CAREGIVING IN THE U.S.

EXECUTIVE SUMMARY

conducted by
The NATIONAL ALLIANCE for CAREGIVING
in collaboration with AARP

Funded by
MetLife Foundation

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

AARP is a nonprofit, nonpartisan membership organization that helps people 50+ have independence, choice and control in ways that are beneficial and affordable to them and society as a whole. We produce *AARP The Magazine*, published bimonthly; *AARP Bulletin*, our monthly newspaper; *AARP Segunda Juventud*, our bimonthly magazine in Spanish and English; *NRTA Live & Learn*, our quarterly newsletter for 50+ educators; and our website, www.aarp.org. AARP Foundation is our affiliated charity that provides security, protection, and empowerment to older persons in need with support from thousands of volunteers, donors, and sponsors. We have staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.

MetLife Foundation, established in 1976 by MetLife, has been involved in a variety of healthy aging initiatives addressing issues of caregiving, intergenerational activities, mental fitness, health and wellness programs and volunteer opportunities. Since 1986, the Foundation has supported research on Alzheimer's disease. The Foundation was the sponsor of *The Forgetting: A Portrait of Alzheimer's*, the Emmy-winning primetime PBS documentary and educational outreach program on Alzheimer's disease, which provides resources for caregivers. For more information about MetLife Foundation, visit www.metlife.org.

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Introduction and Background

The purpose of this study was to determine how many caregivers there are in the U.S., who they are, what they do as caregivers, and how caregiving affects their lives. We also wanted to learn about the people who benefit from the care they provide.

We estimate there are 44.4 million caregivers age 18 and older in the U.S. (21% of the adult U.S. population) who provide unpaid care to an adult family member or friend who is also age 18 or older. These caregivers are present in an estimated 22.9 million households (21% of U.S. households)

Most caregivers in our study say they experience little physical strain, emotional stress, or financial hardship as a result of being a caregiver. Nonetheless, caregivers who provide the greatest number of hours of care and the most intense care are likely to say caregiving takes a toll on them physically, emotionally, and financially. These caregivers often feel they had to assume the responsibility for caring for another person. Although this group represents 10-31% of all caregivers, they are the group most at risk for experiencing negative consequences from this role. With the existing shortage of health care workers in the U.S. today, these caregivers represent the backbone of the long-term care system.

Overview of Methodology

This study is based on a national survey of 6,139 adults from which 1,247 caregivers were identified.[1] The interviews included 200 African-American, 200 Hispanic and 200 Asian-American caregivers who were obtained through oversampling using additional targeted and surname samples for Hispanic and Asian-American caregivers. Most interviews were conducted in English over the telephone between September 5 and December 22, 2003. A Spanish version of the interview was initially offered to non-English speaking people of Hispanic descent.[2]

For purposes of this study, caregivers were defined as people age 18 and over who help another person age 18 or older with at least one of thirteen tasks that caregivers commonly perform. These activities range from helping another manage finances, shop for groceries, or do housework (instrumental activities of daily living) or personal care such as to helping someone get in and out of a chair or bed, get dressed, bathe, use the toilet, or eat (activities of daily living). By using this definition of caregiving, the study focused on those caregivers who are actively engaged in providing specific types of care for adults of all ages.

To understand the range of experiences and impact on caregivers, a Level of Burden Index was used. Level of Burden is based on an index derived from the activities of daily living (ADLs), instrumental activities of daily living (IADLs) and the amount of time devoted to caregiving. Level 1 represents the least amount of responsibility and Level 5 the greatest amount of responsibility. This measure is important as Level of Burden, the feeling of having a choice in being a caregiver, and the caregiver's reported health status have the biggest influence on whether or not a caregiver reports emotional stress, physical strain or financial hardship.

Study Limitations

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. Consequently, the findings from the ethnic oversample may not represent all Hispanic or Asian caregivers.

Caregivers from the three sub-ethnic groups, African-Americans, Hispanics and Asian-Americans, under-represent recent immigrants or first generation caregivers who speak little or no English. It is also important to note that sub-ethnic group respondents may not have interpreted all questions identically due to their diverse cultural and linguistic backgrounds.

[1] With a sample this size, the margin of error is plus/minus 2.8 percentage points at the 95 percent confidence level. This means that 95 times out of 100, differences of greater or less than 2.8 percent would not have occurred by chance.

[2] 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. At this point, we were no longer able to offer the option of conducting the interview in Spanish.

Key Findings

Profile of Caregivers

> We estimate that there are 44.4 million caregivers in the U.S. age 18 and older who provide unpaid care to another adult age 18 or older (21% of the adult U.S. population). They are present in an estimated 22.9 million households (21% of U.S. households).

> Although one profile does not fit all caregivers, a "typical" caregiver in the U.S. is a 46-year-old female, who has some college education, works, and spends more than 20 hours a week providing care to her mother.

> More caregivers are women (61%) than men (39%).

> More caregivers are between the ages of 18-49 years (58%) than are 50 years of age or older (42%).

> Many caregivers work either full or part-time while providing care (59%). More than six in ten (62%) working caregivers say they have had to make some adjustments to their work life as a result of their caregiving responsibilities.

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

> On average, caregivers provide 21 hours of care per week. Nearly half (48%) of all caregivers say they provide eight hours or less of care per week and one in five (17%) says they provide more than 40 hours of care per week. The average length of care is 4.3 years.

> Overall, female caregivers are providing more hours of care and a higher level of care than male caregivers.

> Because female caregivers give more care, 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 highest levels of stress rating).

> Most caregivers say they are in good health with more than eight in ten describing their health as excellent (25%), very good (30%), or good (28%). One in six caregivers (17%) says their health is fair or poor.

> Caregivers who report their health is fair or poor are more likely to be Level 5 caregivers, lower income, living with the care recipient, less educated, age 50+.

Profile of Care Recipients

> More care recipients are female (65%) than male, and many are widowed (42%).

> More care recipients are older (80% are age 50 or older) rather than younger.

> The average age of all care recipients is 66 years. The average age of younger care recipients is 33 years old, and the average age of older care recipients is 75 years.

> Among care recipients who do not live with their caregiver, more than half (55%) live in their own home.

> Caregivers who help someone age 50 or older say the main problem or illness the person they care for has is "old age" followed by diabetes, cancer, and heart disease.

> Caregivers who help someone between the ages of 18-49 say the main problem or illness the person they care for has is mental illness or depression (23%).

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

> Most caregivers (85%) say the person they care for takes prescription medicine.

Carrying the Load

> More than one in three caregivers (37%) say no one else provided unpaid help to the person they cared for during the past year. Among caregivers who say someone else did provide assistance during the past year, one in three (34%) says they provide most of the unpaid care, and ten percent say they split the care 50/50.

> 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 41 percent say their care recipient received paid services during the past year from an aide or nurse, hired housekeeper, or others paid to help.

> Half of all caregivers say they provide care at the lower ranges of the Level of Burden Index. About thirty percent say they provide care in the higher range at Levels 4 and 5.

> Although a minority (10%) of caregivers say they provide care at Level 5, these caregivers are, by definition, involved in the most intense caregiving situations.

