

CAREGIVING IN THE U.S.

National Alliance for Caregiving and AARP

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Gail Gibson Hunt, National Alliance for Caregiving
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NAC Advisory Panel

Marge Cantor, Fordham University
John Crews, DPA, Centers for Disease Control and Prevention
Pamela Doty, Ph.D., U.S. Department of Health and Human Services
Lynn Friss Feinberg, PhD, Family Caregiver Alliance
Rick Greene, Administration on Aging
Carol Levine, United Hospital Fund
Katie Maslow, The Alzheimer's Association
Skip Schlenk, AT&T (Retired)
Melissa Talamantes, University of Texas
Donna Wagner, Ph.D., Towson University
Donna Yee, Asian Community Center, Sacramento, CA

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I. Introduction

People who care for adult family members or friends fulfill an important role not only for the people they assist, but for society as a whole. While this care is unpaid, its value has been estimated at 257 billion dollars annually.¹ Although caregivers make many contributions, being a caregiver may take a personal toll.

We find the demand on caregivers' time can range from a few hours a week to 40 or more hours per week - essentially constant care. Caregivers also provide a range of activities. These activities can be relatively undemanding, such as driving the person you care for to an appointment. Or the activities can be highly demanding, such as bathing, dressing, and feeding the care recipient. Therefore, it is not surprising that some caregivers report experiencing little physical strain, emotional stress, or financial hardship as a result of providing care, while others report a far different experience.

The purpose of this study is to update and expand our knowledge about the activities caregivers say they perform, the perceived impact of caregiving on their daily lives, and the unmet needs of this population. We believe our study makes several unique contributions. For example, this is the first study to our knowledge that includes caregivers ages 18 and older who care for people ages 18 and over.

Secondly, while we asked respondents if they are caregivers, we also asked them whether or not they help the person they care for with at least one activity of daily living (such as helping another get in and out of beds or chairs, get dressed, get to and from the toilet, bathe or shower, eat, and so forth) or instrumental activity of daily living (such as helping another manage finances, shop for groceries, do housework and so forth). By using this definition of caregiving, we narrowed our focus on those people who are actively engaged in providing specific types of care.

One of the tools we adopted to understand the variety of experiences caregivers face is the Level of Burden Index.² Level of Burden is based upon an index derived from the activities of daily living (ADLs), instrumental activities of daily living (IADLs), and amount of time devoted to caregiving.

¹ Arno, P. S. Economic Value of Informal Caregiving. Annual Meeting of the American Association of Geriatric Psychiatry, Orlando, FL, February 24, 2002.

² Family Caregiving In The U.S.: Findings from a National Survey, National Alliance for Caregiving and AARP, 1997.

There are five successive levels of caregiver burden or intensity. Each level involves a higher degree of caregiving responsibility ranging from the least amount of responsibility at Level 1 to the greatest amount of responsibility at Level 5. This measure is important because Level of Burden, having a choice to take on caregiving responsibilities, and caregivers' reported health status appear to have the greatest influence on whether caregivers perceive emotional stress, physical strain, or financial hardship as a result of being a caregiver.

II. Overview of Methodology

This study is based on a national survey of 6,139 adults in the U.S., from which 1,247 caregivers were identified.³ Caregivers are defined as 18 years of age or older living in the U.S., and providing one or more ADLs or IADLs for someone 18 years of age or older. The 1,247 caregiver interviews include a total of approximately 200 African-American, 200 Hispanic, and 200 Asian-American caregivers obtained through over-sampling. Interviewing was conducted from September 5 through December 22, 2003.

The questionnaire was designed by a research team representing the National Alliance for Caregiving (NAC), AARP, Belden Russonello & Stewart, and Research / Strategy / Management. The team drew from a 1997 NAC / AARP study on caregiving, and made several revisions and additions to update and expand the survey.⁴ All interviews were conducted by telephone. Most interviews were conducted in English. A Spanish version of the interview was initially offered to non-English speaking people of Hispanic descent.

The majority of the sample was obtained by using a random digit dial technique. However, we found that the incidence of caregivers in the Hispanic and Asian ethnic sub-groups was so small that additional targeted and surname samples were used, as well as an existing representative panel, to achieve the desired sample size.⁵ At this point, we were no longer able to offer the option of conducting the interview in Spanish.

³ All respondents live in the continental U.S. Most respondents were interviewed in English. This means that caregivers drawn from the three ethnic sub-groups under-represent recent immigrants for first generation caregivers who speak little or no English.

⁴ Family Caregiving In The U.S.: Findings from a National Survey, National Alliance for Caregiving and AARP, 1997.

⁵ While the proportion of some ethnic sub-groups has been increasing in the general population, the incidence of caregivers within these sub-groups remains small and special techniques were required to reach them.

To estimate the proportion of caregivers and caregiving households in the U.S., demographic and household data were obtained from a randomly selected respondent in each household contacted. The randomly selected respondent was asked whether or not a caregiver lives in the household. For the purposes of this study, caregivers were identified by self report and by verifying that he or she assists another with at least one ADL or IADL.

The survey results are weighted by household, based on the demographic data (gender, age, race, and household type) obtained from the randomly selected respondent in each household contacted. The same weight is used to estimate caregiving households in the U.S. A population weight, created from the gender, age and race of the randomly selected respondent, is used to estimate the proportion of caregivers in the U.S. adult population.

The sampling tolerance for a sample size of 1,247 is plus or minus 2.8 percentage points at the 95% confidence level. This means that 95 times out of 100, a difference of greater or less than 2.8 percent would not have occurred by chance.

Reading this report

When reading this report, it is helpful to understand that when the percent sign (%) appears at the top of a column, the numbers add vertically; when the % appears at the left of a row, the numbers add horizontally. An asterisk (*) indicates less than one percent; a double hyphen (--) indicates zero. All figures have been rounded so all tables may not add to 100%. This is due to weighting, rounding, omission of "don't know," or "refused," and other responses. In the case of multiple response questions, percentages may add to more than 100%.

Key Findings

One of our original questions was: “How *many* caregivers are there in the U.S.?” We estimate there are 44.4 million American caregivers (21% of the adult population) age 18 and older who provide unpaid care to an adult age 18 or older.⁶ These caregivers are present in an estimated 22.9 million households (21% of U.S. households).⁷

We are aware that other studies estimate the number and/or proportion of caregivers in the U.S. and that the estimates vary from one study to another.^{8,9,10} One of the primary reasons for this variation is that different studies use different definitions of caregiving and caregivers often do not identify themselves with this role. The use of different research methods may also influence the results.

We meticulously gathered all the information we needed to make accurate estimates of our caregiver population. Full details describing how these estimates were calculated appear in Appendix A.

In addition to determining these broad population estimates, several key themes emerged from the data. Not surprisingly, we find one’s caregiving experience varies by caregiver and care recipient profiles (demographic characteristics) and by caregivers’ perceived level of burden.

Profile of caregiving

Almost seven in ten (69%) caregivers say they help one person. Nearly half (48%) of all caregivers say they provide eight hours or less of care per week and one in five (17%) say they provide more than 40 hours of care per week. The average length of caregiving is 4.3 years.

⁶ The actual numerical estimate of caregivers is 44,443,800.

⁷ The actual numerical estimate of caregiving households is 22,901,800.

⁸ AARP Caregiver Identification Study, AARP, February 2001.

⁹ Random Sample Survey of 1000 Adults, National Family Caregivers Association, Summer, 2000, www.nfcacares.org.

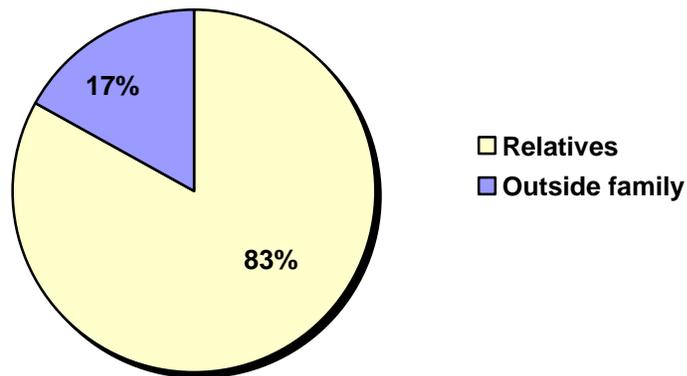
¹⁰ How Many Caregivers in the U.S.? National Family Caregivers Association, www.nfcacares.org.

Caregivers tend to live near the people they care for. Among caregivers who do not live with the person they care for, a large majority (85%) say they live within an hour of their care recipient and 74% say they visit at least once a week. One in four (24%) says the person they care for lives with them.

Many caregivers fulfill multiple roles. Most caregivers are married or living with a partner (62%), and most have worked and managed caregiving responsibilities at the same time (59%). The great majority of caregivers (83%) are helping relatives (Figure 1).

Figure 1: Relationship between Caregiver and Care Recipient

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



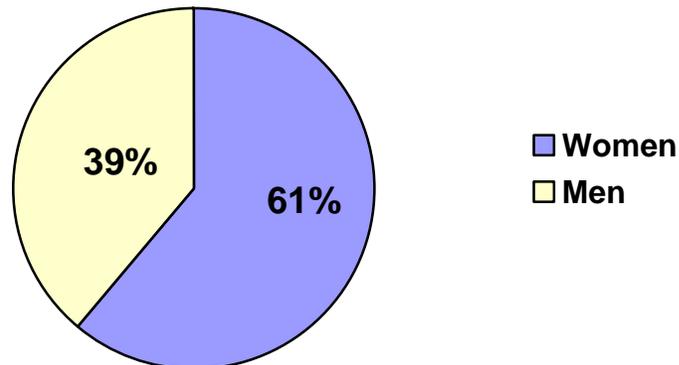
Base: 1,247 caregivers in the U.S.

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

Caregivers are often stereotyped as women taking care of women. Like most stereotypes, there is a kernel of truth at the core of this one. The typical caregiver is a 46 year old woman who has at least some college experience and provides more than 20 hours of care each week to her mother.

Although the caregiving landscape is still dominated by women helping women, the proportion of caregivers who are men is substantial. Nearly four in ten caregivers are men (Figure 2).

Figure 2: Gender of Caregivers



Base: 1,247 caregivers in the U.S.

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

Male caregivers are more likely to be working full-time (60%) than female caregivers (41%) and female caregivers are more likely to be working part-time (14%) than male caregivers (6%).

Male caregivers tend to help other men while female caregivers help fewer men (35% v 28%). That is, about one in three (35%) of male caregivers help male care recipients, whereas only 28% of female caregivers help male care recipients.

Male caregivers are more likely to be working full or part-time than female caregivers (66% v 55%).

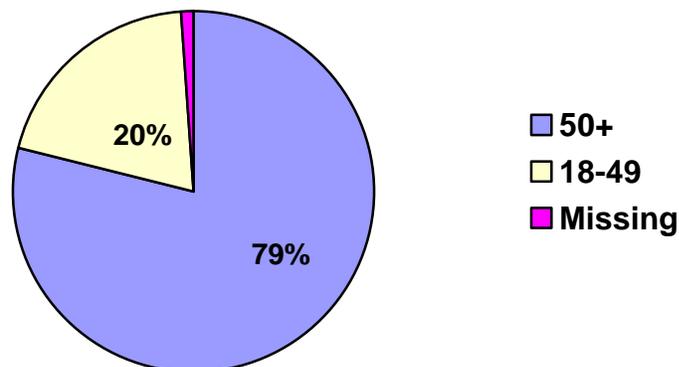
Overall, female caregivers are providing more hours of care and they are providing a higher level of care than male caregivers. For example, women spend an average of four hours more caregiving per week than men (22.9 hours for women v 18.9 hours for men). Seven in ten (71%) Level 5 caregivers are women and three in ten Level 5 caregivers are men (29%). Women and men are more evenly split at lower levels of care (58% of Level 1 caregivers are women, 42% of Level 1 caregivers are men and 55% of Level 2 caregivers are women, 45% of Level 2 caregivers are men). Women are also more likely to say they feel they did not have a choice in taking on this role than men (42% v 34%).

Given these findings, it is not surprising that women are more likely to report experiencing emotional stress as a result of caregiving than men (40% v 26% in the two more serious stress rating levels of four and five on a five point scale). Women and men report equal proportions of physical strain (16% and 13% report four or five on a five point scale) and financial hardship (13% and 11% report four or five on a five point scale).

Profile of Care Recipients

Most care recipients are female (65%) and many care recipients are widowed (42%). One in five care recipients is between the ages of 18–49 years, and nearly eight in ten care recipients is age 50 or older (Figure 3).

Figure 3: Age of Care Recipient



Base: 1,247 caregivers in the U.S.

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

More than half of care recipients live in their own home (55%).

The average age of younger care recipients (ages 18-49) is 33 years old. Caregivers who help someone between the ages of 18-49 years old say the most common main problem or illness the person they care for has is a mental illness or depression (23%). Another 5% are mentally retarded – resulting in nearly three in ten care recipients who are in need of care for non-physical reasons.

Caregivers of young adults (ages 18-49) are likely to be taking care of their own children (27%), a non-relative (25%), or a sibling (15%). Many younger care

recipients are single (45%) or divorced (16%). About one in four lives alone (26%).

The average age of care recipients 50+ is 75 years old. Caregivers who help someone age 50 or older say the main problem or illness the person they care for has is aging (15%) followed by diabetes, cancer, and heart disease. One quarter (25%) of caregivers helping someone age 50 or older reports the person they care for is suffering from Alzheimer's, dementia, or other mental confusion but less than one in ten (8%) say this is their care recipient's main problem or illness.

Caregivers of older adults (age 50+) are likely to be taking care of their mother (34%), grandmother (11%), or father (10%). Many older care recipients are widowed (52%). More than half (53%) live alone.

Most caregivers (85%) say the person they care for takes prescription medicine. This is especially the case for care recipients over age 50. Caregivers say that nine in ten care recipients (92%) age 50 or older take prescription medicine compared to six in ten (60%) of those under age 50. Slightly more than half of caregivers who say the person they care for takes prescription medicine also say their care recipient manages their prescription use well on her or his own (55%). On the other hand, 45% of caregivers of people who take prescription medicine say their care recipient needs someone to oversee or manage their medication usage.

Carrying the Load

More than one in three (37%) caregivers say no one else provided unpaid help to the person they care for during the past 12 months. Among caregivers who say someone else did help provide assistance during the past 12 months, one in three (34%) say they provide most of the unpaid care, 55% say someone else provided most of the unpaid care, and 10% say they split the care 50/50. When others provide unpaid care, the help usually comes from the care recipient's children (42% daughter, 26% son).

Using the services of paid personal helpers is less common than obtaining help from unpaid caregivers. Among caregivers who help those living outside of a nursing home, only four in ten (41%) say their care recipient received paid services from an aide or nurse, hired housekeeper, or other people who are paid to help the care recipient during the past 12 months.

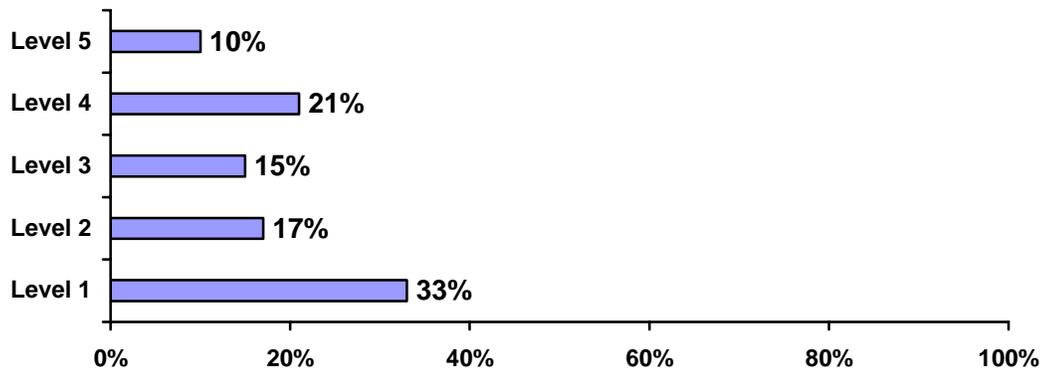
Almost half (48%) of caregivers say they asked for, or used, at least one of a variety of services we inquired about including such things as asking for information about how to get financial help for their care recipient (25%), or having an outside service provide transportation for their care recipient (18%). Conversely, slightly more than half (52%) of the caregivers say they did not ask for, or use, any of the services listed.

The use of outside services varies by where caregivers say the care recipient lives. Care recipients who live in urban areas are more likely to use any of the outside services we asked about compared to care recipients who live in suburban or rural areas (58% urban 42% suburban v 44% rural).

With regard to specific services, care recipients who live in urban areas are more likely to use a transportation service than those who live in a suburban or rural area (24% urban v 17% suburban v 13% rural). Caregivers who say the care recipient lives in an urban area are also more likely to say they have requested information about how to get financial help for their care recipient than those who have care recipients living in suburban or rural areas (33% urban v 19% suburban v 22% rural).

As noted earlier, the level of care that caregivers say they provide has an impact on the caregiver's load. Half of all caregivers (50%) age 18 and older say they provide care at the lower ranges of the Level of Burden Index (33% at Level 1 and 17% at Level 2) see Figure 4. Fifteen percent of caregivers say they are in the middle of the Index, and about three in ten say they provide care at the higher range of the Index (21% at Level 4 and 10% at Level 5).

Figure 4: Caregiver Level of Burden



Base: 1,247 caregivers in the U.S.

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

Although a minority (10%) of caregivers say they provide care at Level 5, these caregivers are involved in the most intense caregiving situations. Their intense caregiving responsibilities are no doubt complicated by the fact that these caregivers tend to be older and are more likely to say their health is only fair compared to other caregivers.

Impact on Caregivers' Lives

Most caregivers say they experience little physical strain (67% rate it a one or two on a five point scale), emotional stress (44% rate it a one or two on a five point scale), or financial hardship (77% rate it a one or two on a five point scale) as a result of being a caregiver.

However, the impact of caregiving on caregivers' lives is influenced by their reported Level of Burden. Generally, caregivers who say they provide Level 1 care are less impacted by their responsibilities than those who say they provide Level 5 care. Given the intense responsibilities faced by Level 5 caregivers, it is not surprising that this group is more likely to say they experience physical strain (46% rate it four or five on a five point scale v 3% of Level 1), emotional stress (63% rate it four or five on a five point scale v 15% of Level 1 caregivers), and financial hardship (34% Level 5 rate it four or five on a five point scale v 6% Level 1).

Our analysis shows that the two greatest predictors of caregivers' physical strain are the caregivers reported health and whether they feel they had a choice in taking on caregiving responsibilities. Caregivers who report poorer health and those that feel they did not have a choice in taking on this role perceive the greatest physical strain. Another factor which also contributes to caregivers' physical strain is Level of Burden. The higher the Level of Burden, the greater the caregivers' perceived physical strain.

Our analysis also shows that the two greatest predictors of caregivers' emotional stress are their Level of Burden and whether or not the caregiver feels they had a choice in taking on caregiving responsibilities. Caregivers at the highest Level of Burden and those that feel they had no choice perceive the highest levels of emotional stress. Other factors which contribute to caregivers' emotional stress are caregivers' reported health, living in the same household with the care recipient, and being female.

Almost half of Level 5 (49%) caregivers say they need help managing their stress, and finding time for themselves (53%). Level 5 caregivers are also more likely to say they have less time for friends and family (84% v 29% at Level 1) as well as vacations, hobbies or their own social activities (76% v 23% at Level 1). Nearly half (49%) of Level 5 caregivers say they are getting less exercise than before becoming a caregiver (compared to only 9% of Level 1 caregivers). Not surprisingly, Level 5 caregivers rate their own health lower than caregivers at other levels, and they are more likely to say that caregiving has affected their health by making it worse than caregivers at other Levels (34% for Level 5 v 8% for Level 1).

While most caregivers report they experience little financial hardship as a result of being caregivers, Level of Burden also impacts this caregiver experience. One in three Level 5 caregivers reports experiencing financial hardship (34% rate financial hardship as a four or five on a five point scale compared to 6% of Level 1 caregivers). Furthermore, Level 5 caregivers are the least likely to be employed full or part-time (43% v 63% of Level 1 caregivers), and on average, they say they spend more money on the person they care for than caregivers at other levels (\$324 per month v \$142 for Level 1 caregivers excluding care of spouses). They are also more likely to say they have asked for information on getting financial help for the person they care for than caregivers at other levels (35% v 20% of Level 1 caregivers).

Our analysis shows that the two greatest predictors of caregivers' financial hardship are Level of Burden and whether they feel they had a choice in taking on caregiving responsibilities. Caregivers at higher Levels of Burden and those who do not feel they had a choice to take on this role report greater financial hardship. Other factors contributing to financial hardship are the caregiver's age, health, and living with the care recipient. The older the caregiver, the poorer the caregiver's perceived health, and living with the care recipient increase the reported level of financial hardship.

Finally, nearly six in ten caregivers (59%) say they have worked at some time while they were actively providing care. Of these, six in ten (62%) say they had to make some work-related adjustments in order to help the person they care for. More than half (57%) of working caregivers say that as a result of their caregiving responsibilities they have had to go in (to work) late, leave early, or take time off during the day to provide care.

Caregivers' Unmet Needs

We asked caregivers if they felt they needed more help or information on fourteen items. We find two in three (67%) caregivers say they need help or information with at least one of these items. The most frequently reported unmet needs are finding time for myself (35%), managing emotional and physical stress (29%), and balancing work and family responsibilities (29%).

In addition, we asked caregivers if they used at least one of seven outside services such as how to get financial help, transportation, meals on wheels, respite, adult day care and so forth. Almost half (48%) of caregivers say they use at least one of these outside services. Among these caregivers (who already use outside services) almost eight in ten (79%) say they still need help with such things as finding time for myself, managing my emotional and physical stress, and balancing work and family responsibilities.

It is noteworthy that about three in ten caregivers say they need help keeping the person I care for safe (30%) and finding easy activities I can do with the person I care for (27%). One in five caregivers say they need help talking with doctors and other healthcare professionals (22%) or making end-of-life decisions (20%).

We asked caregivers where they would turn for information to help them with some aspect of helping to take care of the person they support. Almost three in ten say they would turn to the Internet (29%) or a doctor (28% - another 10% would turn to a nurse or other health professional). Caregivers who turn to the Internet for information are likely to look for information about health conditions and treatments (88%) or information about services available for people like they care for (55%). Caregivers with higher Levels of Burden are more likely to turn to doctors, nurses and other health professionals than people with lower Levels of Burden. For example, four in ten (42%) Level 5 caregivers turn to doctors for information compared to one in four (24%) Level 1 caregivers.

Finally, we asked caregivers about seven different ways they might cope with their caregiving responsibilities. Nine in ten (91%) caregivers say they use at least one of these methods to cope. Seven in ten (73%) caregivers say praying helps them cope with caregiving stress, six in ten (61%) caregivers say they talk with or seek advice from friends or relatives, and four in ten (44%) caregivers say they read about caregiving in books or other materials.

Caregivers in ethnic sub-groups

We over-sampled three ethnic sub-groups for this study to examine whether these groups have different caregiving experiences. The over-sampled groups are African-Americans, Hispanic and Asian Americans.

More than one in three (35%) African-American caregivers say they spend one to eight hours per week providing care. African-American caregivers are more likely to say they spend 9-20 hours a week providing care than white caregivers (31% v 21%). African-American caregivers are also more likely to say they have children less than 18 years of age living in their household than white, Hispanic or Asian caregivers (53% v 35% white, 39% Hispanic, 34% Asian). African-American caregivers are more likely to be single, never married than white or Hispanic caregivers (32% v 14% white, 23% Hispanic).

African-American caregivers are more likely to say they were working while they were a caregiver than white caregivers (68% v 56%). They are also more likely than white caregivers to say they spend \$101 - \$500 in a typical month for groceries, medicines, or other kinds of cash support for the non-spousal person they care for (36% v 22%). Therefore, it is not surprising that African-American caregivers are more likely than white, Hispanic, and Asian caregivers to say caregiving is a financial hardship (22% v 10% white, 14% Hispanic, 11% Asian caregivers reporting 4 or 5 on a 5 point scale). African-American caregivers are also more likely to ask for information on how to get financial help for the person they care for than Asian caregivers (30% v 19%).

More than eight in ten (84%) African-American caregivers say they cope with caregiving stress by praying.

Hispanic caregivers are more likely to say they live with the person they care for than white caregivers (34% v 22%) and they are also more likely to say they help the person they care for with at least one ADL than white caregivers (59% v 48%). Hispanic caregivers are more likely to say they provide Level 4 care than white caregivers (14% v 8%). Like African– American caregivers, Hispanic caregivers use praying as a method of coping with the stress of caregiving (79% v 71% white, 50% Asian caregivers).

Asian caregivers are likely to be well educated (61% have at least four years of college v 36% white, 30% of African-American, and 27% Hispanic caregivers). Asian caregivers report higher household incomes than other caregivers from other ethnic backgrounds and are more likely to say caregiving is not a financial

hardship by rating it one or two on a five point scale (77% v 66% African-American).

Caregivers by age of recipient

Almost eight in ten (79%) caregivers provide care to someone age 50 or older and two in ten (20%) caregivers provide care to someone between the ages of 18-49 years. When we look more closely at these two groups, several distinctions emerge.

Caregivers who care for someone age 50 or older tend to be helping their mothers (34%), grandmothers (11%), or fathers (10%). The average age of these care recipients is 75 years. Almost two in three (65%) of these caregivers say other unpaid helpers provide assistance. In addition, almost half (46%) of caregivers who help others age 50 and older who are not living in a nursing home say their care recipient also received some paid help within the past year.

Caregivers who care for someone between the ages of 18-49 years are more likely to say they are caring for an adult child (27%), a non-relative (25%) or a sibling (15%). The average age of these care recipients is 33 years. Less than four in ten (38%) of these caregivers say other unpaid helpers provide assistance. Less than one in four (23%) of caregivers of younger care recipients say they received some paid help within the past year. Caregivers of younger care recipients also report experiencing financial hardship as a result of being a caregiver (25% v 9% of caregivers of older care recipients age 50+) and have requested information about how to get financial help for the person they care for (35% v 22% of older care recipients age 50+).

