

FAMILY CAREGIVING IN THE U.S.  
Findings from a National Survey

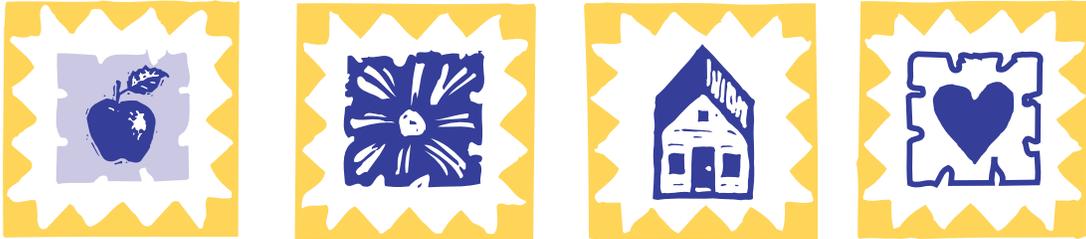
FINAL REPORT



NATIONAL ALLIANCE FOR CAREGIVING  
A National Resource for Caregivers of Older Americans



American  
Association of



The NAC, located in the Washington, DC, area, is a non-profit joint venture of several national aging organizations that have allied themselves to focus attention on the issue of family caregiving of the elderly through research, program development, and public awareness activities.

AARP is the nation's leading organization for people age 50 and over. It serves their needs and interests through legislative advocacy, research, informative programs and community services provided by a network of local chapters and experienced volunteers throughout the country. The organization also offers members a wide range of special membership benefits, including Modern Maturity magazine and the monthly Bulletin.

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# FAMILY CAREGIVING IN THE U.S.

## Findings from a National Survey

Sponsored by

The National Alliance for Caregiving  
Bethesda, MD

and

The American Association of Retired Persons  
Washington, DC

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Glaxo Wellcome, Inc.

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# FAMILY CAREGIVING IN THE U.S.:

## FINAL REPORT

### Introduction and Background

Numerous studies have been conducted on various aspects of informal (unpaid) or family caregiving of older adults. Nationwide information on the magnitude, intensity, and types of informal caregiving provided, however, together with its physical, emotional and financial repercussions, has been lacking. In particular, similarities and differences among racial/ethnic groups with respect to caregiving practices and the impact of informal caregiving on caregivers' lives have not been systematically studied on a nationwide basis.

This study attempts to identify and profile the various impacts of family caregiving in today's society. Using a broad definition of caregiving, the survey documents for corporate America, policymakers, and the general public the experiences and attitudes of persons who provide care to older Americans. A broad definition was used in order to determine

the type of care family and friends provide to older persons, ranging from light, occasional tasks, to round-the-clock care, including care provided from a distance.

The present study is the first of its kind to address these issues systematically, using survey methodology, across four racial/ethnic groups within the United States: Whites, Blacks, Hispanics, and Asians<sup>1</sup>. It was sponsored and designed by the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP), with funding provided by a grant from Glaxo Wellcome, Inc.<sup>2</sup> Additional funding was provided by the Archstone Foundation, ManorCare Health Services, and Metropolitan Life Insurance Company.



<sup>1</sup> These designations are adapted from OMB's "Directive No. 15," Race and Ethnic Standards for Federal Statistics and Administrative Reporting (as adopted on May 12, 1977). The term "White" refers to persons self-identified as White and having origins in any of the original peoples of Europe, North Africa, or the Middle East, but in this case exclusive of persons who designate themselves as of Hispanic origin. The term "Black" refers to persons who identify themselves as Black (having origins in any of the black racial groups of Africa), but in this case not of Hispanic origin. The term "Hispanic" refers to persons who identify themselves as of Mexican, Puerto Rican,

Cuban, Central or South American, or other Spanish culture of origin, regardless of race. The term "Asian" refers to persons who identify themselves as having origins in any of the peoples of the Far East, Southeast Asia, the Indian subcontinent, or the Pacific Islands.

<sup>2</sup> Funding for this survey was provided by a grant from Glaxo Wellcome, Inc., a research based company whose people are committed to fighting disease by bringing innovative medicines and services to patients, their families, and the healthcare providers who serve them.

## Overview of Methodology

The study was designed as a telephone survey to be used with a nationwide random sample of caregivers aged 18 and over, with oversamples of Black, Hispanic, and Asian caregivers to ensure adequate numbers of each of these groups for analytic purposes. NAC contracted with the ICR Survey Research Group, Inc., of Media, PA, to generate the samples, conduct the survey, and prepare a topline report.

The survey was conducted between August 13 and September 20, 1996 with respondents capable of answering questions in English by telephone. (Funds were not available to conduct the survey in languages other than English.) See the Appendix for a detailed description of the methodology used to generate the samples.

A total of 1,509 English-speaking family caregivers participated in this telephone survey: 623 Whites, 306 Blacks, 307 Hispanics, and 264 Asians.

## Limitations of This Study

Although this is the first U.S. study of its kind to include large enough oversamples of caregivers drawn from three racial/ethnic minority groups, these samples underrepresent recent immigrant or first generation caregivers who speak little or no English, such as Hispanics who are fluent only in Spanish or Portuguese, or Asians who speak only Chinese, Japanese, Korean, or Vietnamese, or other Far Eastern languages. It is also possible that the respondents, being of diverse cultural and

linguistic backgrounds, may not have interpreted all questions identically.

Additionally, because this was a survey conducted by telephone, it underrepresents households that do not have a telephone (6% of households nationwide).

## This Report and Its Companion Volumes

This report summarizes the findings from the survey and their implications. It does not contain the survey instrument.

Also available are a copy of the survey instrument (D16476), and a report entitled *Caregiving Among American Indians: A Review of the Literature* (D16477)<sup>3</sup>, which highlights caregiving issues among American Indians. A report on implications for employers is also available.<sup>4</sup>

## Caregiving, Caregiver: Definitions Used for This Study

What is informal or family caregiving, and who is an informal or family care-giver? These terms are used inconsistently in the literature; there are no universally accepted criteria for designating an activity as caregiving or a person as a caregiver among scholars, policymakers or advocates.

Informal or family caregiving is typically performed by relatives and close friends for a person who is no longer able to manage all aspects of his or her daily life and/or personal care. It generally involves everyday activities related to managing a household, or to performing personal care, such as dressing, bathing, toileting, and feeding. By providing unpaid

<sup>3</sup> Additional copies of this report and of any of its companion volumes may be obtained by writing the National Alliance for Caregiving, 4720 Montgomery Lane, Suite 642, Bethesda, MD 20814-3425, or the AARP Fulfillment, 601 E Street, NW, Washington, DC 20049. Please use the order number when requesting reports.

<sup>4</sup> Order a copy of the report on the MetLife Study of Employer Costs for Working Caregivers based on data from *Family Caregiving in the U.S.: Findings from a National Survey* from MetLife Mature Market Group, 57 Green Farms Road, Westport, CT, 06880, Phone (203) 221-6580.

assistance and support to older family members or friends who need it, informal or family caregivers may help avoid or delay institutional placement of the older person, or the need for paid caregiving services.

For purposes of this study, the term caregiving was defined to prospective respondents in the following words:

"By caregiving, I mean providing unpaid care to a relative or friend who is aged 50 or older to help them take care of themselves."

"Caregiving may include help with personal needs or household chores. It might be taking care of a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you."

To be included in this study, a caregiver had to be at least 18 years old and either currently providing informal care to a relative or friend aged 50 or older, or to have provided informal care to such a person at some point during the past 12 months. No stipulations were placed on the amount, frequency, or duration of care provided, or on where the care recipient resided.



The decision to use a broad definition of caregiving and caregiver was based on focus group discussions conducted with members of the target racial/ethnic groups prior to designing the survey instrument.

Illustrative comments made by focus group participants are interspersed throughout this report to provide glimpses into the experience of caregiving.

## Intensity of Care: The Level of Care Index

A major purpose of this study was to understand how the level of demand pre-

It is like when I was growing up, my mother cared for others. She would send me to deliver food to a sick neighbor so I learned it from my mother. I've been like this all my life.

vented by the caregiving situation (i.e., the difficulty of the tasks caregivers perform and the amount of time they devote to caregiving) impacts caregivers' lives and attitudes. To measure the intensity of caregiving, a Level of Care Index was developed which classifies caregivers into different levels of care according to the kinds and numbers of assistive activities they perform and the number of hours per week they devote to caring for their principal care recipient. (How the Level of Care Index was developed is discussed in detail in the Appendix to this report.)

Each caregiver was classified into one of five levels, with Level 1 being the lowest in caregiving demand or intensity, and Level 5 being highest. Within each level, there is a range of activities and number of hours of care provided per week. Each successive level involves a higher degree of caregiving responsibility or demand. Level 1 caregivers, for example, provide no assistance with personal care activities such as dress-

TABLE 1  
CAREGIVERS BY LEVEL OF CARE

	Number of Caregivers	Percent of All Caregivers
Total	1,509	100.0
Level 1	389	25.8
Level 2	208	13.8
Level 3	287	19.0
Level 4	355	23.5
Level 5	185	12.3
Missing	85	5.6

ing or bathing their care recipient, and typically provide care for a maximum of eight hours per week. Level 5 caregivers, in contrast, assist with at least two personal care activities and provide care for more than 40 hours per week. (See the Appendix for additional information.) Table 1 shows the distribution of caregivers in this survey by level of care provided.

### Presentation of Findings

All findings presented in this report refer to caregiving and caregivers as defined above. For ease of reporting, caregiving statistics are typically expressed in the present tense, whether or not the caregivers in question are currently providing care. Noteworthy findings, or key differences between subgroups, may be bulleted and/or italicized.

While some caregivers report that they care or cared for more than one person, the survey inquired only about relationships with and activities pertaining to the recipient for whom the caregiver provides the most care.

In addition, all percentages cited in this report refer to proportions of the entire U.S. population of informal caregivers, and not to the sample of caregivers included in this study. That is, the findings from this sample of caregivers have been adjusted or weighted to reflect accurately the distribution of U.S. telephone households with a caregiver, based on sampling techniques used by the contractor in combination with U.S. Census projections and estimates. (For a more complete discussion of weighting, see the Appendix.)

When percentages are cited and compared across subgroups, the differences are statistically significant at the .05 level or better, unless otherwise indicated. This means that no more than five times in 100 would the particular finding be expected to occur by chance, and that there is a 95 percent probability that the difference is a true difference between groups. When “no differences” are reported, it means that percentage differences found across comparison groups did not reach statistical significance at the .05 level and thus could have been due to chance.



### Prevalence of Caregiving in the United States

- Just over 23% of all U.S. households

fourths (76%) are currently caring for a relative or friend who is at least 50 years old. The remaining 24% report having provided informal care to a relative or friend within the past 12 months, but are not currently doing so. Higher proportions of Level 1 and 2 caregivers are currently providing care than Level 4 and 5 caregivers.

