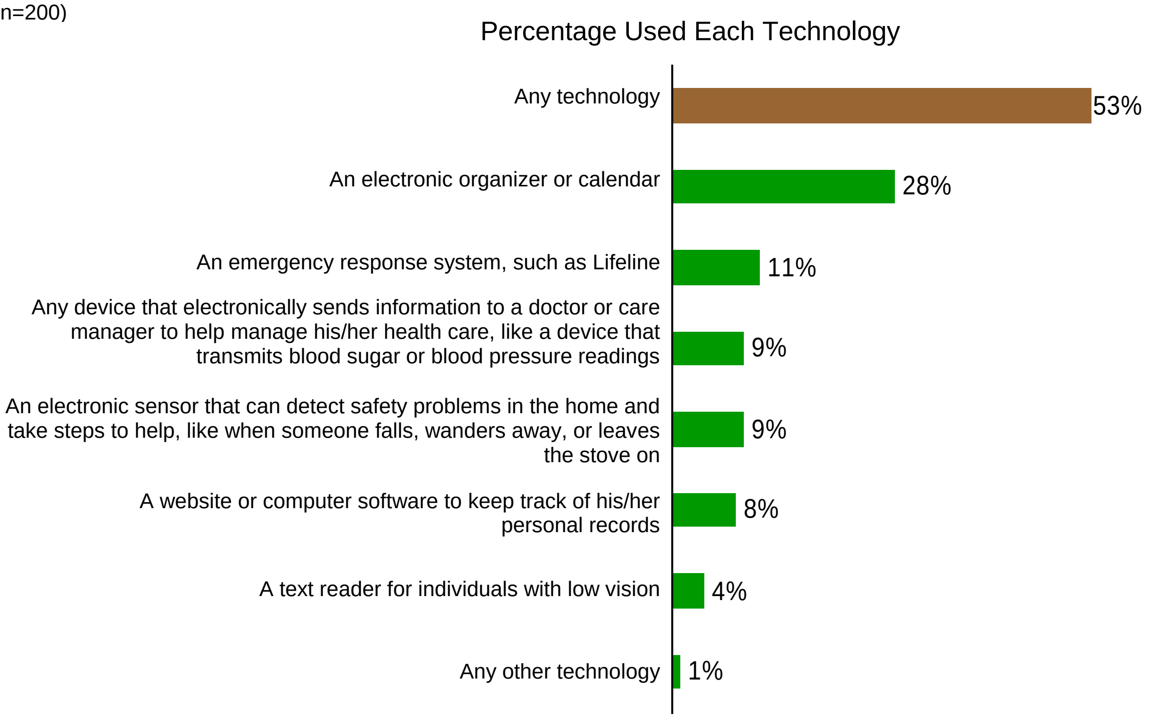
Use of Technology

Despite the numbers on Internet use, today, the use of other technology is widespread. We found that half (53%) of Hispanic caregivers say they have ever used one of the six technologies in caring for their care recipient.

Figure 11: Use of Technology in Caregiving - Hispanics

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

Base: 2009 Hispanic caregivers of 50+
(n=200)



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

Almost three in ten (28%) say they have used an electronic organizer or calendar for caregiving. About one in ten has used a device that electronically sends information to a doctor or other care manager (11%), an emergency response system (9%) or has electronic sensors that detect safety problem in the care recipient's environment (8%).

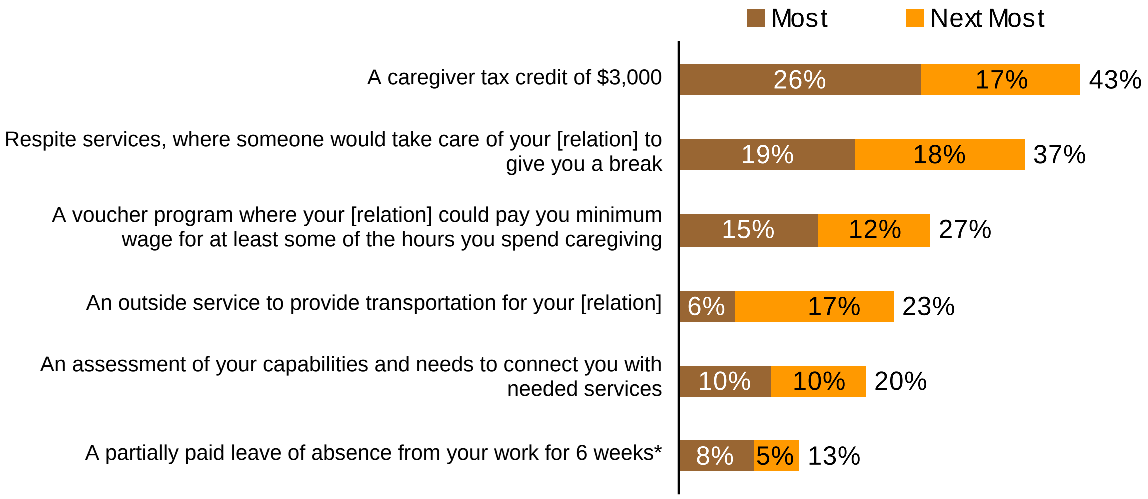
Reaction to Caregiving-Related Policy

Caregivers were asked about six potential caregiving-related policies. Four in ten (43%) Hispanic caregivers say the policy they would find most or second most helpful would be a caregiver tax credit of three thousand dollars. More than a third (37%) selected a voucher program where their care recipient could pay them a minimum wage for at least some of the hours the spent caregiving. Hispanic caregivers were more likely to support a voucher program than White caregivers (37% vs. 24%).

Figure 12: Reaction to Caregiving-Related Policies - Hispanics

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 Hispanic caregivers of 50+



Source: Caregiving in the U.S. 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.

Almost three in ten (27%) Hispanic caregivers selected respite services as their first or second choice, one-quarter (23%) selected an outside service to provide transportation for their care recipient, and one in five (20%) said a caregiver needs assessment. Few said a partially paid leave of absence from work for six weeks (13%) would be something they would find helpful.

Caregiver Ethnicity: African-American Caregivers

Most of the findings for ethnic subgroups are descriptive. African-American caregivers and the people they assist are not significantly different from other caregivers or care recipients unless specifically noted.

Basics of the Caregiving Situation

The African-American caregivers in this study are all 18 years of age and older and they provide help to someone age 50 and older. Like other caregivers, African-American caregivers are mostly female (71%). They are, however, older and more likely to be single, never married than certain other caregivers. While African-American caregivers tend to be well educated, most have an annual household income of less than $50,000. Specific information about these observations appears below:

- African-American caregivers' average age is 48, significantly older than Hispanic caregivers whose average age is 43.
- African-American caregivers are more likely to be single, never married (28% vs. 15% of caregivers overall of the 50+, or 12% of White caregivers).
- One-quarter (23%) of African-American caregivers completed high school or have a GED, three in ten (29%) have some college, and another quarter (26%) are college graduates, and 15% have done graduate work or completed graduate school which is less than one-third (32%) of Asian-Americans who have done graduate work or completed graduate school.
- Most African-American caregivers (59%) have an annual household income of less than $50,000 and are more likely to have this lower income than other caregivers (39% of caregivers overall, 34% of White caregivers, and 31% of Asian-American caregivers.

Most African-American caregivers assist one person (70%). The majority provide care for a relative (87%), with less than half (46%) caring for a parent (37% care for their mother and 9% care for their father). African-American caregivers are more likely to provide care to an aunt or uncle (10% vs. 3% of White caregivers). Most of the African-American caregivers in this study are currently providing care (72%) and one-quarter (27%) provided care in the past twelve months. The average duration of care is four and a half years.

Care Recipient Condition

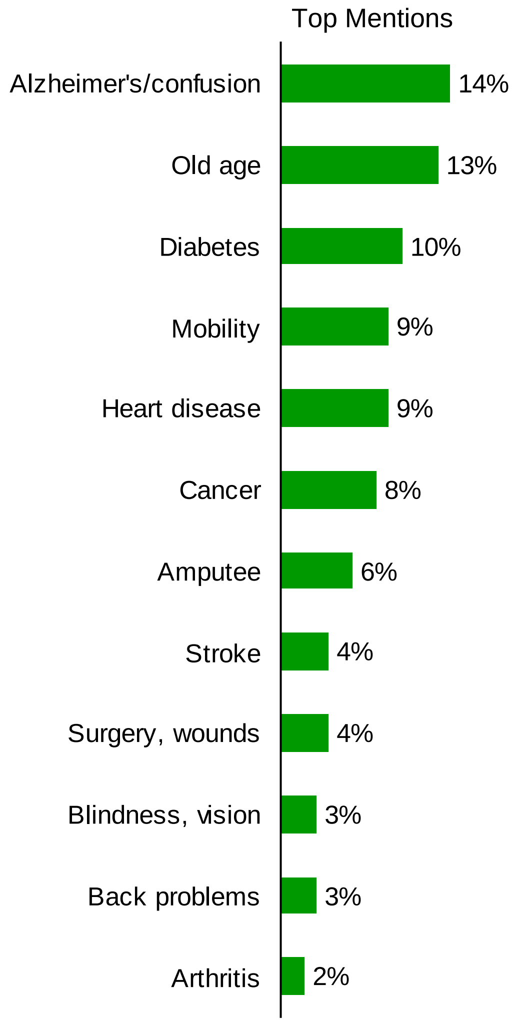
Most care recipients of African-American caregivers are female (69%). Their average age is 74.