Summary and Conclusions

It is obvious that caregiving is primarily a family issue. It is often an intergenerational family issue and most care recipients are older family members. We also find that while both women and men are caregivers, the intensity and length of the care they provide differs. Women provide more hours of care, higher levels of care and feel they have less of a choice in taking on the role compared to men. These factors increase a women's risk for emotional stress and lower quality of life.

We also find that mental illness is the main challenge for younger care recipients ages 18-49. Three in ten younger care recipients have some mental illness,

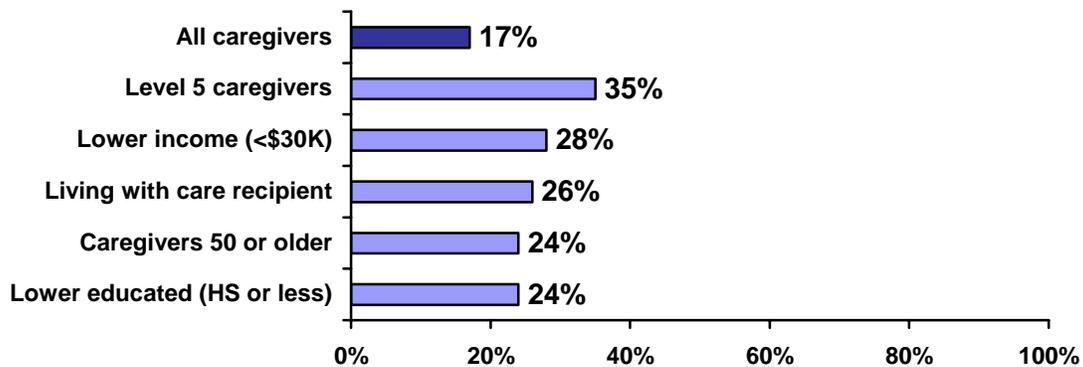
emotional illness or depression. One in four caregivers of older care recipients say the person they care for has Alzheimer's or other types of mental confusion. This finding has a variety of implications including the ability of caregivers to provide care at home over the course of the care recipients' lifetime.

We have seen that the Level of Burden, having a choice to take on the role of caregiver, and caregivers' reported health status have the greatest influence on whether caregivers perceive emotional stress, physical strain, or financial hardship as a result of being caregivers. However, socio-economic factors such as the amount caregivers spend on care recipients' needs and caregivers' lower educational attainment appear to increase caregiver risk for financial hardship for some caregivers. African-American and Hispanic caregivers appear to be more disadvantaged as a result of these factors while Asian caregivers are more protected from financial hardship as a result of having higher annual household incomes (Figure 5).

We have also identified the types of help that caregivers say they most need. If we are going to protect the health and well-being of caregivers who are at risk, it is important to help them fulfill their needs so that they do not sacrifice themselves in the service of others.

Figure 5: Fair or Poor Health Status
% of caregivers saying own health is fair or poor

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



Base: 1,247 caregivers in the U.S.

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

IV. Detailed Findings

A. Prevalence of Caregiving in the United States

Two mechanisms were used to define and identify caregivers: a screening question that probes for providing unpaid care in the past twelve months, and a series of items identifying help with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs).

The following screening question was asked of randomly-selected respondents in all households contacted, and was used as the first component in identifying the presence of a caregiver in the household:

In the last 12 months, have you or anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you. (IF YES: IS THAT YOU OR SOMEONE ELSE IN THE HOUSEHOLD?)

We asked all self-reported caregivers (those answering “yes” in the question above) about whether they provide assistance with a list of ADLs and IADLs. Respondents who did not report performing any of these activities were excluded in any analysis or estimates.

See Detailed Methodology in Appendix A for a full explanation of the procedures used for making population and household estimates.

1. Population Estimates

We estimate 21% of the U.S. population age 18 and older provides unpaid care to friends or relatives 18 and older. This translates into 44,443,800 caregivers in the U.S.

- While the prevalence of caregiving among non-Hispanic whites and African Americans is 21%, it is slightly lower among Asian-American and Hispanic populations (18% and 16% respectively) see Table 1.
- We estimate 16% of the population, or 33,861,900 adults, provide unpaid care to a recipient who is 50 or older.
- We estimate 5% of the population, or 10,581,900 adults, provide unpaid care to a recipient 18-49.

2. Household Estimates

We estimate 21% of U.S. households contain at least one caregiver, reflecting approximately 22,901,800 households (Table 2).

- The proportion of non-Hispanic white caregiving households (21% of all non-Hispanic white households) and African-American caregiving households (21% of all African-American households) reflect the overall proportion of US caregiving households. Seventeen percent each of Hispanic households and Asian-American households contain at least one caregiver.
- We estimate 17%, or 18,539,500 households in the US, contain at least one caregiver who provides care to someone age 50 or older.
- We estimate 4% of U.S. households, or 4,362,200 households contain a caregiver of someone 18-49 years old.

Table 1: Estimated Percent of Caregivers in U.S. and Within Each Ethnic/Racial Group

	Nat'l	White	Black	Hispanic	Asian
Caregivers	21%	21%	21%	16%	18%
Caregivers of 50+	16%	17%	15%	12%	15%
Caregivers of 18-49	5%	4%	6%	4%	3%
Caregiving households	21%	21%	21%	17%	17%
With caregivers helping 50+	17%	17%	15%	13%	14%
With caregivers helping 18-49	4%	4%	6%	4%	3%

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

Table 2: Estimated Number of Caregivers in U.S. and Within Each Ethnic/Racial Group¹³

	Nat'l	White	Black	Hispanic	Asian
Caregivers	44,443,800	32,337,000	5,119,900	3,734,200	1,527,500
Caregivers of 50+	33,861,900	26,177,500	3,657,100	2,800,700	1,272,900
Caregivers of 18-49	10,581,900	6,159,400	1,462,800	933,600	254,600
Caregiving households	22,901,800	16,943,400	2,816,600	1,777,700	765,500
With caregivers helping 50+	18,539,500	13,716,100	2,011,800	1,359,400	630,400
With caregivers helping 18-49	4,362,200	3,227,300	804,700	418,300	135,100

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

B. Profile of Caregivers

A typical caregiver in the U.S. is female (61%), approximately 46 years old, has at least some college experience (66%), and spends an average of twenty hours or more per week providing unpaid care to someone 50 or older (79%). A

¹³ All estimates have been rounded to the nearest 100.

majority of caregivers are married, and most have juggled work with caregiving responsibilities at some point during their role as caregiver.

1. Level of Burden

Our measure of Level of Burden is based upon an index derived from the amount of time caregivers spend per week helping his or her care recipient and the number / types of activities performed for the care recipient.¹⁴ This measure is important because we found that the greater the level of caregiver burden, or intensity, the stronger the impact caregiving has on caregivers' perceived health (regardless of age, gender, education or other factors).

The amount of time caregivers say they spend giving care ranges from less than one hour a week to more than 40 hours per week. Furthermore, they provide a variety of types of support ranging from no activities of daily living (ADL) to more than four ADLs and three to five instrumental activities of daily living (IADL). In order to measure intensity, the Level of Burden Index classified caregivers into one of five levels.

Each successive level involves a higher degree of caregiving responsibility or demand. "Level 1" caregivers perform no ADLs, and devote relatively few hours per week providing care. "Level 5" caregivers reflect those with the heaviest burden. They help with at least two ADLs and provide more than 40 hours per week of care. Table 3 shows the distribution of caregivers in this study by Level of Burden.

Table 3: Caregivers by Level of Burden Index

	Level 1	Level 2	Level 3	Level 4	Level 5
Total	33%	17	15	21	10
9+ hours per week	2%	59%	50%	100%	100%
Mean hours per week	3.5	9.8	12.0	33.1	87.2
Mean number of IADLs	3.1	4.0	4.3	5.2	5.9
Mean number of ADLs	0	.4	2.2	2.9	4.2

Base: 1,247 caregivers in the U.S.

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

Table 4 shows caregiver demographics by Level of Burden.

¹⁴ Family Caregiving in the U.S. Findings from a National Survey: National Alliance for Caregiving and AARP, 1997.

Table 4: Caregiver Demographics by Level of Burden Index

	Total	Level 1	Level 2	Level 3	Level 4	Level 5
Male	39%	42%	45%	40%	34%	29%
Female	61	58	55	60	66	71
< 35 years old	26%	25%	34%	33%	23%	12%
35-49	32	36	29	32	33	28
50-64	30	27	28	25	32	38
65 or older	13	12	9	10	12	22
White	73%	79%	73%	71%	64%	76%
Black	12	8	16	13	17	8
Hispanic	10	8	8	12	14	13
Asian	4	4	4	4	5	3
Less than h.s.	5%	3%	6%	5%	8%	9%
High school grad	29	29	30	24	28	35
Some college	27	22	24	27	32	29
Technical school	3	3	2	3	4	2
College grad	22	26	20	29	17	19
Grad school +	13	15	18	12	10	6
<\$30K	24%	20%	24%	25%	27%	34%
\$30K-\$49K	26	28	28	18	28	22
\$50K-\$99K	27	29	28	30	22	25
\$100K+	15	16	12	19	18	8
Recipient 18-49	20%	24%	24%	11%	20%	13%
Recipient 50+	79	75	75	86	79	87
Lives in HH	24%	9%	21%	14%	35%	65%
< 1 hour	61	76	66	67	54	18
1 hour +	15	15	13	18	11	17
Primary care.	57%	54%	51%	44%	67%	80%
Secondary care.	39	39	45	53	33	19
Work full-time	48%	53%	53%	48%	47%	33%
Work part-time	11	10	10	10	13	10
Not employed	41	37	37	42	40	57
Excellent health	25%	29%	26%	25%	23%	21%
Very good health	30	30	31	36	30	24
Good health	28	29	23	24	33	21
Fair health	12	8	12	12	11	24
Poor health	5	4	8	3	3	11

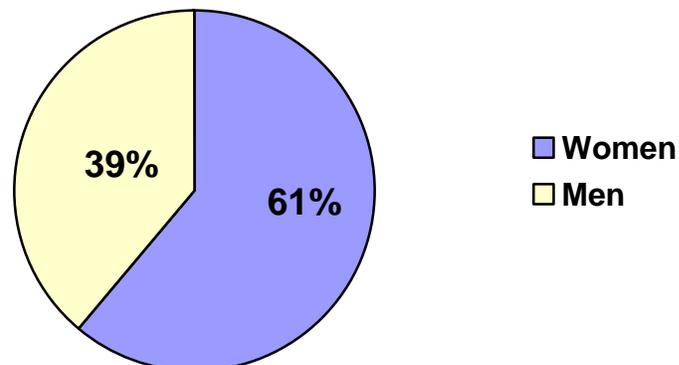
Base: 1,247 caregivers in the U.S. Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004

2. Gender

While the majority of caregivers are female, a substantial proportion of caregivers are men (Figure 6).

- Female caregivers are more likely to provide care at the highest Level of Burden (71% Level 5 v 58% Level 1). Male caregivers are more likely to provide care at the lowest Levels of Burden 42% Level 1 v 29% Level 5).
- Male caregivers are more likely to be Asian than any other ethnic background surveyed (54% v 38% white, 33% African-American, 41% Hispanic).

Figure 6: Gender of Caregivers



Base: 1,247 caregivers in the U.S.

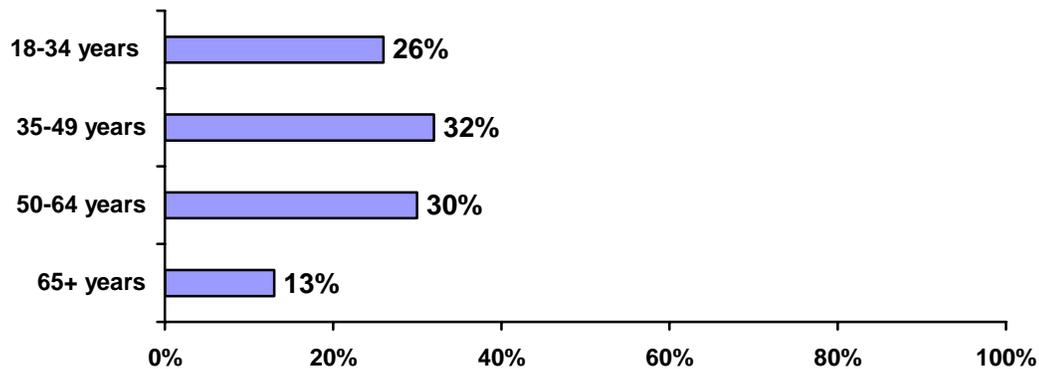
Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

3. Age

The average age of caregivers is 46. More than half of all caregivers are between the ages of 18-49 years (Figure 7).

Figure 7: Age of Caregivers

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



Base: 1,247 caregivers in the U.S.

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

- Minority caregivers are more likely to be between the ages of 18-34 than caregivers of any other ethnic group surveyed (35% African-American, 33% Hispanic, 38% Asian v 22% white). Conversely, white caregivers are more likely to be age 65+ than African-American or Asian caregivers (15% v 5% African-American, 8% Asian). This undoubtedly reflects socio-economic factors leading to a longer lifespan among the white sub-group.
- A greater proportion of Level 5 caregivers are age 50 or older compared to Level 1 caregivers (60% v 39%).
- Younger caregivers tend to provide assistance to younger care recipients. For example, caregivers 18-34 years are more likely to care for someone age 18-49 than someone age 50+ (42% v 22%). Caregivers age 50-64 and 65+ are more likely to care for someone age 50+ than someone 18-49 (32% v 19% and 13% v 9% respectively).

Table 5: Demographic Profile of Caregivers by Race

	Total	White	Black	Hispanic	Asian
Gender					
Male	39%	38%	33%	41%	54%
Female	61	62	67	59	46
Age of caregiver					
18-34	26%	22%	35%	33%	38%
35-49	32	32	36	33	27
50-64	30	31	24	24	27
65 or older	13	15	5	10	8
<i>Mean (years)</i>	<i>46 yrs</i>	<i>48 yrs</i>	<i>41 yrs</i>	<i>43 yrs</i>	<i>42 yrs</i>
Marital status					
Married/living with partner	62%	65%	44%	57%	61%
Single, never married	18	14	32	23	28
Separated/divorced	14	14	18	16	5
Widowed	6	7	6	4	3
Children in household					
Yes	37%	35%	53%	39%	34%
No	62	65	47	61	58
Educational attainment					
Less than high school	5%	4%	10%	8%	6%
High school grad	29	29	29	34	12
Some college	27	27	27	29	19
Technical school	3	3	3	2	1
College grad	22	22	22	22	36
Grad school +	13	14	8	5	25
Current employment					
Employed full-time	48%	49%	51%	41%	44%
Employed part-time	11	11	7	11	8
Not employed	41	39	41	46	48
Household income					
<\$15K	8%	7%	9%	12%	9%
\$15K-\$30K	17	16	20	20	10
\$30K-\$50K	26	25	30	28	17
\$50K-\$75K	18	17	18	21	17
\$75K-\$100K	9	9	6	8	18
\$100K+	15	16	9	9	17

Base: 1,247 caregivers in the U.S.

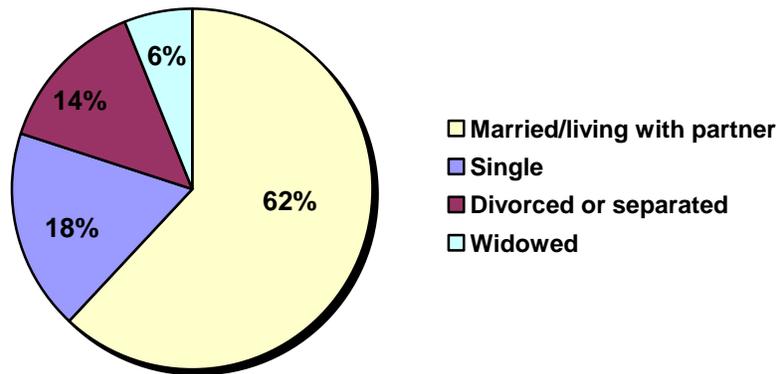
Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

4. Family Make Up

More than six in ten caregivers are married or living with a partner, nearly two in ten are single, fewer are divorced or separated, and widowed (Figure 8).

Figure 8: Marital Status of Caregivers

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



Base: 1,247 caregivers in the U.S.

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

- African-American caregivers are more likely to be single-never married than white and Hispanic caregivers (32% v 14% white, 23% Hispanic).

Thirty-seven percent of all caregivers report a child under age 18 living in the household, and:

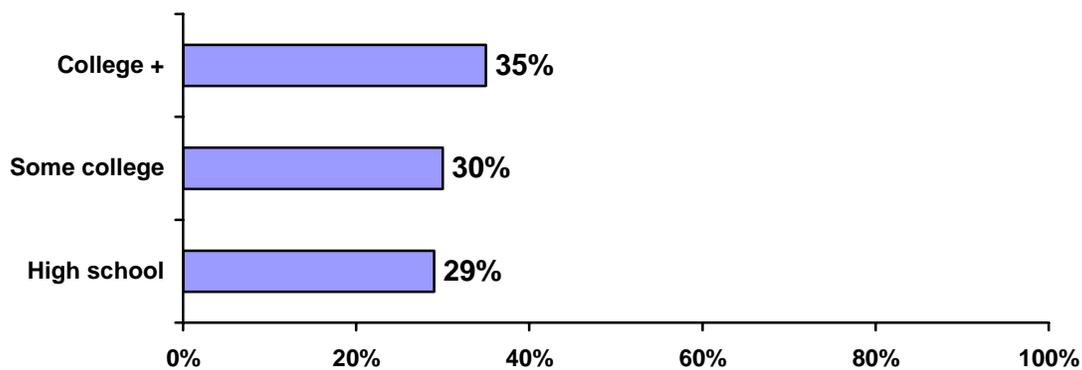
- Caregivers ages 18 to 34 (52%), and 35 to 49 (57%) are more likely to have a child under age 18 than caregivers 50-64 years (17%) or 65+ (2%);
- African-American caregivers (53%) compared to all other ethnic sub-groups (35% white, 39% Hispanic, 34% Asian);
- Those reporting excellent health (44%) compared to those who say their health is good (35%), fair / poor (34%);
- Secondary caregivers (43%) v primary caregivers (32%); Level 1 through 4 caregivers (37%, 44%, 38%, and 36% respectively) v Level 5 (26%).

5. Education

Caregiving is spread almost equally across all educational groups (Figure 9). Although we do not have exactly comparable data for the adult population, we know that less than one in five (17%) people age 18 and older say they completed the eighth or ninth grade, nearly one in three (32%) say they have completed high school, another one in five (19%) say they have some college but did not earn a degree, about eight percent say they earned an associate's degree and sixteen percent say they earned a bachelor's degree.¹⁵

Figure 9: Education of Caregivers

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



Base: 1,247 caregivers in the U.S.

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

- However, one third of the youngest caregivers (18-34 years, 33%) and oldest caregivers (65+, 35%) say the last grade of school they completed was high school.
- Caregivers who are high school graduates are more likely to say they provide 21 hours or more of care per week than 0-8 hours per week (33% v 26%). These caregivers are more likely to live in rural than urban, or suburban settings (36% rural, 26% urban, 25% suburban).

¹⁵ U.S. Census Bureau, www.census.gov/population/socdemo/education/ppl-169/tab11.txt. Table 11. Educational Attainment of People 18 Years and Over, by Metropolitan and Nonmetropolitan Residence, Age, Sex, Race, and Hispanic Origin: March 2002.

- Not surprisingly, education levels and annual household income are connected among our caregivers. Four in ten (42%) caregivers who are high school graduates report an annual household income of \$30,000 or less. More than a third (36%) of caregivers who are college graduates report an annual household income of \$100,000 or more. Three in ten (31%) caregivers who complete graduate work report an annual household income of \$100,000.
- Caregivers who completed a college degree or graduate work are more likely to live an hour or more away from the person they care for than to live near or with the person they care for. For example, among college graduates one third (33%) live one hour or more away from their care recipient compared to one in five for those that co-reside (19%) or live less than an hour away (21%). Among those with graduate work, one in five live one or more hours away (20%) compared to one in ten of those who co-reside (10%), and 13% who live less than an hour away.
- Asian-American caregivers are the most educated of the racial/ethnic groups, with six in ten (61%) having a college degree or higher. Among white caregivers, 36% have a college degree or higher compared with 30% of African-American caregivers and 27% of Hispanic caregivers.

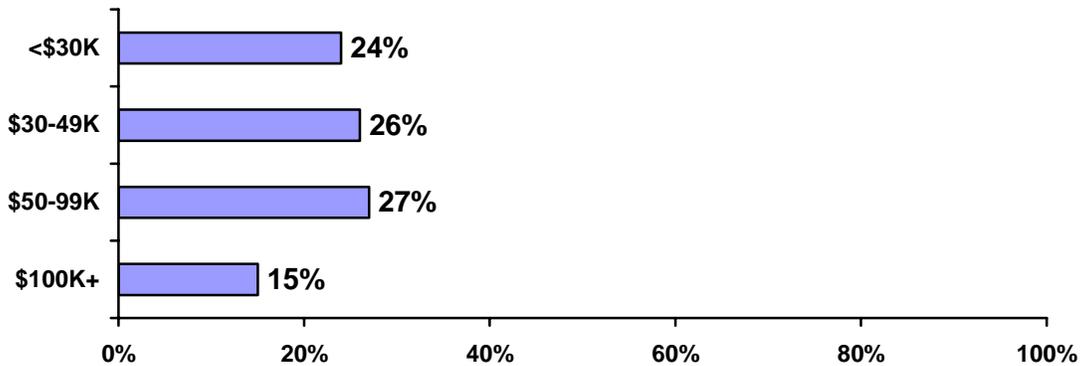
6. Income

Figure 10 shows the distribution of caregivers by reported annual household income. The median household income of caregivers is an estimated \$37,312, and among those providing care to someone 50 or older, the median income is an estimated \$38,125.¹⁶

¹⁶ The median was calculated using the mid-point of each income category (see Q95 in questionnaire) and \$125,000 for those falling into the \$100,000 or higher category.

Figure 10: Income of Caregivers

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



Base: 1,247 caregivers in the U.S.

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

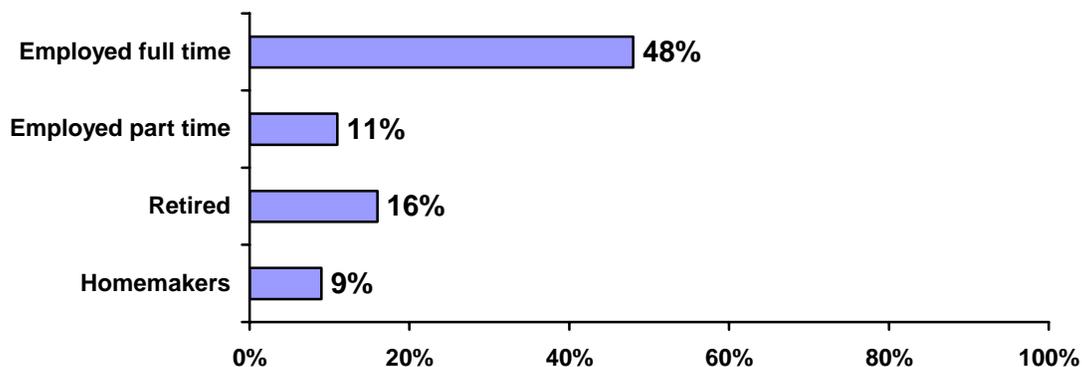
- Slightly more than half of Asian-American caregivers (53%) and four in ten white caregivers (42%) report household incomes of \$50,000 or more. Only one-third of African-American caregivers (33%) and 37% of Hispanic caregivers report the same.
- Four in ten (43%) caregivers helping someone age 50+ report an annual household income of \$50,000 or more. One in three (35%) caregivers helping someone 18-49 years reports an annual household income of \$50,000 or more.

7. Employment Status

Nearly six in ten caregivers are currently employed (59%). Some are employed full-time and some are employed part-time. Those currently unemployed are most likely to be retired or homemakers (Figure 11).

Figure 11: Employment Status of Caregivers

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



Base: 1,247 caregivers in the U.S.

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

- Male caregivers are more likely to be employed full-time than female caregivers (60% v 41%).
- Caregivers between the ages of 35-49 are more likely to be working full-time than caregivers 18-34 years, 50-64 years or 65+ (64% 35-49 years, 52% 18-34 years, 48% 50-64 years 3% 65+).
- Caregivers of those under age 50 are more likely to be working full or part-time than those caring for someone over age 50 (66% v 57%).
- Caregivers who live more than an hour away from those they care for are much more likely to be working full-time than caregivers who live with the person they care for (63% v 39%).

- Caregivers with the heaviest caregiving responsibility are less likely to be employed and more likely to be retired than caregivers with less caregiving responsibility. For example, one in three Level 5 caregivers is employed full-time compared to almost half or more at other Levels of Burden (33% Level 5 v 53% Level 1, 53% Level 2, 48% Level 3, 47% Level 4). Close to three in ten (27%) Level 5 caregivers are retired compared much smaller proportions of caregivers at the other Levels of Burden (15% Level 1, 14% Level 2, 11% Level 3, 15% Level 4).

Table 6: Employment Status by Age and Other Characteristics

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

	Employed full time
Total	48%
Male	60%
Female	41%
White	49%
African American	51%
Hispanic	41%
Asian American	44%
18-34	52%
35-49	64%
50-64	48%
65 or older	3%
Recipient age 18-49	54%
Recipient age 50+	47%
Recipient lives in household	39%
< 1 hour away	48%
1 hour + away	63%
Level 1 caregivers	53%
Level 5 caregivers	33%

Base: 1,247 caregivers in the U.S.

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

8. Military Status

While only 14% of caregivers report having served on active duty in the armed forces, 33% of male caregivers report having served. No significant differences emerge across racial/ethnic subgroups. Almost one in five (17%) care recipients served in the U.S. armed forces. One in five (19%) care recipients who served in the U.S. armed forces is age 50 or older.