Unmet Needs of Caregivers

- The most frequently reported unmet needs of caregivers are finding time for one's self (35%), managing emotional and physical stress (29%), and balancing work and family responsibilities (29%).
- About three in ten caregivers say they need help keeping the person they care for safe (30%) and finding easy activities to do with the person they 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%).
- The Internet is the place caregivers turn to most for information (29%), followed by doctors (28%).
- Seven in ten caregivers (73%) say praying helps them cope with caregiving stress, six in ten caregivers (61%) say they talk with or seek advice from friends or relatives, and four in ten caregivers (44%) say they read about caregiving in books or other materials.

Detailed Findings

Prevalence of Caregiving in the United States

We estimate there are 44.4 million (21% of the adult population) caregivers age 18 and older in the U.S. who provide unpaid care to an adult family member or friend who is also age 18 years or older. These caregivers are present in an estimated 22.9 million households (21% of U.S. households).

Number of American Adult Caregivers and Numbers of U.S. Households with Caregivers Age 50+

Key Finding: An estimated 16 percent of American adults, or 33.9 million adult caregivers, provide unpaid care to a recipient age 50 and older and an estimated five percent, or 10.6 million adult caregivers, help someone age 18 through 49.

Estimated Percent of Caregivers in U.S. and Within Each Ethnic 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.

Who Are the Caregivers?

The typical caregiver in the United States is a 46-year-old female, who has some college education, works, and spends more than 20 hours per week providing unpaid care to her mother.

Gender

Key Finding: The caregiving landscape is dominated by women. However, the proportion of men who provide care is substantial (39%).

> Female caregivers are more likely to provide care at the highest Level of Burden (71% at Level 5 and 58% at Level 1). Male caregivers are more likely to provide care at the lowest Level of Burden (42% at Level 1 and 29% at Level 5).

> One third (35%) of caregivers say they experience emotional stress (rate four or five on a five-point scale) as a result of being a caregiver. However, female caregivers (40%) are more likely to report experiencing emotional stress from caregiving than are male caregivers (26%).

> Women (42%) are also more likely than men (34%) to report they didn't have a choice in becoming a caregiver.

> Male caregivers are more likely to be Asian (54%) than any other ethnic background surveyed.

Age

Key Finding: The average age of a caregiver is 46. More than half (58%) of all caregivers are between the ages of 18-49 years.

> Younger caregivers tend to care for younger care recipients.

> Level 5 caregivers are more likely to be age 50 or older (60%) compared to Level 1 caregivers (39%).

> Minority caregivers are more likely to be 18-34 years old than white caregivers.

Level of Burden

Background: To measure the intensity of caregiving, caregivers were classified into different levels of burden. This was based upon the amount of time per week a caregiver spends helping his or her care recipient and the number and types of caregiving activities performed. Caregivers were classified into one of five levels, with Level 1 being the lowest in caregiving intensity, and Level 5 being the highest. Each successive level brings 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 typically help with four ADLs, six IADLs and provide constant care.

Key Finding: The greater the level of caregiver burden (as measured by the Level of Burden Index), the stronger the impact caregiving has on the caregiver's perceived health.

Marital Status

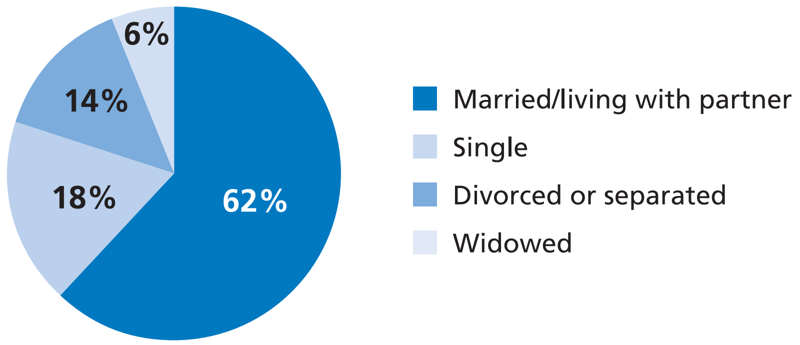
Key Finding: The majority of caregivers are married or living with a partner (62%). Far fewer numbers of caregivers are single (18%), divorced or separated (14%), or widowed (6%).

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

> Thirty-seven percent of all caregivers report a child under age 18 lives in the household. These caregivers are most likely to be under age 50 and African-American.

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.

Education

Key Finding: Almost equal proportions of caregivers have graduated from high school (29%), as those who have some college experience (30%) and those who are college graduates (35%).

- Not surprisingly, a caregiver's education level and their annual household income are related. Forty-two percent of caregivers who are high school graduates report an income of $30,000 or less while 36 percent of caregivers who are college graduates report an income of $100,000 or more.
- Asian-American caregivers are the most highly educated ethnic group in this study with 61 percent having earned a college degree or higher.

Employment Status

Key Finding: With over 44.4 million Americans providing care to another adult, the impact on the workplace is substantial. Almost six in ten caregivers (59%) either work or have worked while providing care, and 62 percent of caregivers report having had to make some work-related adjustments ranging from going in late and leaving early to having to give up work entirely.

- More male caregivers say they are working full time (60%) than female caregivers (41%). Caregivers who live more than an hour away from their care recipient (63%) are more likely to work full time than caregivers who live with the person they care for (39%).
- More caregivers between the ages of 35-49 (64%) work full time than do caregivers in the 18-34 year (52%) and 50+ (51%) age brackets.
- Caregivers with the heaviest caregiving responsibilities are less likely to be employed and more likely to be retired than caregivers with less caregiving responsibility.
- More than half of working caregivers (57%) say they have to go into work late, leave early or take time off during the day to provide care. Fewer working caregivers report having to take a leave of absence (17%), go from full-time to part-time work (10%), quit working entirely (6%), lose job benefits (5%), turn down a promotion (4%), or choose early retirement (3%).

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[2] U.S. Census Bureau, Current Population Survey, 2002 and 2003 Annual Social and Economic Supplements, Table 3.

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 or part-time
Total	**59%**
Male	66%
Female	55%
White	61%
African-American	58%
Hispanic	53%
Asian-American	52%
18-34	65%
35-49	74%
50-64	58%
65 or older	12%
Recipient age 18-49	66%
Recipient age 50+	57%
Recipient lives in household	49%
< 1 hour away	61%
1 hour + away	69%
Level 1 caregivers	63%
Level 5 caregivers	43%

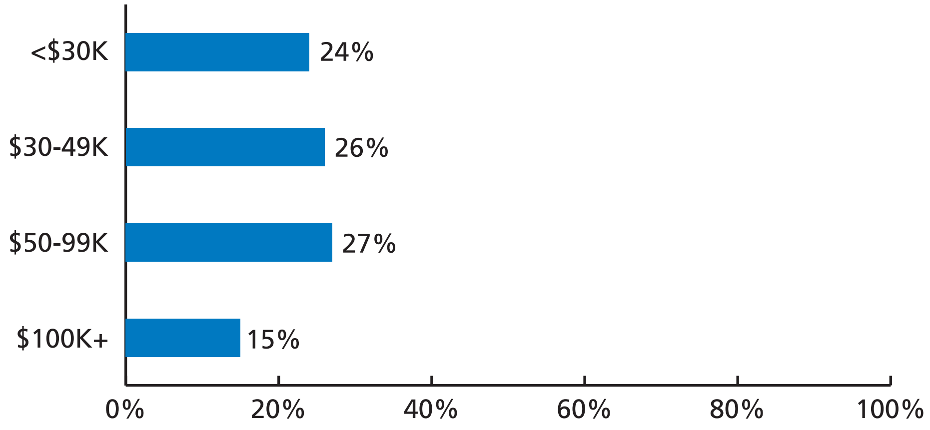
Base: 1,247 caregivers in the U.S.
Source: *Caregiving in the U.S.*, National Alliance for Caregiving and AARP, 2004.