African-American caregivers most frequently cite two problems as the main reason the person they assist needs care: 1) Alzheimer's disease, confusion, dementia or forgetfulness (14%) and (2) old age or aging (13%).

Figure 13: Main Problem or Illness Identified by Caregiver – African-Americans

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 African-American caregivers of 50+
(N=206)



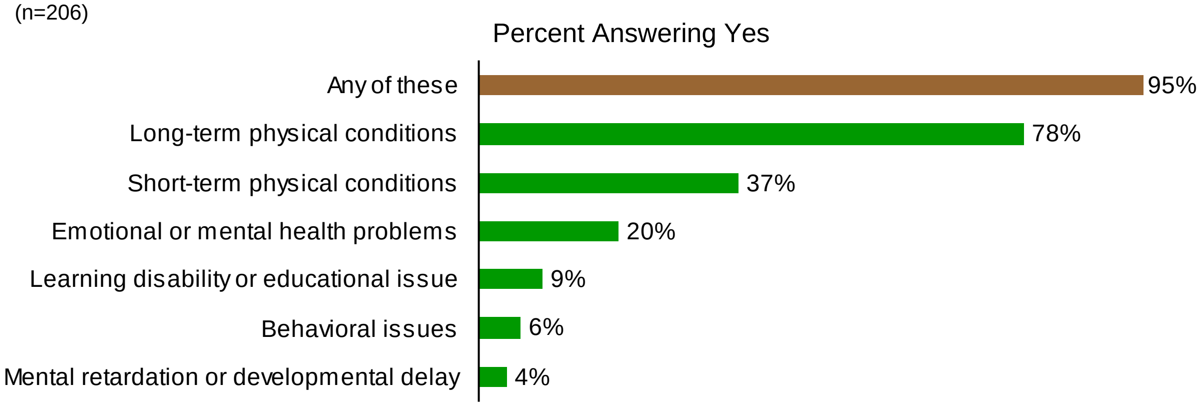
Source: Caregiving in the U.S. 2009, National Alliance for Caregiving and AARP

Most African-American caregivers say the person they help needs care because of long-term physical conditions (78%). About four in ten (37%) needs care because of a short-term physical condition. One in five (20%) needs care because of emotional/mental health issues.

Figure 14: Types of Care Recipient Conditions – African-Americans

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

Base: 2009 African-American caregivers of 50+ (n=206)



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

Caregiving Activities and Burden of Care

Hours of Care Provided

While African-American caregivers spend an average of 24 hours in a typical week on caregiving activities, four in ten African-American caregivers report spending between one to eight hours caregiving per week (42%).

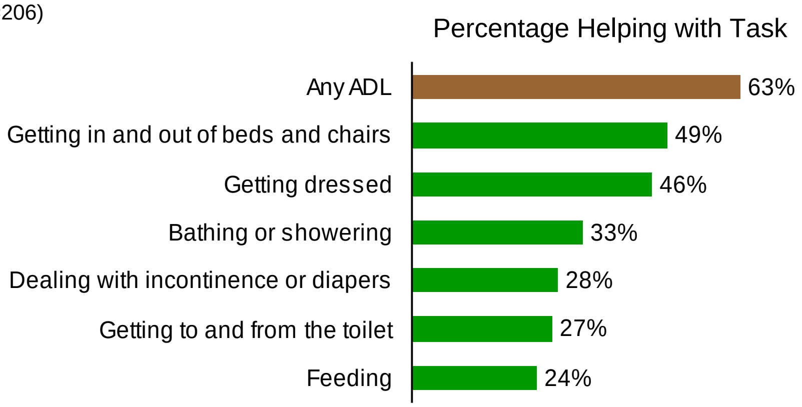
Activities of Daily Living

How do African-American caregivers spend their time? 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). On average African-American caregivers provide care recipients help with two ADLs. African-American caregivers are more likely to provide assistance with three or more ADLs (41% vs. 28% of White caregivers and 23% of Asian-American caregivers). More than one-third (37%) of African-American caregivers do not provide assistance with any ADLs.

Figure 15: Help with Activities of Daily Living (ADLs) – African-Americans

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 African-American caregivers 50+ (n=206)



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

Among African-American caregivers, the most commonly reported ADLs are helping someone get in and out of beds and chairs (49%), get dressed (46%), and to bathe or shower (33%). African-American caregivers are more likely to assist their care recipient with getting dressed (46% vs. 34% overall, 31% of White and 24% of Asian-American caregivers).

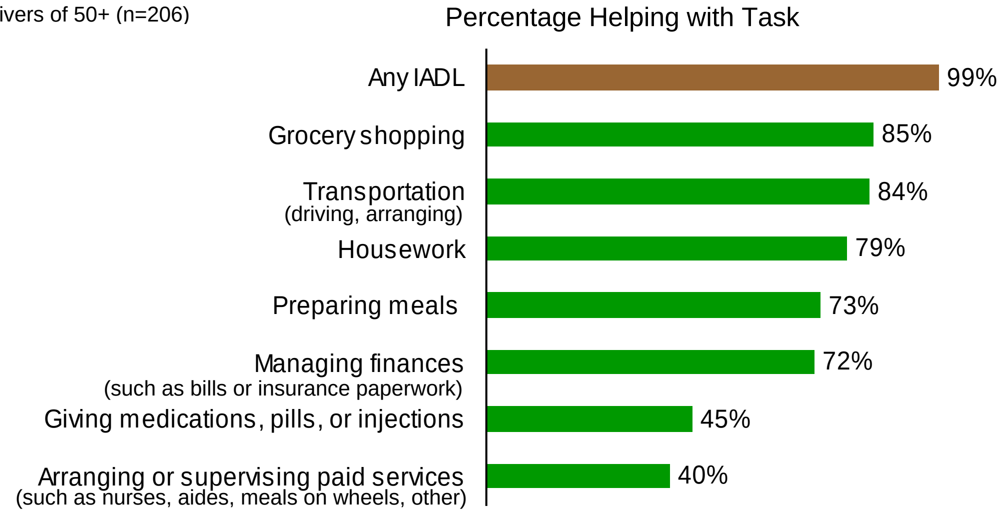
Instrumental Activities of Daily Living

All caregivers perform at least one IADL. On average, African-American caregivers perform five IADLs. Eight in ten (86%) African-American caregivers help their care recipient with three or more IADLs.

Figure 16: Help with Instrumental Activities of Daily Living (IADLs) – African-Americans

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

Base: 2009 African-American caregivers of 50+ (n=206)



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

The most frequently reported IADLs performed by African-American caregivers are providing grocery shopping (85%) and transportation (84%). African-American caregivers are more likely to provide grocery shopping than some other caregivers (85% vs. 75% of caregivers overall, and 72% of White caregivers). African-American caregivers are also more likely to report providing help with preparing meals (73% vs. 61% of White caregivers).

Among African-American caregivers, half (52%) say they have advocated for their care recipient with care providers, government agencies, or schools. Three in ten (29%) say they have performed physical or medical therapies or treatments on their care recipient.

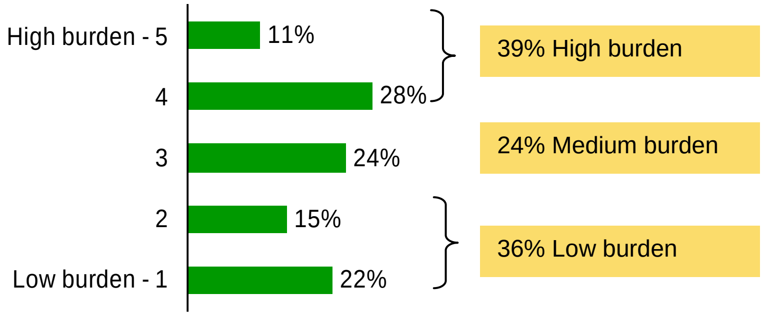
Level of Burden Index

A level of burden 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, with one being the lowest level of burden and five being the highest level of burden.

More than one-third (36%) of African-American caregivers are in a low burden situation, about one-quarter (24%) are in a medium burden situation, and another two in five (39%) are in a high burden situation.

Figure 17: Level of Burden – African-Americans

Base: 2009 African-American caregivers of 50+
(n=206)



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

African-American caregivers are more likely to be in a high burden situation than Asian-American caregivers (39% vs. 20%).

Presence of Other Caregivers

Unpaid Caregivers

Caregiving is often a shared responsibility. More than half (58%) of African-American caregivers say at least one other person has provided unpaid help to their care recipient in the past 12 months, and they are less likely to say this than White caregivers (72%) and caregivers overall (70%). However, caregiving responsibilities are rarely shared equally. Among African-American caregivers who say another unpaid caregiver provided help in the last 12 months, a minority (12%) say they split care equally.

Six in ten (57%) African-American caregivers say they are the "sole" caregiver (36%) or the caregiver who provides the most unpaid care among the unpaid caregivers (21%). Collectively, we call these two groups primary caregivers.

Paid Caregivers

Among African-American caregivers of those who do not live in nursing homes, three in ten (29%) say that during the past 12 months the person they assist received paid help from aides, housekeepers, or other people, fewer than Whites (43%). Among this subgroup of African-American caregivers half (50%) say the paid helper provided their care recipient the most help, while one in four (25%) say they provided the most help or another unpaid caregiver provided the most help to the care recipient (24%).