- This translates into an estimated 22,411,200 caregiving households nationwide with English speaking caregivers<sup>6</sup>, of which there are approximately:
  - 18,290,000 White, non-Hispanic households
  - 2,380,000 Black, non-Hispanic households
  - 1,050,000 Hispanic households and
  - 400,000 Asian households.

The remaining caregiving households are of other races.

- The prevalence of informal caregiving is higher among Asian and Black households (31.7% and 29.4%, respectively) than among Hispanic households (26.8%) or White households (24%).

## Demographic Profile of Caregivers

As shown in Table 2, (page 10), the typical caregiver is a married woman in her mid-

<sup>5</sup> In a 1988 study of caregivers, 7.8 percent of U.S. households were identified as having a caregiver when a more restrictive definition of caregiving was used than in the present study. In the 1988 study, to be defined as a caregiver, a person must have been helping with at least two Instrumental Activities of Daily Living (IADLs) or one Activity of Daily Living (ADL). See [A National Survey of Caregivers: Final Report](#), (D13203) conducted by Opinion Research Corporation of Washington, DC, for the American Association of Retired Persons of Washington, DC, and The Travelers Foundation of Hartford, CT.

forties who works full-time, is a high school graduate, and has an annual household income of \$35,000. Highlights of findings by race/ethnicity and other characteristics are presented below.

### Age

- The average age of caregivers is 46.
- More than one in five caregivers is under age 35 (22%), close to four in 10 are 35 to 49 (39%), about one in four is 50 to 64 (24%), and 12 percent are 65 and older.
- Asian and Hispanic caregivers are significantly younger than Whites, with average ages of 39 and 40, respectively, compared with 47 for Whites. More than one-third of Asian and Hispanic caregivers are under 35, compared with just over one in five White caregivers.
- Level 5 caregivers are much more likely to be at least 65 years than any other caregivers: 30 percent, in contrast with only 10 percent of Level 1 caregivers, for example.

### Gender

- More than seven in 10 caregivers (73%) are female and 27 percent are male.
- Asian caregivers are most evenly split among female and male caregivers: 52 percent of Asian caregivers are women (in contrast with 77% of Blacks, 74% of Whites, and 67% of Hispanics) and 48

September 1988.

<sup>6</sup> The 1988 report estimated that there were seven million U.S. caregiving households at that time, based on the definition of a caregiver used for that study. Applying the same definition of a caregiver as used in the 1988 study to the current study (i.e., the caregiver must be providing assistance with at least two Instrumental Activities of Daily Living or one Activity of Daily Living), the number of caregivers providing this level of care as of 1996 is 21,290,000, or triple the number in 1988.

percent are men.

### Education and Income

- Thirty five percent of caregivers are high school graduates, 23 percent have some college education, and 29 percent are college graduates or have post graduate education. Nine percent have less than a high school education.
- Asian caregivers in the sample are more highly educated than caregivers of other racial/ethnic groups, with 39 percent being college graduates and 21 percent having had graduate education. In contrast, only 15 percent of Blacks and 18 percent of Hispanics are college graduates, and fewer than seven percent of either group have had graduate education. Sixteen percent of Black caregivers have less than a high school education, compared with only two percent of Asians.
- The median annual household income of caregivers is \$35,000.
- Asian caregivers also report considerably higher annual household incomes than other groups (averaging more than



\$45,000, compared with just under \$28,000 for Blacks, for example). The differences may reflect, in part, the fact that more recent Asian immigrants, whose incomes might be expected to be lower, were not included in the sample because they do not speak English.



### Marital Status and Presence of Children under 18

- Close to two-thirds of caregivers nationwide are married (66%), 13 percent are single, 13 percent are separated or divorced, and eight percent are widowed.
- Black caregivers are the least likely to be married or living with a partner—just over half (51%) are, compared with two-thirds of Asians and Whites (68%), and 64 percent of Hispanics.
- While 41 percent of caregivers have one or more children under age 18 living in their households, more than half of all Black, Hispanic, and Asian caregivers report having one or more children under age 18 in their households, in contrast with 39 percent of White caregivers.

### Employment Status

- Close to two in three caregivers (64%) are working, 52 percent full-time and 12 percent part-time; and 16 percent are retired. One in five (20%) say they are "not employed." Table 3 shows the percentages of working caregivers by age and other key characteristics.

TABLE 2  
CAREGIVER PROFILE  
(Base = Total Caregivers)

	TO TAL	WHITE	BLACK	HISPANIC	ASIAN
Number interviewed (unweighted)	n=1,509	n= 623	n=306	n=307	n=264
Number in U.S. population (weighted)*	n=2,241	n=1,829	n=238	n=105	n= 40
<b>GENDER</b>					
Female	72.5%	73.5%	76.8%	67.4%	52.3%
Male	27.5	26.5	23.2	32.6	47.7
<b>AGE OF CAREGIVER</b>					
Under 35	22.3%	20.5%	23.5%	37.1%	38.6%
35-49	39.4	39.0	44.4	37.5	43.6
50-64	26.0	26.8	22.5	21.2	14.4
65 or Older	12.4	13.6	9.5	4.2	3.4
Mean (years)	46.15	46.93	44.75	40.01	39.01
<b>MARITAL STATUS</b>					
Married or living with partner	65.7%	67.8%	50.9%	63.8%	64.4%
Single, never married	12.6	11.1	19.3	18.2	26.1
Separated or divorced	13.0	12.1	19.0	15.7	6.0
Widowed	8.0	8.3	9.8	2.0	3.0
<b>CHILDREN UNDER AGE 18 IN HOUSEHOLD</b>					
Yes	41.3%	38.8%	51.0%	58.3%	51.1%
No	57.8	60.2	48.4	41.7	48.1
<b>EDUCATIONAL ATTAINMENT</b>					
Less than high school	9.0%	8.2%	16.3%	11.1%	2.3%
High school graduate	35.3	36.0	32.0	35.2	18.2
Some college	22.5	22.2	26.8	26.7	17.0
College graduate	20.1	20.4	15.4	18.2	39.0
Graduate School +	8.8	8.8	5.6	6.5	20.8
Technical school	3.5	3.5	3.3	2.3	1.9
<b>EVER ON ACTIVE DUTY/ U.S. ARMED FORCES</b>					
	11.5%	11.1%	11.1%	11.4%	7.2%

	TOTAL	WHITE	BLACK	HISPANIC	ASIAN
Number interviewed (unweighted)	n=1,509	n= 623	n=306	n=307	n=264
Number in U.S. population (weighted)*	n=2,241	n=1,829	n=238	n=105	n= 40

#### CURRENT EMPLOYMENT

Employed full-time	51.8%	51.0%	55.6%	51.8%	63.3%
Employed part-time	12.3	12.7	10.5	13.4	14.0
Retired	15.9	17.0	13.7	6.8	4.2
Not employed	19.7	18.9	20.3	28.0	18.2

#### HOUSEHOLD INCOME

Under \$15,000	14.0%	11.7%	29.1%	21.1%	8.3%
\$15K-24.9K	18.0	17.3	24.8	22.5	11.0
\$25K-29.9K	9.3	9.5	9.8	7.8	8.0
\$30K-39.9K	14.0	14.0	12.4	16.3	13.3
\$40K-49.9K	10.3	10.4	7.8	11.1	14.0
\$50K-74.9K	14.0	14.4	9.5	10.4	15.5
\$75K or higher	10.9	12.1	3.0	6.2	19.7
Median	\$35K	\$35K	\$22.5K	\$27.5K	\$45K

Note: Column percentages may not total 100% because of refusals.

\* Weighted numbers refer to numbers of caregiving households in the U.S. population. Each number must be multiplied by 10,000 to determine the U.S. population prevalence for that cell. For example, 2,241 means 22,410,000 (i.e., there are an estimated 22,410,000 caregiving households in the U.S.). All percentages are based on weighted data.

- Of those not currently employed (36% of caregivers), about one in three (34%) said they had even been employed while taking care of their care recipient.
- Asian caregivers are more likely to be employed full- or part-time (77%) than Whites (65%), Blacks (66%), or Hispanics (65%), and also more likely to be employed full-time. This may reflect the fact that, in general, their caregiving demands are lower than those of all other racial/ethnic groups.
- On the other hand, both White and Black caregivers are more likely to be retired than either Hispanics or Asians.
- Hispanic caregivers are more likely to report they are not working (28%) than either Asians (19%) or Whites (18%).
- Those providing Level 5 care are more likely to be retired (32%) than caregivers of any other level, which suggests that the persons they provide care for (including spouses) may themselves be older and require more care.

TABLE 3  
EMPLOYMENT STATUS BY AGE AND  
OTHER CHARACTERISTICS  
(percentages)

	Employed Full or Part-Time
Total	64.2
18-34	77.2
35-49	75.8
50-64	60.3
65+	12.1
Asians	77.3
Women	60.5
HH income < \$15,000	36.5
HH income > \$50,000	77.8
R is primary caregiver	54.5
Care recipient has dementia	59.8
Level 1 caregivers	70.1
Level 5 caregivers	40.5

## Military Status

- Eleven and a half percent of all caregivers and 38.9 percent of male caregivers have been on active duty in the U.S. Armed Forces. Fewer Asian caregivers (7.2%) than White (11.1%), Black (11.1%) or Hispanic caregivers (11.4%) had served in the military.

I miss the office, the people, the socializing. I don't get out, can't get away.

## Characteristics of the Caregiving Situation

### Number of Persons Cared For

- Close to seven in 10 caregivers (69%) provide care to just one person, 23 percent take care of two people, and eight percent care for three or more people.
- Asian and Black caregivers are more likely than White caregivers to be involved in caring for more than one person.
- Level 5 caregivers are more likely than Level 1, 2, and 4 caregivers to be taking care of only one person.

### Duration of Caregiving

- The average duration of caregiving is 4.5 years.
- Close to two-thirds of caregivers (64%) have provided care to their primary care recipient for less than five



We were raised in our culture to take care of each other

years, while 21 percent have done so for five to nine years, and 10 percent for 10 years or more. There are no differences by caregiver level, except that Level 3, 4, and 5 caregivers are more likely to have been providing care for less than six months than are Level 1 caregivers.

## Recipients of Care: To Whom Do Caregivers Provide Care?

### Relationship between Caregiver and Care Recipient

- Overall, more than eight in 10 caregivers (85%) take care of a relative, and 15 percent take care of a friend or neighbor. Level 5 caregivers are more likely than other caregivers to be taking care of a relative and less likely to be taking care of a friend.
- Care recipients are typically female relatives: 31 percent of caregivers take care of their own mothers, nine percent care for their mother-in-law, and 12 percent take care of a grandmother. There are no differences by level of care.
- While only five percent of caregivers report taking care of a spouse<sup>7</sup>, 23 percent of Level 5 caregivers take care of a spouse (in contrast with less than one percent for Level 1 and Level 2 caregivers).
- Spousal caregivers are also much more common among caregivers aged 65+ (23%), when compared with all other age groups<sup>8</sup>.