Income and Spending

Key Finding: Caregivers' median household income in 2003 was $37,312. (The median household income for people in the U.S. in 2002 was $42,409).[2]

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.

> Among those providing care to someone 50 or older, the median household income is $38,125.

> Not counting those who care for a spouse, about half of caregivers contribute financially to the care of their recipient, spending an average of $200 a month.

> A few caregivers spend more per month on out-of-pocket expenses than others. For example, Level 5 caregivers spend $324 per month while primary caregivers spend $232 per month.

> About half of Asian-American caregivers (53%) and White caregivers (42%) report higher household incomes ($50,000 or more) than do African-American caregivers (33%) or Hispanic caregivers (37%).

Military Service

> Fourteen percent of all caregivers say they are veterans.

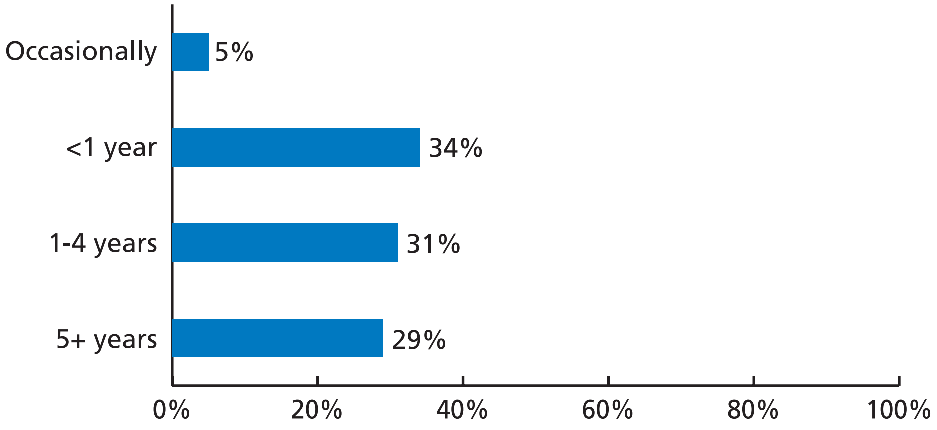
Characteristics of the Caregiving Situation

Duration of Care of Persons Being Cared For

Key Finding: The average length of time caregivers provide care is 4.3 years.

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.

Duration of Care	Caregivers 18-49 years	Caregivers 50+ years	All Caregivers
Occasionally	5%	5%	5%
Less than 1 year	37%	30%	34%
1-4 years	31%	32%	31%
5 or more years	26%	33%	29%
Mean length	3.7 years	4.9 years	4.3 years

> Older caregivers are more likely to say they have provided care for 10 years or more, usually for their parent or spouse. Conversely, younger caregivers say they are more likely to have been providing care for less than six months, mostly to younger care recipients.

Living Arrangements

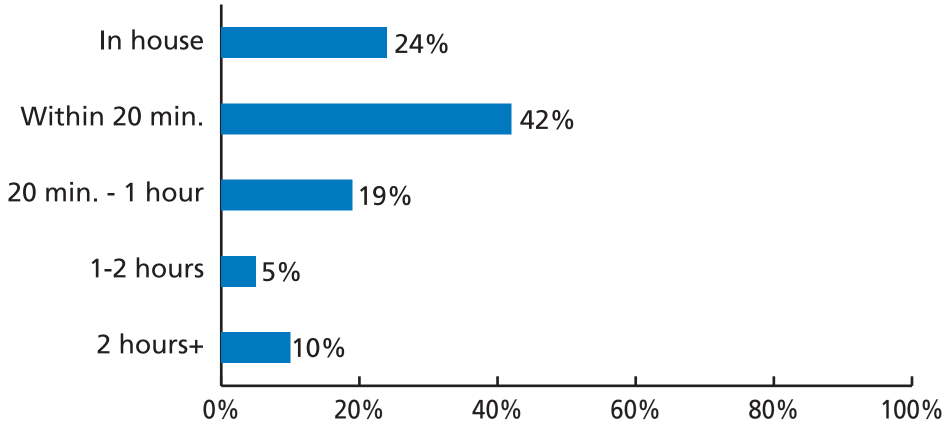
Key Finding: One in four people who receives care lives with his or her caregiver.

> Forty-two percent of caregivers say they live within 20 minutes of their care recipient.

> Fifteen percent of caregivers are considered long-distance since they live more than one hour away.

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?

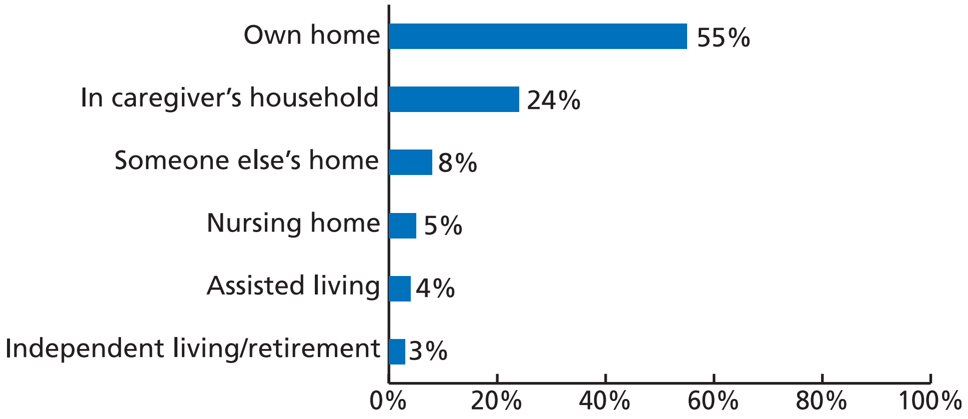


Base: 1,247 caregivers in the U.S.
Source: *Caregiving in the U.S.*, National Alliance for Caregiving and AARP, 2004.

> Among the approximately three-quarters of care recipients who do not live with their caregiver, 55 percent live in their own home.

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.

> Not surprisingly, care recipients living in nursing homes tend to be older and to live in an urban setting. Those who live in an assisted living facility are more likely to have an older caregiver.

Who Are the Care Recipients?

The typical care recipient in the United States is a female, widowed, approximately 66 years old, being cared for by a relative.

Relationship between Caregiver and Care Recipient

Key Finding: Most care recipients are related to the person who cares for them (83%). Care recipients are often the caregiver's mother (28%), grandmother (9%), or father (8%).

Gender

Key Finding: More care recipients are female (65%) than male (31%).

Age

Key Finding: More care recipients are older (79% are age 50+) than younger (20% are between the ages of 18-49 years).

- The average age of younger care recipients is 33 years; the average age of those 50+ is 75 years.
- One in five care recipients (20%) is 85 years of age or older.
- African-American caregivers (27%) are more likely to be caring for someone under 50 than white caregivers (21%).

Marital Status

Key Finding: Forty-two percent of care recipients are widowed, and 27 percent are married. Fewer are divorced or separated (15%) or are single (14%).

- African-American caregivers are more likely than other ethnic group to be helping a single person.

Military Service

- Seventeen percent of care recipients are veterans.