Care Recipient Living Situation

Where Care Recipients Live

African-American caregivers are more likely to say the person they assist lives in an urban area (49% vs. 32% of caregivers overall and 26% of White caregivers). This is likely to be an artifact of the density sampling done to obtain respondents. About one-third (34%) of African-American caregivers say the person they assist lives in a suburban area, and about one in seven (15%) say the person they assist lives in a rural area. They are less likely to live in a rural area than their White counterparts (32%), or caregivers overall (28%).

Most African-American caregivers say their care recipient continues to live in their own home (51%) and more than one in four (26%) lives in the caregiver's home. Few live in other settings.

Almost half (47%) of African-American caregivers say the person they assist lives alone, while almost one in five say she or he lives with a spouse (18%) or with his or her adult children (13%).

Almost half (45%) of African-American caregivers say they live within twenty minutes from the home of the care recipient.

Among African-American caregivers who do not live with the person they assist, two-thirds (66%) say they visit with their care recipient more than once a week which is significantly more than Asian-American caregivers (47%). About one in ten African-American caregivers visit once a week (12%) or a few times a month (11%). Less than one in ten (6%) visit less than once a month.

Stress and Strain of Caregiving

Among African-American caregivers half (51%) describe their health as excellent or very good. Three in ten (28%) rate their health as good and one in five (20%) rate their health as fair or poor. Eight in ten (79%) African-American caregivers say caregiving has not affected their health. About one in ten (9%) say caregiving has made their health worse. African-Americans caregivers are less likely than White caregivers to say caregiving has made their health worse (9% vs. 17%).

Six in ten (62%) African-American caregivers rate the physical strain of caregiving low (rating of one or two on a five-point scale), and one in five (22%) rate it moderate and one in six rate (15%) it high (rating of four or five).

Half (49%) of African-American caregivers rate their emotional stress associated with caregiving low on a five-point scale (one or two on a five-point scale). One-quarter (25%) indicate they have moderate stress and about one-quarter (24%) rate the emotional stress of caregiving high (a four or five).

Most African-American caregivers (75%) rate the financial hardship of caring for their care recipient low (one or two on a five-point scale). About one in ten rates the financial hardship as moderate (9%) and one in six rate it as high (16%).

Time is an important issue for caregivers because caregiving can take time they would otherwise devote to other parts of their lives. This situation can be further complicated when the caregiver does not feel she or he had a choice in taking on the caregiving role. Among African-American caregivers, four in ten (43%) say they feel they did not have a choice in taking on the caregiving role and a similar proportion (46%) say they have less time for friends or other family members than before becoming a caregiver. At the same time, more than a third (35%) of African-American caregivers says they need help finding time for themselves.

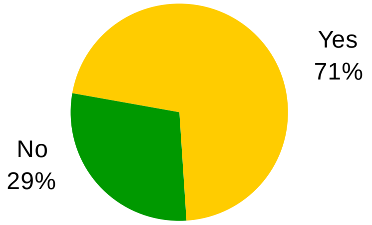
Impact of Caregiving on Work

Most African-American caregivers (71%) have been employed at some point while they were providing care.

Figure 18: Concurrence of Employment and Caregiving – African-Americans

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 African-American caregivers of 50+ (n=206)



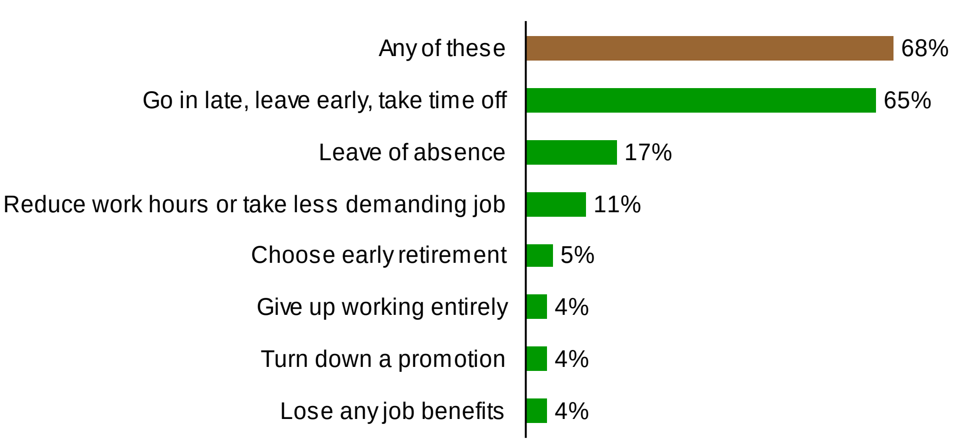
Source: Caregiving in the U.S. 2009, National Alliance for Caregiving and AARP

Among those who have been employed while caregiving, most have had to make at least one workplace accommodation due to caregiving (68%). In addition, among African-American caregivers, more than one-quarter (28%) feel they need more help or information on balancing their work and family responsibilities.

Figure 19: Work Accommodations Due to Caregiving –African-Americans

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

Base: 2009 African-American caregivers 50+ who worked while caregiving (n=134)



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

The most common workplace accommodation is going in late, leaving early, or taking time-off during the day (65%).

Information Sources and Needs

Sources of Information

More than one-third (35%) of African-American 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. About one in five say they would turn to the Internet or print media (19%); to family, friends, or other caregivers (19%); or to aging or disease-specific organizations (18%). Few would turn to social or community services (5%) or government programs (2%).

Figure 20: Sources Used for Caregiving Information – African-Americans

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

Base: 2009 African-American caregivers of 50+ (n=206)

	2009
Health or caregiving provider	35%
Doctor	15%
Nurse, other health professional	12%
Caregiving provider (such as a nursing home, assisted living facility, home care, senior day care)	5%
Hospital, clinic	3%
Social worker, case worker	3%
Hospice	0%
Mental health provider	0%
Internet and print media	19%
Internet	19%
Books, magazines, library	2%
Government programs	8%
Veteran's administration	3%
Government	2%
Social Security, Medicaid, Medicare	2%
Family, friends, caregivers	19%
Family, friends, colleagues, word of mouth	18%
Family caregivers, support groups, people with similar experience	<0.5%
Aging or disease specific organizations	18%
Senior citizen's center, aging organization	16%
Disease-specific organization	3%
Social services, community services	5%
Other	9%
Church, minister	2%
Insurance company	1%
Employer	0%
School	0%
Other	6%

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

Internet Usage

Among African-American caregivers, seven in ten (70%) 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, with most having never done this (55%). Three in ten (30%) say they have sometimes or often gone to Internet websites in the past year for such information.

Among those African-American 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 while six in ten (58%) looked for information about services for recipients.

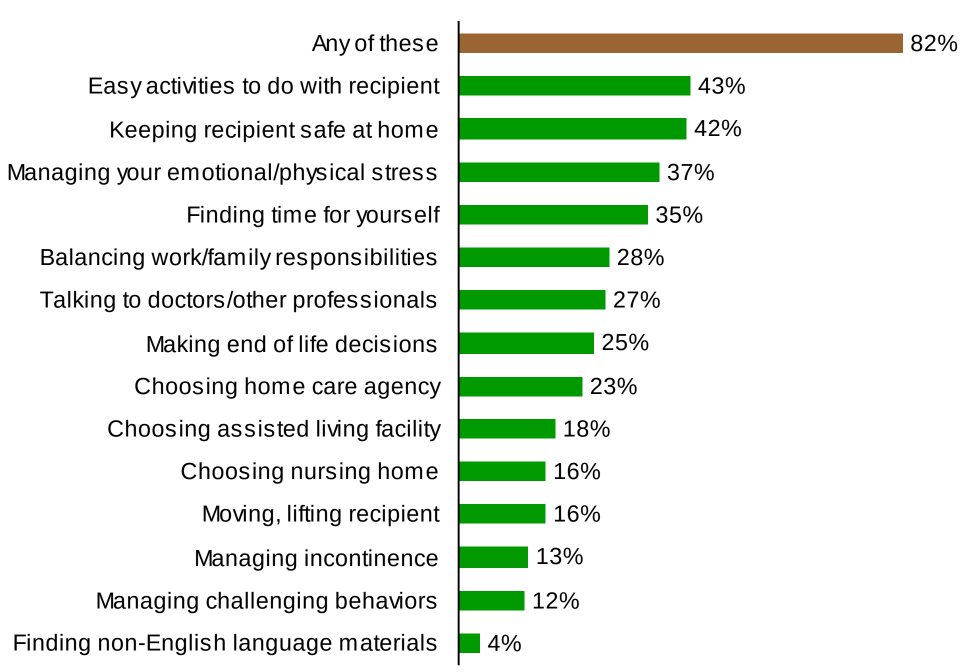
Information Needs

Eight in ten (82%) African-American caregivers feel the need for more help or information on at least one of the fourteen categories we asked about.

Figure 21: Caregiving Information Needs – African-Americans

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

Base: 2009 African-American caregivers 50+ (n=206)



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

African-American caregivers generally have the same information needs as other caregivers.

Among African-American caregivers, the top information needs are finding easy activities they can do with the person they care for (43%), keeping the person they care for safe at home (42%), and managing their own emotional and physical stress (37%).