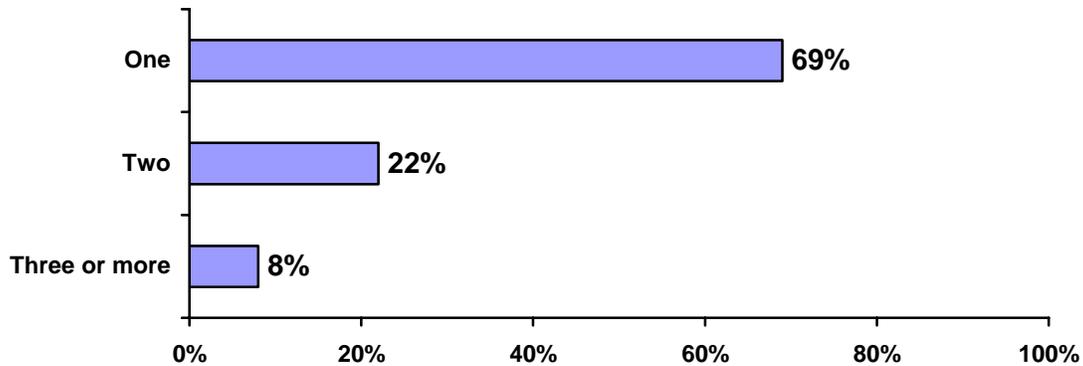
C. Characteristics of Caregiving Situation

1. Number of Recipients

While most caregivers say they care for one person, two in ten caregivers say they care for two people. Few caregivers say they help three or more people (Figure 12).¹⁷

Figure 12: Number of Care Recipients

Q1. How many adults [do you provide this care for? / did you provide this care for in the past 12 months?]



Base: 1,247 caregivers in the U.S.

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

- Older caregivers are more likely to say they provide care for one person compared to younger caregivers. For example, more than eight in ten

¹⁷ Interviewers asked those who provide care to more than one recipient to answer all questions based on the recipient for whom he/she provides the *most* care.

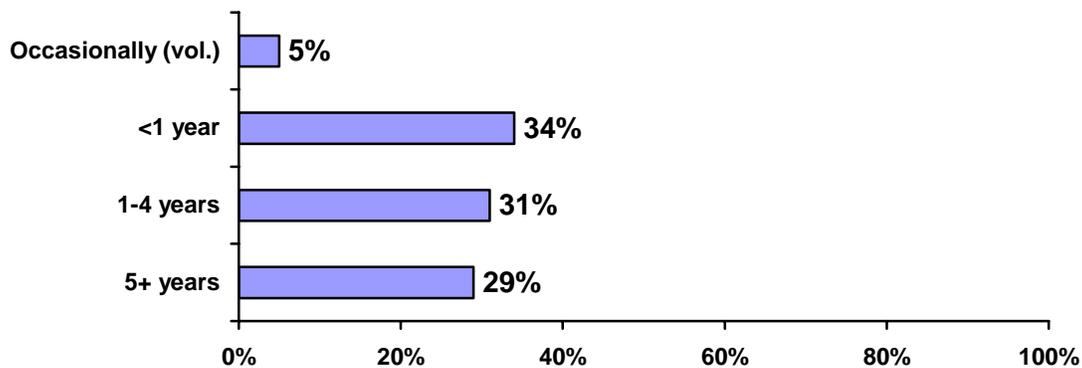
(83%) caregivers' age 65+ care for one person compared to caregivers 18-34 years (62%), 35-49 years (68%) or 50-64 years (71%).

2. Duration of Care

The average duration of caregiving is 4.3 years. About three in ten caregivers say they have provided care for more than five years, another three in ten say they have provided care for one to five years. One-third say they have cared for the recipient for less than one year and fewer say they have been providing care “occasionally” (Figure 13).

Figure 13: Duration of Care for Recipient

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



Base: 1,247 caregivers in the U.S.

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

- Older caregivers are more likely to say they have been providing care for 10 years or more compared to younger caregivers (17% of caregivers 50-64 years and 18% of caregivers 65+ v to 9% of caregivers 18-34 years). These older caregivers tend to be caring for parents and spouses.
- Conversely, younger caregivers are more likely to say they have been providing care for less than six months compared to older caregivers (22% of caregivers 18-34 years v 13% of caregivers 50-64 years and 11% of caregivers 65+).

D. Recipients of Care

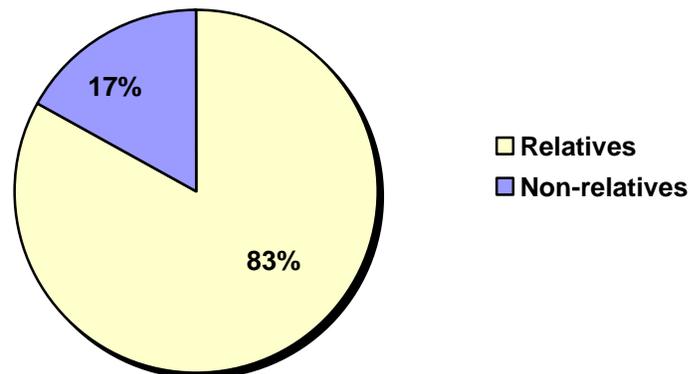
The typical care recipient in the U.S. is female, widowed, and approximately 66 years old. Most are cared for by a relative. The majority of recipients either live in the same household as the caregiver or less than an hour away.

1. Relationship between Caregiver and Recipient

More than eight in ten caregivers say they provide care for relatives. Fewer say they provide care to friends or non-family members (Figure 14). Mothers are the most frequently cared for family member (28%).

Figure 14: Relationship between Caregiver and Care Recipient

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



Base: 1,247 caregivers in the U.S.

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

- Caregivers at higher levels of burden are more likely to say they help a family member than caregivers at lower levels of burden (89% of Level 5 caregivers help a family member v 76% of Level 1 caregivers).
- Looking at caregivers across age categories, we find middle aged and late middle aged caregivers say they are more likely to be caring for their mother than the youngest and oldest caregivers (33% age 35-49 and 35% age 50-64 v 21% age 18-34 and 16% age 65+). Older caregivers are more

likely to say they are caring for a spouse than caregivers at other ages (22% 65+ years v 1% ages 18-34, 3% ages 35-49, and 8% ages 50-64).

- African-American caregivers are more likely to say they help an aunt or uncle than whites or Hispanics (11% v 4% and 3%). Asians and Whites are more likely to say they provide care for a father than African-Americans (13% and 9% v 4%).
- Caregivers who say the person they care for is under age 50 tend to be parents or siblings of the recipient, whereas caregivers who say they help someone age 50+ tend to be the son or daughter of the recipient (Table 7).

Table 7: Care Recipient by Age (Top Mentions)

1b. What [is/was] this person's relationship to you?

	Total	Recipients 50+	Recipients 18-49
Relatives (Net)	83%	85%	74%
Mother	28%	34%	7%
Grandmother	9	11	*
Father	8	10	3
Mother in law	7	8	1
Spouse	6	6	6
Sibling	5	4	20
Daughter/Son	6	1	27
Non-relative (Net)	17	14	25

Base: 1,247 caregivers in the U.S.

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

2. Care Recipient Demographics

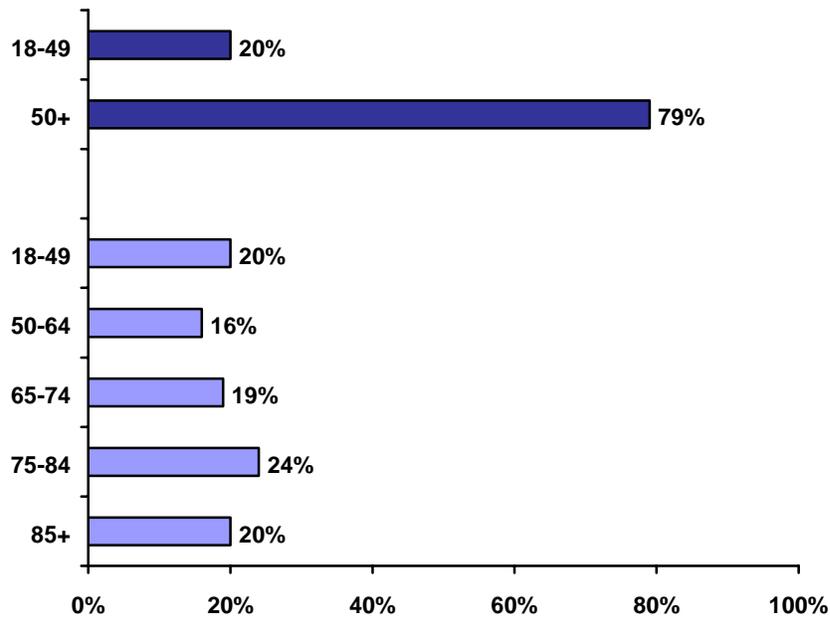
Almost two-thirds of care recipients are female (65%), and three in ten are men (31%). There is a tendency to become the caregiver of someone who is the same gender as the care recipient.

- Female caregivers are slightly more likely than male caregivers to care for women (68% v 60%), and male caregivers more than female caregivers tend to care for men (35% v 28%).
- Caregivers 65 or older tend to be helping men more often than younger caregivers (42% v 28% of caregivers 18-34) – whereas many caregivers under 65 are helping women (*e.g.*, 67% of caregivers 18-34).

A typical care recipient is female (65%) and widowed (42%). Twenty percent of care recipients are 18 to 49, 16% are 50 to 64, 19% are 65 to 74, 24% are 75 to 84, and 20% are 85 or older (Figure 15).

Figure 15: Age of Care Recipient

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



Base: 1,247 caregivers in the U.S.

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

- The average age of recipients 18 to 49 years old is 33, whereas for those 50 or older, the average age is 75.
- African-American caregivers are more likely to be helping a recipient under 50, than white caregivers (27% compared to 21%).

A plurality of care recipients are widowed (42%), while 27% are still married, 14% single, and 15% divorced or separated.

- African-American caregivers more than others care for recipients who are single (31%).

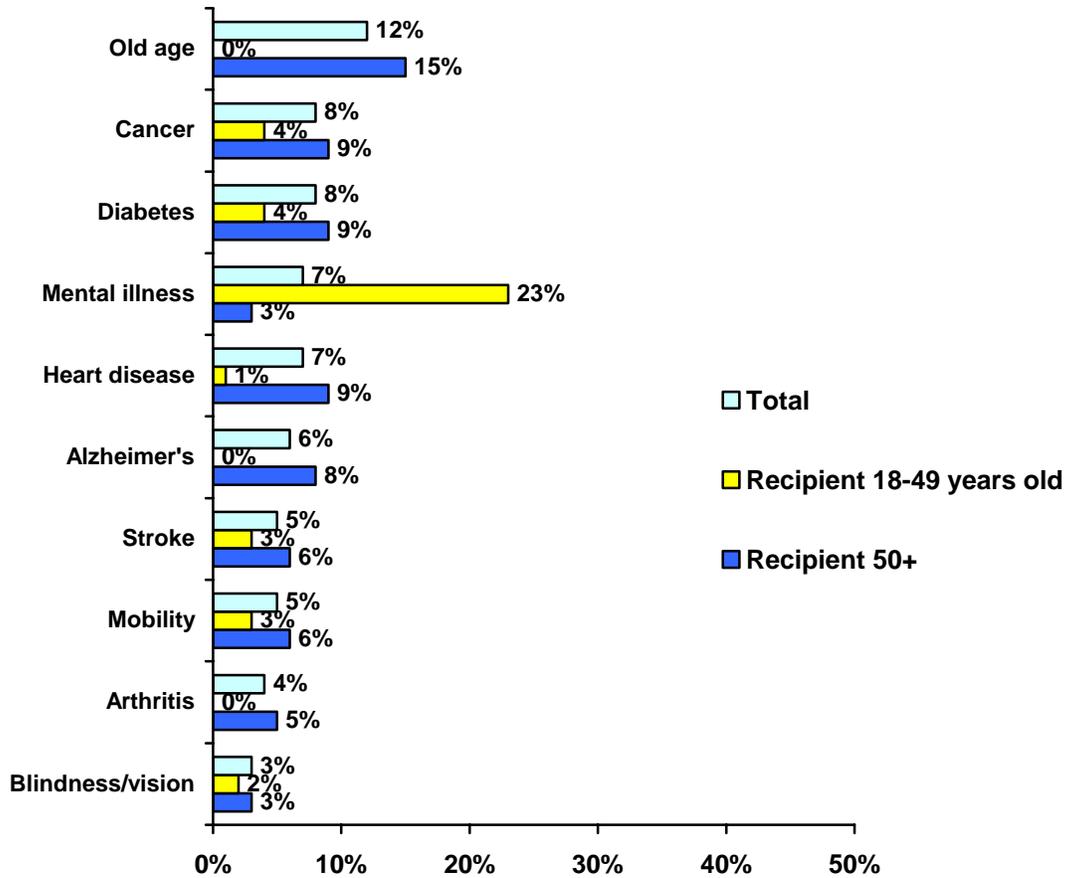
3. Health of Care Recipient

a. Main problem or illness of care recipient

The incidence of primary illness or problem reported by caregivers varies by age. Among caregivers who say they help someone under age 50, the most commonly reported problem is mental or emotional illness. Among caregivers who say they help someone age 50+, aging or being old is the most commonly reported problem (Figure 16).

Figure 16: Main Problems or Illnesses Identified by Caregiver

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



Base: 1,247 caregivers in the U.S.

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

- Asian-American caregivers are more likely to say old age or being old is the main illness or problem the person they care for has compared to White, African-American, and Hispanic caregivers (23% v 12%, 10%, 9%).
- Hispanic caregivers are more likely to report diabetes as a main illness the person they care for has compared to White or Asian caregivers (14% v 7%, 7%).
- Level 4 caregivers are more likely to say they are caring for someone who has cancer than Level 1, 2, or 3 caregivers (14% v 4%, 7%, 6%). Level 5 caregivers are also more likely to say they are caring for someone who has

cancer compared to Level 1, 2, or 3 caregivers (15% v 4%, 7%, 6%). Level 5 caregivers are also more likely to say they are caring for someone who had a stroke than Level 1, 2, and 3 caregivers (14% v 3%, 4%, 5%).

- Level 1, 2, and 3 caregivers are more likely to report old age or being old as their care recipient's main problem compared to Level 4 and 5 caregivers (18%, 13%, 15% v 6%, 5%).

When we asked caregivers an open-ended question about the main problem or illness the person they care for has, only six percent of caregivers say it is Alzheimer's or dementia. However, we asked caregivers who did not identify Alzheimer's or dementia a closed-ended follow-up question which specifically asked whether the person they care for has Alzheimer's or other mental confusion. An additional 17% of caregivers say yes to this question. Taken together, 23% of caregivers report providing care to someone with Alzheimer's, dementia, or other mental confusion.

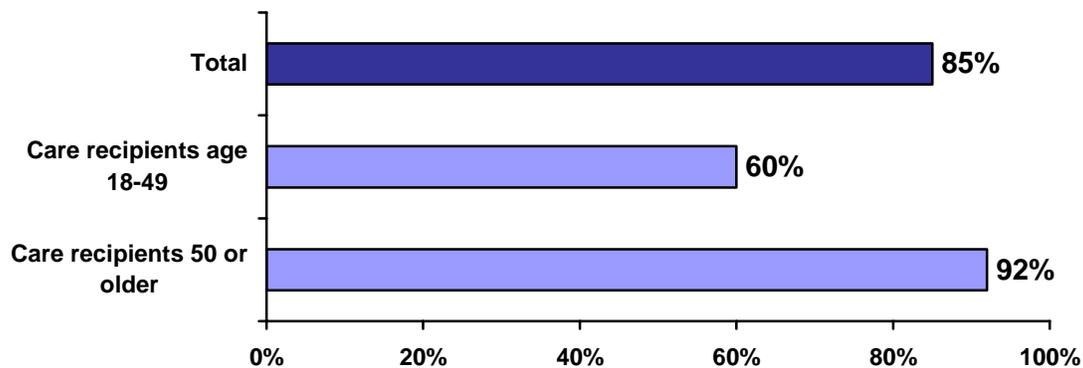
- Caregivers who say they care for someone who has Alzheimer's, dementia or other confusion provide more than 20 hours of care per week (29%) and are Level 3, 4, and 5 caregivers (36%, 26%, and 32% respectively).

b. Medication management

Most caregivers say the person they care for takes prescription medicine. Older care recipients are more likely to take prescription medicine than younger care recipients (Figure 17.)

Figure 17: Percentage of Care Recipients Taking Medication

Q28. [Does/Did] your (__) take any prescription medicine?



Base: 1,247 caregivers in the U.S.

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

Female caregivers are more likely to say the person they take care of uses prescription medications than male caregivers (87% v 82%). Caregivers who assist older care recipients are more likely to say the care recipient uses prescription medications than caregivers who assist younger care recipients (92% of care recipients 50+ v 60% of care recipients ages 18-49).

Of caregivers whose recipient takes prescription medicine, 45% say the person they care for needs someone to oversee or manage taking medicine, while 55% say the person they care for manages on their own.

- Caregivers who assist those with Alzheimer's or dementia say the person they care for needs help with their prescription medications (75% v 34%).
- The greater the caregiver Level of Burden, the more likely the caregiver is to say the person they take care of needs help with their prescription medications such as taking the right amount on time. This is especially

the case for Level 5 compared to caregivers at other levels (75% v 24% at Level 1, 37% at Level 2, 52% at Level 3, and 59% at Level 4).

Three in four (76%) caregivers who care for someone who takes prescription medicine feel that they know as much as they need to know about the prescription medicine their care recipient takes.

- However, African-American and Hispanic caregivers are more likely than white caregivers to say they need to know more about the prescription medicines their care recipient takes (28% and 29% v 20%).
- Secondary caregivers are more likely than primary caregivers to say they need to know more about the prescription medicines their care recipient takes (26% v. 18%).
- Caregivers who spend relatively little time with their care recipient are more likely than those who spend more time with their care recipient to feel a need to know more about the prescription medicines their care recipient takes (27% of those spending less than nine hours per week v 17% of those spending nine or more hours).

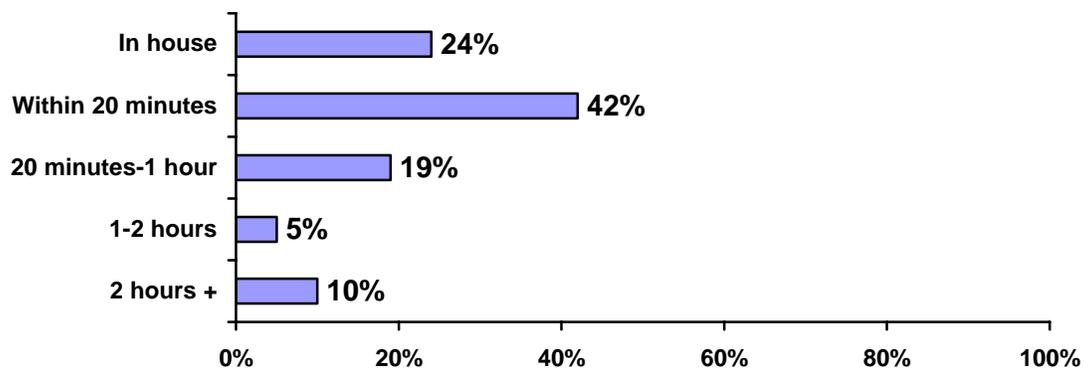
4. Living arrangements

Three in ten (29%) caregivers say they live in an urban area or rural area, and nearly four in ten (39%) caregivers say they live in a suburban area.

Most caregivers live in close proximity to the person they provide care. One-quarter of caregivers report the recipient living in their household, four in ten say they live within 20 minutes of the recipient, two in ten live between twenty minutes and one hour away, and few are a one to two hour drive or more away (Figure 18).

Figure 18: Distance of Caregiver to Recipient

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



Base: 1,247 caregivers in the U.S.

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

Caregivers who tend to live with the recipient (24% overall) include:

- Level 5 caregivers (65% v 9% Level 1, 21% Level 2, 14% Level 3, 35% Level 4);
- Older caregivers (44% of 65+ v 16% 18-34 years, 18% 35-49 years, 29% 50-64 years);
- Caregivers whose own health is only fair or poor (36% v 18% who rate health excellent);
- Primary caregivers (35% v 9% secondary caregivers);
- Hispanics (34% v 22% white);
- Those who help younger recipients (33% of 18-49 v 22% 50+);

- Those who are not employed while caregiving (33% v 22% employed); and
- Lower income (27% less than \$30,000 v 18% of \$100,000).

Long-distance caregivers, *i.e.*, those who live more than one hour away (15% overall), tend to be:

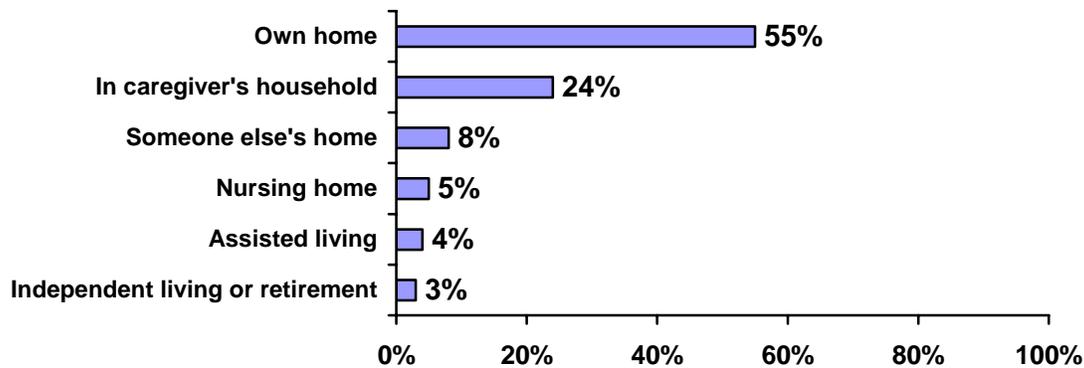
- College educated (23%);
- Upper income (19% of those earning \$100,000+);
- Secondary caregivers (22% v 11% primary);
- Those in excellent health (19%); and
- Age 35-49 and 50-64 (18% and 15% respectively).

Overall, one-third (33%) of care recipients live in an urban setting, more than a third (38%) live in a suburb, and about one in four (27%) live in a rural area.

More than half of care recipients live in their own home. One in four care recipients lives with their caregiver and fewer live in other settings (Figure 19).

Figure 19: Living Arrangements of Care Recipient

Q6. IF NOT IN HOUSEHOLD, DK, OR REF IN Q4: [Does/Did] your (__) live in: his or her own home, someone else's home, an independent living or retirement community, in an assisted living facility where some care may be provided, a nursing home or facility, somewhere else?



Base: 1,247 caregivers in the U.S.

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

- Care recipients who live in a nursing home are more likely to be older (8% age 50+ v 1% age 18-49) and to live in an urban setting rather than in the suburbs (10% v 4%). Care recipients who live in an assisted living facility

are more likely to have an older caregiver (8% age 50-64 and 12% 65+ v 3% age 18-34).

E. Intensity of Caregiving: Hours of Care Provided and Activities Performed

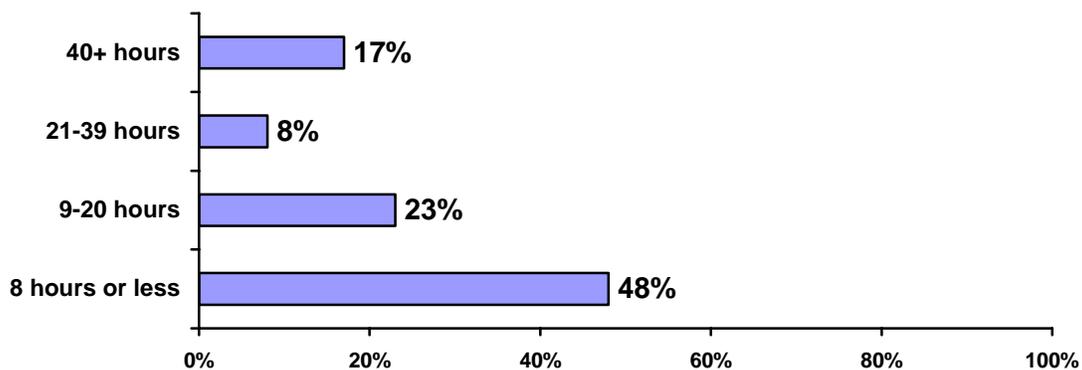
The intensity of the caregiving experience varies in terms of the amount of time spent giving care and the kinds of care provided. More than half of caregivers visit their recipient at least once a week, and a majority of caregivers perform three or more IADLs. While assisting with ADLs is less common, fully half of caregivers help with these tasks.

1. Hours of Care and Frequency of Visits

Almost half of caregivers report spending more than eight hours per week helping the relative or friend for whom they provide care. Almost one in four spend nine to 20 hours per week providing care; a minority spend 21 to 39 hours per week, and almost one in five report providing 40 or more hours or “constant care” (Figure 20).

Figure 20: Hours of Care Provided Per Week

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



Base: 1,247 caregivers in the U.S.

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

- There is no significant difference in the average (mean) number of hours caregivers spend providing care by race.

Caregivers who provide 40 hours or more per week (17% overall) tend to be:

- Living with the care recipient (44% v 7% living less than an hour away, 16% one hour or more away);
- In fair or poor health (29% v 16% excellent health, 15% very good health);
- 65 or older (28% v 11% 18-34, 15% 35-49);
- Caring for someone with Alzheimer's or dementia (24% v 16%);
- Lower income (23% of those earning less than \$30,000 v 16% \$30,000-49,000, 15% \$50,000-99,000, 12% \$100,000); and
- Less well educated (21% of those with a high school education or less v 12% college graduate).