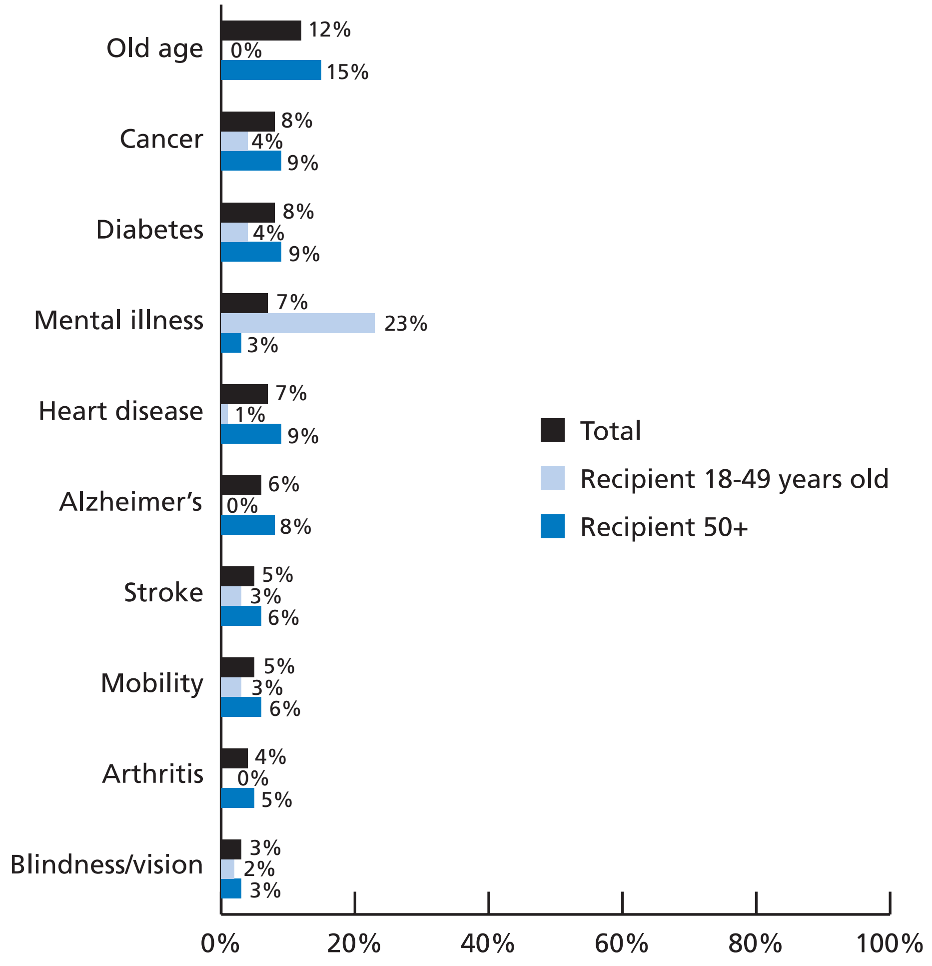
Health Status of Care Recipients

The types of health problems care recipients experience vary by age. Caregivers who assist younger persons most commonly report their care recipient as having mental or emotional illness. Caregivers assisting someone over 50 say aging or "being old" is the main problem or illness of their care recipient (see graph on page 11).

- 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 the person they care for has Alzheimer's or dementia. However, when we asked caregivers who did not identify Alzheimer's or dementia as the main problem or illness a follow-up question that specifically asked about Alzheimer's or other mental confusion, an additional 17 percent said yes. Taken together, 23 percent of caregivers report providing care to someone with Alzheimer's, dementia, or other mental confusion.
- Levels 4 and 5 caregivers are more likely to say they are caring for someone who has cancer than lower level caregivers. Level 5 caregivers are also more likely to say they are caring for someone who has had a stroke than Level 1, 2, and 3 caregivers.
- Asian-American caregivers are more likely than other ethnic group to say being old is their care recipient's main illness or problem. Hispanic caregivers cite diabetes as their care recipient's main health problem more than white or Asian-American caregivers.

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.

Medication Management

Key Finding: Most caregivers (85%) say the person they care for takes prescription medicine. Among caregivers who say the person they care for takes prescription medicine, 45 percent say the person they care for needs someone to oversee or manage taking medicine.

- Among caregivers who care for people age 50+, 92 percent say the person they care for takes prescription medicine.
- In addition, 75 percent of caregivers who assist those with Alzheimer's say they need to oversee or manage prescription medications for their care recipient.

Intensity of Caregiving: Hours of Care and Types of Assistance Provided

The amount of time spent giving care and the kind of care being provided varies greatly between caregivers. Therefore, it is not surprising that some caregivers experience more physical, emotional and financial stress than others.

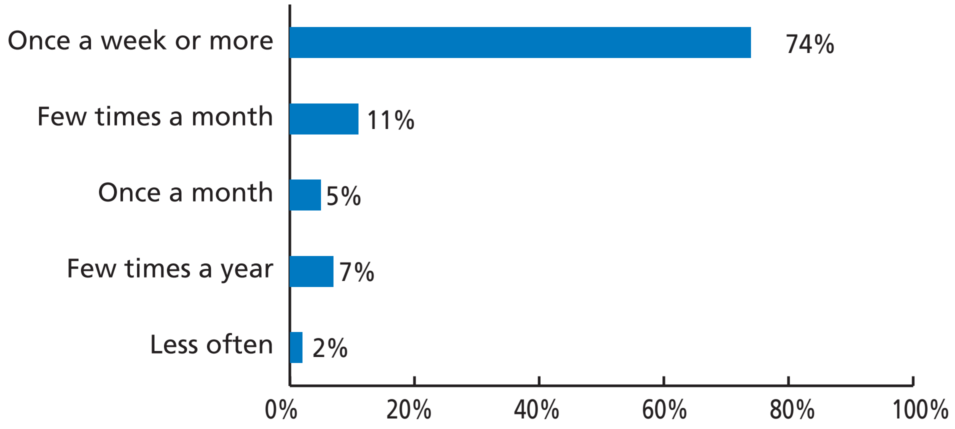
Hours of Care Provided and Frequency of Visits

Key Finding: Caregivers are evenly split between those who say they spend eight hours or less per week providing care (48%) and those who report spending nine hours or more per week providing care (48%).

- On average, caregivers spend 21 hours per week assisting another person.
- Caregivers who provide constant care (40+ hours per week) tend to:
  - live with the care recipient;
  - be in fair or poor health themselves;
  - care for someone with Alzheimer's or dementia;
  - have a lower income;
  - have a high school education or less.
- Caregivers who spend eight hours or less a week on caregiving are more likely to be male, white, Asian, or employed.
- A majority of caregivers who do not live with the person they care for say they visit their care recipient at least once a week (74%).

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.

Types of Assistance Caregivers Provide

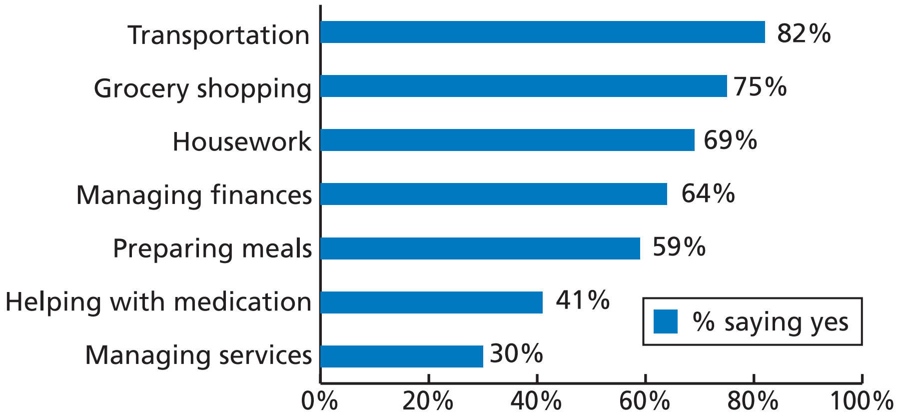
Instrumental Activities of Daily Living (IADLs): Managing Everyday Living

Key Finding: Because of the way we defined caregiving, all of our caregivers provide at least one IADL or ADL. Eighty percent of caregivers are helping with three or more IADLs.