Support for Caregivers

Supportive Services and Practices

Two-thirds (68%) of African-American caregivers say coordinating the care of the person they help is very or somewhat easy, and one-quarter (25%) say it is somewhat or very difficult to coordinate the care between various health care professionals or service providers.

There are a variety of services that could support African-American caregivers. More than half (56%) report using any of the three services we asked them about. Four in ten (41%) say they had an outside transportation service for their care recipient. One-quarter (24%) of African-American caregivers say they have requested information for financial help for their care recipient.   Few African-American caregivers report using respite services (7%).

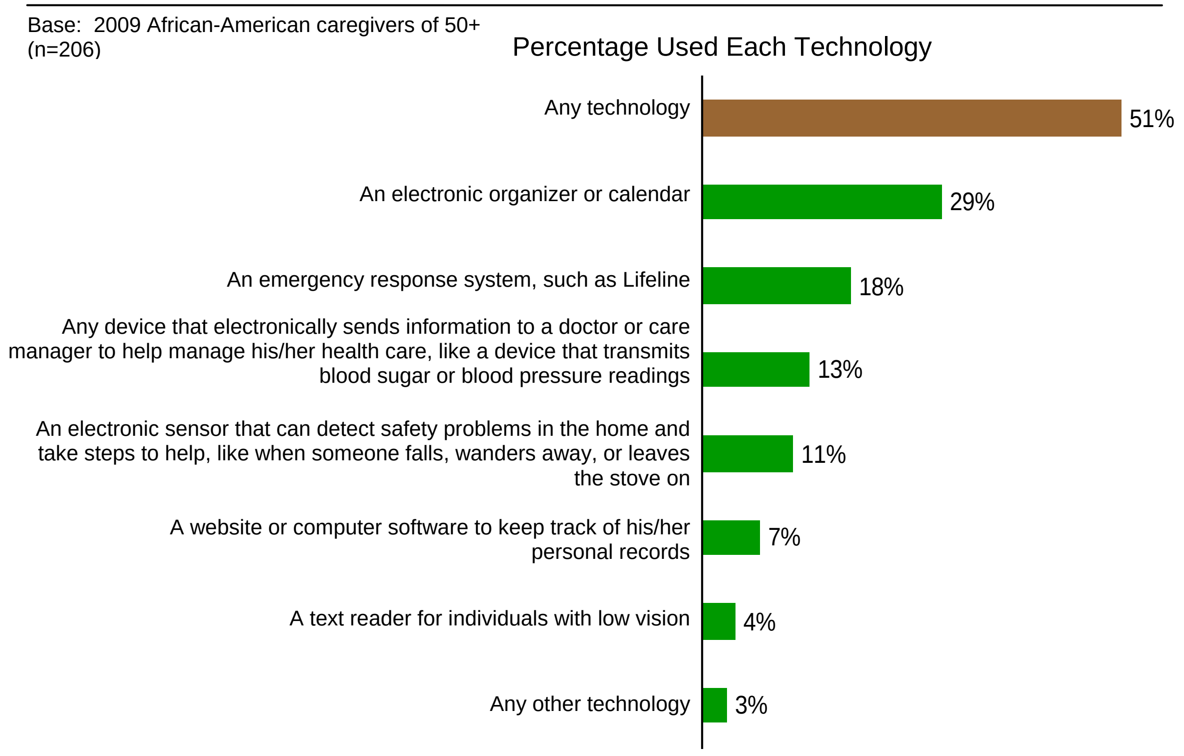
Four in ten (40%) African-American caregivers say they have had some modification made in the house or apartment where their care recipient lives. African-American caregivers are more likely than other caregivers to say they have obtained formal training of some sort about how to care for the person they help (29% vs. 16% of caregivers overall, 14% of White caregivers, and 15% of Asian-American Caregivers).

Use of Technology

Despite the numbers on Internet use, today, the use of technology is widespread. We found that half (51%) of African-American caregivers say they have ever used one of six technologies in caring for their care recipient. Almost three in ten (29%) say they have used an electronic organizer or calendar for caregiving, while almost one in five (18%) has used a device that sends information to a doctor or care manager.

Figure 22: Use of Technology in Caregiving – African-Americans

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



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

About one in ten have used an emergency response system (13%) or electronic sensors that detect safety problems in the care recipient's environment (11%).

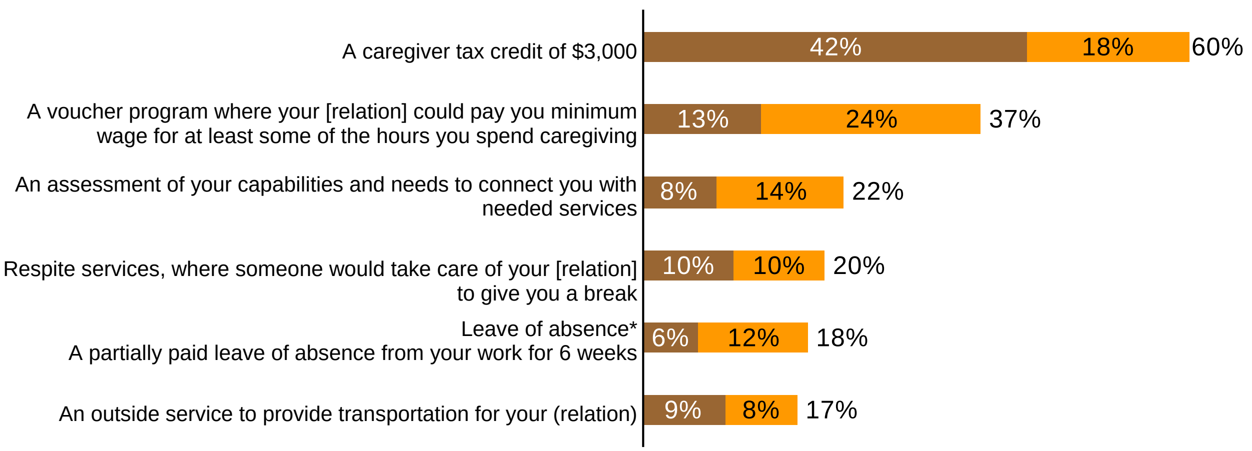
Reaction to Caregiving-Related Policy

Caregivers were asked about six potential caregiving-related policies. Six in ten (60%) African-American caregivers say the policy they would find most or second most helpful would be a caregiver tax credit of three thousand dollars. African-American caregivers are more likely to say they would find this helpful than some other caregivers (60% vs. 43% of Hispanic caregivers. More than a third (37%) selected a voucher program, where their care recipient could pay them a minimum wage for at least some of the hours they spent caregiving. African-American caregivers were more likely to support a voucher program than some other caregivers (24% of White caregivers). About one in five African-American caregivers selected respite services (20%), a needs assessment (20%), and an outside service to provide transportation for their care recipient (17%) or a partially paid leave of absence (17%).

Figure 23: Reaction to Caregiving-Related Policies – African-Americans

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 African-American caregivers of 50+ (n=206)



Source: Caregiving in the U.S. 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.

Caregiver Ethnicity: Asian-American Caregivers

Most of the findings for ethnic subgroups are descriptive. Asian-American caregivers and the people they assist are not significantly different from other caregivers or care recipients unless specifically noted.

Basics of the Caregiving Situation

The Asian-American caregivers detailed in this report are all 18 years of age and older and they provide help to someone age 50 and older. Asian-American caregivers are, on average, 45 years old.

Asian-American caregivers are a study in contrast. They are almost equally likely to be male or female. While most are married, a fair share is single, never-married. Asian-American caregivers are highly educated and have a relatively high annual income. Details about these caregivers appear below.

- Among Asian-American caregivers, almost half (48%) are male. Asian-American caregivers are more likely to be male than other caregiver groups (48% vs. 33% of caregivers overall, 33% of White caregivers and 29% of African-American caregivers).[4]
- Most Asian-American caregivers are married (58%) but a fair share, significantly more than other caregiving groups, are single never-married (29% vs. 15% of all caregivers and 12% of White caregivers).
- Asian-American caregivers 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). Asian-American caregivers are more likely to have done graduate work (32% vs. 15% of African-American caregivers and 14% of Hispanic caregivers).
- Asian-American caregivers are more likely to have an annual household income of $50,000 or more compared to caregivers in other ethnic groups (64% vs. 38% of African-American and 38% of Hispanic caregivers). Even at the highest income levels, Asian-American caregivers are more likely than other ethnic caregivers to earn $100,000 or more per year (30% vs. 15% of African-American caregivers and 10% of Hispanic caregivers).

Most Asian-American caregivers assist one person (71%). The majority provide care for a relative (93%), with more than half (52%) caring for a parent (35% care for their mother and 17% care for their father). Most of the Asian-American caregivers in this study are currently providing care (67%) while one-third (33%) provided care in the past twelve months. The average duration of care is four years.

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[4] “overall caregivers” refers to the total sample of caregivers 18 and over caring for someone 50 and older.