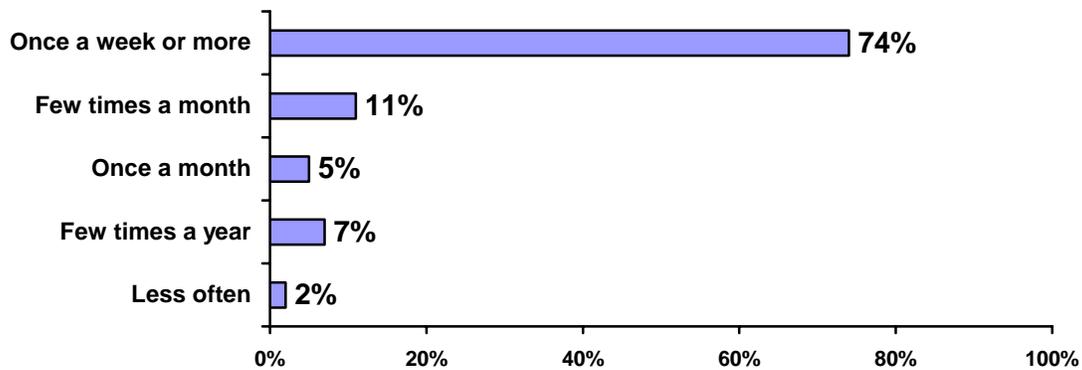
Those spending eight hours or less per week (48% overall) include:

- Male caregivers (54% v 44% women);
- Employed caregivers (52% v 39% not employed); and
- White (51%) and Asian-American (48%) caregivers.

Nearly three in four caregivers who do not co-reside with the person they care for, say they visit one or more times each week. One in ten say they visit a few times a month, and few say they only visit about once per month or less (Figure 21).

Figure 21: Number of Visits to Care Recipient

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



Base: 924 caregivers in the U.S. not living with care recipient.

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

Among caregivers who do not co-reside with the person they care for, more than half (56%) say they visit more than once a week. These caregivers can be described as:

- Level 4 (82%) and Level 5 (72%) caregivers (v 45% Level 1);
- Those in fair or poor health (72% v 48% in excellent health, or 55% in very good health);
- African-American caregivers (65%) more than white (55%) or Asian (44%) caregivers; Hispanics fall in the middle (54%);
- Lower income (65% of those earning less than \$30,000 v 48% \$50,000-99,000, 53% \$100,000+);
- Those living less than an hour away (65% v 16% one hour or more);
- Primary caregivers (63% v 49% secondary caregivers);
- Those not employed while providing care (63% v 53% employed);
- Less well educated (62% of those without a college degree v 45% with a college degree); and
- Caregivers in urban areas (61% v 50% suburban).

2. Activities Performed

a. Instrumental Activities of Daily Living (IADLs): Managing Everyday Living

Number of IADLs. Because of the way we defined caregiving, our caregivers seldom perform only one or two tasks for the person they help. To qualify as a caregiver in this study, a person must perform at least one IADL or ADL. Using this definition, 100% of caregivers report performing at least one IADL for their care recipients, and fully 80% of caregivers provide help with three or more IADLs (Table 8). Across demographic subgroups, we find that caregivers who perform three or more IADLs are likely to:

- live with the person they care for (95% v 73% less than one hour away, 84% one hour or more away),
- report fair or poor health (89% v 76% excellent health, 80% very good health);
- be African-American (88% v 78% of white, 79% of Asian-American, and 82% of Hispanic caregivers); and
- be female (83% v 76% male).

**Table 8: Performance of ADLs & IADLs:
Total and by Level 1, Level 4, and Level 5 Caregivers**

Q14-Q19. 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 ()...Q20-Q26. [Do/Did] you provide help for your () with:

	Total	Level 1¹⁸	Level 4	Level 5
IADLs				
Transportation	82%	73%	90%	95%
Grocery shopping	75%	65%	85%	94%
Housework	69%	47%	85%	94%
Managing finances	64%	60%	72%	76%
Preparing meals	59%	32%	79%	97%
Giving medicines	41%	13%	65%	85%
Arranging services	30%	16%	45%	51%
<i>Three or more IADLs</i>	80%	63%	93%	100%
<i>None of these IADLs</i>	*	--	--	--
ADLs				
In/out of bed and chairs	36%	--	67%	83%
Dressing	29%	--	61%	88%
Bathing	26%	--	51%	83%
Toileting	23%	--	47%	68%
Feeding	18%	--	30%	44%
Continence/diapers	16%	--	29%	53%
<i>Three or more ADLs</i>	26%	--	53%	84%
<i>None of these ADLs</i>	50%	100%	9%	--

Base: 1,247 caregivers in the U.S.

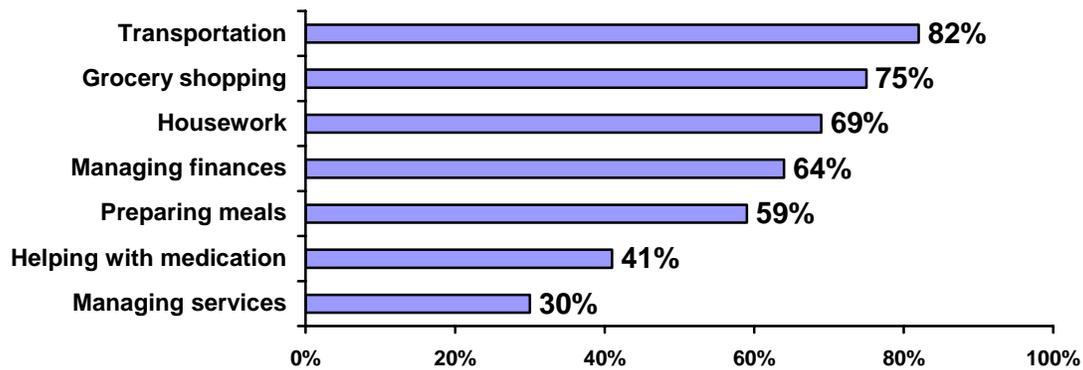
Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

¹⁸ By definition, Level 1 caregivers perform one or more IADLs, but no ADLs. See Detailed Methodology for a full description of the Level of Burden Index.

Types of IADLs. Caregivers most frequently report arranging transportation (either by driving the care recipient, or helping to get transportation), grocery shopping, housework (such as doing dishes, laundry, or straightening up), and managing finances such as paying bills, or filling out insurance claims (Figure 22).

Figure 22: Helping with IADLs
% saying yes

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



Base: 1,247 caregivers in the U.S.

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

- Few gender differences emerge among types of IADLs, with the exception that women are more likely than men to help with housework (72% v 64%) and preparing meals (62% v 53%).
- A higher proportion of African-American and Hispanic caregivers assist with giving medicines (48% and 46%) than white (39%) or Asian-American (32%) caregivers.
- Younger caregivers are more likely to help with housework and less likely than their older counterparts to arrange outside services. For example, eight in ten (79%) of those 18-34 years say they help with housework (v 69% 35-49 years, 64% 50-64 years, 58% 65+). Younger caregivers are less likely to arrange outside services than their counterparts (18% 18-34 v 31% 35-49, 37% 50-64, 32% 65+).

- Younger caregivers are also less likely to help manage finances such as paying bills or filling out insurance claims (54% 18-34 v 68% 35-49, 67% 50-64, 69% 65+).

Income and education relate to the types of IADLs performed, due in part perhaps to the fact that higher income and upper-educated caregivers live farther away from recipients than other caregivers.

- Lower income and less educated caregivers tend to provide more help than their counterparts with every day practical tasks such as grocery shopping, housework, and help with preparing meals.
- Those with higher incomes and more education tend to help with arranging outside services from agencies. Upper income caregivers are also more likely than those with less income to assist with managing finances.

b. Activities of Daily Living (ADLs): Personal Care

Number of ADLs. Half of all caregivers (50%) perform the difficult tasks involved in assisting with ADLs.

Those most likely to help with at least one ADL include:

- Caregivers providing more than eight hours of help per week (81% of 21+ hours and 54% of 9-20 hours, whereas only 33% of those who give less than nine hours per week perform at least one ADL);
- Those who provide care to recipients with Alzheimer's or dementia (62% v 47%);
- Caregivers living with the recipient (*e.g.*, 61% v 46% of those who live less than an hour away); and
- Caregivers whose recipient is 50 or older (55% v 33% of those caring for 18-49 year olds).

One-quarter of caregivers (26%) provides assistance with three or more ADLs. Many of the same subgroups of caregivers as above are more likely to provide three or more ADLs:

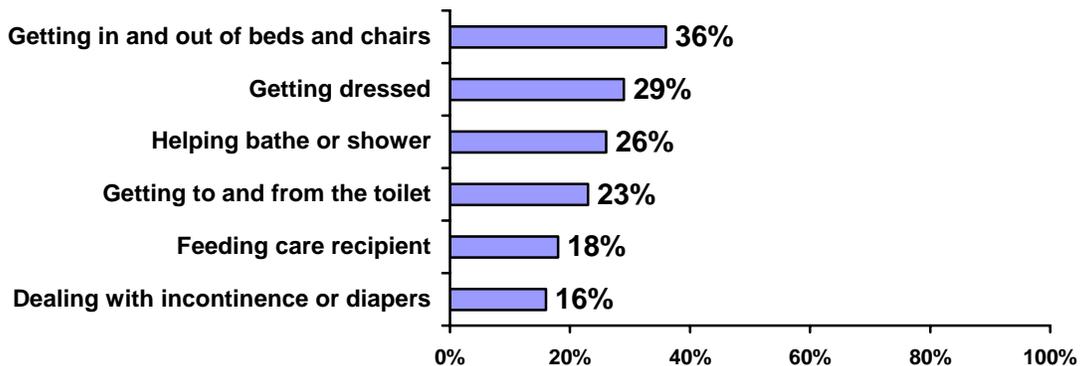
- Level 4 (53%) and Level 5 (84%) caregivers (v 36% Level 3);
- Those devoting more than 20 hours per week of care (55% v 11% for those providing 0-8 hours per week);
- Caregivers living with the recipient (36% v 20% of those living with one hour);

- Those helping someone with Alzheimer's, dementia, or other confusion (36% v 23% not helping someone with Alzheimer's, or other confusion);
- More likely to say they use outside resources (34% v 18%)
- Women (28% v 22% men).

Types of care. The most commonly performed ADLs are helping the care recipient to get in and out of bed and chairs, to get dressed, and with personal grooming (Figure 23).

Figure 23: Helping with ADLs
% saying yes

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



Base: 1,247 caregivers in the U.S.

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

- Female caregivers are more likely than males to help with the personal activities of getting dressed (33% v 24% respectively), bathing or showering (30% v. 20%), and dealing with incontinence or diapers (18% v 13%).
- The same is true for older versus younger caregivers when it comes to bathing or showering (29% 65+ v 17% of 18-34 caregivers) and dealing with incontinence or diapers (18% 50-64 years v 10% 18-34 years).
- Older care recipients age 50+ are more likely to need help with each ADL than younger care recipients' age 18-49 years.

While half of caregivers provide assistance with ADLs, less than two in ten (18%) have received some sort of formal training about how to care for the recipient.

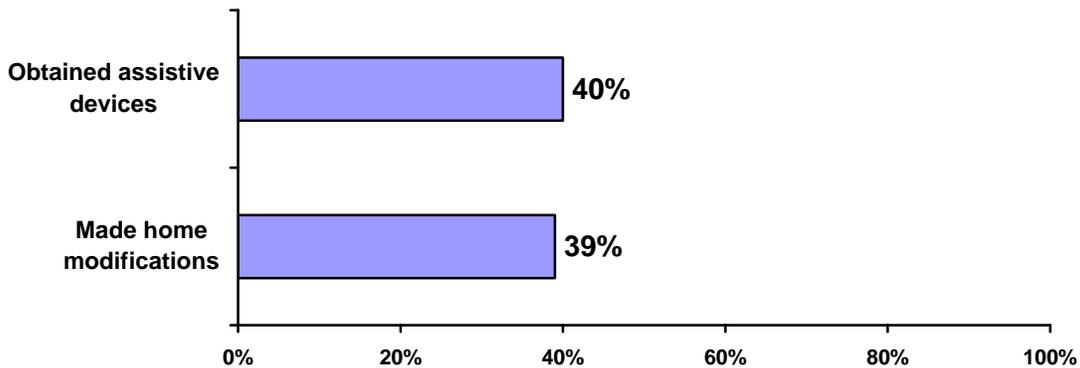
- However, more than one in three (37%) Level 5 caregivers report having some training. They are more likely to report getting training than their counterparts (8% Level 1, 13% Level 2, 23% Level 3, 26% Level 4).
- African-American caregivers (25%) are more likely to report having formal training than Asian-American (15%), white (17%) caregivers.

3. Home Modifications and Assistive Devices

Modifying the home and obtaining assistive devices are two things which can make giving care easier for the caregiver and make life safer for the care recipient. Nearly equal proportions of caregivers say they have modified the home or apartment where the care recipient lives or have obtained assistive devices, such as a bathing bench, for the recipient (Figure 24). Making changes in the home appears related to having the financial resources, or being driven by serious need.

Figure 24: Home Modifications and Assistive Devices
% saying yes

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



Base: 1,247 caregivers in the U.S.

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

- Level 3 - 5 caregivers are more likely to have obtained assistive devices such as a bathing bench or magnifying lens for reading than Level 1 caregivers (52% Level 3, 55% Level 4, 58% Level 5 v 23% Level 1).
- Level 3 - 5 caregivers are also more likely to have made home modifications than Level 1 or Level 2 caregivers (47% Level 3, 53% Level 4, 58% Level 5 v 24% Level 1, 32% Level 2)
- Caregivers helping someone with Alzheimer's or dementia are also more likely than others to have made home modifications (51% v 35%) or obtained assistive devices (46% v 38%) than their counterparts.
- Upper-income caregivers are more likely than others to say they have had modifications made to their care recipients' homes (49% of those making \$100,000+ v 35% of those earning less than \$30,000, 38% \$30,000-49,000 or \$50,000-99,000).

F. Caregiver Support

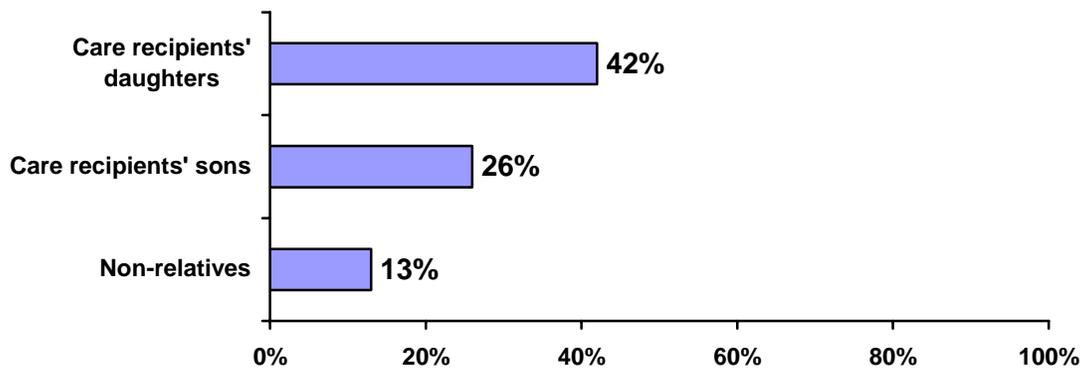
While caregivers shoulder most of the unpaid help for their recipients, many do receive other unpaid help, typically from the recipient's children. Paid help is more common among caregivers in higher income brackets and among those carrying the heaviest burdens.

1. Unpaid Help

Nearly six in ten caregivers (59%) report that someone else has provided unpaid care in the past 12 months. The majority of this care comes from the recipient's children (Figure 25).

Figure 25: Other Unpaid Help Provided By

Q31. Has anyone else provided unpaid help to your (__) during the last 12 months?



Base: 742 caregivers in the U.S. who report other unpaid help.

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

- African-American caregivers are significantly more likely to receive help from the recipient's niece or nephew (12%), than other subgroups (4% of white, 4% of Asian, and 2% of Hispanic caregivers).
- Care recipients under age 50 are more likely to receive additional unpaid support from mothers (35% v 2%), other friends or neighbors (27% v 9%), sisters (12% v 4%), and other relatives (11% v 1%).

- Care recipients age 50 and older are more likely to receive additional unpaid support from daughters (47% v 7%) and sons (29% v 2%)

Although many caregivers receive some level of help from others, the majority say they assume the role as a primary caregiver. Fifty-seven percent of caregivers act as primary caregivers – that is, either they receive no other unpaid help or they consider themselves to provide *most* of the unpaid help.

The following subgroups are more likely than their counterparts to act as primary caregivers:

- Female (60% v 53% male);
- Living with the care recipient (84% v 51% less than one hour away, 39% one hour or more away);
- Level 4 (67%) or Level 5 (80%) caregivers (v 54% Level 1, 51% Level 2, 44% Level 3);
- Older (66% 50-64 or 74% of 65+ v 46% 18-34, 52% 35-49);
- Caring for someone under 50 (70% v 54% 50+);
- Report fair or poor health (69% v 54% excellent health, 55% very good health);
- Not employed while providing care (68% v 54% employed);
- Less educated (62% of those with high school or less v 49% with college degree);
- Less income (64% of less than \$30,000 v 53% \$50,000-99,000, 52% \$100,000+); and
- Provide 21+ hours of help (75% v 47% 0-8 hours, 60% 9-20 hours); and
- Live in urban areas (64% v 54% suburb, 56% rural).

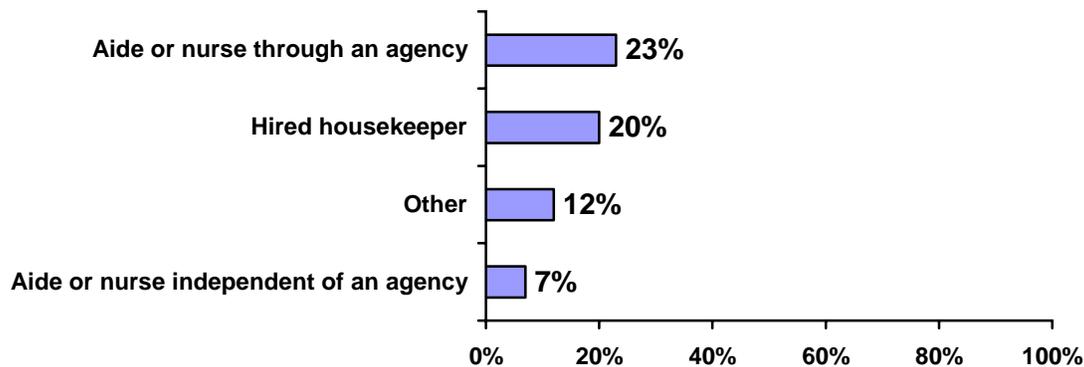
2. Paid Help

Caregivers who help care recipients who do not live in a nursing home were asked about the types of paid care the recipient may have received in the past year. Among these caregivers four in ten report using paid care through an aide or nurse, a housekeeper, or other paid helpers.

The most commonly reported help is an aide or nurse through an agency or a hired housekeeper (Figure 26).

Figure 26: Type of Paid Care

Q34-36. IF NOT IN NURSING HOME: During the past 12 months, did your () receive paid help from any of the following – regardless of who paid for it. First:



Base: 1,191 caregivers in the U.S. not living in a nursing home.

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

Among caregivers whose care recipient does not live in a nursing home, we find that those who are most likely to report the use of any paid help include:

- Upper income (56% of those earning \$100,000+ v 37% less than \$30,000, 34% \$30,000-49,000, 43% \$50,000-99,000);
- Level 3 (54%), Level 4 (53%), and Level 5 (50%) caregivers v 30% Level 1 or 37% Level 2;
- Older caregivers (43% 50-64 and 50% of 65+ v 35% 18-34);
- College educated (51% v 34% high school or less and 37% some college);
- Those caring for someone with Alzheimer’s or dementia (50% v 38%);
- Those living one hour or more away (50% v 36% of those who co-reside);
- Secondary caregivers (50% v 35% primary caregivers);
- Those not working while caregiving (47% v 39% employed); and

- Those whose recipients are 50 or older (46% v 23% of those 18-49).

Looking across subgroups, some differences emerge among the specific types of paid care used:

- Of those whose care recipients are not in nursing homes, white caregivers are more likely to report using a hired housekeeper (22% white v 11% African-American, 14% Hispanic, 13% Asian-American caregivers). Older caregivers are more likely to say they use a housekeeper than younger caregivers (22% 50-64 and 28% 65+ v 14% 18-34) as well as those with a college education, higher annual household income, secondary caregivers and those that live in the suburbs.
- Similarly, caregivers who live outside the household both those less than an hour away (22%) or more than an hour away (25%) are significantly more likely to hire a housekeeper than caregivers who live in the same household as the recipient (12%).
- Caregivers spending more than twenty hours per week providing care are more likely than others to hire an aide or nurse from an agency (31% v 19% of those spending eight hours or less) as well as those who care for someone with Alzheimer's, those with at least a college degree, secondary caregivers and those caregivers at Level 3 or higher.

G. Strain and Stress of Caregiving

When we examine a number of ways caregiving may impact caregivers' lives, we find that caregiving most often diminishes the amount of time with family, friends, and doing leisure activities. Many working caregivers say they adjust their work schedule as a result of their caregiving responsibilities. One-third of caregivers say they experience emotional stress. Caregivers are less likely to say caregiving has negatively affected their physical health or finances.

1. Impact on Caregivers' Physical and Emotional Health

a. Physical Health

Most caregivers say they are in good physical health. In fact, more than eight in ten caregivers describe their health as excellent (25%), very good (30%), or good (28%). About one in six (17%) considers their health as fair or poor (12% and 5%, respectively). In general, about six in ten (61%) members of the adult population

in the U.S. say their health is very good or excellent, three in ten (29%) say their health is good, and one in ten (9%) say their health is fair or poor.²⁰

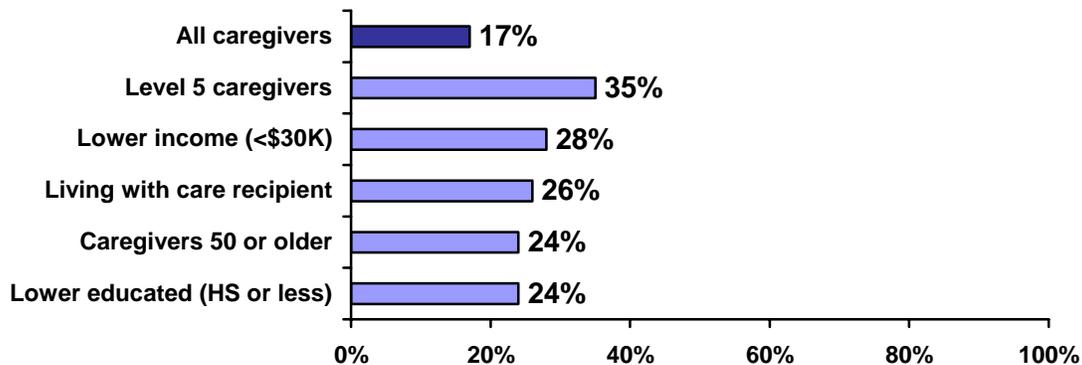
While most caregivers report good health, several factors are associated with the degree of one's health: gender, age, education, income, and living with the recipient. Additionally, the greater the caregiving responsibilities, the greater the chance the caregiver's health is in fair or poor condition.

Caregivers who report their health is fair or poor are more likely than their counterparts to be (Figure 27):

- Level 5 caregivers (35% v 12% of Level 1 report fair or poor health);
- Lower income (28% of those making less than \$30K v 2% of caregivers earning \$100K+);
- Living with the care recipient (26% v 12% of those more than an hour away);
- Caregivers 50-64 (24%) or 65+ (24%) v 9% of 18-34 caregivers);
- Lower educated (24% of those with a high school diploma or less v 10% of college educated);
- Primary (20%) more than secondary (12%) caregivers; and
- Female (19%) more than male caregivers (13%).

Figure 27: Fair or Poor Health Status
% of caregivers saying own health is fair or poor

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



Base: 1,247 caregivers in the U.S.

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

²⁰ Personal correspondence dated March 25, 2004 from John Crews, DPA, Health Scientist, Centers for Disease Control and Prevention. Data to be published later this year.

We asked caregivers how they would say taking care of the person they assist has affected their health. Almost three in four caregivers (74%) say being a caregiver has had no effect on their health. Fifteen percent say caregiving has made their health worse. Fewer (9%) say being a caregiver has made their health better.

Caregivers who say caregiving has made their health worse closely mirror those who report being currently in fair or poor health:

- Level 4 (20%) and Level 5 (34%) caregivers (v 8% Level 1, 12% Level 2, 12% Level 3);
- Co-residents (22% v 11% of those more than an hour away);
- Older (19% 50-64 and 21% 65+ v 9% 18-34);
- Caring for someone with Alzheimer's or dementia (20% v 13% of others);
- Lower income (19% of those earning less than \$30,000 v 7% of \$100,000+);
- Female (18% v 10% of male caregivers); and
- Primary (18%) more than secondary (11%) caregivers.

Our analysis indicates that age is the best *demographic* predictor of caregivers saying being a caregiver has made their health worse. That is, the older a caregiver is, the more likely the caregiver is to say that caregiving has made their health worse. A caregiver's gender is also an important demographic variable that helps predict the impact of being a caregiver on the caregivers' health. Other variables that also help predict the impact of caregiving on the caregiver's health is whether or not the caregiver feels that they had a choice in taking on this role and Level of Burden. The higher the reported Level of Burden, the greater the perceived impact on caregiver's health.²¹

Few caregivers say caregiving is a physical strain. This may be a reflection of the fact that many caregivers consider themselves healthy or the fact that most common ADLs and IADLs do not require a great deal of physical strength. On a scale of 1 to 5, where 5 is "very much a physical strain," a relatively small proportion of caregivers (15%) rate their caregiving situations as a 4 or 5. However, we find again the most burdened caregivers tend to experience more strain than others (rating a 4 or 5 on physical strain):

- Level 5 caregivers (46% rate their physical strain a four or five on a five point scale v 3% Level 1, 14% Level 2, 16% Level 3, 19% Level 4);
- Caregivers in fair or poor health (34% v 8% of those in excellent health);

²¹ See methods for a description of variables entered into the regression model.

- Those living with the recipient (25% v 11% who live less than an hour away or 14% one hour or more away);
- Older caregivers (17% 50-64 and 22% 65+ v 10% 18-34); and
- Primary caregivers (19% v 10% of secondary caregivers).