- Caregivers who perform three or more IADLs are more likely to be female, African-American, in fair or poor health, or live with the person they care for.
- Women are more likely to help with housework and prepare meals than men.
- More African-American (48%) and Hispanic (46%) caregivers report their care recipient needs assistance with medications compared to white (39%) or Asian-American (32%) caregivers.
- Younger caregivers are more likely to help with housework and are less likely than their older counterparts to arrange outside services or manage finances.

Helping with IADLs

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.

> Caregivers at different income and education levels tend to perform different types of IADLs. For example, caregivers with lower incomes and less education tend to help with everyday tasks such as grocery shopping, housework, and meal preparation. Caregivers with higher incomes and more education tend to help with arranging outside services from agencies. Higher income caregivers are also more likely to assist with managing the care recipient's finances.

Activities of Daily Living (ADLs): Personal Care

Key Finding: Half of all caregivers perform the difficult tasks involved in personal care.

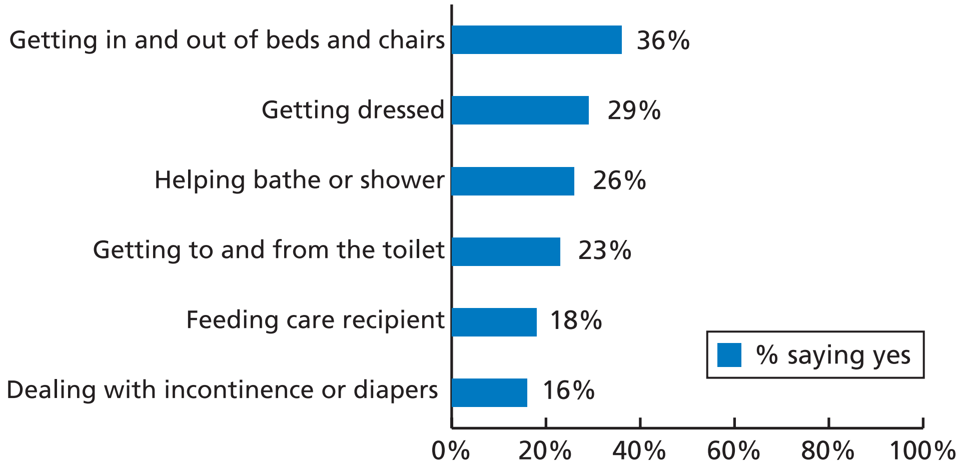
> Providing help getting in and out of bed and chairs, getting dressed, and personal grooming are the most commonly performed ADLs.

> While half of all caregivers say they perform at least one form of personal care (ADL), less than one in five (18%) says they have received formal training on how to care for their recipient. African-American caregivers are more likely to report having received some formal training than Asian-American or white caregivers.

> Male caregivers are less likely to help with dressing, bathing or showering, and dealing with incontinence than female caregivers. The same is true of younger caregivers compared to older caregivers.

Helping with ADLs

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.

Performance of ADLs & IADLs:

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:

IADLs	**Total**	**Level 1**[3]	**Level 4**	**Level 5**
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%
Three or more IADLs	*80%*	*63%*	*93%*	*100%*
None of these IADLs	*	—	—	—

ADLs	**Total**	**Level 1**[3]	**Level 4**	**Level 5**
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%
Three or more ADLs	*26%*	—	*53%*	*84%*
None of these ADLs	*50%*	*100%*	*9%*	—

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

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[3] 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.

Home Modifications and Assistive Devices

Key Finding: Forty percent of caregivers say they have obtained an assistive device to make it easier to care for the person they help and nearly 40 percent have modified the home to make it easier to provide care.

> Caregivers with a Level of Burden between 3-5, and those helping someone with Alzheimer's or dementia, are more likely than others to have made home modifications or obtained assistive devices.

> Not surprisingly, caregivers who have greater financial resources are more likely to make home modifications than those who do not.

Caregiver Support: Who Else Helps Provide Care?

Many caregivers receive unpaid help from others. This assistance most commonly comes from the recipient's children. Caregivers who have higher incomes and those who have higher Levels of Burden use paid help more.

Primary vs. Secondary Caregivers

Key Finding: Although many caregivers receive help from others, the majority of caregivers (57%) say they are the primary caregiver and receive no other unpaid help or they consider themselves to provide *most* of the unpaid help. Thirty-seven percent of caregivers say no one else provided *unpaid* help during the last 12 months. Almost six in ten (59%) say they did not receive *paid* help during the last 12 months from four categories of helpers including nurses, aides, or housekeepers.

> Caregivers who provide most of the help are typically caring for someone age 18-49. They are most likely to be female, older, unemployed or have an income less than $30,000. They provide at least 21 hours of higher level of care each week.

Unpaid Care

Key Finding: Nearly six in ten caregivers (59%) say that someone else, usually the recipient's daughter or son, helped provide unpaid care in the past year.

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[4] Personal correspondence dated March 25, 2004 from John Crews, DPA, Health Scientist, Centers for Disease Control and Prevention.

Other Unpaid Help

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

	Primary Caregivers	Secondary Caregivers	Total Caregivers
Any relative	87%	89%	88%
Daughter	39%	43%	42%
Son	24%	26%	26%
Non-relative	12%	10%	11%

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

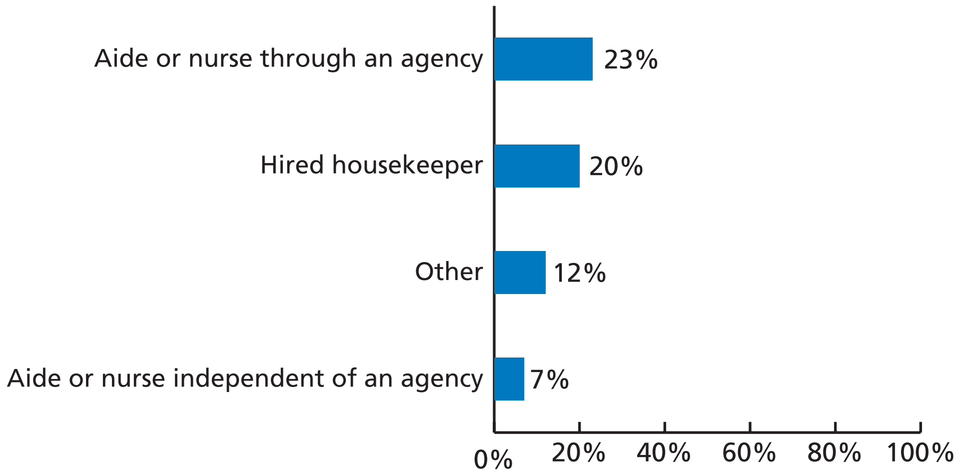
> African-American caregivers (12%) are much more likely to receive help from the recipient's niece or nephew than white (4%), Asian-American (4%), or Hispanic (2%) caregivers.