Care Recipient Condition

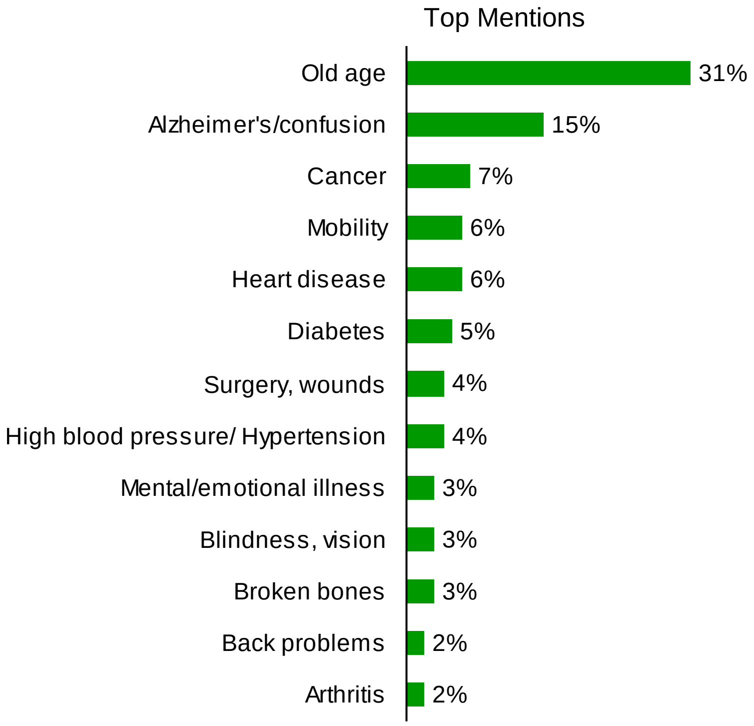
Most care recipients of Asian-American caregivers are female (72%). Their average age is 80.

Asian-American caregivers most frequently cite two problems as the main reasons why the person they assist needs care: 1) old age or aging (31%), and 2) Alzheimer's disease, confusion, dementia or forgetfulness (15%). Asian-American caregivers are more likely than caregivers overall and caregivers in all other ethnic groups to say their care recipient's main problem is old age or aging (31% vs. 15% of caregivers overall, 15% of White caregivers, 16% of Hispanic caregivers, and 13% of African American caregivers).

Figure 24: Main Problem or Illness Identified by Caregiver - Asian-Americans

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 Asian-American caregivers of 50+
(n=170)



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

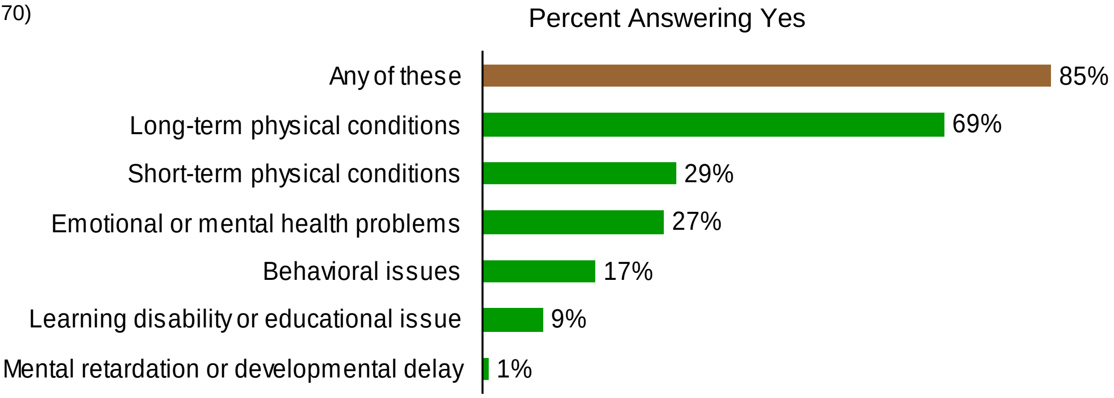
Asian-American caregivers are significantly less likely than other caregivers to say their care recipient has any of these conditions (85% vs. 95% of caregivers overall, 95% of White caregivers, 95% of African-American caregivers, and 94% of Hispanic caregivers). However, they are more likely to say their care recipient has behavioral problems (17% vs. 6% of African-American caregivers).

Most Asian-American caregivers say the person they help needs care because of long-term physical conditions (69%). Three in ten (29%) need care because of a short-term physical condition. Almost three in ten (27%) need care because of emotional or mental health issues.

Figure 25: Types of Care Recipient Conditions – Asian-Americans

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

Base: 2009 Asian-American caregivers of 50+
(n=170)



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

Caregiving Activities and Burden of Care

Hours of Care Provided

Asian-American caregivers spend an average of 13 hours in a typical week on caregiving activities. Asian-American caregivers are more likely to spend one to eight hours caregiving per week than other caregiver groups (60% of Asian-American caregivers vs. 48% of all caregivers, 42% of African-American caregivers and 36% of Hispanic caregivers).

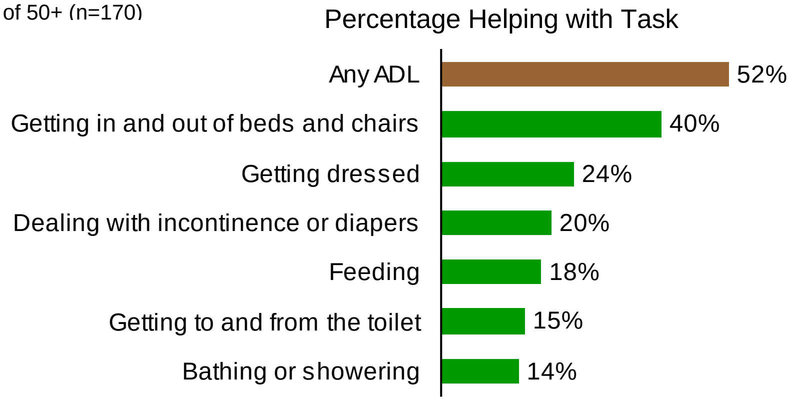
Activities of Daily Living

How do Asian-American caregivers spend their time? 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). On average, Asian-American caregivers provide care recipients help with one ADL. About one-fourth (23%) provide assistance with three or more ADLs. Almost half (48%) do not provide assistance with any ADLs.

Figure 26: Help with Activities of Daily Living (ADLs) - Asian-Americans

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 Asian-American caregivers of 50+ (n=170)



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

Among Asian-American caregivers, the most commonly reported ADLs are helping their care recipient get in and out of beds and chairs (40%), get dressed (24%), and dealing with incontinence (20%). Asian-American caregivers are less likely than other caregivers to say they help with getting to and from the toilet (15% vs. 28% of caregivers overall, 28% of White caregivers, and 30% of Hispanic caregivers). They are also less likely to say they help with bathing or showering (14% vs. 33% of African-American caregivers, 29% of Hispanic caregivers, 26% of caregivers overall, and 24% of White caregivers). Since male caregivers typically perform less hands-on care associated with ADLs, it may be possible that the larger proportion of male Asian-American caregivers helps explain these findings.

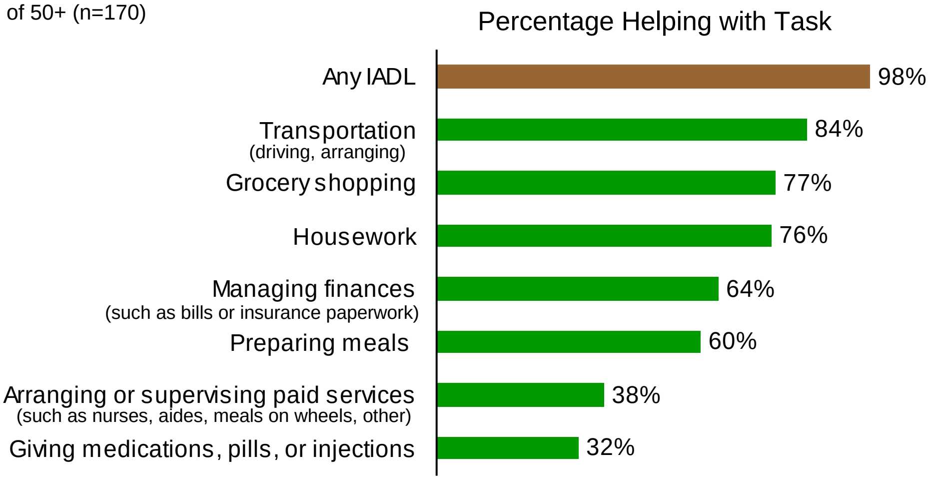
Instrumental Activities of Daily Living

All caregivers perform at least one IADL. Nearly eight in ten (78%) Asian-American caregivers help their care recipient with three or more IADLs. On average, Asian-American caregivers perform four IADLs. The most frequently reported IADLs performed by Asian-American caregivers are providing transportation (84%), doing grocery shopping (77%), and housework (76%).

Among Asian-American caregivers, half (54%) say they have advocated for their care recipient with care providers, government agencies, or schools. Three in ten (31%) say they have performed physical or medical therapies or treatments on their care recipient.

Figure 27: Help with Instrumental Activities of Daily Living (IADLs) - Asian-Americans

Base: 2009 Asian-American caregivers of 50+ (n=170)



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

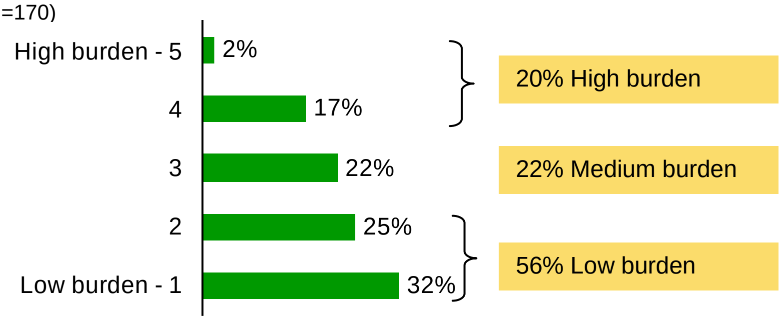
Level of Burden Index

A level of burden 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, with one being the lowest level of burden and five being the highest level of burden.