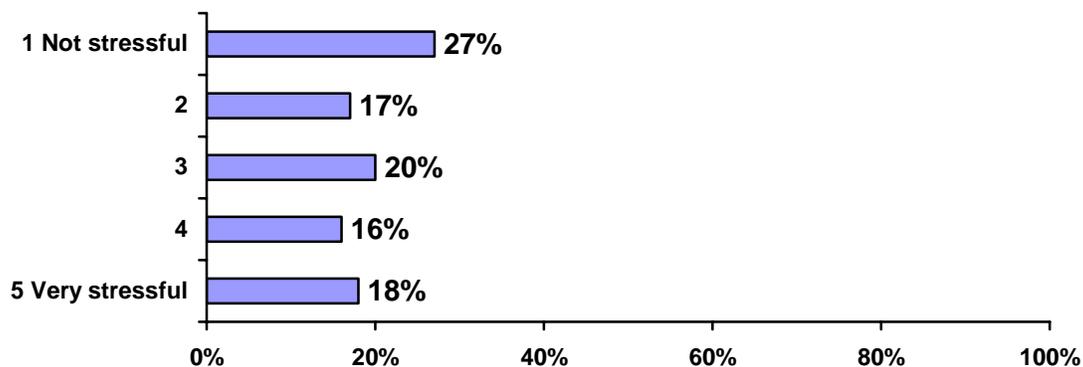
Additionally, one-quarter of caregivers (26%) admit that they get less exercise than before they took on caregiving responsibilities.

b. Emotional Health

Caregiving appears to create more emotional stress than physical strain. One third (35%) of caregivers say taking care of the person they help rates a four or five, on a five point scale where five is very stressful. Approximately one in four say taking care of the person they help is not at all stressful (Figure 28).

Figure 28: Emotional Stress of Caregiving

57. 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 (___) [is/was] for you?



Base: 1,247 caregivers in the U.S.

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

Caregivers who experience the greatest emotional stress (rate the situation as a four or five) tend to be:

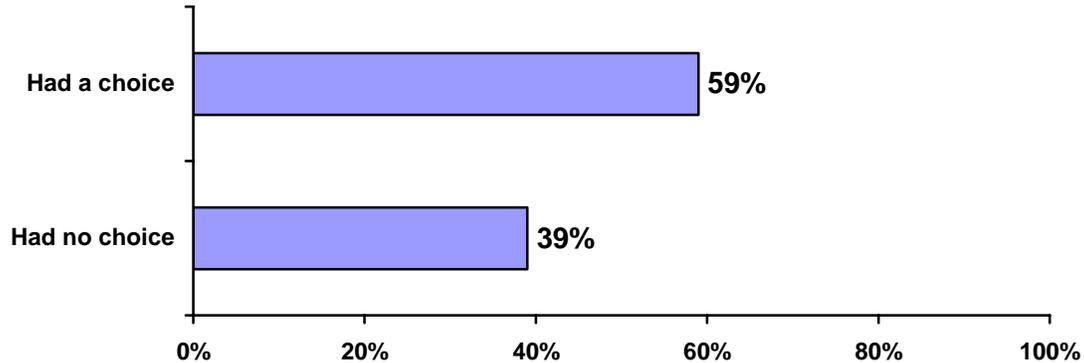
- Females (40% v 26% of male caregivers);
- Between the ages of 35-49 years (38%), 50-64 years (38%) v 18-34 (28%)
- Co-residing (43%) or living at a distance of one hour or more (47%) v less than one hour away (28%)

- Caring for someone with Alzheimer's or dementia (42% v 32%); and
- White (36%), Hispanic (36%), or African American (30%) compared to Asian-American caregivers (23%); and
- In only fair or poor health themselves (47% v 27% excellent, 34% very good);

Feeling one had a choice in taking on the role of a caregiver is linked with the degree of emotional stress felt. Nearly four in ten caregivers say they feel they had no choice in taking on caregiving responsibilities (Figure 29).

Figure 29: Choice of Becoming a Caregiver

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



Base: 1,247 caregivers in the U.S.

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

Women are more likely to say they felt they did not have a choice in taking on this responsibility than men (42% v 34%). Caregivers between the ages of 50-64 years are less likely to feel they had a choice compared to those 18-34 years (42% v 34%). Co-residing caregivers are less likely to feel they did not have a choice than caregivers who live less than an hour away (45% v 36%).

- Half of caregivers (51%) who feel they had no choice in taking on caregiving responsibilities also feel the situation is emotionally stressful (rate a four or five on a five point scale).
- However, only one-quarter (24%) of those who feel they did have a choice experience emotional stress at this level.

Caregivers who say they feel they did not have a choice in taking on the caregiver role also say they are less healthy and more heavily burdened than caregivers who say they feel they had a choice in taking on this responsibility. Caregivers who say they feel they did not have a choice in taking on the caregiving role are typically:

- Female (42% v 34% male);
- Primary caregivers (45% v 32% secondary caregivers);
- Caregivers at higher Levels of Burden (47% Level 4, 51% Level 5 v 32% of Level 1 caregivers);
- Those living with the care recipient (45% v 36% of those living less than an hour away); and
- Those in fair or poor health (51% v 38% good health, 34% excellent health).

Our analysis indicates that Level of Burden and whether or not one feels a choice in taking on caregiving responsibilities are the two greatest influences in caregiver's perceived emotional stress. Other significant factors include the condition of one's health, followed by living in the same household as the recipient.²²

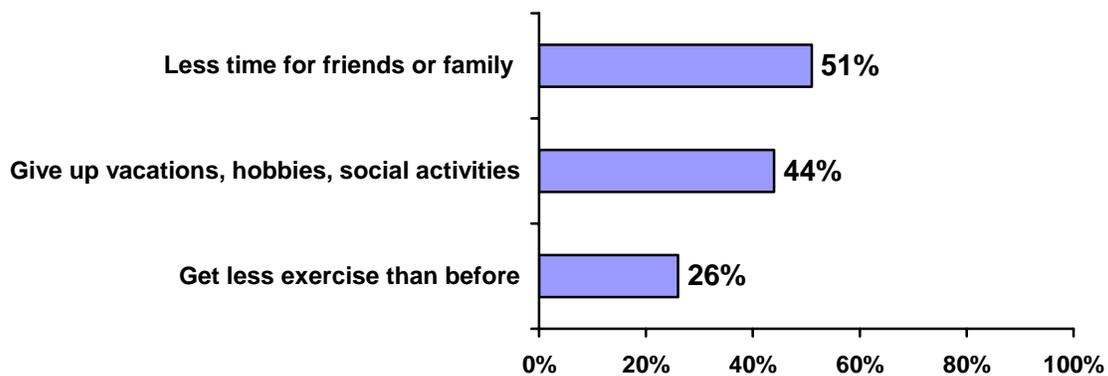
²² See methods for a description of variables entered into the regression model.

2. Impact of Caregiving on Family and Leisure Activities

Half of caregivers say they have less time for families and friends than before taking on caregiving responsibilities. A substantial proportion say also say they have given up vacations, hobbies, or other social activities as a result of caregiving (Figure 30).

Figure 30: Impact of Caregiving on Family and Leisure Activities
% saying yes

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



Base: 1,247 caregivers in the U.S.

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

Caregivers who experience the greatest impact on family include:

- Female caregivers (54% v 47% of male caregivers);
- Primary caregivers (55% v 49% secondary caregivers);
- Caregivers at a higher Level of Burden (69% Level 4 84% Level 5 v 29% Level 1, 47% Level 2, 57% Level 3);
- Those living with the recipient (67% v 44% of those living less than an hour away and 56% living one hour or more away);
- Caregivers who consider their health as fair or poor (60% v 44% of those in excellent health);
- Caregivers in child-rearing years: 35-49 and 50-64 years old (58% and 55% respectively, v 42% of 18-34 and 46% of 65+);

Giving up vacations, hobbies, and other activities affects:

- Caregivers at a higher Level of Burden (52% Level 3, 64% Level 4, 76% Level 5 v 23% Level 1, 37% Level 2);
- Those reporting fair or poor health (52%) more than those in excellent health (37%);
- Primary caregivers (49%) more than secondary (40%);
- White (45%), Hispanic (48%) caregivers more so than African-American caregivers (35%); and
- Those that co-reside or live more than an hour away compared to those that live within an hour (59%, 52% v 36%).

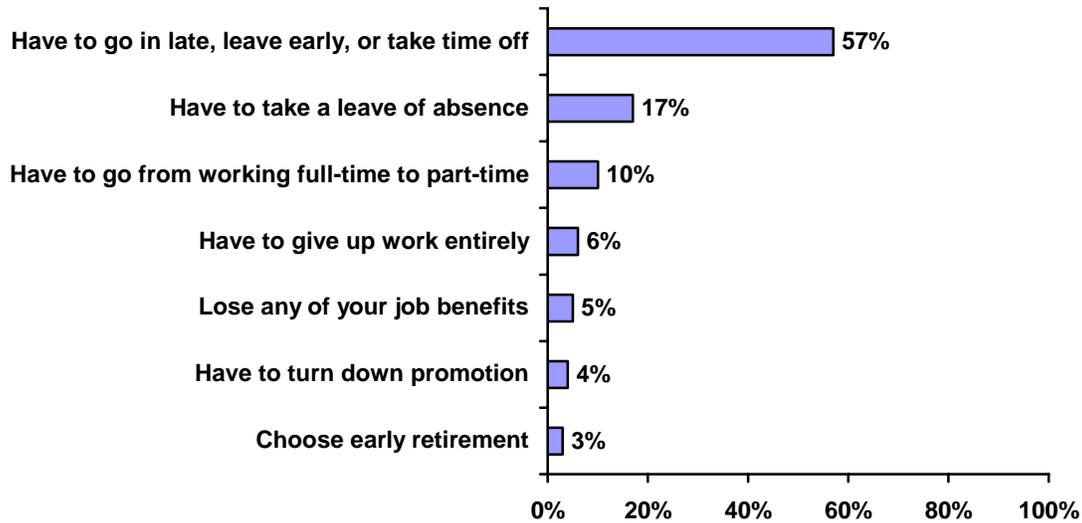
3. Impact of Caregiving on Work

Most caregivers currently work (48% full-time and 11% part-time) while providing care, or have worked at some time while being a caregiver (59%). More than six in ten of these working caregivers (62%) report their caregiving responsibilities have affected their work.

More than half of working caregivers say holding these two roles simultaneously has resulted in having to go in (to work) late, leave early, or take time off during the day to provide care. Fewer caregivers report having to take a leave of absence, go from full-time to part-time work or taken a less demanding job, quit working, lose job benefits, turn down a promotion or choose early retirement (Figure 31).

Figure 31: Impact of Caregiving on Work
% saying yes

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



Base: 935 caregivers in the U.S. who are currently or have worked while caregiving
Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004.

The following subgroups are most likely to report making one or more of these work-related adjustments:

- Female more than male (65% v 57%) caregivers;
- Primary more than secondary (67% v 58%) caregivers;
- Caregivers at a higher Level of Burden (92% Level 5, 79% Level 4, 69% Level 3 v 43% Level 1);
- Ages 35-49 (65%) and 50-64 (66%) compared to those ages 18-34 (54%);
- African-American caregivers (72%) compared to white (60%), Asian-American (54%);
- Those living with the recipient (71%) or those living more than an hour away (68%) compared to 57% of those who live less than one hour away; and
- Those helping someone with Alzheimer’s or dementia (70% v 59%).

Table 9: Work-Related Adjustments by Level of Burden
(Base = Caregivers employed while caregiver)

Q41-Q47. IF WORKING WHILE A CAREGIVER: In your experience as both a worker and a caregiver, did you ever:

	Total	Level 1	Level 2	Level 3	Level 4	Level 5
In late, leave early etc.	57%	40%	51%	63%	75%	83%
Took leave of absence	17%	8%	17%	14%	22%	41%
Went from full time to part time	10%	3%	7%	9%	15%	37%
Gave up work entirely	6%	1%	3%	4%	4%	35%
Lost any job benefits	5%	2%	2%	5%	9%	15%
Turned down promotion	4%	2%	3%	5%	6%	14%
Chose early retirement	3%	1%	1%	2%	3%	12%
None of the above	38%	57%	44%	31%	21%	8%

Base: 935 caregivers in the U.S.

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

4. Financial Hardship on Caregivers

Not counting those who care for a spouse, about half of caregivers (54%) report contributing financially to the care of their recipient. These caregivers spend an average of \$200 in a typical month on the recipient's care.

The following caregivers spend significantly more per month than others:

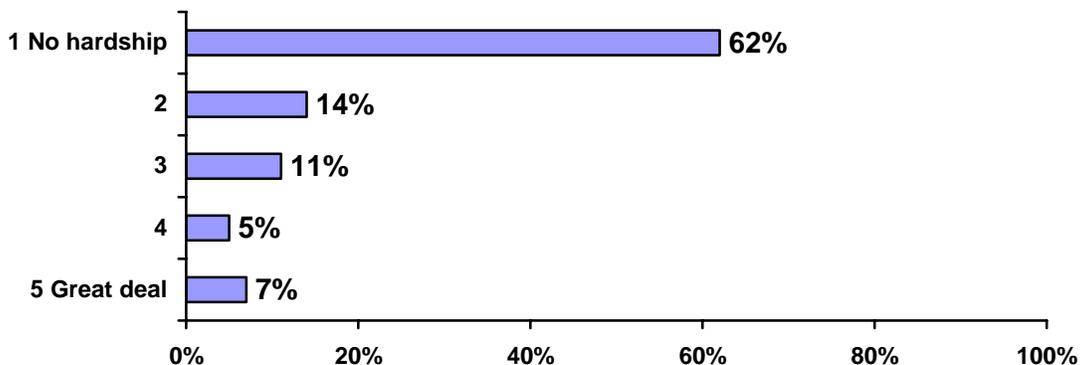
- Level 5 caregivers (\$324);
- Primary caregivers (\$232); and
- Caregivers 65 or older (\$217).

The majority of caregivers say they feel little or no financial hardship as a result of providing care (Figure 32).

Our analysis shows that the two greatest predictors of caregivers' financial hardship are Level of Burden and whether they feel they had a choice in taking on caregiving responsibilities. Caregivers at higher Levels of Burden and those who do not feel they had a choice to take on this role report greater financial hardship. Other factors contributing to financial hardship are the caregiver's age, health, and living with the care recipient. The older the caregiver, the poorer the caregivers' perceived health, and living with the care recipient increase the reported level of financial hardship.

Figure 32: Financial Hardship on Caregivers

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



Base: 1,247 caregivers in the U.S.

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

However, twelve percent say they experience considerable financial hardship, in the 4 or 5 ranges. This hardship is most severe among those who do the most, especially for young care recipients, and have the least resources to begin with.

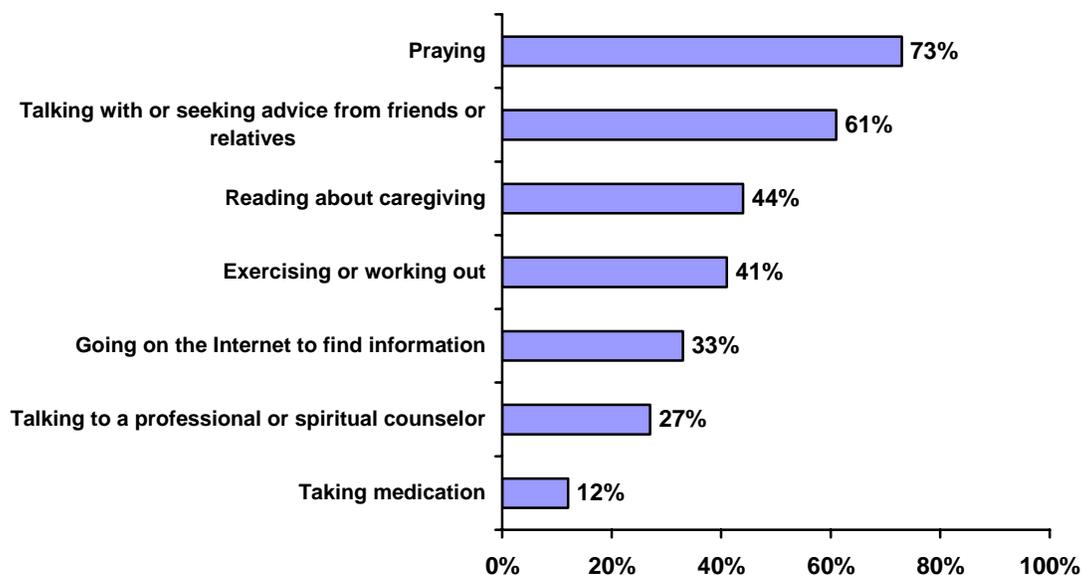
- One-third of Level 5 caregivers (34%) say they feel a financial hardship as a result of providing care (v 6% of Level 1 caregivers rating a 4 or 5).
- Caregivers who live with the recipient (24%) are more likely to say they experience financial hardship as a result of being a caregiver than caregivers who do not live with the person they care for (8% of those who live less than an hour away and 9% of those who live more than an hour away).
- One-quarter of caregivers who help someone under age 50 (25%) report financial hardship compared to 9% of those helping someone age 50+.
- Not surprisingly, lower income caregivers (19% of those earning less than \$30,000) experience more financial hardship than those in other income categories (12% \$30,000-49,000, 11% \$50,000-99,000, 5% \$100,000 or more). Caregivers who report they have graduated from college are less likely to say they experience financial hardship as a result of caregiving than those with less education (9% v 14% with high school or less and 15% of those with some college).
- African-American caregivers (22% say 4 or 5) more likely than white (10%), Hispanic (14%), or Asian-American (11%) caregivers to experience financial hardship as a result of being a caregiver.

H. Coping with Stress

Caregivers say they use a range of coping mechanisms to deal with the demands of caregiving. Praying is the most commonly reported method of coping followed by talking with friends or relatives. Reading about caregiving in books or materials, exercising, and going on the Internet provide other outlets for dealing with stress. Seeking help from a professional or spiritual counselor, and taking medication are less commonly used techniques (Figure 33).

Figure 33: Coping with Demands of Caregiving
% saying yes

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



Base: 1,247 caregivers in the U.S.

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

- While many caregivers across all subgroups use prayer to help with caregiving stress, African-American (84%) and Hispanic (79%) caregivers are significantly more likely to cope by praying than white (71%) or Asian (50%) caregivers.

- Women are also more likely to say they pray as a way to cope with caregiving stress more than men (80% v 61%) as are caregivers at higher Levels of Burden (78% Level 4, 85% Level 5 v 66% Level 1 and 67% Level 2).
- Caregivers in fair or poor health tend to use prayer more than others (82% v 70% of those in excellent health), and Level 5 caregivers are more likely to say they pray than Level 1 caregivers (85% v 66%).
- Female caregivers also tend to relieve stress through talking to friends and relatives more so than male caregivers (67% v 51%).
- While one third (33%) of caregivers overall use the Internet as a tool for dealing with caregiving demands, those most likely to use this mechanism include Asian-American caregivers (43%), those under 65 (for example, 41% of 35-49 caregivers), college educated (41%), upper income (44% of those making \$100,000+), caregivers helping someone with Alzheimer's or dementia (42%), and secondary caregivers (40%).

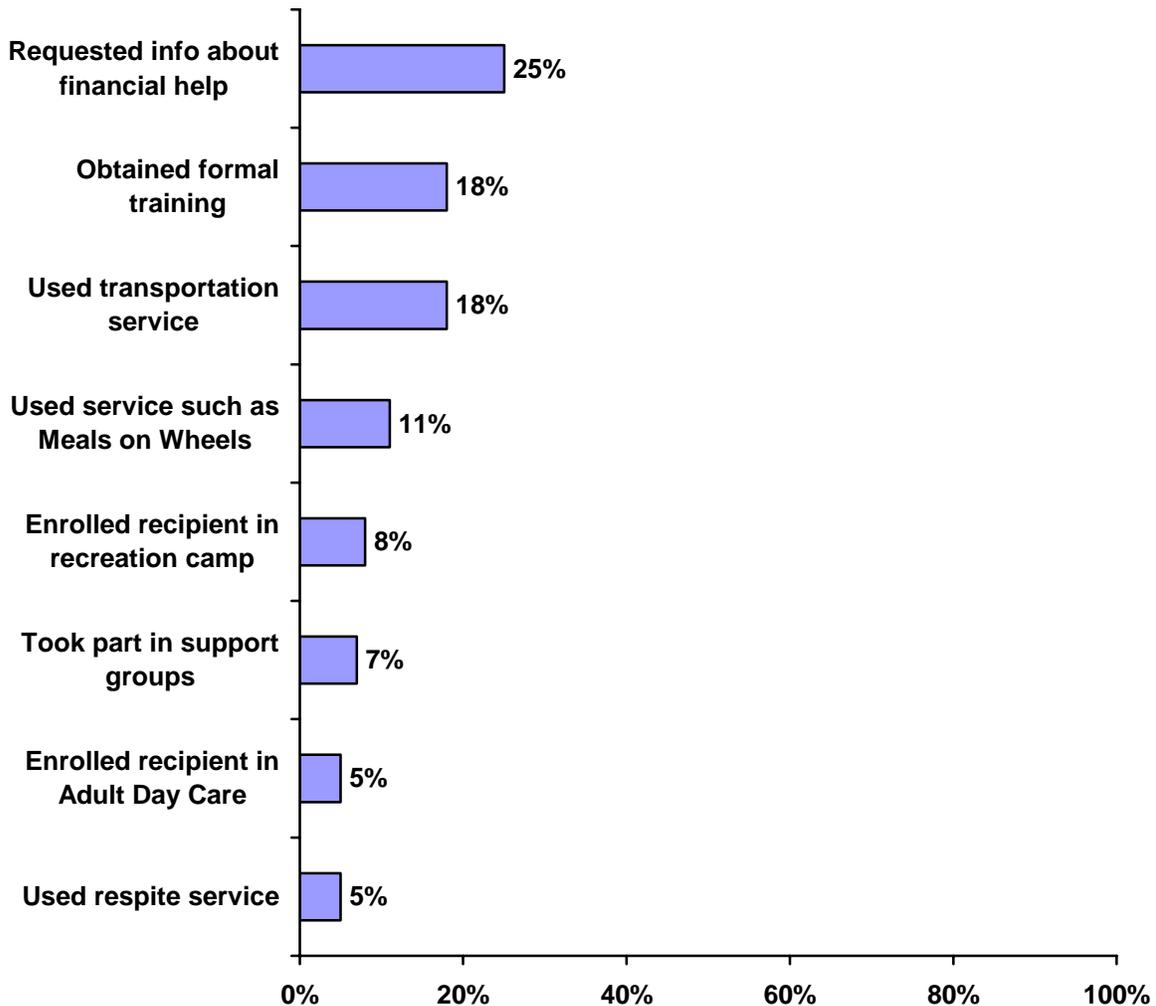
Among those who use the Internet as a coping mechanism, nearly nine in ten (88%) search for information about the care recipient's condition or treatment, more than half (55%) seek information about services available for care recipients, and four in ten (39%) look for support or advice from other caregivers.

I. Use of Supportive Services in the Community

Nearly half of caregivers (48%) say they have used some type of supportive service to help care for their relatives and friends. Requesting information about financial help for the care recipient is more common than any other service we asked about (Figure 34).

Figure 34: Use of Outside Services

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



Base: 1,247 caregivers in the U.S.

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

- Caregivers who help someone with Alzheimer's or dementia (58%) are more likely than other caregivers to seek the seven types of services we asked about than those without Alzheimer's (58% v 45%).
- Caregivers who co-reside with the person they care for are also more likely to seek these services than those who live within an one hour of the person they care for (55% v 46%).
- Caregivers age 50-64 years and those age 65+ are more likely to seek these services than caregivers ages 18-34 (55%, 56% v 40%).
- Hispanic caregivers (3%) are least likely to have participated in support groups, compared to Asian-American (12%), African-American (11%), or white (7%) caregivers.
- Caregivers who care for people living in urban areas are more likely to report using the services we asked about (58%) than caregivers who care for people living in suburban (42%) or rural (44%) areas. Specifically, urban caregivers tend to request financial information, use transportation services, and use adult day care more so than others.
- Level 5 caregivers are more likely to say they experience financial hardship than caregivers at other Levels of Burden, and they are more likely to say they have requested information about how to get financial help for the person they care for than caregivers at Levels 1, 2, and 3 (35% v 20%, 23%, 21%).
- Caregivers who help those between ages 18-49 are more likely to say they experience financial hardship than caregivers who help someone age 50+, and they are also more likely to say they have requested information about getting financial help for the person they care for (35% v 22%).

J. Unmet Needs for Help, Information, or Support in Caregiver Role

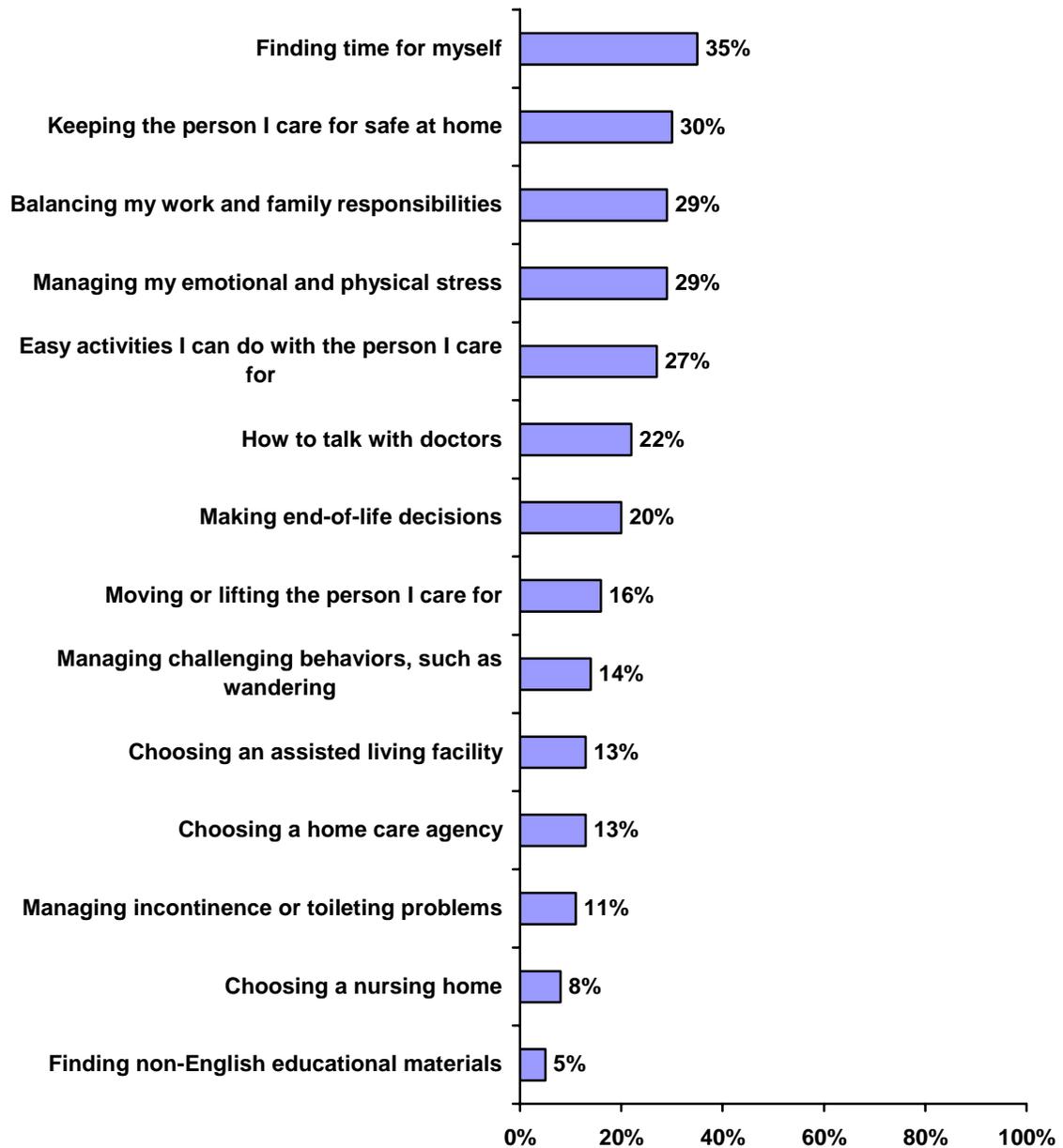
1. Identifying Unmet Needs

We asked caregivers if they need more help or information about fourteen activities or issues that caregivers commonly face. Two-thirds (67%) say they need more help with or information about at least one of these items.