Paid Care

Key Finding: Four in ten caregivers who help someone not living in a nursing home report using paid care in the past year. The most common type of paid care is the use of an aide or nurse obtained through an agency or a housekeeper.

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.

> Caregivers most likely to use paid help are older, college educated, upper income, and caring for someone with Alzheimer's or dementia.

Stress and Strain of Caregiving

Most caregivers report low emotional stress, physical strain, and financial hardship as a result of caregiving.

Impact on Caregiver's Physical and Emotional Health

Physical Health

Key Finding: A majority of caregivers say they are in good health. The two greatest predictors of caregivers' physical strain are the caregivers' reported health and whether they felt they had a choice in taking on caregiving responsibilities.

> Twenty-five percent describe their health as excellent, 30 percent say their health is very good, and 28 percent say their health is good. About one in six (17%) considers their health as fair or poor. In general, about six in ten members of the adult population in the U.S. say their health is very good or excellent, three in ten say their health is good, and one in ten says their health is fair or poor.[4]

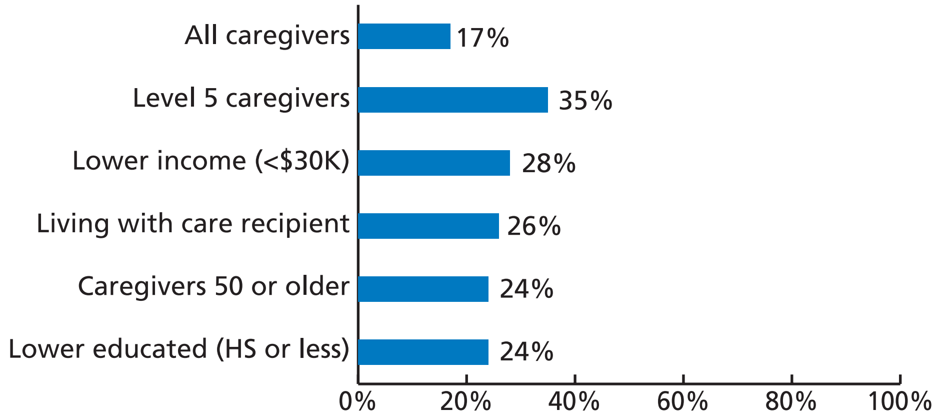
> Almost three in four caregivers say being a caregiver has had no effect on their health. Caregivers who report caregiving has made their health worse tend to be lower income, women, age 50+, provide higher levels of care, and live with the person they provide care for.

> Few caregivers say caregiving is a physical strain. Only 15 percent rate physical strain from caregiving a four or five on a five-point scale (where five is very much and one is not at all).

> The two greatest predictors of physical strain are caregivers' reported health and whether they felt 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 perceived the greatest physical strain. Level of Burden is another factor contributing to caregivers' physical strain. The higher the Level of Burden, the greater the caregivers' perceived physical strain.

Proportion of caregivers who say their 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.

Emotional Health

Key Finding: 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 (27%) say taking care of the person they help is not at all stressful.

> The two greatest predictors of emotional stress are the caregivers' Level of Burden and whether or not they feel they had a choice in assuming the role of caregiver. Caregivers at the highest Level of Burden and those who feel they had no choice perceive the highest levels of emotional stress. Other factors associated with caregivers' emotional stress are caregivers' reported health, living in the same household with the care recipient, and being female.

> Nearly four in ten caregivers (39%) say they feel they had no choice in taking on the role of a caregiver, and half of these people feel their situation is emotionally stressful. Conversely, just a quarter of those who felt they did have a choice in becoming a caregiver report experiencing emotional stress at the highest levels.

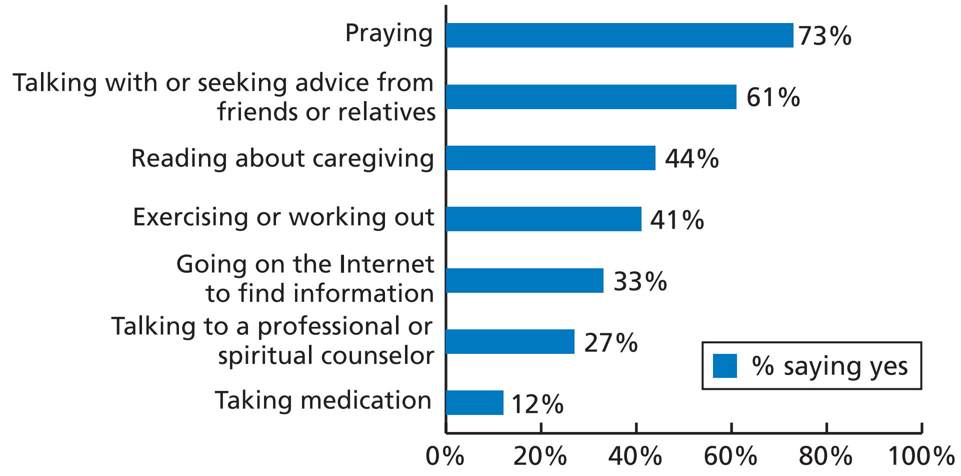
> Those who say they had no choice in becoming a caregiver tend to be female, primary caregivers, live with the care recipient, say they are in fair to poor health and provide the highest levels of care.

Coping with Stress

Caregivers say they deal with the demands of caregiving by using various coping mechanisms. The most common are praying (73%) and talking with friends or relatives (61%). Reading about caregiving (44%), exercising (41%), and going on the Internet to find information (33%) are other ways they say they cope with the demands of caregivng. Smaller percentages of caregivers seek help from professional or spiritual counselors (27%) and fewer use medication (12%) to cope.

Coping with Demands of Caregiving

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 report praying as a way to cope with the demands of caregiving, African-American (84%) and Hispanic (79%) caregivers use this method of coping significantly more than white (71%) or Asian-American (50%) caregivers.

> More women (80%) than men (61%) say praying is a way they cope with caregiving demands. Women also tend to cope by talking with friends or relatives (67%) more than men (51%).

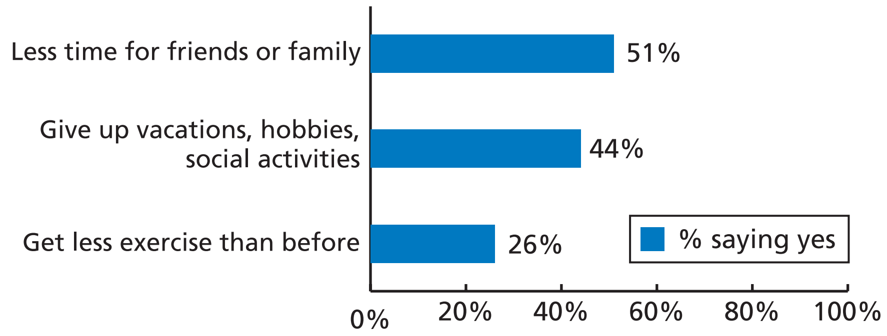
> Those more likely to use the Internet as a tool for dealing with caregiving demands include Asian-American caregivers (43%), college educated (41%) and upper income (44% of those making $100,000+) caregivers as well as those helping someone with Alzheimer's or dementia (42%).