I would say 80 percent of the people I associate with, it's the daughter who comes every weekend rain or shine.

- Of all racial/ethnic groups, Asian caregivers are the least likely to be caring for a spouse (only 1%) and the most likely to be assisting a father (18%).
- Hispanic caregivers are more likely to be caring for a grandparent (22%) than

When they asked me at the adult day care center to come to this meeting, I didn't know why. I don't consider myself a caregiver. I take care of my wife.

other caregivers (15%).

- Black caregivers are the most likely to be taking care of a relative other than an immediate family member or grandparent—14 percent, in contrast with nine percent of White, seven percent of Hispanic, and six percent of Asian caregivers.

<sup>7</sup> A 1995 survey of caregivers aged 18 and older that used a very similar definition of caregiving found almost the same low percentage of caregivers taking care of a spouse (4%). (See Findings from an Excel Omnibus Survey of Caregivers Conducted May 19-28, 1995, prepared for AARP's Long-term Care Team/Health Advocacy

#### Age of Care Recipient

- The average age of care recipients is 77 years.
- About two in three care recipients (64%) are over age 75, and almost one in four (24%) is over age 85. There are no differences in the ages of care recipients by caregiver level.
- White caregivers, on average, care for persons who are older than those cared for by caregivers of other racial/ethnic groups: the mean age of care recipients of White caregivers is 77.6 years, compared with 75.2 for Blacks, 74.7 for Hispanics, and 74.4 for Asians.
- Asian caregivers provide care to persons least likely to be 85+ (only 15% are). The comparable figures for White and Black caregivers are 25 percent and 24 percent.

#### Health Status of Care Recipients

- Better than seven in 10 caregivers (71%) report that their care recipient's illness or condition is long-term or chronic in nature, and an additional 11 percent say the conditions/illnesses are both chronic and short-term. Twelve percent say their care recipient's illness or condition is short-term (expected to last up to three



Services/Programs Division by Jane Takeuchi, Evaluation Research Services/Research Division/AARP, August 28, 1995.)

<sup>8</sup> This finding is consistent with the 1995 survey, in which 14 percent of caregivers aged 65+ were caring

months); and six percent say they do not know. There are no differences by level of care.

Figure 1 shows the main illnesses or problem of care recipients, as reported by their caregivers.

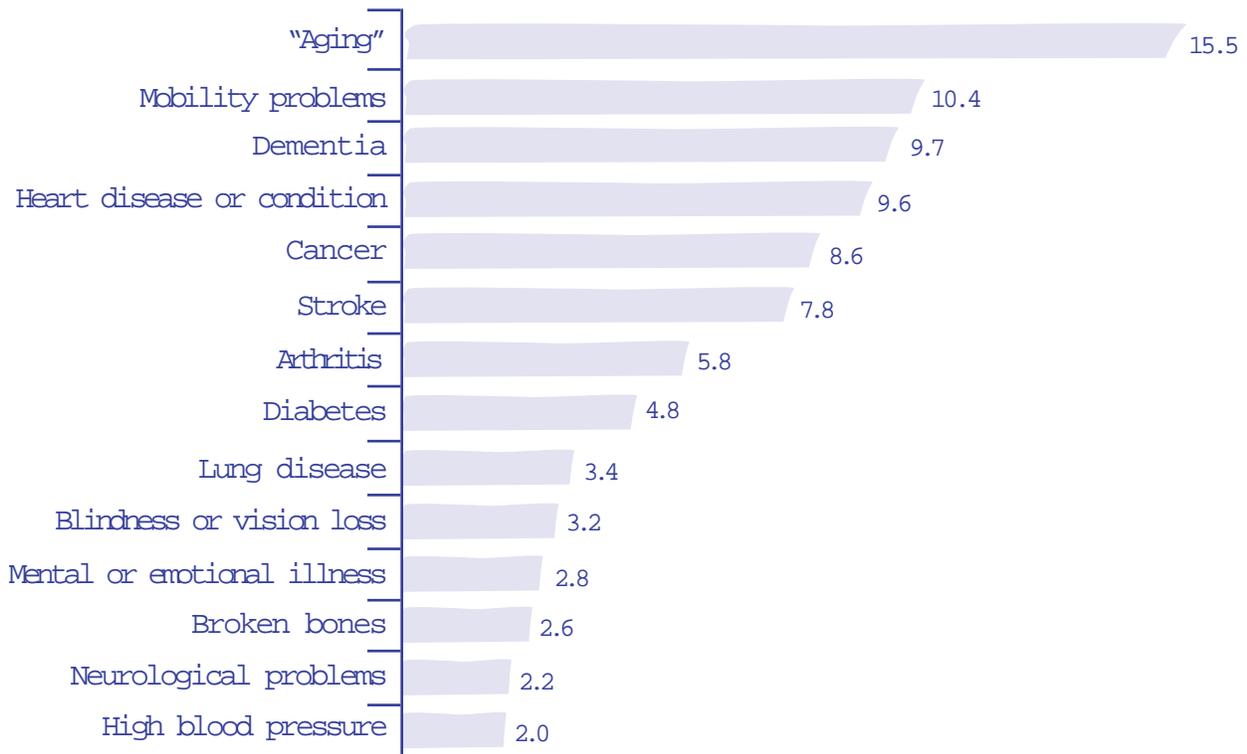
Presence of Dementia, Stroke and Diabetes

- More than one in five caregivers (22.4%) say they take care of someone with Alzheimer’s disease, confusion, dementia, or forgetfulness (hereafter referred to as dementia) as the primary or a secondary illness or condition. This find-

ing translates into an estimated 5,020,000 caregiving households nationwide that provide care for someone with dementia.

- Black caregivers are more likely than any other group to report dementia in their care recipient (28%, in contrast with 22% of White, 20% of Hispanic, and only 3% of Asian caregivers). Asian caregivers also are less likely than other racial/ethnic groups to report dementia as the main illness or problem.
- Black caregivers also report a higher incidence of stroke (12%, in contrast with 7% for each other group.)
- Not surprisingly, higher percentages of Level 4 and 5 caregivers than Level 1 caregivers report that the main illness or problem of their care recipient is demen-

FIGURE 1  
MAIN ILLNESS OR PROBLEM OF CARE RECIPIENTS  
(percentages)



tia. This is also the case for stroke. (See Figure 2.)

- Higher proportions of Level 3, 4, and 5 caregivers report caring for someone with dementia as either the main or secondary problem. (See Figure 2.)
- Both Hispanic and Black caregivers are more likely than Whites to report diabetes as the care recipient's main illness (9.4% and 9.2% vs. 3.7%).

### Living Arrangements

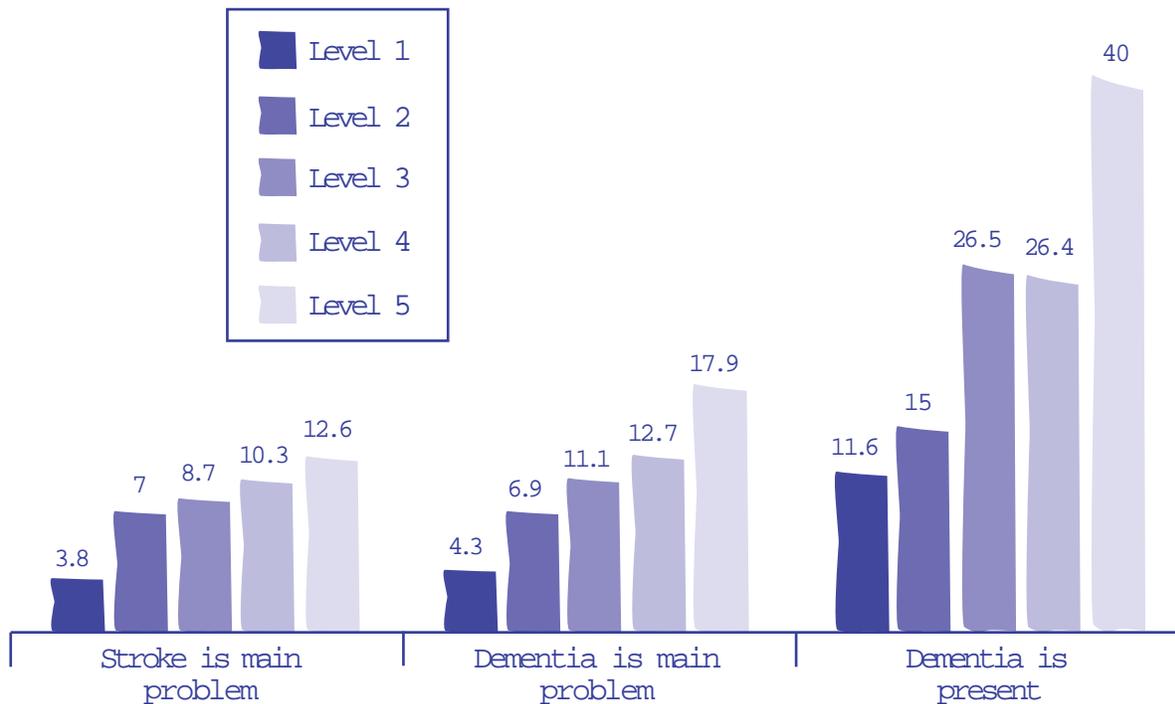
Despite the frequency of chronic and long-term illnesses or conditions necessitating care, very few caregivers said their care recipient resides in a nursing home, assisted living facility, or group home. One-fifth

of care recipients live in the same household as their caregiver, and this living arrangement was established in most cases (69%) because of the recipient's need for care. Slightly more than half of all care recipients live alone, either in their own home (37%) or in an apartment or retirement community (17%). The remaining 37 percent live with another family member or friend.

No matter where the care recipient lives, most caregivers and care recipients live in close proximity to each other. Not counting the 21 percent of care recipients who live with their caregiver, more than half of all care recipients (55%) live within a 20-minute com-



FIGURE 2  
PREVALENCE OF STROKE AND DEMENTIA BY LEVEL OF CARE  
(percentages)



Even if she is in a facility, I am a caregiver just because I try to be there for her when she needs me, to lighten her days, to give back a little of the love she showed me as I was growing up.

more of their caregiver, 69 percent live between 20 minutes and one hour away, and 94 percent live within two hours' commuting distance of their caregiver. Only six percent of care recipients live further than two hours away from their caregiver.

- While just over one in five care recipients (21%) live in the caregiver's home, 70 percent of those who receive Level 5 care live in the caregiver's home.
- Asian caregivers are more likely to live in the same household with their care recipient (36%) than Blacks (26%) or Whites (19%).
- Care recipients of Asian, Hispanic, and Black caregivers are more likely than those of White caregivers to live with another family member or friend if they do not live with the caregiver.