More than one in three caregivers (35%) say they need help to find more time for themselves. Three in ten say they need help or information about balancing work and family responsibilities as a caregiver, and managing emotional and physical stress (Figure 35).

Figure 35: Unmet Needs
% saying yes

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



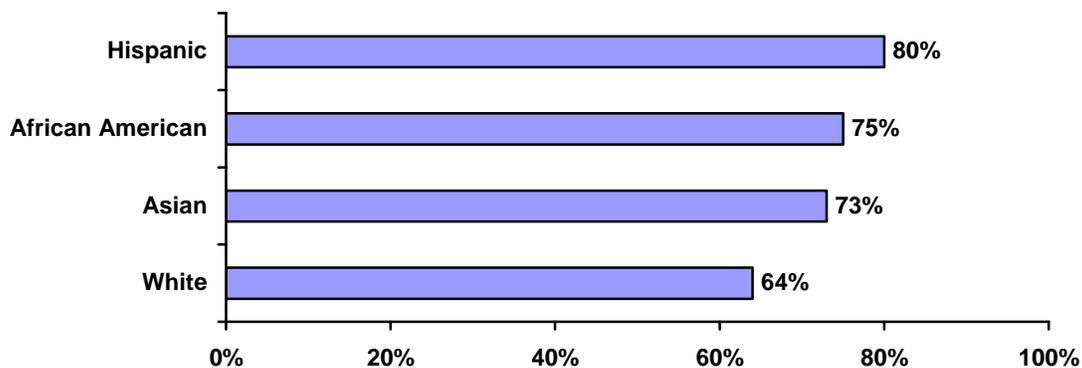
Base: 1,247 caregivers in the U.S.

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

Minority caregivers are much more likely to say they need more help with information than white caregivers (Figure 36).

Figure 36: Reporting One or More Unmet Needs

Q. Are you of Hispanic origin or background? Q. Would you say you are white, black or African American, Asian or Pacific Islander, or something else?



Base: 1,247 caregivers in the U.S.

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

- Caregivers helping someone with Alzheimer's or dementia say they need help or more information than caregivers who do not care for an Alzheimer's patient or someone with dementia (74% v 65%).
- Level 5 caregivers are also more to say they need help or more information than Level 1 or 2 caregivers (82% v 55%, 65%).
- Nearly eight in ten of those caregivers (79%) who already receive an outside support service say they need more help or information about at least one item.
- Caregivers who live in urban areas (28%) are more likely to say they need help or information on how to talk to doctors and other health professionals than suburban (20%) or rural (17%) caregivers.
- Female caregivers, caregivers under age 65, and caregivers who live with the person they care for are more likely to say they need help or information related to personal needs such as reducing stress, finding

more time for oneself, and balancing work and family than their counterparts.

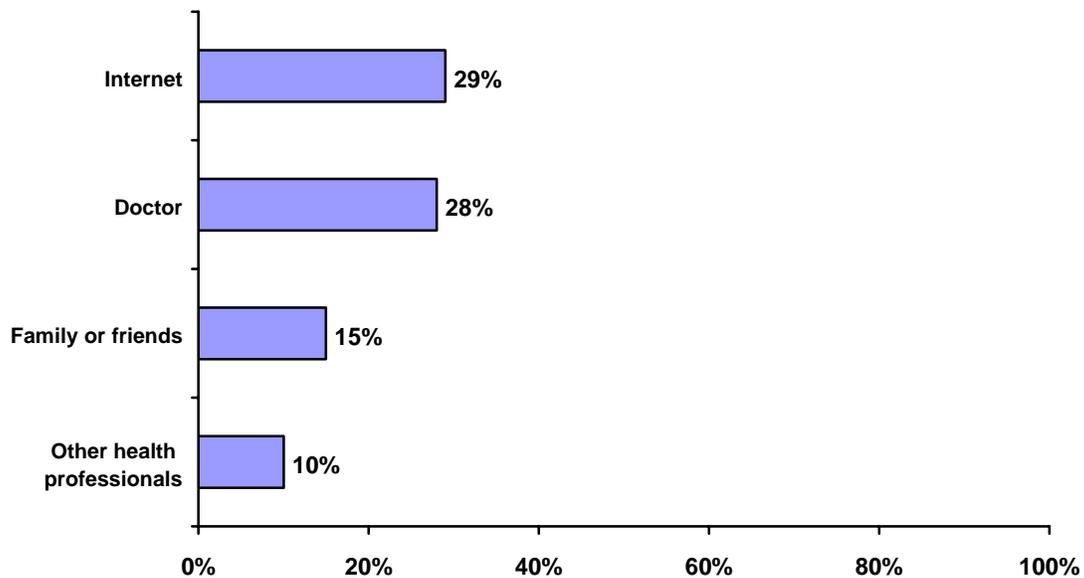
- Caregivers who report providing care for 21 or more hours per week are more likely to say they need help or information on six items than those who provide less than 20 hours of care per week. These items include: finding time for myself, keeping the person I care for safe at home, managing emotional and physical stress, learning how to talk with doctors and other health care professionals, moving or lifting the person I care for.

2. Where Caregivers Would Go For Information

We asked caregivers where they look for information about some aspects of caregiving. Caregivers say they turn to the Internet, a doctor, family or friends, and other health professionals (Figure 37).

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

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



Base: 1,247 caregivers in the U.S.

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

- Caregivers under age 65 (36% of those ages 18-34), college graduates (37%), upper income (44% of those with annual household income of \$100,000+), those living an hour or more away from the person they care for (41%), secondary caregivers (37%), employed caregivers (32%), and those living in an urban (34%) and suburban (32%) areas are more likely to turn to the Internet for information than their counterparts.
- Level 5 caregivers are more likely to turn to a doctor for information than Level 1, 2, or 3 caregivers (42% v 24%, 22%, 24%). Caregivers who live with the person they care for are more likely to turn to a doctor for information than those who co-reside with the person they care for (36% v 26% of caregiver who live less than an hour away from the person they care for and 22% of caregivers who live an hour or more away from the person they care for).
- Caregivers who care for someone over age 50 are more likely to turn to a doctor for information than caregivers who care for someone under age 50 (31% v 18%).
- Younger caregivers are less likely to turn to a doctor for information than older caregivers (19% age 18-34 v 27% of caregivers age 35-49, 35% of caregivers age 50-64, and 31% of caregivers age 65+).
- Younger caregivers are more likely to turn to friends or family for information than older caregivers (25% of caregivers age 18-34 v 13% of caregivers age 35-49, 9% of caregivers age 50-64, and 12% of caregivers 65+).
- Caregivers at Level 1 are more likely to turn to friends or family than Level 4 or Level 5 caregivers (19% v 11%, 10%)

K. Spotlight on Caregivers in Racial/Ethnic Subgroups

We over-sampled members of three ethnic groups to enable us to examine the potential impact of ethnicity on caregiving. Overall, we find caregivers provide similar types of care and experience similar stresses regardless of ethnic background.

- **African-American caregivers.** African-American caregivers are more likely to have children under age 18 living in the household than caregivers from other racial or ethnic groups (53% v 35% white, 39% Hispanic, 34% Asian). African-American caregivers are also more likely to be single, never married (32% v 14% white, 23% Hispanic caregivers) and less likely to be married (13% v 28% white, 30% Hispanic, 33% Asian caregivers).

African-American caregivers are more likely to be ages 18-34 (17% v 10% 50-64 years, 5% 65+).

Among caregivers who do not live with the person they care for, African-Americans are more likely to say they visit the person they care for more than once a week (65% v 55% white, 44% Asian caregivers).

African-American caregivers are more likely to live in urban areas (49% v 24% white, 35% Asian caregivers). Similarly, African-American care recipients are more likely to live in urban areas (49% v 28% white care recipients).

African-American caregivers are more likely to say they have been employed since becoming a caregiver (68% v 56% white caregivers). They are also more likely to say they spend \$101-\$500 in a typical month for groceries, medicines, or other kinds of cash support for the non-spousal person they care for (36% v 22% white caregivers). Therefore, it is not surprising that African-American caregivers are more likely to say caregiving is a financial hardship (22% say four or five on a five point scale v 10% white, 14% Hispanic, 11% Asian caregivers). African-American caregivers are also more likely to ask for information on how to get financial help for the person they take care of (30% v 19% Asian caregivers).

African-American caregivers are more likely to say they perform three or more IADLs for the person they care for (88% v 78% white, 79% Asian). They are also more likely to say they obtained formal training of some sort

about how to care for a person with the kinds of needs their care recipient has (25% v 17% white and 15% Asian caregivers).

African-American caregivers are more likely to say they give medicine, pills or injections to the person they care for (48% v 39% white, 32% Asian caregivers). These caregivers are more likely to say they need to know more about the prescription medication the person they care for takes (28% v 20% white caregivers).

African-American caregivers are more likely to say they obtained an outside service to provide transportation for the person they care for (28% v 16% white, 18% Hispanic caregivers).

African-American caregivers are more likely to say they cope with the caregiving stress by praying (84% v 71% white, 50% Asian Caregivers). African-American caregivers are also more likely to say they cope with caregiving stress by talking to a professional or spiritual counselor (35% v 26% white, 25% Hispanic, 21% Asian caregivers).

- **Hispanic caregivers.** Like African-American caregivers, Hispanic caregivers are likely to spend more than eight hours a week providing care.

Hispanic caregivers are more likely to say they live with the person they care for (34% v 22% white caregivers) and they are also more likely to say help the person they care for with at least one ADL (59% v 48% white caregivers).

Hispanic caregivers are likely to say they are Level 4 or 5 caregivers (41%). They are also more likely to say they have given up vacations, hobbies, or their own social activities than African-American caregivers (48% v 35%).

- **Asian-American caregivers.** Asian-American caregivers stand out as being well educated (61% have at least four years of college v 36% white, 30% African-American, 27% Hispanic caregivers).

Asian caregivers also report higher household incomes than others (53% report a household income of \$50,000+ v 42% white, 33% African-American caregivers, 38% Hispanic caregivers). It is therefore not surprising that Asian caregivers are more likely to say caregiving is not a financial hardship (one or two on a five point scale, 77% v 66% African-American).

Asian caregivers, like white caregivers, are more likely to say the person they care for lives in the suburbs (43% v 27% African-American, 28% Hispanic caregivers). Similarly, Asian caregivers are more likely to say they live in the suburbs (56% v 40% white, 34% African-American, 37% Hispanic caregivers).

Interestingly, Asian caregivers are less likely to say the person they care for has Alzheimer's or other mental confusion (86% v 75% white, 72% African-American, 75% Hispanic caregivers).

Asians are less likely to report emotional stress (only 23% rate a 4 or 5, on a 5 point scale where five is very stressful (v 36% white, 36% Hispanic caregivers).

Asian caregivers are more likely to say they have tried to cope with caregiving stress by going on the Internet to seek information (43% v 33% white, 29% African-American caregivers). Sixteen percent of Asian-American caregivers report needing help finding non-English educational materials about caregiving. This figure is undoubtedly a low since we only interviewed English speaking Asians. If we had interviewed Asian caregivers in their native language, we probably would have found a greater need for non-English educational materials.

- **White caregivers.** White caregivers are more likely to say they are 50 years of age or older than those in other racial/ethnic subgroups (46% of white caregivers, 29% African-American, 34% Hispanic, 35% of Asian-American caregivers).

Like Asian-American caregivers, white caregivers tend to report higher incomes (42% make \$50,000 or more). However, unlike Asian caregivers, white caregivers are more likely to say they are currently providing care (68% v 56%).

While a large proportion of white caregivers say they live in a suburb (40%), white caregivers are more likely to say they live in a rural area (34% v 15% African-American, 19% Hispanic, 9% Asian caregivers). Similar to Asian caregivers, white caregivers also more likely say the person they care for lives in the suburbs (40% v 27% African-American, 28% Hispanic caregivers).

Like Hispanic caregivers, white caregivers are likely to say they have given up vacations, hobbies, or their own social activities (45% v 35% African-American caregivers). Yet white caregivers are less likely to say caregiving is a physical strain (69% v 61% African-American caregivers), and they are

more likely to say caregiving is not a financial hardship (one or two on a five point scale 79% v 66% African-American).

White caregivers are also less likely to say they feel a need for more help or information keeping the person they care for safe at home, balancing their work and family responsibilities, finding easy activities they can do with the person they care for, moving or lifting the person they care for than African-American, Hispanic, or Asian caregivers.

L. Comparing Caregivers by Age of Recipient

Several key distinctions emerge looking at caregivers of those 50 or older, and caregivers of 18-49 year olds.

- Caregivers who help someone 50 or older tend to be older than caregivers who help someone between the ages of 18-49 years (mean age 47 years v 41 years). The average (mean) age of a younger care recipient (18-49) is 33 years and the average (mean) age of a care recipient age 50 or older, is 75 years.
- Two in three (66%) of caregivers who help someone between the ages of 18-49 years are employed full or part-time, compared to 57% of caregivers who help someone age 50+.
- The caregivers who help someone 50 or older tend to be better educated and earn higher incomes than those helping recipients 18-49. For example, 37% of those caring for people 50 and up have a college degree, compared to 26% of those helping 18-49 recipients; and 44% helping the older set make \$50,000 or more, whereas only 35% of caregivers helping those 18-49 do so.
- Caregivers helping someone 18-49 are also more likely to be providing unpaid care for more than one person: these caregivers help an average of 2.6 recipients, compared to 1.4 for those helping someone 50 or older.
- While caregivers who care for someone 50 or older tend to be helping their mothers (34%), grandmothers (11%), or fathers (10%), those helping someone 18-49 are much more likely to be caring for an adult child (27%), a sibling (15%) or a non-relative (25%).
- Caregivers of younger care recipients (ages 18-49) most commonly report mental illness or depression as the biggest problem or illness for the

person they care for (23%). On the other hand, caregivers of older care recipients (age 50+) most commonly report the main problem or illness as aging (15%), cancer (9%), diabetes (9%), and Alzheimer's (8%), and heart disease (9%).

- Caregivers of younger care recipients (ages 18-49) are more likely to report being primary caregivers (70%) than caregivers of older care recipients ages 50+ (54%), and tend to be living with the recipient (33%) more often than caregivers helping 50+ recipients (22%). In fact only 38% of those helping 18-49 recipients report the presence of some other type of unpaid help, whereas 65% of those helping 50+ recipients have done so.
- One in three (33%) caregivers of younger care recipients (ages 18-49) report assisting the person they care for with at least one ADL, whereas more than half (55%) of caregivers helping older recipients do so (age 50+). Instead, caregivers of people 18-49 are more likely performing IADLs, especially helping managing finances (79%) and transportation (77%).
- While nearly half (46%) of caregivers helping someone 50 or older not in a nursing home receive some type of paid help, only 23% of those caring for 18-49 recipients have done so.
- Caregivers who help younger care recipients provide an average of \$205 per month financial support. Caregivers who help older care recipients provide an average of \$197 per month. Caregivers of younger care recipients are more likely to report financial hardship (25% rate four or five on a five point scale) than caregivers of older care recipients (9%), and to report having requested information about how to get financial help for the recipient (35% v 22%).

Table 10: Comparing Caregivers Characteristics by Age of Recipient

	Recipients 18 - 49	Recipients 50 or older
Average recipient age	33	75
Relationship	Adult child, sibling, or non-relative	Mother, grandmother, or father
Problems/Illnesses	Mental illness, depression, or emotional problems financial problems	Aging, Alzheimer's, cancer, diabetes, heart disease, mobility, blindness
Average caregiver age	41	47
Demographics	Working	Retired, married
Support	Primary caregivers Feel financial hardship	Get more paid Provide three or more activities of daily living

Base: 1,247 caregivers in the U.S.

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

Table 11: Demographic Profile of Caregivers by Age of Recipient

	Total	Caregivers of 18-49 recipients	Caregivers of recipients 50+
Total	100%	20%	79
Gender			
Male	39%	44%	37%
Female	61	56	63
Race of caregiver			
White	73%	69%	74%
African American	12	16	11
Hispanic	10	11	10
Asian American	4	4	4
Age of caregiver			
Under 35 years old	26%	42%	22%
35-49	32	30	33
50-64	30	19	32
65 or older	13	9	13
<i>Mean (years)</i>	<i>46 yrs</i>	<i>41 yrs</i>	<i>47 yrs</i>
Marital status			
Married/living with partner	62%	53%	63%
Single, never married	18	22	17
Separated/divorced	14	17	14
Widowed	6	7	6
Educational attainment			
High school or less	34%	41%	33%
Some college	27	3	26
Technical school	3	2	3
College grad	22	18	23
Grad school +	13	8	14
Current employment			
Employed full-time	48%	54%	47%
Employed part-time	11	12	10
Not employed	41	33	43
Household income			
< \$30K	25%	32%	22%
\$30K-\$50K	26	27	25
\$50K-\$75K	18	19	18
\$75K-\$100K	9	9	9
\$100K+	15	7	17

Base: 1,247 caregivers in the U.S.

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

Appendix A: Detailed Methodology

The national study contains the results of 6,139 interviews among adults in the U.S., of whom 1,247 were caregivers. A total of approximate 200 caregiver interviews each of African American, Hispanic, and Asian caregivers were obtained.

A companion study was conducted for AARP in seven states, resulting in approximately 400 caregiver interviews in each: California (from a total of n=2,040 interviews), Delaware (n=1,827), Illinois (n=2,072), Kansas (n=1,833), Ohio (n=1,864), Virginia (n=1,885), and Washington (n=1,979).

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

A. Research Design

The research design of this study is based on achieving several goals for NAC and AARP. One driving goal of the project is to estimate the number of caregivers in the U.S. population, as well as the number of caregiving households. Other aims include comparing caregiving roles and impacts across racial and ethnic groups and expanding on the understanding gained from the 1997 NAC/AARP caregiving survey.

In conjunction with NAC and AARP, Belden Russonello & Stewart (BRS) and Research/Strategy/Management, Inc. (RSM) designed a survey research project to achieve these goals. The project design included developing a methodology for calculating incidences, drafting and pre-testing a questionnaire, and devising a series of sample frames to achieve a nationally representative sample of caregivers, as well as over-samples of three racial/ethnic groups (African Americans, Hispanics, and Asian Americans).

B. Questionnaire Design

The questionnaire was drafted by BRS, NAC, AARP, and RSM, and drew from the 1997 NAC/AARP study, *Family Caregiving in the U.S.* The questionnaire has two components. The first comprises a screener used to a) identify caregiver(s) in the household, and b) obtain a host of demographic information from a randomly-selected respondent in all households contacted – regardless of the presence of caregiving in the household. As described below, these data are necessary to compile the base from which we estimate the proportion of caregivers.

The second part of the questionnaire reflects the substantive questions administered to all caregivers. For the state surveys, a shorter version of the questionnaire was used. See Appendix D for the CATI versions of the questionnaire.

After undergoing several iterative revisions, a final draft was programmed into a CATI system and pre-tested. BRS participated in training the interviewers, who were then monitored by members of the research team.

Based on the results of the pretest and a debriefing of the interviewers, changes were made in question wording and length. The questionnaire was then translated into Spanish for those respondents who preferred to be interviewed in Spanish. BRS back-coded the Spanish questionnaire, and input from AARP helped polish the final version. The interviews averaged 20 minutes in length for the national study, and 10 minutes for the state surveys.

C. Sample

1. Sample design

The research design for the national study called for completing about 1,200 interviews with caregivers, including samples of at least 200 caregiver interviews among African Americans, Hispanics, and Asian Americans. To achieve this result in the most cost-effective way, we used a combination of RDD, surname and targeted RDD sample frames. The supplemental samples (surname and targeted RDD) were implemented after the main RDD sample was finished and the number of remaining caregiver interviews in each subgroup needed to reach 200 interviews could be determined.

Soon after interviewing began with the supplemental samples, we noticed the productivity was much lower than anticipated (based on 1997 incidence reports for minorities in the NAC/AARP study) for the Asian surname, Hispanic surname, and targeted Hispanic samples. For example, 3% of contacts from the Asian surname sample produced an English-speaking caregiver. This low incidence raised questions about previously reported incidence among these minorities, was prohibitively expensive, and would take much longer to obtain the necessary interviews than time permitted.

Based on these factors and the dearth of other supplemental sample, the research team consulted with Knowledge Networks to draw on their panel of Americans to complete the remaining Asian and Hispanic interviews. Knowledge Networks has recruited the first online research panel that is designed to be representative of the entire U.S. population. The panel is recruited using high quality probability sampling techniques, and is not limited to current Web users or computer owners. Knowledge Networks selects households using random digit dialing (RDD) and provides selected households with free hardware and Internet access for participating in online surveys.¹

RDD sample was used exclusively for the states surveys, obtained from Survey Sampling, Inc. (SSI).

2. Sample specifics for national study

The national RDD sample, also obtained from SSI, was stratified by geography to generate a set of telephone numbers proportionate to the population. The telephone numbers were then organized into replicates of 200 numbers each. SSI

¹ For more information, see www.knowledgenetworks.com

provided the targeted RDD samples, which were drawn from telephone exchanges in areas with higher than average (at least 30 percent density) concentrations of Hispanics and African Americans. SSI also provided randomly selected samples from a list of telephone numbers across the country linked to Hispanic and Asian surnames.

Knowledge Network's entire Asian sample was used for screening, and a random sample of their Hispanic panelists was drawn for the study. While panelists typically participate in online surveys, Knowledge Networks allowed us to screen for caregivers using an online screener, but administer the substantive questions to caregivers by telephone. Thus we were able to minimize any mode effects in caregiver results.

A total of 1,247 caregivers were obtained from the following samples:

- The main RDD sample produced 3,684 total interviews;
- Targeted samples produced 1008 total interviews; and
- Knowledge Network sample produced 1,447 total interviews.

From all of these interviews, we obtained interviews from 628 white, non-Hispanic caregivers, 200 African-American caregivers, 204 Hispanic caregivers, and 200 Asian-American caregivers.

3. Comparing data from different sample types for national study

Data from all samples were combined and weighted for final analysis. Prior to that, the results from each sample were first compared with Census and the main RDD sample, where appropriate, in effort to detect bias stemming from the different frames utilized in the study. Comparative analyses were conducted in two steps: 1) comparing sex, age, and race of all randomly-selected respondents; and 2) comparing sex, age, and race of all caregiver respondents. For example, all African-American randomly-selected respondents from the targeted RDD over-sample were compared with their counterparts in the main RDD sample. Additionally, demographics of the African American caregivers from the targeted sample were compared with those obtained from the main RDD. These comparisons indicated that the best representative sample would be a combination of all, weighted to known population or household parameters, depending on the level of analysis.

D. Field Methodology

Interviews from the main RDD national sample, the African American over-sample, and the state surveys were conducted September 5 through October 14, 2003. The Hispanic and Asian over-samples continued through December 22, 2003.

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

When contact was established, the interviewer asked to speak with the person in the household aged 18 or older with the most recent birthday – our random selection process. In the case of the racial/ethnic over-samples, race was also determined for eligibility. The interviewer continued with the screener among all randomly-selected respondents, and proceeded to the substantive portion of the questionnaire if a caregiver was identified and agreed to participate.

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

E. Definition of a Caregiver

For the purposes of this study, a caregiver was defined using two mechanisms: self report from a screening question, and verification through reporting assistance with at least one ADL or IADL.

The screening question used for the randomly selected respondent to identify the presence of a caregiver in the household is as follows:

In the last 12 months, have you or anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you. (IF YES: IS THAT YOU OR SOMEONE ELSE IN THE HOUSEHOLD?)

If a caregiver did not report providing help with at least one ADL or IADL in our series, the respondent was thanked for her/his participation and the interview was terminated. For all analytic purposes in this study, these self-reported caregivers are included as non-caregivers in the base of the 6,139 interviews.

F. Estimating Incidence of Caregiving

Estimating the number of caregivers and caregiving households for the national study involves two major components. The first component is the collection of all data necessary to make the estimates. This includes randomly selecting a respondent from all households contacted and obtaining a) demographic data on that individual; b) information about their household composition; c) the report of a caregiver(s) living in the household; and d) interviewing the caregiver.

The second component of estimating incidence involves weighting our large sample of data to a representative sample of the U.S. population and households, based on 2003 U.S. Census population projections and 2003 household projections from Harvard's Joint Center for Housing Studies (JCHS), which used U.S. Census 2000 household data to make their projections. From the weighted data we can estimate the proportion of caregivers and caregiving households in the U.S.