Impact of Caregiving on Family and Leisure Activities

Half of caregivers say their caregiving has resulted in less time for family and friends. A substantial proportion also report giving up vacations, hobbies or other social activities as a result of caregiving responsibilities.

Impact of Caregiving on Family and Leisure Activities

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 and leisure activities are primary caregivers, those residing with the care recipient, those who provide the highest levels of care, and who consider their own health to be fair or poor.

Impact of Caregiving on Work

Fifty-nine percent of caregivers say they are currently working (48% full time and 11% part time), or have worked at some time while being a caregiver. More than six in ten (62%) of these working caregivers say their caregiving responsibilities have led them to make adjustments to their work life, including such things as reporting late to work, leaving early, or taking time off, taking a leave of absence or leaving the workforce entirely.

- Making schedule changes such as going to work late, leaving early or taking time off during the day to provide care, is the most frequently reported work adjustment (57%).
- Those most likely to say they have made one or more work schedule adjustments are:
  - female;
  - primary caregivers;
  - caregivers at higher Levels of Burden;
  - those between the ages of 35-64;
  - African-American caregivers;
  - those living with the care recipient;
  - those helping someone with Alzheimer's or dementia.
- More than one third of Level 5 caregivers (35%) say they chose to give up work entirely as a result of their caregiving responsibilities and 12% chose early retirement.

Work-Related Adjustments by Level of Burden

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
Go in late, leave early, etc.	**57%**	40%	51%	63%	75%	83%
Take leave of absence	**17%**	8%	17%	14%	22%	41%
Go from full-time to part-time	**10%**	3%	7%	9%	15%	37%
Give up work entirely	**6%**	1%	3%	4%	4%	35%
Lose any job benefits	**5%**	2%	2%	5%	9%	15%
Turn down promotion	**4%**	2%	3%	5%	6%	14%
Choose early retirement	**3%**	1%	1%	2%	3%	12%
None of the above	**38%**	57%	44%	31%	21%	8%

Base: 935 caregivers employed while caregiving.
Source: *Caregiving in the U.S.*, National Alliance for Caregiving and AARP, 2004.

Financial Hardship on Caregivers

Only twelve percent of caregivers say caregiving is a financial hardship for them (rate it a four or five on a five-point scale where one is no hardship at all and five is a great deal of hardship). More than three in four (77%) report that caregiving is very little financial hardship (rate it one or two on a five-point scale).

- Our analysis shows that the two greatest predictors of caregivers' perception of financial hardship are Level of Burden and whether they felt 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, living with the care recipient, and income. The older the caregiver, the poorer the caregiver's perceived health, and living with the care recipient and having a lower income increase the reported level of hardship.
- Level 5 caregivers are more likely to say they experience financial hardship (35%) than caregivers at other Levels of Burden, and they are more likely to say they have requested information about financial help for their care recipient than caregivers at Level 1 (20%), Level 2 (23%), and Level 3 (21%).
- Caregivers who report their annual income is less than $30,000 are more likely to say caregiving is a financial hardship (rate it as a four or five on a five-point scale) than caregivers who report their annual household income is $30,000 or more.
- Caregivers who help younger care recipients (25%) are more likely to say caregiving is a financial hardship than those who assist older care recipients (9%).
- Younger caregivers (35% of those 18-49 years) are more likely to say they experience financial hardship as a result of being a caregiver than older caregivers (22% of those age 50+).
- African-American caregivers (22%) say they experience financial hardship as a result of caregiving more than other ethnic groups Hispanic (14%), Asian-American (11%) or white (10%) caregivers.
- Caregivers who live with the person they provide care for are more likely to say they experience financial hardship as a result of caregiving than those who do not live with the person they care for.

Supportive Services in the Community

Supportive services are used by almost half of all caregivers (48%). One-quarter of caregivers say they requested information about financial help for their care recipient.

> Those caring for someone with Alzheimer's or dementia are more likely to use outside services than other caregivers.

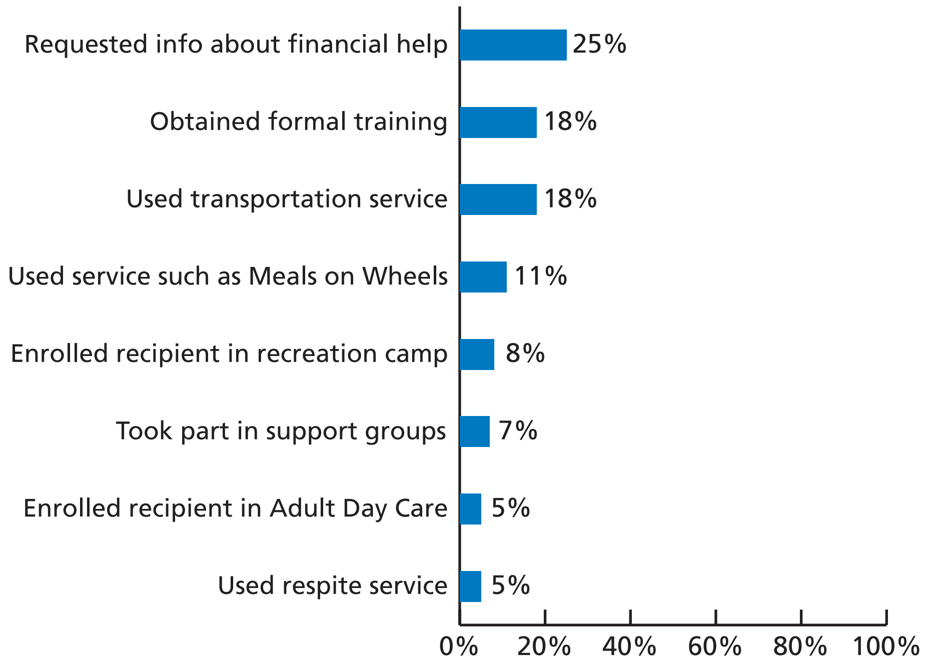
> Caregivers whose care recipient lives in an urban setting (58%) are more likely than caregivers helping someone in a suburban (42%) or rural setting (44%) to say they use supportive services. Caregivers who live with their care recipient tend to seek supportive services more often than caregivers who live within an hour of the person they care for.

> Midlife caregivers age 50-64 (55%) and those age 65+ (56%) are more likely to use supportive services than younger caregivers (40%).

> More Asian-American (12%), African-American (11%), and white (7%) caregivers say they have taken part in support groups than Hispanic (3%) caregivers.

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.

Unmet Needs for Help, Information or Support

Finding time for oneself, keeping the care recipient safe at home, and balancing work and family responsibilities are the top unmet needs identified by caregivers (see graph on page 26).

> Minority caregivers (Hispanic 80%, African-American 75% and Asian-American 73%) are much more likely to say they need more help with information than white caregivers (64%).

> Caregivers of those with Alzheimer's or dementia and those providing the highest level of care say they need help or additional information more often than other caregivers.

> Of caregivers already receiving an outside service, almost eight in ten (79%) say they need more help or information about at least one of the unmet needs listed.

> Fulfilling personal needs, such as managing stress, finding time for oneself, and balancing work and family are more likely to be mentioned as a need by female caregivers, caregivers under 65, and those living with their care recipient.

Unmet Needs

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.

Where Caregivers Go For Information

Key Finding: Almost three in ten caregivers say they get information on caregiving from the Internet (29%) or a doctor (28%). Smaller percentages rely on family and friends (15%) or other health professionals (10%) for their caregiving information. Other sources of information on caregiving, such as libraries, employers, and senior centers, were identified by too few caregivers to be significant.