### Intensity of Caregiving: Hours of Care Provided and Activities Performed

As discussed in the introduction to this report, and further elaborated on in the Appendix, a Level of Care Index was created to categorize caregivers according to the amount of time they devote to caregiving and the number and types of activities they assist with when caring for the person to whom they provide the most care. This section addresses these aspects of care-

giving.

### Estimated Hours per Week of Care Provided

Caregivers in this survey provide anywhere from less than one hour of care per week to "constant care." Table 4 shows the mean number of hours of per week that caregivers estimate they provide, by level of care. Table 4 shows that the increases for Level 4 and 5 caregivers are dramatic.

- All Level 5 caregivers, by definition, provide "constant care" or 40 or more hours of care per week (an estimated 2,910,000 caregiver households nationwide), and 25 percent of Level 4 caregivers (or 1,200,000 caregiving households nationwide) also provide this

TABLE 4  
MEAN HOURS OF CARE PROVIDED  
PER WEEK BY CAREGIVER LEVEL

	Number in Sample	Hours Per Week
All Caregivers	1,509	17.9
Level 1	389	3.6
Level 2	208	8.2
Level 3	287	9.1
Level 4	355	27.3
Level 5	185	56.5

amount of care. This means that a total of at least 4,110,000 caregiving households have a caregiver who provides at least 40 hours of care per week.

- On the other hand, close to all Level 1 (N=389) caregivers surveyed (99%), by definition, spend eight or fewer hours per week providing care.
- Almost half of all caregivers perform care for at least 8 hours per week, and 21% report spending between nine and 20 hours on caregiving per week.
- While the average caregiver provides care for 18 hours per week, close to one in five (18%) provides either "constant care" or at least 40 hours of care per week.
- Women spend significantly more time caregiving than men—an average of 18.8 hours per week, in contrast with 15.5 hours per week for men.
- While women constitute 73% of all caregivers, they are 79% of the constant/40-hour-per-week caregivers.
- Asian caregivers spend significantly less time providing care per week, on average, than other minority caregivers: 15.1 hours, in contrast with 20.6 hours for Blacks and 19.8 hours for Hispanics. (Whites average 17.5 hours of caregiving per week.)

#### Types of Assistance Caregivers Provide

##### 1. INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADLs):<sup>9</sup> Managing Everyday Living

Close to all caregivers surveyed (98%) say they assist their care recipient with at least one IADL, and more than four in five (81%) assist with three or more IADLs.

- Almost eight in 10 caregivers (79%) say they help with transportation, 77 percent do grocery shopping, 74 percent do household chores, 60 percent prepare meals, and more than half manage

finances (56%) and/or arrange or supervise the provision of outside services (54%).

- More than one in three caregivers (37%), or 8,370,000 caregiving households nationwide, give medications, pills, or injections to the person they care for. Black caregivers are more likely than either White or Asian caregivers to report that they give medications (51% vs. 35% and 38%); and Hispanic caregivers are more likely to give medications (45%) than Asian caregivers (38%). (Issues concerning the management of medications are discussed in a separate section beginning on page 20.)
- While men and women perform most IADLs in equal proportions, women are more likely than men to do housework (77% vs. 65%) and to prepare meals (65% vs. 47%).
- There are no differences in the incidence of assisting with IADLs by employment status (working compared with non-working caregivers).
- Income, however, does make a difference in the kinds of IADLs performed. For example, caregivers with household incomes under \$15,000 are more likely than high-income caregivers (with household incomes of \$50,000 or more) to provide assistance with housework (84% vs. 73%) and meal preparation (69% vs. 55%). Similarly, caregivers with household incomes over \$50,000 are more likely than caregivers with household incomes under \$15,000 to arrange for or supervise outside services (61% vs. 48%) and to manage finances (61% vs. 46%).

There are no differences by race/ethnicity in the extent to which caregivers provide

<sup>9</sup> Instrumental Activities of Daily Living (IADLs) are activities performed to manage one's daily life or maintain a household and live independently, such as preparing

meals, grocery shopping, driving or using transportation systems, doing light housework, taking medications, managing finances and paying bills and using the tele-

help with IADLs, though there are differences by level of care, as shown in Table 5, which highlights differences between Level 1 and Level 5 caregivers. Level 5 caregivers (and in most cases Level 4 caregivers, as well) are more likely than caregivers of any other level to provide assistance with each IADL.

## 2 ACTIVITIES OF DAILY LIVING (ADLs)<sup>10</sup>

Personal Care such as Bathing or Eating

More than half of all caregivers (51%) help with at least one ADL, and 29 percent help with at least three.

- Overall, women are more likely than men to assist with ADLs (54% vs. 45%),

I do all the laundry for my sister. I help her bathe. I cook her all her favorite foods. I play cards with her an hour a day to keep her mind active. I do literally everything for her.

TABLE 5  
PERFORMANCE OF IADLS:  
TOTAL AND BY LEVELS 1 AND 5  
(percentages)

	Total	Level 1	Level 5
Transportation	79.3	72.0	89.6*
Grocery shopping	77.3	67.9	93.7*
Housework	73.6	53.2	96.0*
Preparing meals	60.0	28.9	94.6*
Managing finances	55.6	48.3	74.4*
Arranging/supervising outside services	53.9	42.9	74.6*
Giving medicine	37.3	0.0	86.6*
No ADLs	2.0	2.6	—

\*Differences between Level 5 and Level 1 caregivers are statistically significant at the .05 level.

and higher proportions of women than men assist with dressing, bathing or showering, and with continence or diapers.

- Black caregivers are more likely to help with at least one ADL (60%) than Whites (50%) or Asians (44%); half of all White caregivers and 56 percent of Asian caregivers do not assist with any ADLs. Higher proportions of Blacks than Asians report assisting with each ADL, except for feeding.
- A higher percentage of Hispanic caregivers assist with at least one ADL (58%) than Asians (44%); and Hispanics are more likely than Whites to assist with dressing, bathing, toileting, and continence.

- Non-working caregivers are more likely to perform ADLs than employed caregivers (59% vs. 48%).
- While employed caregivers are as likely as those not employed to provide assistance with IADLs, a significantly smaller percentage provide assistance with any ADLs (48%, as compared with 59% of non-working caregivers).

While, by definition, Level 1 caregivers provide no help with ADLs, high proportions of Level 4 and 5 caregivers do, as shown in Table 6.

#### Receipt of Instruction in How to Perform Caregiving Activities

- Just over two in five caregivers (41%) report that someone taught them how to perform at least one of the activi-

TABLE 6  
PERFORMANCE OF ADLS:  
TOTAL AND BY LEVELS 4 AND 5  
(percentages)

	Total	Level 4	Level 5
Getting in/out of chairs	36.8	56.7	77.8*
Dressing	31.4	56.2	79.9*
Bathing	26.6	47.4	77.5*
Toileting	26.2	47.8	63.2
Feeding	19.2	29.5	43.9
Continence/diapers	13.6	20.2	44.6*
No ADLS	48.5	15.9	—

\*Differences between Level 5 and Level 4 are significant at the .05 level.

<sup>10</sup> Activities of Daily Living (ADLs) are activities involving personal care, such as eating, toileting, getting in and out

of bed and chairs, bathing, dressing and grooming, and managing continence or changing adult diapers/briefs.

ties they assist with, while 59 percent have received no instruction. There are no differences by level of care, gender, income, education, or employment status.

That fewer than half of all caregivers have received any instruction in providing care may reflect the fact that many activities they assist with, such as providing transportation or grocery shopping, require no particular skill to be performed satisfactorily.

- There are differences, however, by race/ethnicity. Asian caregivers are the least likely to have been taught how to perform any of the tasks they assist with—only 32% have received any training. This figure is significantly lower than for Black caregivers (46%).

## Medication Management

More than seven in 10 caregivers say their care recipients take their own medications as directed—on time, in

I was scared of the IV. I had to keep the wounds clean, then there was an abscess in her knee. I asked a lot of questions of the nurse until I understood what I was supposed to do.

the right amount, and with no problem. Fewer than one in four caregivers (23%) report that their care recipient has trouble taking medicines, and six percent say their care recipient takes no medicines. There are no differences by

race/ethnicity.

- Level 3, 4, and 5 caregivers are more likely than Level 1 caregivers to say their care recipient has trouble taking medications as directed (at least 30%, compared to 9% for Level 1 caregivers).

Of those who do help with medications, a very high percentage (96%) say they know how to administer them as prescribed (on time and in the right amount). Again, there are no differences by race/ethnicity or by level of care.

High proportions also report knowing what each medication is for (90%), the possible side effects of each medication (78%), and how medicines may react with each other (69%).

- Asians are less likely to know these things than caregivers of other racial/ethnic groups.
- Level 4 and 5 caregivers are more likely to be well-informed about these issues than Level 2 caregivers. (Level 1 caregivers do not administer medications.)

More than three in four caregivers who help with medications (77%) say they have asked someone about a medication that was prescribed. Asian caregivers who help with medications are less likely than either Whites or Hispanics to have consulted anyone about them (63% vs. 80% and 78%). There are no differences by level of care.

The person most frequently consulted is a doctor (61%), pharmacist (24%), or a nurse (9%). Four percent report having consulted a family member.

## Caregiver Support: Who Also Helps Provide Care?

Almost three in four caregivers (73%) report that someone else also helps provide care to the care recipient. Typically

the other helpers are the care recipient's daughter (34%), son (25%), spouse (9%), daughter-in-law (6%), grandson (6%), "the whole family" (5%), or son-in-law (5%). Sisters and nieces of the care recipient were each mentioned by four percent of caregivers. Thirteen percent of caregivers report that a friend or other unpaid non-relative also helps in providing care.

- Hispanic caregivers are more likely than Asians to report that a daughter of the care recipient also provides care (45% vs. 33%); and a higher proportion of Asians (11%) than any other racial/ethnic group report that daughters-in-law also provide care.
- Level 1 caregivers are more likely to say that a relative of the care recipient also helps provide care than are Level 5 caregivers (78% vs. 64%), and that person is less likely to be the care recipient's spouse for Level 5 caregivers than for Levels 2, 3, and 4 caregivers. (This latter finding reflects the fact that Level 5 caregivers are more likely to be caring for a spouse than lower level caregivers.)

#### Primary vs. Secondary Caregivers

Just over two in five caregivers (41%) say they provide most of the care or that no one else helps, while an equal percentage say someone else provides most of the care. This means that 41 percent of caregivers can be considered primary caregivers and an equal percentage can be considered secondary caregivers. Seventeen percent say the care is split equally between themselves and another person.

- A higher percentage of Black than Asian caregivers report that they themselves provide most of the care or that no one else helps (49% vs. 36%).
- While only 18 percent of caregivers report that no one else helps them with the

caregiving, more than one in three Level 5 caregivers (34%) say no one else helps them (which amounts to 980,000 caregiving households), more than for caregivers of any other level.