Among Asian-American caregivers, more than half (56%) are in a low burden situation, about one in five (22%) are in a medium burden situation, and another one in five (20%) are in a high burden situation.

Figure 28: Level of Burden - Asian-Americans

Base: 2009 Asian-American caregivers of 50+ (n=170)



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

Asian-American caregivers are less likely to say they are in a high burden situation than other caregiver groups (20% vs. 40% of Hispanic caregivers, 39% of African-American caregivers, 32% of caregivers overall, and 30% of White caregivers).

Presence of Other Caregivers

Unpaid Caregivers

Caregiving is often a shared responsibility. Three-fourths (73%) of Asian-American caregivers 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 Asian-American caregivers who say another unpaid caregiver provided help in the last 12 months, only a small minority (15%) say they split care equally.

One-quarter (26%) of Asian-American caregivers say they are the “sole” caregiver while nearly two in ten (17%) indicate they provide the most unpaid care among the unpaid caregivers. Collectively, we call these two groups primary caregivers. Among Asian-American caregivers, four in ten (43%) are primary caregivers. However, Asian-American caregivers are more likely to be non-primary caregivers (54% vs. 37% of African-American caregivers or 36% of Hispanic caregivers). This finding may be related to having more male Asian-American caregivers.

Paid Caregivers

Among Asian-American caregivers of people who do not live in nursing homes, almost four in ten (37%) say that during the past 12 months, the person they assist received paid help from aides, housekeepers, or other people. Among this subgroup of Asian-American caregivers, more than one-third (36%) say the paid helper provided their care recipient the most help, while one in four (23%) say they provided the most help and more than one-third (36%) say another unpaid caregiver provided the most help to their care recipient.

Care Recipient Living Situation

Where Care Recipients’ Live

Asian-American caregivers are more likely to say the person they assist lives in an urban area (46% vs. 32% of caregivers overall and 26% of White caregivers). Similar shares (45%) of Asian-American caregivers say their care recipient lives in a suburban area, and less than one in ten (9%) of Asian-American caregivers say the person they assist lives in a rural area. These results may be an artifact of the sample design.

Most Asian-American caregivers say their care recipient continues to live in their own home (54%), while one in four (25%) lives in the caregiver’s home. Few live in other settings.

Among Asian-American caregivers, almost four in ten (38%) say the person they assist lives alone, or with his or her spouse (37%), while one in five lives with his or her adult children (19%).

Excluding care recipients who live with their caregiver, another four in ten (40%) Asian-American caregivers say their care recipient lives within twenty minutes of their home.

Among Asian-American caregivers who do not live with the person they assist, almost half (47%) say they visit their care recipient more than once a week, and about one in five visit once a week (20%) or a few times a month (19%). Few (10%) visit less than once a month.

Stress and Strain of Caregiving

More than half (58%) of Asian-American caregivers describe their health as excellent or very good. Another three in ten rate their health as good (27%), and around one in seven (14%) rate their health as fair or poor. Most Asian-American caregivers (79%) say caregiving has not affected their health. About one in ten (11%) say caregiving has made their health worse.

Two-thirds (67%) of Asian-American caregivers rate the physical strain of caregiving low (rating of one or two on a five-point scale), one in five (21%) rate the physical strain of caregiving as moderate, and one in ten (11%) rate the physical strain of caregiving or high.

Almost half (48%) of Asian-American caregivers rate the emotional stress of caregiving low (one or two on a five-point scale). Three in ten (30%) indicate they have moderate stress, while about one in five (22%) rate the emotional stress as high (a rating of four or five).

Most Asian-American caregivers (77%) rate the financial hardship of caring for their care recipient low (one or two on a five-point scale). About one in ten rate the financial hardship as moderate (10%) or high (12%).

Time is an important issue for caregivers because caregiving leaves them with less time to devote to other parts of their life. This situation is further complicated when the caregiver does not feel he or she had a choice in taking on the caregiving role. More than four in ten (46%) Asian-American caregivers did not feel they had a choice in taking on their caregiving role, and six in ten (61%) feel they have less time for friends or other family members than before they became a caregiver. Furthermore, among Asian-American caregivers, one-third (34%) say they need help with finding time for themselves.

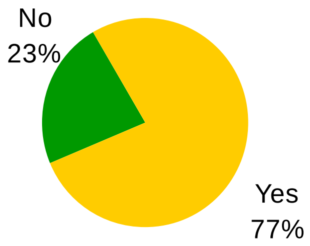
Impact of Caregiving on Work

Most Asian-American caregivers (77%) were employed while they were providing care.

Figure 29: Concurrence of Employment and Caregiving - Asian-Americans

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 Asian-American caregivers of 50+ (n=136)



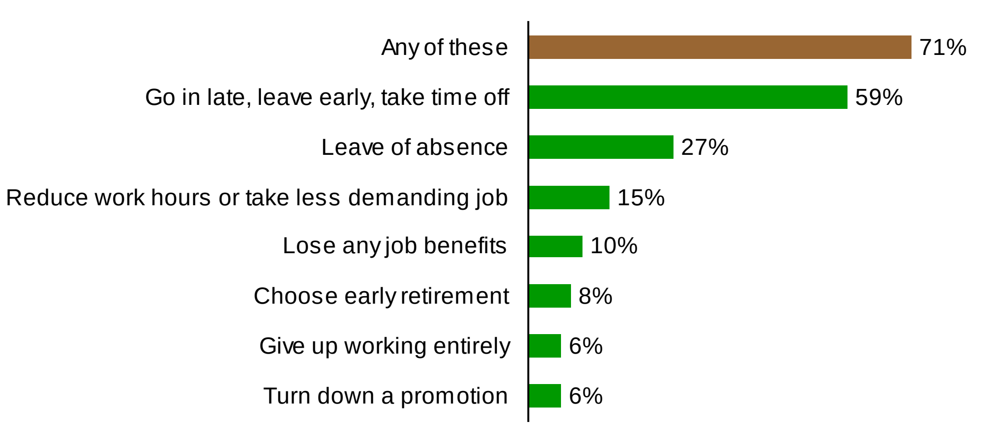
Source: Caregiving in the U.S. 2009, National Alliance for Caregiving and AARP

Among those were been employed while caregiving, most (71%) indicated they had to make a workplace accommodation due to caregiving. The most common work place accommodation is going in late, leaving early, or taking time-off during the day (59%). Furthermore, one-third (32%) of Asian-American caregivers say that as a caregiver they feel they need more help or information on balancing their work and family responsibilities.

Figure 30: Work Accommodations Due to Caregiving – Asian-Americans

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

Base: 2009 Asian-American caregivers of 50+ who worked while caregiving (134)



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

Information Sources and Needs

Sources of Information

Among Asian-American caregivers, four in ten (39%) say they would turn to the Internet or print media for caregiving information, while three in ten (29%) would turn to a health or other caregiving provider (such as a doctor, nurse, caregiving provider, hospital, social worker, hospice or mental health provider). In fact, Asian-American caregivers are more likely to turn to the Internet or print media than other caregiver groups (39% vs. 25% of caregivers overall, 24% of White caregivers, and 19% of African-American caregivers). One-quarter (26%) of Asian-American caregivers would turn to family, friends, or fellow caregivers. Fewer (11%) would turn to an aging or disease specific organization, a government program (7%), or social or community services (3%).

Figure 31: Sources Used for Caregiving Information - Asian-Americans

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

Base: 2009 Asian-American caregivers
of people 50+

	2009
Health or caregiving provider	29%
Doctor	17%
Nurse, other health professional	12%
Caregiving provider (such as a nursing home, assisted living facility, home care, senior day care)	1%
Hospital, clinic	3%
Social worker, case worker	1%
Hospice	0%
Mental health provider	0%
Internet and print media	39%
Internet	39%
Books, magazines, library	2%
Government programs	7%
Government	5%
Veteran's administration	1%
Social Security, Medicaid, Medicare	1%
Family, friends, caregivers	26%
Family, friends, colleagues, word of mouth	26%
Family caregivers, support groups, people with similar experience	1%
Aging or disease specific organizations	11%
Senior citizen's center, aging organization	9%
Disease-specific organization	4%
Social services, community services	3%
Other	15%
Church, minister	1%
Employer	0%
Insurance company	0%
School	0%
Other	15%

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

Internet Usage

Among Asian-American caregivers, six in ten (61%) 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, including four in ten who have never done this (38%). A similar share, (39%) say they have sometimes or often gone to Internet websites in the past year for such information.

Among Asian-American caregivers who have used the Internet for a caregiving-related purpose, eight in ten (78%) say they looked for information about their care recipient's condition or treatment. Half (50%) have looked for information about doctors or health professionals or services available for recipients (49%). Four in ten (43%) have searched for information on care facilities.