> Those who turn to the Internet for information are likely to have a higher income and be college educated. Forty-one percent say they live an hour or more away from their care recipient.

> Level 5 caregivers (42%), those living with their care recipient (36%) and caregivers who help someone age 50 or older (31%), are more likely to obtain caregiving information from a doctor.

> Younger caregivers are more likely to turn to friends and family for information about caregiving.

Caregivers in Ethnic Subgroups

Overall, African-American, Hispanic and Asian-American caregivers provide similar types of care and experience similar stresses regardless of ethnic background. The following bullets report statistically significant differences based on ethnicity. When an ethnic group is not mentioned, the difference was not significant.

African-American Caregivers

> African-American caregivers are more likely to have children under age 18 living in the household than caregivers from other ethnic groups (53% v 35% white, 39% Hispanic, 34% Asian). They 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).

> 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-American caregivers).

> African-American caregivers are more likely to live in urban areas (49% v 24% white, 35% Asian-American caregivers). African-American care recipients are also 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 between $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 4 or 5 on a 5-point scale v 10% white, 14% Hispanic and 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-American 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-American caregivers). They are also more likely to say they obtained formal training of some sort about how to care for their care recipient (25% v 17% white and 15% Asian-American 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-American 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 transportation services for the person they care for (28% v 16% white, 18% Hispanic caregivers).
- African-American caregivers are more likely to say they cope with caregiving stress by praying (84% v 71% white, 50% Asian-American 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-American 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 they help the person they care for with at least one ADL (59% v 48% white caregivers).
- Hispanic caregivers are more likely to say they are Level 4 or 5 caregivers (41%) and have given up vacations, hobbies or their own social activities (48% v 35% African-American caregivers).

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-American caregivers also report higher household incomes than others (53% report a household income of $50,000+ v 42% white, 33% African-American, 38% Hispanic caregivers). Therefore, it is not surprising that Asian-American caregivers are less likely to say caregiving is a financial hardship.
- Like white caregivers, Asian-American 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-American caregivers are more likely to say they live in the suburbs (56% v 40% white, 34% African-American, 37% Hispanic caregivers).
- Asian-American caregivers are less likely to say the person they care for has Alzheimer’s or other dementia (86% v 75% white, 72% African-American, 75% Hispanic caregivers).
- Asian-American caregivers 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-American caregivers are more likely to say they tried to cope with stress by going to the Internet to seek information (43% v 33% white, 29% African-American caregivers).

White Caregivers

- > White caregivers are more likely to say they are age 50 or older than members of other ethnic groups (46% white, 29% African-American, 34% Hispanic, 35% Asian-American caregivers).
- > Like Asian-American caregivers, white caregivers tend to report higher incomes (42% make $50,000+). However, unlike Asian-American 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-American caregivers). White caregivers are also more likely to 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-America caregivers), and they are more likely to say caregiving is not a financial hardship (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-American caregivers.

Comparison of Caregivers by Age of Recipient

Key differences between caregivers of persons age 50 and over and persons age 18-49 are summarized in the following table.

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.

Summary and Conclusions

Caregivers are a diverse group. Their caregiving experiences range from those that are relatively easy to manage, to those that are burdensome. We know that most caregivers today are able to fulfill this role without experiencing overwhelmingly negative physical, emotional, or financial consequences. We also know that being a caregiver makes those who carry the heaviest responsibilities vulnerable to risks associated with poorer health, emotional stress, and economic hardship.

As the baby boom generation ages over the next 25 years, the ranks of those needing care will swell and the numbers of those available to provide care are likely to dwindle. This suggests that in the future, our caregivers may feel even less choice about becoming a caregiver than they do today. It also suggests that they may provide care to two, three, or even more care recipients. Even if the care recipient has “simple” needs, the sheer numbers of people needing help may increase the caregiver burden.

Indicators from this survey, as well as a weak economy and the aging of the baby boomers, tell us that those who provide unpaid care deserve our attention and our assistance.

It is important that we use information from this study to do at least three things. First, we need to help current at-risk caregivers so that they can continue to provide care to family and friends without sacrificing their health, financial security and quality of life in the process. Secondly, we need to expand current caregiver programs to include all caregivers regardless of the age of their care recipient. Thirdly, we need to begin to prepare for the future. This includes encouraging family members to plan ahead and discuss their changing needs as they age, as well as advocating for more public funding for policies and programs that provide needed services for the long-term care population.

Appendix A: Topline Results

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.

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	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: 1.7 adults

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 <u>most</u> 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
GRANDPARENT-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

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.

18-29	8%
30-49	13
50-64	16
65-74	19
75-84	24
85-89	11
90+	9
DK/REF	1

Mean age is 66.

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?
Base N = 924

> 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

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? *Base N = 924*

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? *Base N = 869*

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? *Base N = 925*

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	*

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
AMPUTEE	1
HIGH BLOOD PRESSURE/HYPERTENSION	1
BROKEN BONES	2
DEAFNESS/HEARING LOSS	*
FEEBLE, UNSTEADY, FALLING	1
MENTAL RETARDATION	1
MENTAL/EMOTIONAL ILLNESS/DEPRESSION	7
OSTEOPEROSIS	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/ CONFUSION/DEMENTIA NOT MENTIONED: [Does/Did] your (__) suffer from Alzheimer's or other mental confusion? *Combined with "Alzheimer's" responses in Q11.*

YES	23%
NO	76
DK/REF	1

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.	5%
< 6 MONTHS	16
6 MOS – 1 YR	18
1-4 YEARS	31
5-9 YEARS	15
10 YEARS+	14
DK/REF	1

Mean: 4.3 years

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

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? *Base N = 1049*

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? *Base N = 1049*

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

32a. IF YES IN Q31: What relationship [are/were] they to your (__)? MULTIPLE RESPONSE

IF "CHILDREN", PROBE: Would that be (__)'s son or daughter or both?
Base N = 742

SPOUSE/FORMER	7%
MOTHER	6
FATHER	1
MOTHER/FATHER-IN-LAW	*
SON	26
DAUGHTER	42
SON/DAUGHTER-IN-LAW	6
BROTHER	1
SISTER	5
BROTHER/SISTER-IN-LAW	*
NIECE/NEPHEW	5
GRANDSON/GRANDDGHTR	9
OTHER RELATIVE	3
ALL FAMILY	4
NON-REL./FRIEND/NEIGH.	11
VOLUNTEER	1
OTHER (SPECIFY)	1
DK/REF	1

33. IF YES IN Q31: Who would you consider to be the person who [provides/provided] *most* of the unpaid care for your (__): you yourself, or someone else? *Base N = 742*

SELF	34%
SOMEONE ELSE	55
SPLIT 50-50 (VOL.)	10
DK/REF	1

IF NOT IN NURSING HOME: During the last 12 months, did your (__) receive paid help from any of the following—regardless of who paid for it.
First: *Base N = 1191*

	YES	NO	DK/REF
34. An aide or nurses hired through an agency or service?	23%	74	3
35. An aide or nurse hired <u>independently</u>—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

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? *Base N = 468*

RESPONDENT	44%
OTHER UNPAID	34
PAID HELPERS	19
DK/REF	3

39. 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?

FULL TIME	48%
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 (__)]? *Base N = 782*

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.
Base N = 1180

$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

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

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	*

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	*

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	*

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