#### Are Others Doing Their Fair Share of the Caregiving?

Just under half of all caregivers (49%) feel that other relatives are doing their "fair share" of the caregiving. One in five say their relatives are not doing their fair share, and just over three in 10 (31%) say no one else helps or they get help from a non-relative.

- Asian and Hispanic caregivers are more likely to feel that other relatives are doing their fair share of the caregiving (61% and 54%) than Blacks (43%), and Asians are also more likely to feel that way than Whites (49%).
- A higher proportion of Level 4 and 5 caregivers than Level 1 caregivers feel that other relatives are not doing their fair share (26% and 28% vs. 13%).

#### Perceptions of Family Conflict Over Caregiving

Only five percent of all caregivers report that they experience a lot of family conflict over caregiving, just over one-fifth (21%)

My brothers would provide just as much assistance to my father as I do, if I called them to do so. My brothers do help with bathing my father, as does my son. If I call them at any time, I know they will come.

report some conflict, and 73 percent report no family conflict at all. There are no differences by race/ethnicity, but there are differences by level of care, by age, and by employment status.

- Level 1 caregivers are more likely to report no family conflict (80%) than either Level 4 or Level 5 caregivers (67% and 68%); and Level 3 caregivers are almost twice as likely as Level 1 caregivers to say they experience some family conflict (30% vs. 16%).
- Caregivers aged 18–34 are more likely than those over 65 to say they experience some family conflict over caregiving (27% vs. only 8%), and are less likely than caregivers aged 50–64 and 65+ to say there is no family conflict at all.
- Employed caregivers are more likely to report family conflict over caregiving (24%) than caregivers who are not working (16%).

### Physical, Emotional, and Financial Strain and Stress of Caregiving

While relatively small percentages of all

I'm really angry because there's no reason why they can't come and sit a couple of hours or a day where we can get away.

caregivers say their caregiving responsibilities have seriously interfered with their usual activities, caused them physical or mental health problems, been highly stressful physically or emotionally, or posed a serious financial hardship, there is

considerable variation in the responses of caregivers by the level of care they provide, by race/ethnicity, and by other demographic variables.

### Impact of Caregiving on Time for Family and Leisure Activities

More than four in 10 caregivers (43%) report that their caregiving responsibilities have caused them to have less time for other family members than before, and an equal proportion say that caregiving has necessitated giving up vacations, hobbies, or their own activities. More than half of all caregivers (55%) have experienced one or both of these.

- Not surprisingly, Level 3, 4 and 5 caregivers are more likely to report either of these situations than Level 1 or 2 caregivers. For example, two-thirds of Level 5 caregivers (68%) report having less time for family, in contrast with 22 percent of Level 1 caregivers and 35 percent of Level 2 caregivers; and almost three in four Level 5 caregivers (73%) have had to give up vacations, hobbies, or their own activities (as compared with 25% of Level 1 caregivers and 33% of Level 2 caregivers).
- Those caring for someone with dementia are more likely than other caregivers to have had less time for other family members or leisure activities (66%).

Sometimes it's not good for the caregiver to have to split her time between young children and an aging parent. He or she can't do justice to either.

- Asian caregivers are less likely than caregivers of other racial/ethnic groups to say they have less time for other family members due to caregiving (only 31%, compared with 42%–44% of other caregivers). There are no other differences by racial/ethnic group.
- A higher percentage of caregivers with at least some college education report both less time for family and less time for leisure activities than those with a high school education or less.

#### Experience of Physical or Mental Health Problems

Fifteen percent of all caregivers report that they have suffered any physical or mental health problems as a result of caregiving, and 85 percent say they have not.

- Among Level 5 caregivers, however, more than three in 10 (31%) say they have experienced physical or mental health problems due to caregiving (compared with seven percent of Level 1 caregivers, 13 percent of Level 2 caregivers, and 12 percent of Level 3 caregivers.)
- A higher proportion of Black than Asian caregivers report having suffered physical or mental health problems as a result of caregiving (19% vs. 10%).
- Women are more likely than men to have experienced physical or mental health problems as a result of caregiving (17% vs. 9%), and non-working caregivers are more likely than working caregivers to have experienced such problems (19% vs. 12%).
- A higher proportion of caregivers aged 50–64 report having experienced physical or mental health problems (21%) than those aged 18–34 (9%) or 35–49 (13%).

#### Experience of Physical Strain

More than half of all caregivers (56%) report that their caregiving activities cause no physical strain at all (a rating of 1 on scale of 1 to 5, where 1 is low and 5 is high), and only six percent say that caregiving has been very much of a physical strain for them.



- Level 5 caregivers, however, experience more physical strain than caregivers of any other level. One in three (33%) rank their physical strain as a 4 or a 5 on the five-point scale.
- A higher proportion of Blacks (19%) report experiencing high levels of physical strain (a rating of 4 or 5) than either Whites or Asians (10% apiece).
- A higher percentage of women than men report experiencing physical strain (13% vs. 5%); and those with annual household incomes under \$30,000 are more likely than those with incomes of at least \$50,000 to experience high physical strain (17% vs. 6%).

#### Experience of Emotional Stress

One in four caregivers experience caregiving as emotionally stressful (a rating of 4 or 5 on a scale of 1 to 5), while more than half (55%) find it not very stressful (a rating of 1 or 2). In contrast, more than half of Level 5 caregivers (53%) find caregiving emotionally stressful.

- Of the racial/ethnic groups, Asians report the least amount of emotional stress.
- Women are more likely than men to experience their caregiving as stressful (30% vs. 13%), and a still higher percentage of those caring for a person with dementia say that caregiving is stressful (43%).

#### Experience of Financial Hardship

Only a small percentage of all caregivers (7%) report that caregiving is a financial hardship for them (a rating of 4 or 5 on a scale of 1 to 5), and more than three in four caregivers (76%) say that caregiving is not a financial hardship at all (a rating of 1).

- A higher percentage of Level 5 caregivers than caregivers of any other level say their caregiving responsibilities pose a financial hardship (21%).
- Whites are more likely than caregivers of any other racial/ethnic group to say that caregiving poses no financial hardship for them at all (78% vs. 70% of Hispanics, 66% of Asians, and 63% of Blacks).
- Black and Hispanic caregivers are more likely than Whites or Asians to say that caregiving is a financial hardship for them (a rating of 4 or 5): 13% and 11%, compared with 6% of White and Asian caregivers.
- Not surprisingly, those with annual household incomes under \$15,000 are more likely than those with higher incomes to say that caregiving poses a financial hardship (16% vs. only 1% for those with incomes of at least \$50,000, for example). Similarly, those who have not graduated from college are more likely to say that caregiving poses a financial hardship than those who have.
- Non-working caregivers are more likely to find caregiving a financial hardship (10%) than working caregivers (5%).

#### Estimated Out-of-pocket Expenditures on Caregiving Other than for a Spouse

For the 41 percent of caregivers who report that they know how much they spend of their own money on caregiving during a typical month, the average amount spent is \$171, which totals approximately \$1.5 billion per month spent out-of-

pocket on caregiving nationwide.

Nine percent say they do not know how much they spend, and just under half of all caregivers (49%) say they spend no money of their own on caregiving during a typical month.

- Minority caregivers are more likely to have out-of-pocket expenditures for caregiving than Whites. Only 27 percent of Asians, 35 percent of Hispanics, and 37 percent of Blacks report no monthly personal expenditures on caregiving, in contrast with 53 percent of White caregivers.
- About twice as many Level 1 caregivers (67%) report no out-of-pocket expenditures for caregiving than Level 4 or Level 5 caregivers (31% and 34%).
- Excluding those who say they have no out-of-pocket expenses for caregiving, Level 5 caregivers spend considerably more than Level 1, 2, or 3 caregivers, averaging \$357 per month, as compared with \$95.42 for Level 1 caregivers, for example.

#### Caregiving Expenditures for Other than a Spouse, as a Percentage of Monthly Income

More than three in four caregivers (77%) not involved in spousal caregiving report that they spend 10 percent or less of their own monthly income on caregiving, and fewer than one percent of all caregivers

We have just enough money to make ends meet. There is very little left. It goes for medicines, drugs, transportation.

providing non-spousal care report that they spend more than 50 percent of their income on caregiving. Seventeen percent of all caregivers, and 26 percent of Level 5 caregivers, cannot estimate how much they spend per month.

- Of caregivers who can estimate how much they spend out-of-pocket on caregiving, Level 5 caregivers spend an average of 24 percent of their own monthly income on caregiving—a much higher percentage than for caregivers of any other level.
- Of those who spend any money out-of-pocket on caregiving, both Black and Asian caregivers report spending higher proportions of their income on caregiving (averaging 15% and 13%) than White caregivers (6%).

### Dealing with Stress: Coping Mechanisms

Caregivers cope with the strains and stresses of caregiving principally through their personal resources or informal networks. The most common coping mechanisms are prayer (74%), talking with friends or relatives (66%), exercising (38%), and hobbies (36%). Relatively small percentages get help from counselors or other professionals (16%), use medications (7%), or resort to alcohol (3%).



- Prayer is the most common way of coping with the stresses and strains of caregiving—almost three in four caregivers (74%) use this method, but 88% of Black caregivers use prayer.
- Whites and Blacks are more likely than Hispanics or Asians to talk with friends and relatives to relieve stress.

I try to be optimistic.  
Sometimes I bend over backwards to take what might be an unpleasant situation and turn it around to something that could be pleasant just by attitude.

- Asian caregivers are less likely to get help from a counselor or professional than either Whites or Blacks (6% vs. 17% and 14%).

Prayer elevates your mind.  
God is doing this. I am here physically, and He is instilling strength in me to do it.

### Biggest Difficulty and Greatest Reward of Caregiving

#### Biggest Difficulty

One in five caregivers (20%) say the biggest difficulties they face in providing care are the demands on their time or not being able to do what they want; 15 percent say it is watching or worrying about their care recipient's deterioration; 10 percent say it is the care recipient's attitude (uncooperative, "demanding"); and four percent mention a problem with location, distance, or inconvenience. There were no differences by race/ethnicity.

More than one in four caregivers (26%) say they have no difficulty providing care,

though this response was more frequent among Level 1 and 2 caregivers than among Level 4 and 5 caregivers.

- Perhaps not surprisingly, Level 3, 4, and 5 caregivers are more likely to say that watching or worrying about their care recipient's deterioration is their biggest concern (17-21%) than are Level 1 caregivers (just under 8%).
- Blacks are more likely than Whites to mention the physical demands of caregiving as their biggest difficulty (6% vs. 2%).

#### Biggest Reward

The biggest rewards of caregiving are knowing that the care recipient is well cared for, personal satisfaction in knowing one is doing a good deed, and the care recipient's appreciation or happiness. Each of these was mentioned by

It is a strain on you physically and mentally. You don't have a life because you neglect a lot of your own personal needs because you're so wrapped up with taking care of their needs.

16 percent of caregivers. Also mentioned are watching the care recipient's health improve (by 11%), family loyalty, "giving back," fulfilling family obligations (by 11%), and spending time together (by 10%). There are no differences by race/ethnicity.