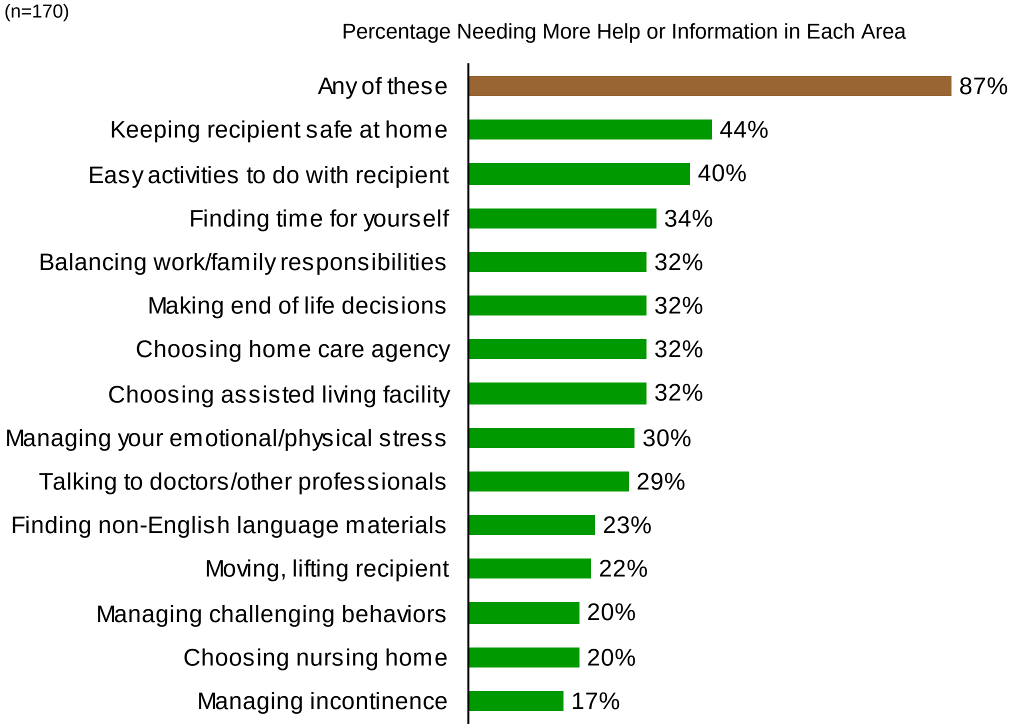
Information Needs

Almost nine in ten (87%) Asian-American caregivers say they need more help or information on at least one of the fourteen categories we asked about.

Figure 32: Caregiving Information Needs - Asian-Americans

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

Base: 2009 Asian-American caregivers of 50+ (n=170)



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

Asian-American caregivers are more likely than some caregivers to need more help for any of the fourteen information items we asked about (87% vs. 77% of caregivers overall and 75% of White caregivers). The most frequently mentioned needs include four in ten who need help or information about keeping their care recipient safe at home (44%), and easy activities to do with their care recipient (40%). One-third need help or information about finding time for themselves (34%), balancing work and family responsibilities (32%), choosing a home health care agency (32%), making end-of-life decisions (32%), and choosing an assisted living facility (32%).

Asian-American caregivers are more likely to need some types of information more than other caregivers. For example, one-third of Asian-American caregivers need assistance choosing an assisted living facility (32% vs. 21% of caregivers overall and 18% of African-American caregivers). Asian-American caregivers are more likely to need help with making end-of-life decisions (32% vs. 19% of White caregivers). Asian-American caregivers are also more likely than other caregivers to say they need help finding non-English language educational materials (23% vs. 4% of caregivers overall, 1% of White caregivers, 4% of African-American caregivers).

Support for Caregivers

Supportive Services and Practices

Among Asian-American caregivers six in ten (62%) say coordinating the care of the person they help is very or somewhat easy, while nearly three in ten (28%) say it is somewhat or very difficult.

There are a variety of services that could support Asian-American caregivers, yet less than half (46%) report using any of the three services we asked them about. One-third (34%) of Asian-American caregivers say they have used an outside transportation service for their care recipient and about one in five (21%) say they have requested information for financial help for their care recipient. Fewer Asian-American caregivers report using respite services (9%).

Four in ten (43%) Asian-American caregivers say they have had some modification made in the house or apartment where their care recipient live, and few have taken formal caregiving training (15%).

Use of Technology

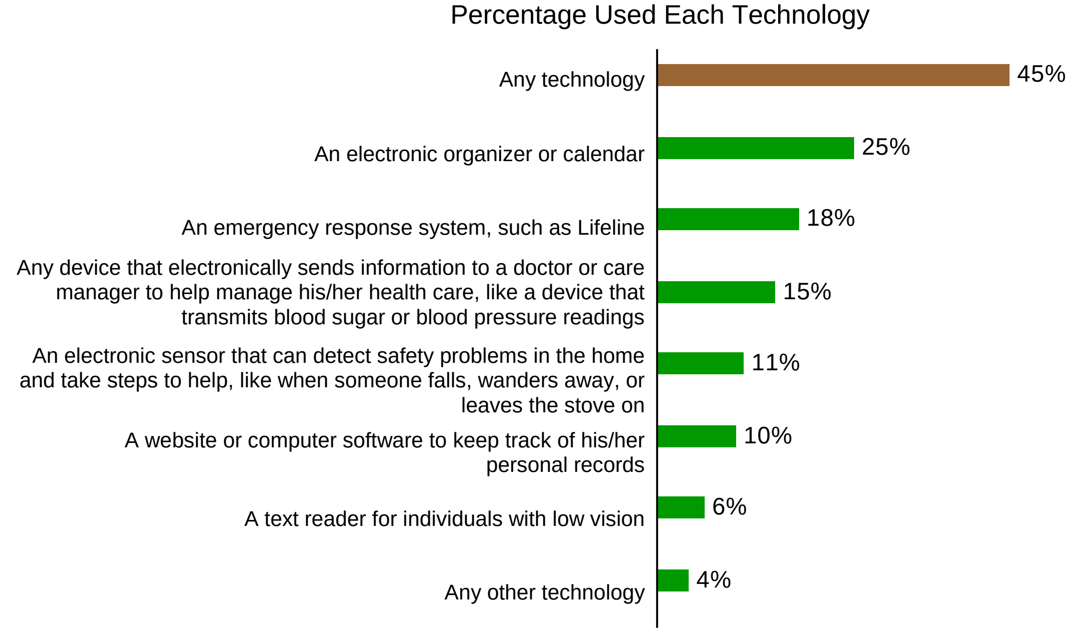
Despite the numbers on Internet use, today, the use of technology is widespread. We found that nearly half (45%) of Asian-American caregivers have ever used one of the six technologies in order to care for the person they assist.

Among Asian-American caregivers, one-quarter (25%) have used an electronic organizer or calendar for caregiving. Almost one in five (18%) have used a website or software to keep track of his or her personal health records. One in six (15%) have used an emergency response system. Approximately one in ten have used any device that electronically sends information to a doctor or other care manager (11%), or have used electronic sensors to detect safety problem in the care recipient's environment (10%).

Figure 33: Use of Technology in Caregiving – Asian-Americans

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

Base: 2009 Asian-American caregivers of 50+ (n=170)



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

Asian-American caregivers are more likely than some other caregivers to have used a website or computer software to keep track of his/her personal health records (18% vs. 7% of caregivers overall and 6% of White caregivers.

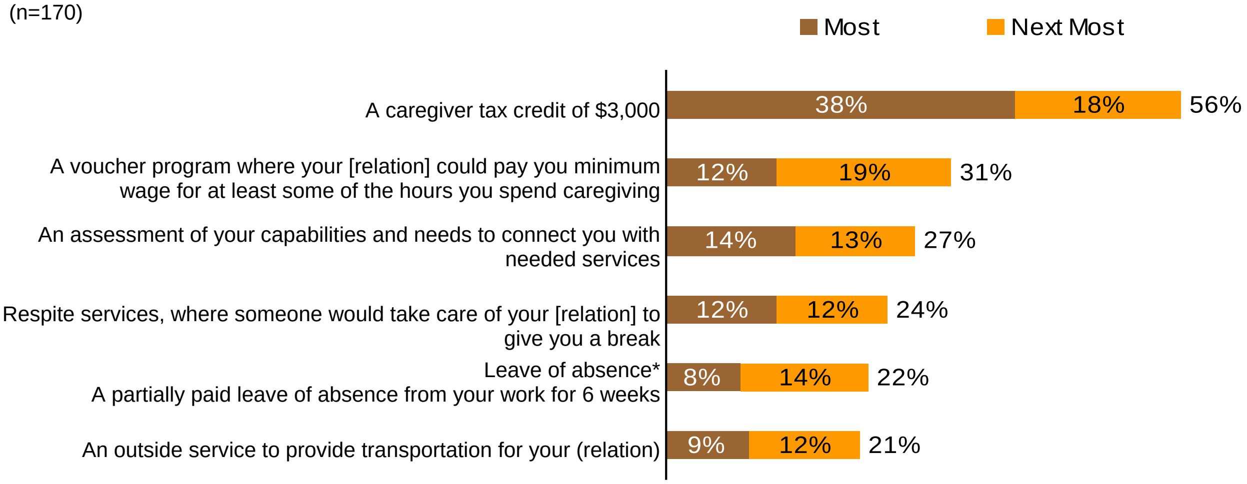
Reaction to Caregiving-Related Policy

Caregivers were asked about six potential caregiving-related policies. Among Asian-American caregivers, more than half (56%) say a tax credit of $3,000 would be the most or next most helpful policy. About three in ten selected either transportation services (31%) or respite services (27%). One in four (24%) said the voucher program, while about one in five said a partially paid leave of absence from work for six weeks (22%) or a needs assessment of their capabilities to connect them with services (21%).