The same procedures were used for the state surveys, except we only make estimates for the population in each state – not households. Therefore, household data were not collected at this level, and we only created one weight based on 2003 population estimates in each state.

1. First Component: Collecting necessary data

The base from which to estimate caregiving in the U.S. – that is, a nationally representative sample of adults and households – was established through interviewing a randomly-selected respondent from each household contacted. Pertinent demographic data were collected on all of these initial, randomly-selected respondents (age, race, and gender). Furthermore, data on the household were gathered for the national study (size, family or non-family status of household members, age of householder, and race of householder).

All randomly-selected respondents were also asked whether or not there was a caregiver in the household. Three scenarios occurred based on the response from this question:

- If the randomly-selected respondent reported no caregiver in the household, the interview ended after obtaining the demographic data for the individual and the household;

- If the randomly-selected respondent was a caregiver, the full questionnaire was administered (only these initially selected respondents were used to determine population incidence to estimate the size of the caregiving population); and
- If the randomly-selected respondent was not a caregiver, but he/she identified someone in the household as a caregiver, the interviewer asked to speak with the caregiver after obtaining necessary demographic data from the randomly-selected respondent. The secondary respondent in a household was a caregiver by definition and was added to initial caregiver respondents to determine household incidence to estimate the number of households with caregivers. (Only one caregiver per household was interviewed.)

The same procedure was used for the states, with the exception of not obtaining household data. See Appendix D for the full CATI-formatted questionnaire with all instructions.

Interviewing continued until we obtained our desired number of caregivers.

2. Second Component: Weighting sample and making estimates

Two weights were computed for estimating in the national study: a “population weight” was used to estimate the proportion of caregivers in the *population*, and a “household weight” was applied to estimate the proportion of caregiving *households* in the US.

Estimating proportion of caregivers in the U.S. population

The population weight was a sex/age/race matrix based on the third quarter (October) 2003 US population projections by the US Census.

After applying the population weight to all data, we looked at the proportion of caregivers among the randomly-selected respondents in our sample. The result shows that caregivers comprise an estimated 21% of the U.S. adult population. The estimated number of caregivers in the US adult population is 44,443,800.

To estimate the incidence of caregivers helping recipients who are 50 or older, the same procedure was used, except we looked at the proportion of caregivers *giving care to 50+ recipients* among the randomly selected respondents in our sample. An estimated 16% of the adult population, or 33,861,900 adults, care for someone 50 or older.

Incidence of Caregivers in the U.S. Population²

	Incidence	X	2003 Census adult pop. estimate	=	Estimated number
Caregivers	21%		[211,637,100]		44,443,800
Caregivers of 50+	16%				33,861,900

The same procedures were used for estimating incidence in each of the seven states.

Incidence of Caregivers in Population by State Over-Sample

	Incidence	X	2003 Census adult pop. estimate	=	Estimated number
California	18%		23,840,900		4,291,400
Delaware	22%		590,700		130,000
Illinois	18%		9,033,000		1,625,900
Kansas	22%		2,026,600		445,900
Ohio	21%		8,603,500		1,806,700
Virginia	21%		5,477,400		1,150,300
Washington	19%		4,619,800		877,800

Estimating proportion of caregiving households in the U.S.:

Household estimates were calculated only for the national study. The household weight was based on the 2003 household projections derived from data supplied by JCHS, and constructed from a matrix of household type (family or non-family), age, and race of householder collected from all randomly-selected respondents.

Using the household weight, we calculated the proportion of all caregivers, including those identified by the randomly-selected respondent who was not him/herself a caregiver, among all households interviewed. We find 21% of U.S. households contain a caregiver(s). The estimated number of caregiving households in the U.S. is 22,901,800.

To estimate the incidence of households in which a caregiver(s) helps a recipient who is 50 or older, the same procedure was used, except we looked at the proportion of all caregivers *giving care to 50+ recipients* among the households interviewed.

² All estimates have been rounded to the nearest 100.

Incidence of Caregiving Households in the U.S.

	Incidence	X	2003 Census household estimate	=	Estimated number
Caregiving HH	21%		[109,056,000]		22,901,800
Caregiving HH of 50+	17%				18,539,500

Estimating proportion of caregivers within racial/ethnic subgroups

The same procedures for making national estimates were used in calculating incidence within racial/ethnic subgroups from the national study. To calculate the incidence of caregivers within a group, the base was either randomly-selected respondents within the designated race (for incidence in the population) or households of the designated race (for incidence of households). See Tables 1 and 2 in the report for percentages and estimated numbers of caregivers and caregiving households within each subgroup.

The following table reflects projections for 2003 total population and total households in the U.S. within each of the following racial/ethnic subgroups:

Population and Household U.S. Census Projections for 2003

	Adult Population N =	Households N =
Total	211,637,100	109,056,000
White, non-Hispanic	153,985,500	80,682,800
African American/Black	24,380,600	13,412,200
Hispanic	23,338,800	10,457,300
Asian-American	8,486,200	4,502,700

G. Weighting Substantive Results

As described above, a population weight and a household weight were created to estimate the incidence of caregiving among the population and in households in the U.S. For reporting the results of the national survey in this report among the 1,247 caregivers interviewed, the data weighted by households was used for two reasons. One is that the 1997 NAC/AARP caregiving study reported household-level data and where questions were similar we desired to make as valid a comparison as possible. The second reason is that the final caregiver sample was derived from identifying caregivers in the household even if they were not the initial, randomly-selected respondent. Hence, the sample is representative of caregivers in U.S. households.

For the state results, the same population weight was applied to the substantive results as was used to calculate incidence in the population of each state (each state had its own weight).

The margin of error for the sample of 6,139 interviews is ± 1.3 . The margin of sampling error for our caregiver sample of 1,247 is conservatively estimated at ± 3.0 percentage points at the 95% level of confidence. Margin of sampling error for state samples, ranging from approximately $n=1,800$ to $n=2,100$ ranges from ± 2.2 to ± 2.3 . For the substantive results in the states surveys, based on the $n=400$ interviews in each, the margin of error is ± 4.9 percentage points. Margin of error will be larger for subgroups within each sample.

H. Cross Tabulations

For the national study, cross tabulations were run on the total 1,247 caregivers, weighted by household. Cross tabulations were also run on each of the state samples of caregivers, with similar variables.

The following tables show key demographic and behavioral variables for the national study, followed by those used in the state studies.

Banner One: Descriptions of Variables

Heading	Labels	Description	Question Root
Gender	Male Female	Gender of caregiver	Recorded gender
Race	Wht	White, Non-Hispanic	Race, from screener
Age	18-34 35-49 50-64 65+	Age of caregiver	Age of caregiver, from screener
Education	<=HS SME CLG CLG+	High school or less Some college, technical college College degree or higher	Q94
Income	Less \$30K \$30-\$49K \$50-\$100K \$100K Plus	Less than \$30,000 household inc. \$30-\$49K household income \$50K-\$100K household income \$100K+ household income	Q95
Emp Care	Yes No	Employed while caregiving Not employed while caregiving	Either a) current caregiver <i>and</i> currently employed, or b) "yes" in Q40 All others, not employed while caregiving
Rec. Age	18-49 50+	Care recipient is 18-49 years old Care recipient is 50+	Q3
Alzheim	Yes No	Care recipient suffers from Alzheimer's or other mental confusion Care recipient does not have Alzheimer's or other mental confusion	Identified in Q11, or Q12 Q12
Distance	In HH < HR 1HR+	Caregiver lives with recipient Caregiver lives less than an hour away from recipient Caregiver lives one hour or more from recipient	Q4

Banner Two: Descriptions of Variables

Heading	Labels	Description	Question Root
Care Status	Prim	Primary caregiver	Either "no", no one else provides unpaid help in Q31, or respondent provides most of the help in Q33
	Sec	Secondary caregiver	Someone else provides most of unpaid help or splits care in Q33
Hrs/Week	0-8	Less than 9 hours	Q27
	9-20	9-20 hours	
	21+	21 or more, including "constant care"	
Care Area	Urb	Caregiver lives in urban area	Q9
	Sub	Caregiver lives in suburban area	
	Rur	Caregiver lives in rural area	
Rec. Area	Urb	Care recipient lives in urban area	Q8 & Q9 (if care recipient lives in caregiver's household)
	Sub	Care recipient lives in suburban	
	Rur	Care recipient lives in rural area	
Health	Exc	Caregiver self reports "excellent" health	Q87
	Very Good	Reports "very good" or "good" health	
	Fair Poor	Reports "fair" or "poor" health	
Outside Resources	Yes	Reports using at least one of the outside/formal services	Q71-Q78
	No	Does not use any of these services	
Level of Burden	1 2 3 4 5	Each caregiver's score on two indices, an hours per week index and type of care index (see tables below) was summed, resulting in his/her assignment to one of seven levels (2, 3, 4, 5, 6, 7, or 8). As in 1996, the seven levels were collapsed into five, with Level 1 being the least intense level of caregiving, and Level 5 being the most intense.	Q27 and Q14-Q26

Level of Burden is the sum of the following two indices:

Hours of Care Index (Q27)	Type of Care Index (Q14-Q26)
0-8 hours = 1	1 IADL / 0 ADLs = 1
9-20 hours = 2	2+ IADLs / 0 ADLs = 2
21-40 hours = 3	1 ADL (with or without IADLs) = 3
41+ or "constant care" = 4	2+ ADLs (with or without IADLs) = 4

Level of Burden:

	Combined score
Level 1	2, 3
Level 2	4
Level 3	5
Level 4	6, 7
Level 5	8

States' Banner: Descriptions of Variables

Heading	Labels	Description	Question Root
Gender	Male Female	Gender of caregiver	Recorded gender
Age	<50 50+	Age of caregiver	Age of caregiver, from screener
Education	<=HS Some Clg Clg+	High school or less Some college, technical college College degree or higher	Q94
Income	Less \$50K \$50K Plus	Less than \$50,000 household inc. \$50K+ household income	Q95
Emp Care	Yes No	Employed while caregiving Not employed while caregiving	Either a) current caregiver <i>and</i> currently employed, or b) "yes" in Q40 All others, not employed while caregiving
Rec. Age	18-49 50+	Care recipient is 18-49 years old Care recipient is 50+	Q3
Rec. Area	URB SUB RUR	Care recipient lives in urban area Care recipient lives in suburban area Care recipient lives in rural area	Q8
Out Res.	Yes No	Reports using at least one of the outside/formal services Does not use any of these services	Q71-Q77
Choice Care	Yes No	Had choice in taking on responsibility of caregiving Did not have choice in taking on responsibility of caregiving	Q59
Type of Care	No ADLs 1+ ADLs	No ADLs/1 or more IADLs 1 or more ADLs (with or without IADLs)	Q14-Q26

I. Regression Analysis

Multiple linear regression investigates the extent to which independent variables (*e.g.*, age, income, race, sex) influence a dependent variable(s) (*e.g.*, hours per week providing care). Regression also helps determine whether a statistically significant influence of an independent variable on a dependent variable indicates a real or superficial relationship by controlling for other independent variables.

Regression analysis was conducted to help determine what factors influence the emotional stress of caregivers, as indicated by a five-point scale in Q57. The following independent variables were used in the model:

- Gender
- Caregiver age
- Education
- Income
- Distance from recipient
- Caregiver status (primary or secondary)
- Self-reported health
- Caring for someone with Alzheimer's or dementia
- Feeling a choice in taking on caregiving responsibilities
- Level of Burden Index

Regressions were also run against feeling the caregiving situation has worsened one's health (Q88). The following independent variables were used:

- Gender
- Caregiver age
- Education
- Income
- Distance from recipient
- Caregiver status (primary or secondary)
- Caring for someone with Alzheimer's or dementia
- Feeling a choice in taking on caregiving responsibilities
- Level of Burden Index

J. Response Rate

The response and refusal rates reported below are based on the Standard Definitions of the American Association for Public Opinion Research (AAPOR) for the final dispositions of cases codes and outcome rates for RDD telephone surveys.³ Information regarding these calculations can be found on AAPOR's website (www.aapor.org).

The overall response rate for the national study is 19%, based on AAPOR's Response Rate 3 formula: $I / (I + P + (R + NC + O) + e(UH + UO))$.⁴ The response rate is higher for the RDD portion of the study (27%), and lower for each of the over-samples conducted from surname and targeted samples (ranges from 5% to 17%).

³ The American Association for Public Opinion Research. 2000. *Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys*. Ann Arbor, Michigan: AAPOR.

⁴ Interviews from Knowledge Networks are not included in the response rate calculation because dispositions for online screening are not comparable.

Appendix B: Topline Results

From a National Survey of Caregivers 18 and Older for National Alliance for Caregiving & AARP January 2004

Interviewing conducted September 5 through December 22, 2003, among N = 1,247 caregivers 18 and older in the United States.

Screening questions, used to identify caregiver respondents at the outset of the interviews for the national study, show the following:

	In the U.S.
Percent of adults who are caregivers	21%
Number of caregivers	44,443,800
Percent of households with caregiver(s)	21%
Number of households with caregiver(s)	22,901,800

Percents may add up to 99% or 101% due to rounding. Data are weighted by gender, age, and race. Margin of sampling error is ± 2.8 percentage points. * indicates less than 1%, and -- indicates zero.

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Appendix B: Topline Results from the National Study

This survey is part of an important national study conducted by AARP and the National Alliance for Caregiving. 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. If you'd like, we could send you a copy of the final report.

1a. Are you <u>currently</u> providing unpaid help to a relative or friend 18 years or older, or, was this something you did in the past 12 months but are no longer doing?	CURRENTLY	66%
	PAST 12 MO.	34
	DK/REF	*

1. How many adults [do you provide this care for? / did you provide this care for in the past 12 months?]	1	69%
	2	22
	3+	8
	DK/REF	1

Mean: 1.7adults

IF ONE PERSON: Now, I'd like to ask you some questions about the adult for whom you [provide/provided] care. IF MORE THAN ONE: Let's focus on the adult for whom you [provide/provided] the most assistance.

1b. What [is/was] this person's relationship to you?	SPOUSE	6%
	MOTHER	28
	FATHER	8
	MOTHER-IN-LAW	7
	FATHER-IN-LAW	2
	SON	3
	DAUGHTER	3
	BROTHER	2
	SISTER	3
	BROTHER-IN-LAW	1
	SISTER-IN-LAW	*
	GRANDMOTHER	9
	GRANDFATHER	3
	GRANDPAR.-IN-LAW	1
	AUNT/UNCLE	5
	OTHER RELATIVE	1
	FRIEND/NEIGHBOR	16
	PARTNER	1
	COUSIN	1
	DK/REF	1

1c&1d. Gender of care recipient. IF NOT KNOWN FROM Q1b RESPONSE: ASK: Would you mind telling me if your () is male or female?	MALE	31%
	FEMALE	65
	DK/REF	4

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2. [Is your (__) currently/ Was your (__) widowed, married, living with a partner, separated, divorced, or single – that is never been married?	WIDOWED	42%
	MARRIED	27
	PARTNER	2
	SEPARATED	3
	DIVORCED	12
	SINGLE	14
	DK/REF	*

3. How old [is/was] your (__)? PROMPT: Your best estimate is fine. <i>Mean age is 66.</i>	18-29	8%
	30-49	13
	50-64	16
	65-74	19
	75-84	24
	85-89	11
	90+	9
	DK/REF	1

4. [Does/Did] your (__) live in your household, within twenty minutes of your home, between 20 minutes and an hour from your home, a one to two hour drive from your home, or more than two hours away?	HOUSEHOLD	24%
	20 MIN AWAY	42
	20 MIN TO 1 HR	19
	1 TO 2 HRS	5
	2 HRS +	10
	DK/REF	*

5. IF NOT IN HOUSEHOLD, DK, OR REF IN Q4: On average, how often [do/did] you visit your (__)? More than once a week, once a week, few times a month, once a month, few times a year, or less often? <i>Base N = 924</i>	> ONCE A WEEK	56%
	ONCE A WEEK	18
	FEW TIMES A MO	11
	ONCE A MONTH	5
	FEW TIMES A YR	7
	LESS OFTEN	2
	DK/REF	1

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6. IF NOT IN HOUSEHOLD, DK, OR REF IN Q4: [Does/Did] your (___) live in: his or her own home, someone else's home, an independent living or retirement community, in an assisted living facility where some care may be provided, a nursing home or facility, somewhere else? <i>Base N = 924</i>	IN OWN HOME	72%
	OTHERS' HOME	11
	IND. LVNG/ RTRMNT	4
	ASSISTED LVING	6
	NURSING HOME	7
	OTHER	*
	DK/REF	*

7. IF NOT IN HOUSEHOLD, DK, OR REF IN Q4 OR NOT IN NURSING HOME IN Q6: [Does/Did] your (___) live: (MULTIPLE PUNCH OKAY) alone, with her/his spouse, with her/his grown children, with other family members, with friends, with an aid, housekeeper, or other staff, or with someone else? <i>Base N = 869</i>	ALONE	47%
	SPOUSE	26
	CHILDREN	11
	OTHER FAMILY	12
	FRIENDS	3
	AID/ HOUSEKPR	3
	SOMEONE ELSE	1
	DK/REF	*

8. IF NOT IN HOUSEHOLD IN Q4: [Does/Did] your (___) live in an urban, suburban, or rural area? <i>Base N = 925</i>	URBAN	33%
	SUBURBAN	38
	RURAL AREA	27
	DK/REF	2

9. And do you live in an urban, suburban or rural area?	URBAN	29%
	SUBURBAN	39
	RURAL AREA	29
	DK/REF	3

10. [Is/Was] your (___) frail, sick, disabled, or none of these? MULTIPLE RESPONSE	FRAIL	28%
	SICK	26
	DISABLED	35
	NONE OF THESE	28
	DK/REF	*

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11. What would you say [is/was] the main problem or illness your () [has/had]?
 PRECODED OPEN END: ACCEPT ONE ANSWER IF "DISABLED", PROBE: What kind
 of disability would that be?

AGING	12%
DIABETES	8
CANCER	8
ALZHEIMER'S	6
HEART DISEASE	7
MOBILITY (CAN'T GET AROUND)	5
STROKE	5
ARTHRITIS	4
BLINDNESS/VISION LOSS	3
LUNG DISEASE/EMPHYSEMA	2
PARKINSON'S	1
SURGERY	2
AMPUTEES	1
HIGH BLOOD PRESSURE/HYPERTENSION	1
BROKEN BONES	2
DEAFNESS/HEARING LOSS	*
FEEBLE, UNSTEADY, FALLING	1
MENTAL RETARDATION	1
MENTAL/EMOTIONAL ILLNESS/DEPRESSION	7
OSTEOPOROSIS	1
PARAPLEGIA	1
NEUROLOGICAL PROBLEM/DISORDER	1
MS	1
KIDNEY	1
FINANCES	2
DRUG/ALCOHOL PROBLEMS	1
BACK PROBLEMS	1
AIDS	*
OTHER (SPECIFY)	9
DON'T KNOW/REFUSE	4

12. IF ALZHEIMER'S/	YES	23%
CONFUSION/DEMENTIA <u>NOT</u>	NO	76
<u>MENTIONED</u> : [Does/Did] your ()	DK/REF	1
suffer from Alzheimer's or other mental		
confusion? <i>Combined with "Alzheimer's"</i>		
<i>responses in Q11.</i>		

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13. For how long [have you been providing/did you provide] help to your (___)? PROMPT: Your best estimate is fine. PRE-CODED OPEN END	OCCASION. < 6 MONTHS 6 MOS - 1 YR 1-4 YEARS 5-9 YEARS 10 YEARS+ DK/REF	5% 16 18 31 15 14 1
<i>Mean: 4.3 years</i>		

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 (___)....

	YES	NO	DK/REF
14. Get in and out of beds and chairs	36%	64	--
15. Get dressed	29%	71	*
16. Get to and from the toilet	23%	77	--
17. Bathe or shower	26%	74	--
18. Dealing with incontinence or diapers	16%	84	*
19. By feeding him or her	18%	82	--

[Do/Did] you provide help for your (___) with:

	YES	NO	DK/REF
20. Giving medicines, pills, or injections	41%	59	--
21. Managing finances, such as paying bills, or filling out insurance claims	64%	36	--
22. Grocery shopping	75%	25	*
24. Housework, such as doing dishes, laundry, or straightening up	69%	31	--
24b. Preparing meals	59%	42	--
25. Transportation, either by driving him or her, or helping your (___) get transportation	82%	18	*
26. Arranging or supervising services from an agency, such as nurses or aides	30%	70	--

IF NO/DK/REF TO ALL Q14-Q26: TERMINATE

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27. Thinking now of all the kinds of help you [provide/provided] for your (___), about how many hours [do/did] you spend in an average week, doing these things?	<1	4%
	1-8	44
	9-20	23
	21-39	8
	40+	17
	DK/REF	5
28. [Does/Did] your (___) take any prescription medicine?	YES	85%
	NO	12
	DK/REF	2
29. IF YES IN Q28: Would you say your (___) [needs/needed] someone to oversee giving him/her medicine in the right amount and on time, or that he/she [manages/had managed] this well on his/her own? <i>Base N = 1049</i>	NEEDS HELP	45%
	MANAGES	55
	DK/REF	1
30. IF YES IN Q28: Do you feel you [know/knew] as much as you [need/needed] to about the prescription medicine your (___) [takes/took], or that you [need/needed] to know more about it? <i>Base N = 1049</i>	KNOW AS MUCH	76%
	KNOW MORE	22
	DK/REF	2
31. Has anyone else provided <u>unpaid</u> help to your (___) during the last 12 months?	YES	59%
	NO	37
	DK/REF	3

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32a. IF YES IN Q31: What relationship [are/were] they to your (___)?	SPOUSE/FORMER	7%	
	MOTHER	6	
	FATHER	1	
MULTIPLE RESPONSE	MOTHER/FATHER-IN-LAW	*	
	SON	26	
IF "CHILDREN", PROBE: Would that be (___)'s son or daughter or both?	DAUGHTER	42	
	SON/DAUGHTER-IN-LAW	6	
	BROTHER	1	
	SISTER	5	
	BROTHER/SISTER-IN-LAW	*	
	NIECE/NEPHEW	5	
	GRANDSON/GRANDDDGHTR	9	
	OTHER RELATIVE	3	
	ALL FAMILY	4	
	NON-REL./FRIEND/NEIGH.	11	
	VOLUNTEER	1	
	OTHER (SPECIFY)	1	
	DK/REF	1	
<hr/>			
33. IF YES IN Q31: Who would you consider to be the person who [provides/provided] <i>most</i> of the unpaid care for your (___): you yourself, or someone else? <i>Base N = 742</i>	SELF	34%	
	SOMEONE ELSE	55	
	SPLIT 50-50 (VOL.)	10	
	DK/REF	1	
<hr/>			
IF NOT IN NURSING HOME: During the last 12 months, did your (___) receive <u>paid</u> help from any of the following - regardless of who paid for it. First: <i>Base N = 1191</i>			
	YES	NO	DK/REF
34. An aide or nurses hired through an agency or service?	23%	74	3
35. An aide or nurse hired <i>independently</i> - that is not through an agency or service?	7%	90	3
36. A housekeeper hired to clean or cook?	20%	80	*
37. Any other people who are paid to help her/him?	12%	86	2
<hr/>			
38. IF YES TO ANY IN Q34-Q37 ABOVE: Who would you say [provides/provided] more of your (___)'s care: you, other unpaid helpers, or <u>paid</u> helpers such as nurses or aides? <i>Base N = 468</i>	RESPONDENT	44%	
	OTHER UNPAID	34	
	PAID HELPERS	19	
	DK/REF	3	

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39. Now I have a few questions about you.	FULL TIME	48%
Are you currently working full time, working part time, a student, disabled, retired, a homemaker, unemployed and looking for work, or something else?	PART TIME	11
	RETIRED	16
	SOMETHING ELSE	*
	DK/REF	*

40. IF NOT CURRENTLY EMPLOYED OR A PAST CAREGIVER: [Have you been employed at any time since you began helping your (___)? / Were you employed at any time while you were helping your (___)]? <i>Base N = 782</i>	YES	59%
	NO	41
	DK/REF	*

IF WORKING WHILE A CAREGIVER: In your experience as both a worker and a caregiver, did you ever: *Base N = 935*

	YES	NO	DK/REF
41. Have to go in late, leave early, or take time off during the day to provide care	57%	43	*
42. Have to take a leave of absence	17%	83	*
43. Have to go from working full-time to part-time, or taken less demanding job	10%	90	*
44. Have to turn down a promotion	4%	95	1
45. Lose any of your job benefits	5%	95	1
46. Have to give up working entirely	6%	94	--
47. Choose early retirement	3%	97	*

52. IF NOT SPOUSE: How much of your money would you estimate you [spend/spent] in a typical month for groceries, medicines, or other kinds of cash support for your (___)'s care if any? Your best estimate is fine. <i>Base N = 1180</i>	\$0	34%
	\$1-\$50	15
	\$51-\$100	11
	\$101-\$500	25
	\$501+	3
	DK/REF	11

*Mean for those who make financial contributions:
\$200 per month*

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There may have been other ways in which providing care to your (__) has affected your life. As a caregiver,

	YES	NO	DK/REF
53. [Do/Did] you have less time for friends or other family members than before?	51%	48	1
54. [Do/Did] you have to give up vacations, hobbies, or your own social activities?	44%	56	*
55. [Do/Did] you have to get less exercise than before?	26%	74	*
56. Think of a scale from 1 to 5, where 1 is not a strain at all and 5 is very much of a strain. How much of a physical strain would you say that caring for your (__) [is/was] for you?	1 NOT A STRAIN		44%
	2		23
	3		17
	4		8
	5 VERY MUCH		7
	DK/REF		1
57. 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 (__) [is/was] for you?	1 NOT STRESSFUL		27%
	2		17
	3		20
	4		16
	5 VERY STRESSFUL		18
	DK/REF		1
58. 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 (__) [is/was] for you?	1 NO HARDSHIP		62%
	2		14
	3		11
	4		5
	5 GREAT DEAL		7
	DK/REF		*
59. We have been talking about the help you [provide/provided] for your (__). Do you feel you had a choice in taking on this responsibility for caring for your (__)?	YES		59%
	NO		39
	DK/REF		1