- Level 2 caregivers are more likely to mention family loyalty or obligation as the biggest reward of caregiving (18%)

than Level 4 or 5 caregivers (6%-7%).

#### Words Caregivers Use to Describe the Caregiving Experience

##### Positive Words

There is still a lot of happiness. My mother comes alive when she interacts with the grandchildren.

A majority of caregivers (57%) use positive words to describe the caregiving experience; and there are no differences in the overall positiveness of their comments by race/ethnicity or level of care.

Words used to describe the experience of caregiving by more than a handful of caregivers include "rewarded"/"rewarding" (mentioned by 19%); "happy," "helpful" (each by 7%); and "thankful"/ "grateful," "enjoyable," and "love"/"loving" (each by 4%). Interestingly, Level 5 caregivers are more likely to report that they feel good, comfortable, content, or "OK" about caregiving than Level 1 or Level 2 caregivers (9% vs. 1%).

##### Negative Words

Just over one-third of caregivers (34%) use negative words to describe their experience as a caregiver. There are no differences by level of care provided or by racial/ethnic group.

The negative words caregivers most frequently use to summarize how they feel about caregiving are "stressful" (12%), "obligation"/"duty" (9%), "burdened" (3%), and "tired"/"exhausting" (3%). There are no differences by level of care.

- Hispanics are more likely than Whites to use the word “stressful” in describing their caregiving experiences (18% vs. 10%).

Eight percent of caregivers say they don’t know how they feel about caregiving.

### Utilization of Supportive Services Available in the Community

Almost three in four caregivers (74%) report having used one or more services or devices shown in Table 7. Not surprisingly, Level 3, 4, and 5 caregivers are more apt to have used wheelchairs or walkers, personal or nursing care services, home modification, and respite care (identified during the interviews as “temporary care services”) than Level 1 or 2 caregivers. The number of such services and devices used also varies by level of care provided. For example, the average number of services used by Level 1 caregivers is 1.36, while for Level 5 caregivers it is 2.94.

- Caregivers who report that their care recipient has dementia are more likely to report the use of at least one of these services (83%) than caregivers overall (74%).
- Asian caregivers are the least likely of the racial/ethnic groups to report having used any of these services—only 62 percent, compared with 72–76 percent of caregivers of other racial/ethnic groups. This finding holds for wheelchairs and other devices, personal or nursing care services, and home-delivered meal services.
- White, Black, and Hispanic caregivers were more than twice as likely as Asian caregivers to have used personal or nursing care services (32% to 44% vs. only 15% of Asians), and Blacks were the most likely to have done so (44%).

It is not clear whether the lower rates of service utilization among Asian care-

givers are a result of the overall lower level of care they provide, cultural factors, or something else.

- Both White and Hispanic caregivers were more likely to say they have made home modifications than Black care-

TABLE 7  
UTILIZATION OF SERVICES  
(Base = Total Caregivers)  
(percentages)

Acquiring a wheel chair, walker, or other device	46.7
Personal or nursing care services	37.8
Home modification	28.1
Home-delivered meal services	15.6
Assistance with housework	15.6
Financial information service	15.5
Transportation service	14.9
Respite care	14.1
Adult day care/senior center	9.5
Support group	6.6

givers (29% and 26% vs. 17%).

- Blacks and Hispanics are more likely to have used transportation services (more than 20% each) than Whites (only 14%), and Blacks are more likely than Whites to have used adult day care or senior centers (14% vs. 9%).
- Asians are the least likely to have used respite care services—only 8

percent have done so, compared with 15 percent of Whites, for example.

- Among Level 5 caregivers, use of respite care (by 23%), adult day care (by 16%), and support groups (by 15%) is modest, even though significantly higher than for caregivers providing lower levels of care. There were no differences by level of care in the extent to which meal services, help with housework, or transportation services are used.
- Female caregivers are more likely than male caregivers to have used a device such as a wheelchair or personal or nursing care services, and caregivers aged 65+ are more likely than caregivers of younger ages to have used a support group (14% vs. 4 to 8%).
- Not surprisingly, college graduates are more likely than caregivers of lower educational attainment to have used housework assistance or adult day care or a senior center to assist with care.

Sixteen percent of caregivers reported they had sought information on how to get financial assistance for the person(s) to whom they provide care. Use of financial information services is more common among Level 4 and 5 caregivers than among Level 1 and 2 caregivers, but does not differ by race/ethnicity (except that Hispanics are more likely to have used them than Asians) or other demographic

I don't know what I would do without the adult day care center. My mother is busy during the day and I get a break. It helps me keep going.

variables.

More than one in four caregivers (27%) say they have used none of the services or devices. Not surprisingly, this is more typically the case among Levels 1 and 2 caregivers than among Levels 3, 4, and 5 caregivers, and also among Asian caregivers.

#### Service Providers

Almost half the caregivers who use any of these services or devices (49%) say they are or were provided by an individual or private commercial agency, paid for by the caregiver. Community or government agencies were a source of services or devices for 45% of the caregivers. Other sources include health care providers (used by 43% of caregivers using any services) and family, friends, and volunteers (used by 23%). Ten percent say the services are or were provided by a church or synagogue.

#### Level of Satisfaction with Providers of Assistive Services and Devices

As Table 8 shows, satisfaction with services and devices is relatively high, with more than four in five caregivers reporting that the devices/services they have used either fully or partially met their needs, except in the area of financial information services.

Caregivers who have used wheelchairs or other devices, home modifications, and transportation services are the most apt to say the service fully met their needs, and those who have used financial information services are least likely to say the services fully met their needs.

#### Reasons for Non-Utilization of Assistive Services and Devices

For each of the 10 services inquired about, caregivers who said they did not use it were asked why. In the great majority of cases, the reason caregivers

did not use a service is that they had no need for it, ranging from 61 percent for support groups to 96 percent for assistive

TABLE 8  
SATISFACTION WITH SERVICES  
AND INFORMATION  
(Base = Total Caregivers)

	Met Need Fully	Met Need Partly
Wheelchair, walker, or other device	81.4	14.1
Home modification	77.9	17.6
Transportation Service	71.8	24.8
Home-delivered meal service	61.0	25.3
Housework	61.9	30.5
Personal care, nursing service	69.6	23.8
Adult day care/senior center	53.6	30.7
Respite care service	62.9	32.4
Support Group	53.4	37.8
Financial information service	33.5	40.7

devices.

Lack of Awareness of the Service

The second most frequent reason for not using a service was not being aware of it, mentioned by 18 percent of all caregivers, but by 30 percent of Level 5 caregivers (a higher percentage than for caregivers of any other level). This reason was cited by

higher percentages of Blacks and Hispanics (27% and 29%) than Whites (17%), and by a higher percentage of primary caregivers (22%) than secondary or co-equal caregivers (16%).

"Too Proud" to Use It

An unusually high percentage of caregivers (15%) said they or their care recipient were too proud to use adult day care or a senior center—a much higher percentage than for any other service/device inquired about (two percent or fewer). There is probably also some confusion as to what adult day care is, because five percent of caregivers mentioned that they didn't use it because they didn't want an outsider coming in to their home. "Too proud" may also reflect resistance to services by the older person.

- This reason was more often cited by caregivers aged 50-64 (23%) than those aged 18-34 (12%), and by primary caregivers (25%) than secondary/co-equal caregivers (12%).

No Special Reason/Never Thought about It

Seventeen percent of caregivers who don't use a particular service said they had no special reason for not using it, or that they had never thought about it. Higher proportions of Level 4 and 5 caregivers mentioned this reason than Level 1 caregivers (23% vs. 12%), and so did higher percentages of Black and Hispanic caregivers (29% and 26%) than White caregivers (15%).

Too Busy

Ten percent of caregivers said they were too busy to use the service, with a higher percentage of Hispanic caregivers (21%) citing this reason than caregivers of any other race/ethnicity (10-11%). A higher percentage of primary caregivers than secondary caregivers also said that they were



too busy.

#### Service Is Not Available

The perception or knowledge that a service is not available also contributes to its non-utilization.

Interestingly, 17 percent of Level 5 caregivers and 13 percent of level 4 caregivers mentioned this as a barrier, in contrast with only four percent of Level 1 caregivers. Those with incomes of less than \$15,000 were more likely to cite this reason (15%) than those with incomes between \$30,000 and \$50,000 (only 4%).

#### Cost

Surprisingly, very few caregivers cited cost as a barrier to obtaining needed services. Factors influencing whether cost is mentioned include intensity of care, race/ethnicity, income, living arrangements, and primary vs. secondary/co-equal caregiver status.

- Although all percentages are small, higher percentages of Level 4 and Level 5 caregivers (9% and 11%, respectively) mention cost as a barrier to service utilization than Level 1 caregivers (1%), and a higher percentage of Hispanic caregivers (10%) cite this reason than Asians (2%).
- Not surprisingly, those with incomes under \$15,000 were more likely to mention cost as a factor than those with incomes of at least \$30,000. A higher proportion of caregivers whose care recipient lives with them cite cost as a reason for non-utilization of services (12%) than those whose care recipient lives up to an hour away (4%). Primary caregivers also are more apt to mention cost as a barrier than secondary/co-equal caregivers (8%

vs. 4%).

#### Unmet Needs for Help, Information, or Support in Caregiver Role

Table 9 shows the kinds of assistance most frequently mentioned in response to a question concerning the kinds of help, information, or support caregivers would use, or would have used, in providing care.

While 38 percent said they didn't know what additional assistance they would use, or would have used, this figure escalates to 49 percent of Asian caregivers—higher than for all other racial/ethnic groups—and to 44 percent for those with a high school education or less (compared with about one-third of more highly educated groups).

Black caregivers were more likely than Whites or Asians to name at least one type of assistance they would use (51%, vs. 43% and 36%, respectively).

Those who have not used any services are more likely not to know what they would use, or would have used, than those who have (48% vs. 35%), and secondary/co-equal caregivers are less likely to know than primary caregivers (43% vs. 31%). This is also the case for higher percentages of Level 1 and 2 caregivers than for Level 5 caregivers.

While 19 percent of all caregivers said there was nothing they needed, those who had never used any services were more likely to say they didn't need any (25%) than those who had (16%).

#### Free Time/A Break from Caregiving

As expected, caregivers who provide the most intense and difficult kinds of care are the ones most likely to report needing more free time or a break from caregiving. There are no differences by race/ethnicity.