Figure 34: Reaction to Caregiving-Related Policies - Asian-Americans

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 Asian-American caregivers of 50+
(n=170)



Source: Caregiving in the U.S. 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.

IV. Summary and Conclusions

Caregivers from different ethnic backgrounds share many common characteristics with all caregivers of people 50+. Yet there are important differences which make them unique. These commonalities and differences have been highlighted throughout this summary. They hold great potential for helping to tailor information, programs and services to the unique needs of these caregiver groups. For example, Hispanic and Asian caregivers are more likely than other caregiver groups to need non-English language educational materials.

Since, Hispanic caregivers are younger than White and African-American caregivers they currently need information on balancing the needs of multiple generations sharing one household. Hispanic and African-American caregivers are also more likely to have lower annual household incomes which have implications for all members of the household. Consequently, it is not surprising these caregivers support public policies such as a $3,000 tax credit and voucher programs to pay the caregiver.

Despite the numbers on Internet usage, caregivers from ethnic backgrounds are likely to use other types of technology to help them meet their needs and the needs of their care recipients. Many of these technologies are currently out-of-pocket expenses. If it can be demonstrated that these technologies improve the quality of life of caregivers and the people they assist, we should consider making them reimbursable as part of a quality health care system.

2009 Respondent Profile 18 + Caring for 50+

	Total (n=1,397) A	White (n=803) B	Black (n=206) C	Hispanic (n=200) D	Asian-American (n=170) E
Gender					
Male	33%	33%	29%	33%	48%ABCD
Female	67E	65E	71E	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	42D	39	30	36
65 to 74	9	10	8	6	7
75 or older	5D	5D	5	1	2
Mean age	*49.9D*	*51.1D*	*48.2D*	*43.1*	*45.1*
Race/Ethnicity of Caregiver					
White	76%	100%	0%	0%	0%
Black/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%C
Living with a partner	5E	5	4	12E	2
Single, never married	15	12	28AB	21	29AB
Separated, divorced	14E	14E	16	15	10
Widowed	7E	7E	8	4	2
Children/Grandchildren <Age 18 in Household					
Yes	32%	30%	30%	47%ABC	37%
No	68D	70D	70D	53	62

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

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

	Total (n=1,397) A	White (n=803) B	Black (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	23E	24E	23E	20E	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	32CD
Household Income					
Less than $50,000 (net)	39%	34%	59%ABE	56%ABE	31%
Less than $15,000	7	6	9	15B	8
$15,000 to $29,999	12	11	19	16	9
$30,000 to $49,999	19	17	31ABE	22	14
Less than $50,000, not fully specified	1	1	1	2	-
$50,000 or more (net)	55CD	60CD	38	38	64CD
$50,000 to $74,999	20	21	16	18	17
$75,000 to $99,999	13C	14C	7	9	14
$100,000 or more	20D	22D	15	10	30CD
$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	19C
Retired	17D	18D	17	8	13
Homemaker	8C	8C	2	10	8
Unemployed and looking for work	5	4	11	9	8
Disabled	5E	5E	8E	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 Profile 18+ Caring for 50+ (Continued)

	Total (n=1,397) A	White (n=803) B	Black (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	39D	41D	36	25	46D
Rural	31CDE	35CDE	13	19	10
Care Recipient Living Location					
Urban	32%B	26%	49%AB	58%AB	46%AB
Suburban	38D	40D	34	22	45D
Rural	28CDE	32CDE	15	18	9

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

Respondent Profile

Trend in Caregivers of Recipient Age 18+ Caring for 50+

	Caregivers of Recipient Age 50+	
	2004 (n=976)	2009 (n=1,397)
Gender		
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
Mean age	*47.7*	*49.9**

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

	Caregivers of Recipient Age 18+	
	2004 (n=976)	2009 (n=1,397)
Race/Ethnicity of Caregiver		
White	74%	76%
Black	11	11
Hispanic	10	10
Asian-American	4*	2
Other	---	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 18+	
	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

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"]**

	1997 (n=--)	2004 (n=976)	2009 (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.]**

	1997 (n=1509)	2004 (n=976)	2009 (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]**

	1997 (n=--)	2004 (n=4)	2009 (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?

	1997 (n=1509)	2004 (n=976)	2009 (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 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]**

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

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

	1997 (n=1509)	2004 (n=976)	2009 (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]**

	1997 (n=--)	2004 (n=976)	2009 (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]

	1997 (n=--)	2004 (n=819)	2009 (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?

	1997 (n=--)	2004 (n=684)	2009 (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/RENTS, WE WANT THE PERSON WHO PAYS THE MORTGAGE OR WHOSE NAME IS ON THE LEASE]

	1997 (n=--)	2004 (n=135)	2009 (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]**

	1997 (n=--)	2004 (n=135)	2009 (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?

	1997 (n=--)	2004 (n=135)	2009 (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 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]**

	1997 (n=--)	2004 (n=135)	2009 (n=115)
White	--	75%	66%
Black	--	15	17
Asian	--	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.

	1997 (n=--)	2004 (n=23)	2009 (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?

	1997 (n=--)	2004 (n=--)	2009 (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]**

	1997 (n=)	2004 (n=)	2009 (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

	1997 (n=1509)	2004 (n=976)	2009 (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?

	1997 (n=)	2004 (n=)	2009 (n=)
Yes			
No			
(VOL) Don't know			
(VOL) Refused			

SC18. Would you say you are White, Black or African American, Asian 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]**

	1997 (n=)	2004 (n=)	2009 (n=)
White			
Black			
Asian			
Other **[SPECIFY____]**			
(VOL) Don't know **[TERMINATE]**			
(VOL) Refused **[TERMINATE]**			

CAREGIVER RACE

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

CAREGIVER GENDER

	1997 (n=1509)	2004 (n=976)	2009 (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.

1. 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.

	1997 (n=1509)	2004 (n=976)	2009 (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}

2. 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.

3. **[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]** ....

4. **[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]** ....
(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

	1997 (n=1509)	2004 (n=976)	2009 (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]**

	1997 (n=1509)	2004 (n=976)	2009 (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 _____?**]**

	1997 (n=1509)	2004 (n=976)	2009 (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

	1997 (n=1509)	2004 (n=976)	2009 (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?

	1997 (n=--)	2004 (n=976)	2009 (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]**

	1997 (n=1509)	2004 (n=976)	2009 (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?

	1997 (n=--)	2004 (n=745)	2009 (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]**

	1997 (n=--)	2004 (n=975)	2009 (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]**

	1997 (n=1509)	2004 (n=694)	2009 (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?

	1997 (n=--)	2004 (n=976)	2009 (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?

	1997 (n=--)	2004 (n=976)	2009 (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 <u>main</u> 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?"**]**

	1997 (n=1509)	2004 (n=976)	2009 (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?

	1997 (n=1509)	2004 (n=976)	2009 (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]**

	1997 (n=1509)	2004 (n=976)	2009 (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

	1997 (n=1509)	2004 (n=976)	2009 (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	*
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

	1997 (n=1509)	2004 (n=976)	2009 (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]**

	1997 (n=1509)	2004 (n=976)	2009 (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
Mean	*23.2*	*22.0*	*18.8*

E. MEDICATIONS

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

	1997 (n=--)	2004 (n=976)	2009 (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?

	1997 (n=1423)	2004 (n=888)	2009 (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?

	1997 (n=1509)	2004 (n=976)	2009 (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?

	1997 (n=1238)	2004 (n=631)	2009 (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

	1997 (n=1509)	2004 (n=976)	2009 (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?

	1997 (n=--)	2004 (n=924)	2009 (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?

	1997 (n=--)	2004 (n=405)	2009 (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]**

	1997 (n=1509)	2004 (n=976)	2009 (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]**}?

	1997 (n=501)	2004 (n=600)	2009 (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	**1997** (n=1193)	**2004** (n=724)	**2009** (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?

	1997 (n=1502)	2004 (n=976)	2009 (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?

	1997 (n=1500)	2004 (n=976)	2009 (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?

	1997 (n=1501)	2004 (n=976)	2009 (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]**

	1997 (n=--)	2004 (n=--)	2009 (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]**?

	1997 (n=--)	2004 (n=976)	2009 (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?

	1997 (n=1509)	2004 (n=976)	2009 (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]**

	1997 (n=--)	2004 (n=976)	2009 (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%

	% Yes	**1997** (n=--)	**2004** (n=--)	**2009** (n=1397)
	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%

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%

	% Yes	**1997** (n=--)	**2004** (n=976)	**2009** (n=1397)
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?

	1997 (n=--)	2004 (n=976)	2009 (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?

	1997 (n=--)	2004 (n=976)	2009 (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]**

	1997 (n=1509)	2004 (n=976)	2009 (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**]**

	1997 (n=1509)	2004 (n=976)	2009 (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?

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

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

	1997 (n=1509)	2004 (n=976)	2009 (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]**

	1997 (n=1509)	2004 (n=976)	2009 (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?

	1997 (n=1509)	2004 (n=976)	2009 (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

	1997 (n=1509)	2004 (n=976)	2009 (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.