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

	YES	NO	DK/REF
60. Talking with or seeking advice from friends or relatives?	61%	39	*
61. Exercising or working out?	41%	59	*
62. Taking any kind of medication	12%	88	*
63. Talking to a professional or spiritual counselor	27%	73	*
65. Praying	73%	27	*
66. Going on the Internet to find information	33%	67	*
67. Reading about caregiving in books or other materials	44%	56	*

IF YES IN Q66: Which of the following things have you looked for on the Internet? *All Base N = 431*

	YES	NO	DK/REF
68. Information about your (___)'s condition and treatment?	88%	11	*
69. Information about services available for people like your (___)?	55%	45	--
70. Support or advice from people with similar caregiving experiences?	39%	61	--

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

	YES	NO	DK/REF
71. [Requested/Request] information about how to get financial help for your (___)?	25%	75	*
72. [Taken/Take] part in support groups for caregivers?	7%	92	*
73. [Used/Use] a respite service to take care of your (___) to free up your time?	5%	93	3
74. [Helped/Help] enroll your (___) in Adult Day Care?	5%	95	*
75. [Helped/Help] enroll your (___) in a recreation program or camp?	8%	92	*
77. [Had/Have] an outside service such as Meals on Wheels deliver meals to your (___)'s home?	11%	89	*
78. [Had/Have] an outside service provide transportation for your (___) instead of you providing the transportation?	18%	82	*

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Have you done or obtained any of these types of things to make it easier to care for your (___):

	YES	NO	DK/REF
79. Had modifications made in the house or apartment where your (___) [lives/lived] to make things easier for your (___)?	39%	61	*
80. Obtained formal training of some sort about how to care for a person with your (___)'s needs?	18%	81	*
81. Obtained a bathing bench, magnifying lens for reading, or other helpful devices for your (___)?	40%	60	1

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

	YES	NO	DK/REF
82a. Keeping the person I care for safe at home	30%	69	1
82b. Managing challenging behaviors, such as wandering	14%	85	1
82c. Easy activities I can do with the person I care for	27%	73	*
82d. Managing incontinence or toileting problems	11%	89	*
82e. Moving or lifting the person I care for	16%	84	*
82f. Balancing my work and family responsibilities	29%	71	1
82g. Finding time for myself	35%	64	1
82h. Choosing an assisted living facility	13%	87	*
82i. Choosing a nursing home	8%	92	1
82j. Choosing a home care agency	13%	86	*
82k. How to talk with doctors and other healthcare professionals	22%	78	*
82l. Managing my emotional and physical stress	29%	70	1
82m. Making end-of-life decisions	20%	80	1
82n. Finding non-English language educational materials	5%	95	*

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83. If you were looking for information about some aspect of helping take care of your (___), where would you turn? MULTIPLE RESPONSE	INTERNET	29%
	DOCTOR	28
	FAMILY/ FRIEND	15
	HEALTH PROFESSIONALS	10
	BOOKS, MAG., LIBRARY	7
	GOV'T AGENCY	5
	SENIOR CITIZEN'S CENTER	3
	CHURCH/REL. ORG.	3
	AGING ASSOC./GRP/ORG	2
	EMPLOYER	1
	SUPPORT GRPS/PPL LIKE ME	1
	HOSPITAL/CLINIC	1
	OTHER	2
DK/REF	10	

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

87. How would you describe your own health? Is it excellent, very good, good, fair, or poor?	EXCELLENT	25%
	VERY GOOD	30
	GOOD	28
	FAIR	12
	POOR	5
	DK/REF	*

88. How would you say taking care of your (___) has affected your health? Has made it better, not affected it, or made it worse?	BETTER	9%
	NO EFFECT	74
	WORSE	15
	DK/REF	2

89. Are you currently:	Married	56%
	Living w/ a partner	6
	Widowed	6
	Separated	3
	Divorced	11
	Single, never married	18
	DK/REF	*

91. 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	YES	14%
	NO	86
	DK/REF	*

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92. Did your () serve in the US Armed Forces?	YES	17%
	NO	82
	DK/REF	1

93. Are there any children or grandchildren living in your household under 18 years of age?	YES	37%
	NO	62
	DK/REF	*

94. What is the last grade of school you completed?	< THAN HS	5%
	HS GRAD	29
	SOME COLL	27
	TECH SCHL	3
	COLL GRAD	22
	GRAD SCHL/ WORK	13
	DK/REF	*

95. Last year, what was your total annual household income from all sources, before taxes?	< \$15K	8%
	\$15K-\$30K	17
	\$30K-\$50K	26
	\$50K-\$75K	18
	\$75K-\$100K	9
	\$100K+	15
	DK/REF	9

Gender	MALE	39%
	FEMALE	61

Race	WHITE	73%
	BLACK	12
	HISPANIC	10
	ASIAN	4
	OTHER	*

Age	18-24	11%
	25-34	15
	35-44	22
	45-54	23
	55-64	18
	65-74	9
	75+	4

Appendix C: CATI Questionnaire

Intro

Hello. My name is _____ and I am an interviewer with Princeton Data Source. 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. (IF NEEDED REASSURE RESPONDENT: This research company will never try to sell you anything. IF ASK: The survey takes about 20 minutes.)

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)

Screen

S1. In the last 12 months, have you or anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you. (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 \$, CODE "NO"

YES -- PERSON ON PHONE IS CAREGIVER

YES -- ANOTHER PERSON IN HOUSEHOLD

NO

DK (TERMINATE)

REF (TERMINATE)

S2. Just to be sure I speak to people of all ages, how old were you on your last birthday?

____ (GO TO S2b)

DK

REF

S2b. IF DK/REFUSE: Well are you between:

18-24

25-34

35-44

45-54

55-64

65-74, or

75 or older?

DK (TERMINATE)

REF (TERMINATE)

S3. Are you of Hispanic origin or background?

YES

NO

DK

REF

S4. Would you say you are white, black or African American, Asian or Pacific Islander, or something else?

WHITE

BLACK

ASIAN

OTHER (SPECIFY____)

DK (TERMINATE)

REF (TERMINATE)

S5. RECORD GENDER

MALE

FEMALE

S6. How many people including children live in the household?

1 -- LIVES ALONE (GO TO S13a)

DK (TERMINATE)

REF (TERMINATE)

S7. 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]

YES

NO (GO TO S9)

DK (TERMINATE)

REF (TERMINATE)

S8. IF HOUSEHOLDER: Are you related by marriage, blood, or adoption to anyone in the household?

YES (GO TO S13a)

NO (GO TO S13a)

DK (TERMINATE)

REF (TERMINATE)

S9. Thinking about the person who owns/rents the house, please tell me if that person is 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]

YES

NO

DK (TERMINATE)

REF (TERMINATE)

S10. Thinking about the person who owns/rents the house, please tell me how old they are? PROMPT: Your best estimate is fine.

DK (TERMINATE)

REF (TERMINATE)

S11. As far as you know, is the person of Hispanic origin or background?

YES
NO
DK
REF

S12. Would you say they are white, black or African American, Asian or Pacific Islander, or something else?

WHITE
BLACK
ASIAN
OTHER (_____)
DK (TERMINATE)
REF (TERMINATE)

S13a.

- IF "NO" CAREGIVER IN S1: END INTERVIEW - TERMINATE AND THANK YOU.
- IF "INITIAL RESPONDENT CAREGIVER": GO TO Q1a.
- IF "INITIAL RESPONDENT NOT CAREGIVER, BUT CAREGIVER IN HH":

S13. May I please speak to the person in your household who is providing unpaid care to a relative or friend 18 years or older? **IF MORE THAN ONE CAREGIVER ASK TO SPEAK TO THE ONE WITH THE LAST BIRTHDAY.**

YES
NOT AVAILABLE (ARRANGE CALLBACK)
NO (CALL BACK TO CONVERT)
DK (CALL BACK TO CONVERT)
REF (CALL BACK TO CONVERT)

CAREGIVER ON PHONE:

S14. Hello. We are conducting a survey about caregiving, by which I mean providing unpaid care to a relative or friend 18 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 need not live with you.

S15. Just to confirm, in the last 12 months, have you provided this kind of unpaid help to a relative or friend who is 18 years or older – or are doing so currently?

YES

NO (Is there someone else in the household who is a caregiver? IF YES: ASK TO SPEAK TO THE PERSON, THEN RETURN TO S14. OTHERWISE TERMINATE.)

DK (CALL BACK TO CONVERT)

REF (CALL BACK TO CONVERT)

S16. Just to be sure I speak to people of all ages, how old were you on your last birthday?

DK

REF

S16b. IF DK/REFUSE: Well are you between:

18-24

25-34

35-44

45-54

55-64

65-74, or

75 or older?

DK (TERMINATE)

REF (TERMINATE)

S17. Are you of Hispanic origin or background?

YES

NO

DK

REF

S18. Would you say you are white, black or African American, Asian or Pacific Islander, or something else?

WHITE

BLACK

ASIAN
OTHER (SPECIFY____)
DK (TERMINATE)
REF (TERMINATE)

S19. RECORD GENDER
GO TO Q1a.

ALL CAREGIVERS:

Characteristics of relationship

This survey is part of an important national study conducted by AARP and the National Alliance for Caregiving. 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. If you'd like, we could send you a copy of the final report.

1a. Are you currently providing unpaid help to a relative or friend 18 years or older, or, was this something you did in the past 12 months but are no longer doing?

CURRENTLY
PAST 12 MONTHS
DK
REF

IF CURRENTLY: USE PRESENT TENSE, FIRST VERB IN [BRACKETS]
IF PAST 12 MONTHS: USE PAST TENSE, SECOND VERB IN [BRACKETS]

1. How many adults do you provide this care for? / did you provide this care for in the past 12 months?]

1

DK
REF

IF ONE PERSON: Now, I'd like to ask you some questions about the adult for whom you [provide/provided] care.

IF MORE THAN ONE: Let's focus on the adult for whom you [provide/provided] the most assistance.

Q1b. What [is/was] this person's relationship to you? PRE-CODED OPEN END

SPOUSE
MOTHER
FATHER
MOTHER-IN-LAW
FATHER-IN-LAW
SON
DAUGHTER
BROTHER
SISTER
BROTHER-IN-LAW
SISTER-IN-LAW
GRANDMOTHER
GRANDFATHER
GRANDPARENT-IN-LAW
AUNT/UNCLE
OTHER RELATIVE (SPECIFY____)
FRIEND/NON-RELATIVE/NEIGHBOR
COMPANION/PARTNER
DK
REFUSE

Q1c. IF "SPOUSE," "AUNT/UNCLE," "GRANDPARENT IN-LAW": RECORD GENDER OF THE RESPONDENT'S (Q1B CODE):

MALE
FEMALE
DK

Q1d. IF "OTHER RELATIVE", "FRIEND", "COMPANION": Would you mind telling me if your (Q1B CODE) is male or female?

MALE
FEMALE
REF

2. [Is your (Q1B CODE) currently/Was your (Q1B CODE)] widowed, married, living with a partner, separated, divorced, or single – that is never been married?

WIDOWED
MARRIED
LIVING WITH A PARTNER
SEPARATED
DIVORCED
SINGLE
DK
REF

3. How old [is/was] your (Q1B CODE)? PROMPT: Your best estimate is fine.

DK
REF

4. [Does/Did] your (Q1B CODE) live....

In your household, (GO TO Q9)
Within twenty minutes of your home,
Between 20 minutes and an hour from your home,
A one to two hour drive from your home, or
More than two hours away?
DK (GO TO Q7)
REF (GO TO Q7)

5. IF NOT IN HOUSEHOLD: On average, how often [do/did] you visit your (Q1B CODE)? More than once a week, once a week, few times a month, once a month, few times a year, or less often?

MORE THAN ONCE A WEEK
ONCE A WEEK
FEW TIMES A MONTH
ONCE A MONTH
FEW TIMES A YEAR
LESS OFTEN
DK
REF

6. IF NOT IN HOUSEHOLD: [Does/Did] your (Q1B CODE) live in:

His or her own home,
Someone else's home,
An independent living or retirement community,
In an assisted living facility where some care may be provided,
A nursing home or facility, (GO TO Q8)
Or somewhere else? (SPECIFY _____)
DK
REF

7. [Does/Did] your (Q1B CODE) live: MULTIPLE PUNCH

Alone,
With her/his spouse,
With her/his grown children,
With other family members,
With friends,
With an aide, housekeeper, or other staff,
Or with someone else? (SPECIFY _____)
DK
REF

8. [Does/Did] your (Q1B CODE) live in an urban, suburban, or rural area?

URBAN
SUBURBAN
RURAL AREA
DK
REF

9. And do you live in an urban, suburban, or rural area?

URBAN
SUBURBAN
RURAL AREA
DK
REF

Characteristics of recipient

10. [Is/Was] your (Q1B CODE) frail, sick, disabled, or none of these? (ACCEPT MULTIPLE RESPONSES)

FRAIL
SICK
DISABLED
NONE OF THESE
DK
REF

11. What would you say [is/was] the main problem or illness your (Q1B CODE) [has/had]? PRECODED OPEN END: ACCEPT ONE ANSWER
IF "DISABLED", PROBE: What kind of disability would that be?

AIDS
ALZHEIMER'S/CONFUSION/DEMENTIA/FORGETFULNESS (GO TO Q13)
AMPUTEE
ARTHRITIS
BLINDNESS/VISION LOSS, CAN'T SEE WELL
BLOOD PRESSURE/HYPERTENSION
BOREDOM, NOTHING TO DO
BROKEN BONES
CANCER
DEAFNESS/HEARING LOSS
DIABETES
FEEBLE, UNSTEADY, FALLING
HEART DISEASE
LUNG DISEASE, EMPHYSEMA
MENTAL RETARDATION
MENTAL ILLNESS, EMOTIONAL ILLNESS, DEPRESSION
MOBILITY (CAN'T GET AROUND)
OLD AGE, JUST OLD
OSTEOPOROSIS
PARAPLEGIA
PARKINSON'S
SPEAKING, CAN'T SPEAK
STROKE
OTHER (SPECIFY____)

DK

REF

12. IF ALZHEIMER'S/CONFUSION/DEMENTIA NOT MENTIONED:
[Does/Did] your (Q1B CODE) suffer from Alzheimer's or other mental
confusion?

YES – ALZHEIMER'S

YES--OTHER

NO

DK

REF

13. For how long [have you been providing/did you provide] help to your (Q1B
CODE)? PROMPT: Your best estimate is fine. PRE-CODED OPEN END

_____ YEARS

SIX MONTHS TO ONE YEAR

LESS THAN SIX MONTHS

OCCASIONALLY, ON AND OFF

DK

REF

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 (Q1B CODE)...

YES

NO

DK

REF

14. Get in and out of beds and chairs

15. Get dressed

16. Get to and from the toilet

17. Bathe or shower

18. Dealing with incontinence or diapers

19. By feeding him or her

20. Giving medicines, pills, or injections

[Do/Did] you provide help for your (Q1B CODE) with:

YES

NO

DK
REF

- 21. Managing finances, such as paying bills, or filling out insurance claims
- 22. Grocery shopping
- 24. Housework, such as doing dishes, laundry, or straightening up
- 24b. Preparing meals
- 25. Transportation, either by driving him or her, or helping your (Q1B CODE) get transportation
- 26. Arranging or supervising services from an agency, such as nurses or aides

IF NO/DK/REF TO ALL Q14-Q26: TERMINATE (TREAT AS NON CAREGIVER HOUSEHOLD)

- 27. Thinking now of all the kinds of help you [provide/provided] for your (Q1B CODE), about how many hours [do/did] you spend in an average week, doing these things?

LESS THAN 1 HOUR PER WEEK
____ HOURS PER WEEK
CONSTANT CARE (VOLUNTEERED)
DK
REF

Medications

- 28. [Does/Did] your (Q1B CODE) take any prescription medicine?

YES
NO - SKIP TO 31
DK- SKIP TO 31
REF- SKIP TO 31

- 29. Would you say your (Q1B CODE) [needs/needed] someone to oversee giving him/her medicine in the right amount and on time, or that he/she [manages/had managed] this well on his/her own?

NEEDS HELP
MANAGES ON OWN
DK
REF

30. Do you feel you [know/knew] as much as you [need/needed] to about the prescription medicine your (Q1B CODE) [takes/took], or that you [need/needed] to know more about it?

KNOW AS MUCH AS NEED TO KNOW
NEEDED TO KNOW MORE ABOUT IT
DK
REF

Other caregiver support

31. Has anyone else provided unpaid help to your (Q1B CODE) during the last 12 months?

YES
NO -SKIP TO 34
DK - SKIP TO 34
REF - SKIP TO 34

32a. What relationship [are/were] they to your (Q1B CODE)? CODE UP TO TWO

IF "CHILDREN", PROBE: Would that be (Q1B CODE)'s son or daughter or both?
CODE IN TWO SEPARATE COLUMNS.

SPOUSE
MOTHER
FATHER
SON
DAUGHTER
FATHER-IN-LAW/MOTHER-IN-LAW
BROTHER
SISTER
BROTHER-IN-LAW/SISTER-IN-LAW
GRANDSON/GRANDDAUGHTER
OTHER RELATIVE
ALL FAMILY
NON RELATIVE/FRIEND/COMPANION/NEIGHBOR
VOLUNTEER (E.G., RED CROSS)
NIECE/NEPHEW
SON-IN-LAW/DAUGHTER-IN-LAW
OTHER (SPECIFY____)
NO ONE ELSE (GO TO Q34)

DK (GO TO Q33)
REF(GO TO Q33)

Q32b. Just to be sure I have this down correctly, that would be your (Q1B CODE)'s (Q32b CODE) who also [provides/provided] care?

YES
NO
DK
REF

33. Who would you consider to be the person who [provides/provided] *most* of the unpaid care for your (Q1B CODE): you yourself, or someone else?

SELF
SOMEONE ELSE
WE SPLIT IT 50-50 (VOLUNTEERED)
DK
REF

(IF NURSING HOME IN 6, SKIP TO Q39)

During the last 12 months, did your (Q1B CODE) receive paid help from any of the following - regardless of who paid for it. First"
REPEAT STEM AS NECESSARY

YES
NO
DK
REF

34. An aide or nurses hired through an agency or service?

35. An aide or nurse hired *independently*- that is not through an agency or service?

36. A housekeeper hired to clean or cook?

37. Any other people who are paid to help her/him?

38. (IF YES TO ANY IN Q34-37 ABOVE): Who would you say [provides/provided] more of your (Q1B CODE)'s care: you, other unpaid helpers, or paid helpers such as nurses or aides?

YOU (THE RESPONDENT)
OTHER UNPAID HELPERS
PAID HELPERS

DK
REF

Stress on working caregivers

39. Now I have a few questions about you. Are you currently:

Working full time, (GO TO 41 IF Q1a = 1, CURRENTLY)
Working part time, (GO TO 41 IF Q1a = 1, CURRENTLY)
A student,
Disabled,
Retired,
A homemaker,
Unemployed and looking for work, or
Something else (SPECIFY _____)
DK
REF

40. [Have you been employed at any time since you began helping your (Q1B CODE)? / Were you employed at any time while you were helping your (Q1B CODE)]?

YES
NO (SKIP TO 52)
DK (SKIP TO 52)
REF (SKIP TO 52)

In your experience as both a worker and a caregiver, did you ever:

YES
NO
DK
REF

- 41. Have to go in late, leave early, or take time off during the day to provide care
- 42. Have to take a leave of absence
- 43. Have to go from working full-time to part-time, or taken a less demanding job
- 44. Have to turn down a promotion
- 45. Lose any of your job benefits
- 46. Have to give up working entirely
- 47. Choose early retirement

Physical, emotional and financial stress of caregiving

52. ONLY ASK IF CARE RECIPIENT IS NOT R's SPOUSE IN Q1b

How much of your money would you estimate you [spend/spent] in a typical month for groceries, medicines, or other kinds of cash support for your (Q1B CODE)'s care, if any? PROBE: Your best estimate is fine.

_____ RECORD AMOUNT TO NEAREST DOLLAR

DK

REF

There may have been other ways in which providing care to your (Q1B CODE) has affected your life. As a caregiver,

YES

NO

DK

REF

53. [Do/Did] you have less time for friends or other family members than before?

54. [Do/Did] you have to give up vacations, hobbies, or your own social activities?

55. [Do/Did] you have to get less exercise than before?

56. Think of a scale from 1 to 5, where 1 is not a strain at all and 5 is very much of a strain. How much of a physical strain would you say that caring for your (Q1B CODE) [is/was] for you?

1 NOT AT ALL A STRAIN

2

3

4

5 VERY MUCH OF A STRAIN

DK

REF

57. 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 (Q1B CODE) [is/was] for you?

- 1 NOT AT ALL STRESSFUL
- 2
- 3
- 4
- 5 VERY STRESSFUL
- DK
- REF

58. 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 (Q1B CODE) [is/was] for you?

- 1 NO FINANCIAL HARDSHIP AT ALL
- 2
- 3
- 4
- 5 GREAT DEAL OF FINANCIAL HARDSHIP
- DK
- REF

59. We have been talking about the help you [provide/provided] for your (Q1B CODE). Do you feel you had a choice in taking on this responsibility for caring for your (Q1B CODE)?

- YES
- NO
- DK
- REF

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

- YES
- NO
- DK
- REF

- 60. talking with or seeking advice from friends or relatives?
- 61. exercising or working out?
- 62. taking any kind of medication?
- 63. talking to a professional or spiritual counselor?
- 65. praying?
- 66. going on the Internet to find information?
- 67. reading about caregiving in books or other materials?

IF YES IN 66. ASK 68-70:

Which of the following things have you looked for on the Internet?

YES
NO
DK
REF

- 68. Information about your (Q1B CODE)'s condition and treatment?
- 69. Information about services available for people like your (Q1B CODE)?
- 70. Support or advice from people with similar caregiving experiences?

Information/Services

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

YES
NO
DK
REF

PLEASE PROGRAM SO THAT Q71 AND Q72 COME LAST IN THE SERIES

- 71. [Requested/Request] information about how to get financial help for your (Q1B CODE)?
- 72. [Taken/Take] part in support groups for caregivers?
- 73. [Used/Use] a respite (**RESS** - PIT) service to take care of your (Q1B CODE) to free up your time?
- 74. [Helped/Help] enroll your (Q1B CODE) in Adult Day Care?
- 75. [Helped/Help] enroll your (Q1B CODE) in a recreation program or camp?
- 77. [Had/Have] an outside service such as Meals on Wheels deliver meals to your (Q1B CODE)'s home?
- 78. [Had/Have] an outside service provide transportation for your (Q1B CODE) instead of you providing the transportation?

Have you done or obtained any of these types of things to make it easier to care for your (Q1B CODE):

YES
NO
DK
REF

79. Had modifications made in the house or apartment where your (Q1B CODE) [lives/lived] to make things easier for your (Q1B CODE)?

80. Obtained formal training of some sort about how to care for a person with your (Q1B CODE)'s needs?

81. Obtained a bathing bench, magnifying lens for reading, or other helpful devices for your (Q1B CODE)?

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

YES
NO
DK
REF

82a. Keeping the person I care for safe at home

82b. Managing challenging behaviors, such as wandering

82c. Easy activities I can do with the person I care for

82d. Managing incontinence or toileting problems

82e. Moving or lifting the person I care for

82f. Balancing my work and family responsibilities

82g. Finding time for myself

82h. Choosing an assisted living facility

82i. Choosing a nursing home

82j. Choosing a home care agency

82k. How to talk with doctors and other healthcare professionals

82l. Managing my emotional and physical stress

82m. Making end-of-life decisions

82n. Finding non-English language educational materials

83. If you were looking for information about some aspect of helping take care of your (Q1B CODE), where would you turn? DO NOT READ CODES MULTIPLE PUNCH IF THEY VOLUNTEER MORE THAN ONE

DOCTOR
NURSE, OTHER HEALTH PROFESSIONALS
INTERNET
BOOKS, MAGAZINES, LIBRARY
EMPLOYER
SENIOR CITIZEN'S CENTER
OTHER (SPECIFY _____)
DK
REF

Demographics

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

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

EXCELLENT
VERY GOOD
GOOD
FAIR
POOR
DK
REF

88. How would you say taking care of your (Q1B CODE) has affected your health? Has it made it better, not affected it, or made it worse?

MADE IT BETTER
NOT AFFECTED IT
MADE IT WORSE
DK
REF

89. Are you currently: READ LIST

Married,
Living with a partner,
Widowed,
Separated,
Divorced,
Single, that is never been married
DK
REF

91. 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

YES
NO
DK
REF

92. Did your (Q1B CODE) serve in the US Armed Forces?

YES
NO
DK
REF

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

YES
NO
DK
REF

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

LESS THAN HS
HS GRAD/GED
SOME COLLEGE
TECHNICAL SCHOOL
COLLEGE GRAD
GRADUATE SCHOOL/GRAD WORK
DK

REF

95. Last year, was your total annual household income from all sources, before taxes over or under \$50,000?

IF UNDER \$50,000:

Over or under 30,000?

OVER (GO TO 96)

UNDER

DK (GO TO 96)

REF(GO TO 96)

If UNDER \$30,000:

Over or under 15,000?

OVER (GO TO 96)

UNDER (GO TO 96)

DK (GO TO 96)

REF(GO TO 96)

IF OVER 50,000:

Over or under 100,000?

OVER (GO TO 96)

UNDER

DK (GO TO 96)

REF(GO TO 96)

IF UNDER 100,000:

Over or under 75,000?

OVER (GO TO 96)

UNDER (GO TO 96)

DK (GO TO 96)

REF(GO TO 96)

96. Besides the telephone number I reached you on, how many other telephone numbers in your house, if any, could I have reached you on? Don't include fax or modem lines or cell phones.

RECORD SINGLE DIGIT NUMBER

—

NONE

REF

If the situation arose, would you be interested in participating in future research on caregivers?

YES (RESPONDENT'S NAME _____, PHONE _____)

NO

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 (THANK AND TERMINATE)

DK (THANK AND TERMINATE)

REF (THANK AND TERMINATE)

IF YES, ASK: Who should the reporter ask for? _____ What is the best number to reach you during the day on weekdays? (____) _____

Thank you very much for your time. Your responses have been very helpful to this research.