- While 17 percent of all caregivers say

TABLE 9  
 KINDS OF HELP, INFORMATION,  
 OR SUPPORT CAREGIVERS  
 WOULD USE/WOULD HAVE USED  
 (Base = Total Caregivers\*)

Don't know	38.1
None/nothing/no help	18.5
Free time/time for self/a break	16.9
Help with housekeeping	9.8
Extra money/financial support	9.5
Central source of information	9.0
Information about paying for services such as nursing homes, adult day care	7.6
Someone to talk with/counseling/support group	6.0
Sitting services/someone to check up on care recipient	5.6
Help with ADLs/personal care	4.9
Help with shopping	4.3
Help with medications	3.2
Information about care recipient's condition	2.7

\*Up to two responses per caregiver were coded.

they could use more free time or a break from caregiving, Level 5 caregivers are more likely to say they need it (33%) than Level 1, 2, or 3 caregivers. Primary caregivers also are more likely to report needing a break than secondary/co-equal caregivers (21% vs.

14%).

- Caregivers taking care of someone with dementia also are more likely to mention needing more free time or a break from caregiving: 24%.

Caregivers who have used formal services are more likely to mention needing a break than those who have not (19% vs.10%).

#### Assistance with Housekeeping and Meal Preparation

Ten percent of caregivers say they could use help with housekeeping. Women are more likely to say this than men (11% vs. 7%). Both low- and high-income caregivers are more likely than middle-income caregivers to need help with housekeeping, as are primary caregivers compared with secondary/co-equal caregivers (13% vs. 8%), and those who have used formal services as compared with those who have not (12% vs. 5%).

Though the percentages are small, Black and Hispanic caregivers are more likely to report needing help with meal preparation than Whites (7% vs. 3%), as are spouse caregivers (9%) when compared to all caregivers (3%).

#### Needs for Financial Help

Very small numbers of caregivers mentioned needing money. Higher percentages of Blacks and Hispanics than Whites report needing extra money or financial support because of their caregiving responsibilities (14% vs. 9%).

Those caring for someone with dementia are also more likely to say they need extra money or financial support than the average caregiver (14% vs. 10%).

- Understanding how to pay for nursing homes, adult day care, or other services was more often mentioned by Hispanic

caregivers (13%) than by Whites (7%), by caregivers with household incomes under \$15,000 (16%) than by those with incomes above \$15,000 (5% to 9%), by persons who have used formal services (9%) than by those who have not (3%).

- Not surprisingly, caregivers assisting persons with dementia were more likely than the typical caregiver to say they could use, or could have used, help in understanding how to pay for long-term care services such as nursing homes and adult day care (12% vs. 8%).

#### Central Source of Information

Having a central place to go to or to call to find out what help is available was mentioned by nine percent of caregivers as a need or service they would use, or could have used. Interestingly, this was mentioned more frequently by those with household incomes over \$50,000 (15%) than by those with lower incomes (8-10%), and more often by those with at least some college education (11-14%) than by those with a high school education or less (5%). It was also more frequently mentioned by those who had used services than those who had not.

#### Someone to Talk with, Counseling, Support Group

While only six percent of caregivers say they could use someone to talk with, counseling, or a support group, a higher percentage of Level 5 caregivers (25%) than all other groups say they could use this kind of assistance. Those caring for someone with dementia were also more likely than the average caregiver to say they could benefit from talking with someone (11%).

Women are more likely to say they could use this type of assistance than men (7% vs. 3%), and caregivers aged 50-64 and 65+ are more likely to say they need it than those aged 18-34 (9% and 10% vs.

2%). Those whose care recipients live with them are more likely to need someone to talk with than those who do not live with their care recipient (13% vs. 4%).

- Caregivers taking care of someone with dementia also are more likely to mention needing someone to talk with, counseling, or a support group (11%).



#### Impact of Caregiving on Work

Since the majority of caregivers are employed (64%), most of them full-time (52%), the impact of caregiving responsibilities on work life can be important.

While relatively few caregivers who ever worked while providing care to their care recipient (79% of caregivers) report having given up working entirely as a result of caregiving (6%), caregiving responsibilities do have a significant impact on caregivers' work life. For example, more than half the caregivers employed while caregiving for this care recipient (54%) have made changes at work to accommodate caregiving.

- Making changes in daily work schedule (going in late, leaving early, or taking time off during the day) are the changes most frequently reported: by 49% of caregivers who ever worked while caring for this care recipient.
- One-fifth of all caregivers ever employed while caring for this care recipient gave up work either temporarily or permanently: 11 percent took or have taken a leave of absence, four percent took early retirement, and six percent gave up working entirely.
- Seven percent report having changed

from full-time to part-time work or taken a less demanding job.

- Relatively few report having lost their benefits (4%) or having turned down a promotion (3%) because of caregiving responsibilities.
- Hispanic and Asian caregivers are more likely to have had to take a leave of absence from work (18% and 22%) than Whites (10%).

As Table 10 shows, there is a correlation between the level of care provided and the likelihood of altering one's daily work schedule, taking a leave of absence, switching to part-time work, or giving up work entirely. For example, three in four Level 5 caregivers, in contrast with 41 percent of Level 1 caregivers, have made at

least one of the work-related adjustments shown in Table 10.

- Thirty percent of Level 5 caregivers report having had to give up work entirely, and 26 percent say they took a leave of absence because of their caregiving responsibilities—much higher percentages than for Level 1, 2 or 3 caregivers.

Other factors associated with higher levels of care or more intense caregiving include caring for a person with dementia, living in the same household as the care recipient, helping with two or more ADLs, and being a primary caregiver. Table 11 below shows the percentages of these types of caregivers who have made work-related adjustments as a result of caregiving.

**TABLE 10**  
**WORK-RELATED ADJUSTMENTS BY LEVEL OF CARE**  
(Base = Caregivers Ever Employed while Providing Care to This Care Recipient)  
(percentages)

	Total	Level 1	Level 2	Level 3	Level 4	Level 5
Total unweighted+	(N=1,193)	(n=330)	(n=174)	(n=240)	(n=277)	(n=113)
Total weighted+	(N=1,716)	(n=530)	(n=245)	(n=331)	(n=363)	(n=166)
Made any changes listed below	54.2	40.8	45.1	58.2*	66.5*	75.0*
Changed daily schedule: go in late, leave early, take time off during work	49.4	36.3	44.0	54.0*	61.5*	64.0*
Took leave of absence	10.9	5.5	5.9	9.1	17.8*	26.0*
Worked fewer hours, took less demanding job	7.3	2.0	3.8	6.5	11.7*	25.0*
Lost any job benefits	4.2	2.4	3.4	1.7	7.5	11.0*
Turned down a promotion	3.1	1.2	2.1	0.7	6.0	10.4*
Chose early retirement	3.6	1.2	0.3	3.0	5.1	14.8*
Gave up work entirely	6.4	1.3	0.2	4.4	10.2*	30.3*

+Unweighted numbers refer to numbers of caregivers in the sample, while weighted numbers refer to numbers of caregiving households in the U.S. population nationwide.

\*Differences in percentages are significant at the .05 level.

I have things set up. He goes to day care three days a week.

I'm a supervisor.

I got my unit together and explained the situation to them so if I have to go anytime during the day, I go.

#### Attitude of Employer toward Caregiver

More than four in five caregivers who have experienced any of these problems (81%) have found their employer's attitude toward the demands of caregiving to be either very understanding (63%) or somewhat understanding (18%). Seven percent said their employer was not very understanding, and 7% said their employer was not aware of their caregiving activities. There are no significant differences by level of care provided.

TABLE 11  
Conditions Increasing the Likelihood  
of Work-Related Adjustments

(Base = Caregivers Ever Employed while Providing Care to This Care Recipient)  
(percentages)

	Alzheimer's or Confusion	Live in Same Household	Help with 2+ ADLs	Primary Caregiver
Total unweighted+	(n=239)	(n=270)	(n=426)	(n=460)
Total weighted+	(n=363)	(n=317)	(n=601)	(n=641)
Made any changes listed below	62.7	64.9	68.2	65.7
Changed daily schedule: go in late, leave early, take time off during work	57.5	57.3	62.1	61.5
Took leave of absence	9.9	15.1	18.5	15.8
Worked fewer hours, took less demanding job	13.7	14.0	14.0	9.6
Lost any job benefits	5.7	7.9	7.4	6.3
Turned down a promotion	5.8	7.4	5.3	4.5
Chose early retirement	6.9	10.2	6.2	6.6
Gave up work entirely	9.8	16.1	13.1	10.0

+Unweighted numbers refer to numbers of caregivers in the sample, while weighted numbers refer to numbers of caregiving households in the U.S. population nationwide.

Family caregiving to persons aged 50 and older is widespread among the U. S. population. In close to one in four households there is at least one person aged 18 or older who presently provides care, or who has been a caregiver, to an older person at some point during the past 12 months.

Sometimes I go to work and get called right back. I get a lot of support at work. If I need to be off, there's no problem giving me time.

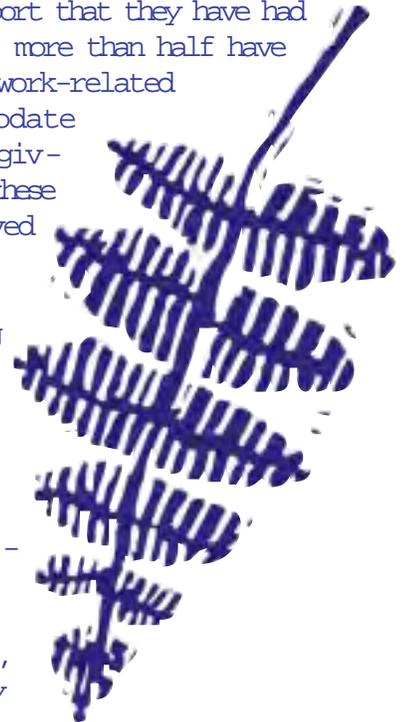
About one in four caregivers is under 35 and more than one in three are age 50 or older, with the bulk of caregivers ranging in age from 35 to 49. The majority of caregivers have provided care to their primary care recipient for less than five years, while about one in five has done so for five to 10 years, and 10 percent have been providing care for at least 10 years.

Not only are family caregivers diverse in age and the length of time they have been providing care, they are also diverse with respect to the types of care and the number of hours of care they provide in a typical week, which range from very modest and non-taxing to heavy-duty, round-the-clock care involving assistance with multiple tasks and personal care. About half of all caregivers provide assistance with at least one personal care activity, and almost every caregiver provides assistance with some aspect of managing a household or coping with the demands of daily living. In general, caregivers and their care recipients live in close proximity to each other.

About one in five lives in the same household with his or her care recipient(s)—typically the case with Level 5 caregivers—and of the remainder, almost seven in 10 caregivers live within an hour's commuting distance from their care recipient.

While a high percentage of caregivers use positive words to describe their feelings about caregiving, and relatively few say they experience family conflict over caregiving, the responsibilities involved in providing care do have an impact on family life, leisure time, work life, personal finances, and in some cases on physical and mental health. More than half of all caregivers report that their caregiving responsibilities cause them to have less time for other family members or have necessitated giving up vacations, hobbies, or their own activities. Not surprisingly, those whose caregiving activities are more intense and require a heavy investment of time are more likely to report these impacts.

Though relatively few caregivers who have ever worked while providing care to their care recipient(s) report that they have had to quit work entirely, more than half have made at least some work-related changes to accommodate the demands of caregiving. Most typically, these changes have involved modifying one's work schedule—going in late, leaving early, or taking time off during the day—though 11 percent report having had to take a leave of absence due to caregiving responsibilities. Level 5 caregivers, however, are much more likely



than Level 1 or 2 caregivers to have made work-related changes of a more serious nature, more than 30 percent reporting that they gave up work entirely and 15 percent saying they took early retirement.

Among those caregivers who take care of someone other than a spouse and who report having out-of-pocket expenditures associated with caregiving, the average monthly outlay is \$171. This estimate may be conservative, in that nine percent of all caregivers say they do not know how much they spend out-of-pocket on caregiving. Some caregivers experience considerable financial hardship due to caregiving responsibilities. For example, Level 5 caregivers, whose monthly outlay for caregiving averages \$357, report out-of-pocket expenses constituting, on average, almost one-fourth of their monthly income. While a relatively small percentage of caregivers overall say that caregiving poses a financial hardship for them, Black and Hispanic caregivers are more likely than either Whites or Asians to say so, as are caregivers with annual household incomes under \$15,000.

Again, while overall only a modest percentage of all caregivers report that they have suffered any physical or mental health problems as a result of caregiving, such problems are cited much more frequently by Level 5 caregivers than by persons providing lower levels of care, by women than by men, and by caregivers aged 50-64 than by younger caregivers. Additionally, more than half of Level 5 caregivers find

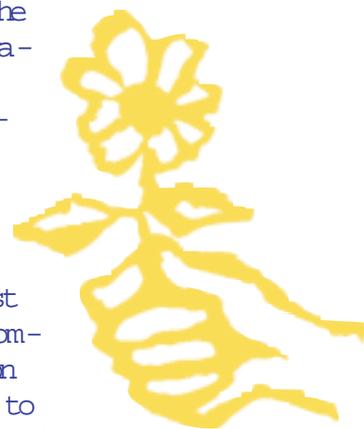


caregiving emotionally stressful, in contrast with one in four caregivers overall. Women are more likely to experience emotional stress than men, and persons caring for someone with dementia are more likely to report that caregiving is emotionally stressful for them than those who are not.

Not surprisingly, utilization of supportive services available in the community, such as home-delivered meals, adult day care, or personal care/nursing services, is correlated with need, with Level 5 caregivers more likely to be using such services than Level 1 caregivers. Service utilization rates are lowest among Asian caregivers, for reasons that are unclear. Very few caregivers cited cost or "bureaucracy" as a barrier to service utilization. When asked what kinds of help, information, or support they would use, or would have used, a high percentage (38%) said they didn't know, and 19 percent said they didn't need any (additional) help. The most frequently cited need, however, was for free time, a "break" from caregiving, or time for oneself—particularly among Level 5 caregivers, those caring for someone with dementia, and primary caregivers.

This study suggests that family caregiving in the United States is prevalent and a normative experience that caregivers by and large accept as a necessary responsibility, and that they provide such care for the most part without many complaints or a perception that they lack access to services they might need.

The findings also suggest, however, that the impact of caregiving on caregivers' lives varies considerably by the type and





amount of care required and provided, by race/ethnicity, and also by other demographic factors such as age. More research is needed on the direct and indirect financial contributions of caregivers, and on how services provided are paid for.

With the projected increase in the minority elderly population in the future, it will also be increasingly important to better understand the needs and experiences of minority caregivers. The present study has made a start in this direction.

Clearly, there is a segment of the caregiving population that provides very intense care that can involve extensive personal and financial sacrifice, as well as physical and/or emotional stress. Providing an average of more than 56 hours of care per week and assisting extensively with both IADLs and ADLs, Level 5 caregivers report spending more out-of-pocket on caregiving than caregivers of any other level, and close to one-third of them say they have experienced physical or mental health problems as a result of caregiving. These

caregivers have also made more extensive work-related adjustments than caregivers providing less intense care. Three in four of them have made at least some change in their work life, 30 percent have had to give up work entirely, and 26 percent report having had to take a leave of absence due to caregiving responsibilities. Though a relatively small proportion of all caregivers, Level 5 caregivers would be appropriate candidates for intervention.

## Appendix/Methodology

### The Samples

Two samples were used to conduct the survey. The first was a fully-replicated, stratified, single-stage random-digit-dial (RDD) sample of U.S. telephone households generated in-house by ICR. The supplemental sample was extracted from ICR's EXCEL Omnibus Service, and included individuals who had previously identified themselves as Hispanic, Black, or Other Race. All respondents were known to be English-speaking because they had been previously so iden-



tified by ICR. (Resources to conduct telephone interviews with non-English speaking Americans were not available.) The supplemental sample was used to oversample by race for Black, Hispanic, and Asian caregivers. Because the EXCEL Omnibus Service uses a sampling model that is similar to the one in the RDD sampling model, the racial/ethnic oversamples extracted from that source are similarly representative of U.S. telephone households within these racial/ethnic groups.

In total (both samples), 1,509 telephone interviews were conducted, all in English and averaging 20 minutes in length. The statistical margin of error for a sample of this size is plus or minus 2.52% at the 95% confidence level. This means that on a question answered by all 1,509 people, it is 95% certain that the total population would fall within 2.52 percentage points of the actual finding. The sampling error widens on questions answered by smaller groups of respondents.

The RDD sample yielded 754 interviews (consisting principally of interviews with Whites) that can be said to be accurate to within +/- 3.58% at the 95% confidence level. By race/ethnicity, the samples, and the 95% confidence interval for each, break out as follows:

#### Weighting of the Findings

To reflect the actual proportion of racial/ethnic groups in the U.S. population, all survey data were weighted using incidence levels derived from the RDD sample and U.S. Census projections. All findings reported are weighted so that they can be projected to U.S. telephone households with an informal caregiver, as defined for purposes of this survey.

Of an estimated 96,600,000 U.S. telephone households, the incidence of caregiver households was determined to be 23.2%, or 22,411,200 households.

Racial/Ethnic Category	Sample Size n	95% Confidence Level
White (non-Hispanic)	623	+/-3.93%
Black (non-Hispanic)	306	+/-5.60%
Asian	264	+/-6.03%
Hispanic	307	+/-5.59%
Other	9	
Total	1,509	

Frequencies shown in the tables in this report refer not to sampled caregivers, but to the U.S. population of caregivers, and must be multiplied by 10,000 to obtain accurate household projections nationwide. For example, the number 2,241 (the estimated number of U.S. caregiving households) is equivalent to 22.4 million households.

Weighted estimates of caregiver households by racial/ethnic group, together with their population percentage of all caregiver households, are as follows:

#### Factor Analysis

A factor analysis was conducted to determine which variables are most closely associated with the intensity, level of difficulty, or amount of wear and tear involved in informal caregiving.

Factor analysis is a statistical technique used to identify the underlying structure within a set of variables. It is used to reduce a large number of variables to a smaller set of factors that greatly simplify the description of the data and aid in its interpretation. Factor analytic techniques generate a smaller set of variables, called

Racial/Ethnic Category	W eighted n	Population Percentage
White (non-Hispanic)	18,287,539	81.6
Black (non-Hispanic)	2,375,587	10.6
Asian	403,402	1.8
Hispanic	1,053,326	4.7
Other	291,346	1.3

"factors," that represent the underlying dimensions of the original (larger) set of variables, based on the degree of association (or correlation) among them. Each factor is not a single, directly measurable entity, but rather a construct derived from the relationships among the original set of variables.

In this study, five questions were asked to assess different aspects of the amount of care, intensity of care, or degree of difficulty involved in informal caregiving, based on caregivers' reported experiences. These five questions concerned (1) the caregiver's estimate of the number of hours of care he/she provides per week; (2) the type of care he/she provides (the numbers of IADLs and ADLs he/she assists with); (3) the amount of physical strain experienced by the caregiver (a subjective measure); (4) the amount of emotional stress experienced by the caregiver (a subjective measure); and (5) the amount of financial hardship experienced by the caregiver (a subjective measure). Coding of these questions is described as follows:

Only a single factor emerged from a factor analysis of these five items. It can be interpreted as a measure of intensity of care, which consists of the number of hours of care provided per week coupled with the type of care provided. (Physical strain, emotional stress, and financial hardship do

not load on this factor.)

#### Level of Care Index

Based on the outcome of the factor analysis, a Level of Care Index consisting of five points was created. This enabled each caregiver to be assigned for analytic purposes to one of the five levels, based on the intensity of caregiving provided.

Variables	Response Categories
Hours of care per week	1 = 0 to 8 hours 2 = 9 to 20 hours 3 = 21 to 40 hours 4 = 41 or more hours
Types of care provided	1 = 0 IADLs/0 ADLs 2 = 1 IADL/0 ADLs 3 = 2+ IADLs/0 ADLs 4 = 1 ADL (with or without IADLs) 5 = 2+ ADLs (with or without IADLs)
Physical Strain	1 Not at all a strain 2 3 4 5 Very much of a strain
Emotional Stress	1 Not at all stressful 2 3 4 5 Very stressful
Financial Hardship	1 No hardship at all 2 3 4 5 A great deal of hardship

The two variables on which the Index is based are "hours of care per week" (four levels, as shown above) and "types of care" (collapsed into four levels), as shown

below:

Each caregiver's score on the two variables was summed, resulting in his/her assignment to one of seven levels (2, 3, 4, 5, 6, 7, or 8). Examination of the frequencies suggested that collapsing the seven levels into five, as shown below, would result in a useful and not very skewed distribution of caregivers across levels, with Level 1 being the least intense level of caregiving, and Level 5 being the most intense.

	Combined Score	Resulting # of Caregivers (unweighted)	Percent of Sample
Level 1	2, 3	389	25.8%
Level 2	4	208	13.8%
Level 3	5	287	19.0%
Level 4	6, 7	355	23.5%
Level 5	8	185	12.3%
Missing		85	5.6%

A National Survey of Caregivers: Final Report. Conducted by Opinion Research



Takeuchi of Evaluation Research Services/Research Division/AARP.

United States Census Bureau. May 1995. Sixty-five Plus in the United States. [<http://www.census.gov/socdemo/www/agebrief.html>]

Variables	Response Categories
Hours of care per week	1 = 0 to 8 hours 2 = 9 to 20 hours 3 = 21 to 40 hours 4 = 41 or more hours, or "constant care"
Types of care provided	1 = 0 IADLs/0 ADLs or 1 IADL/0 ADLs 2 = 2+ IADLs/0 ADLs 3 = 1 ADL (with or without IADLs) 4 = 2+ ADLs (with or without IADLs)

Corporation for the American Association of Retired Persons and The Travelers Foundation. September 1988.

Caregiving Among American Indians: A Review of the Literature. Prepared by Ada-Helen Bayer, consultant to the Research Division/AARP. May, 1997.

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