

Caregiving
Across the
United
States

**Caregivers of
Persons with
Alzheimer's
Disease or
Dementia in
Connecticut, New
Hampshire, New
Jersey, New
York, and
Tennessee**

Data from the 2010 Behavioral Risk Factor Surveillance System

Prepared by:

Erin DeFries Bouldin, MPH
VA Puget Sound Health Care System, Seattle, WA
Department of Epidemiology, University of Washington, Seattle, WA
ebouldin@uw.edu

Elena Andresen, PhD
Institute on Development & Disability, Oregon Health and Science University, Portland, OR
andresee@ohsu.edu

This report was funded by the Alzheimer's Association.

alzheimer's  association®

www.alz.org

Acknowledgement:

We are grateful to the BRFSS Coordinators in Connecticut, New Hampshire, New Jersey, New York, and Tennessee for their assistance and expertise: Diane Aye, MPH, PhD; Kim Lim, PhD, MPH; Kenneth J. O'Dowd, Ph.D; Colleen Baker; and David L. Ridings.

Table of Contents

EXECUTIVE SUMMARY..... 2

CAREGIVING IN THE UNITED STATES 3

ALZHEIMER’S DISEASE & DEMENTIA IN THE UNITED STATES 3

THE BRFSS AND THE CAREGIVER MODULE 3

POPULATION PROFILES 4

METHODS..... 5

RESULTS 6

CONCLUSIONS 16

REFERENCES..... 17

Tables

Table 1.
Number and percent of residents in Connecticut, New Hampshire, New Jersey, New York, and Tennessee who are under age 18 and age 65 or older in 2000 and 2030 according to U.S. Census Projections. Page 5

Table 2.
Caregiving experience characteristics by Alzheimer’s disease or dementia presence among care recipients (weighted). Data from the Connecticut, New Hampshire, New Jersey, New York, and Tennessee Behavioral Risk Factor Surveillance System (BRFSS), 2010. Page 10

Table 3.
Demographic and health behavior characteristics of caregivers by Alzheimer’s disease or dementia presence among care recipients (weighted). Data from the Connecticut, New Hampshire, New Jersey, New York, and Tennessee Behavioral Risk Factor Surveillance System (BRFSS), 2010. Page 13

Executive Summary

This report summarizes data from the 2010 Behavioral Risk Factor Surveillance System (BRFSS) in five states: Connecticut, New Hampshire, New Jersey, New York, and Tennessee. The BRFSS is a telephone survey conducted annually in the United States and its territories to assess the health and health behaviors of non-institutionalized adults. The BRFSS is a joint effort of the Centers for Disease Control and Prevention (CDC) and state departments of health.

Beginning in 2009, states had the option of adding the Caregiver Module, a set of ten cognitively-tested and CDC-approved questions about informal caregiving. The states included in this report are the only areas that chose to include the Caregiver Module in 2010. The purpose of this report is to compare the caregiving experiences, demographic factors, and health behaviors of caregivers who provided care to a person with Alzheimer's disease or dementia to other caregivers who provided care to a person with any other type of health condition or disability. Other caregivers most commonly provided care for people with cancer, heart disease, diabetes, or stroke.

Caregivers of persons with Alzheimer's disease differed in some ways from other caregivers in these states. Their care recipients tended to be older than care recipients without Alzheimer's disease or dementia. Caregivers of persons with Alzheimer's disease or dementia were more likely than other caregivers to be providing care for a parent or parent-in-law and were more likely to report that they provided the most help with learning, remembering, or confusion. Although not statistically significant, a larger proportion of caregivers of persons with Alzheimer's disease or dementia also reported providing the most help with self-care activities, which indicates caregivers of persons with Alzheimer's disease or dementia may be providing more intense care than other caregivers. Nearly all caregivers of persons with Alzheimer's disease or dementia reported a change in the care recipient's cognitive status during the preceding year, and nearly half of other caregivers reported a cognitive change in their recipient as well. Although both groups of caregivers spent a similar amount of time each week providing care, caregivers of persons with Alzheimer's disease or dementia had provided care for longer than other caregivers. They also were more likely to report that caregiving created or aggravated their own health problems compared to other caregivers. Conversely, caregivers of persons with Alzheimer's disease or dementia were less likely to report that caregiving created a financial burden than were other caregivers. Like their care recipients, caregivers of persons with Alzheimer's disease or dementia tended to be older than other caregivers. The differences in the caregiving experience of caregivers of persons with Alzheimer's disease or dementia persisted even when the age of the care recipient was limited to people age 60 and older. On most other demographic and health characteristics including income, disability, mental distress, physical activity, smoking, and alcohol consumption, caregivers were similar regardless of the diagnosis of the person to whom they provided care.

The 2010 BRFSS data provide a population-based snapshot of caregiving in Connecticut, New Hampshire, New Jersey, New York, and Tennessee and suggest that there are important differences between different types of caregivers and potentially some differences between caregivers by state. Based on these data, caregivers of persons with Alzheimer's disease or dementia may need interventions to prevent health problems related to their caregiving more than other caregivers. They also may need support for a longer period of time than other caregivers. Additional and more detailed research at the state level is needed to more fully assess the needs and differences among caregivers.

Caregiving in the United States

America's 65.7 million caregivers form an integral and frequently unrecognized part of the health care team, providing an estimated \$257 to \$389 billion in unpaid care to individuals with disabilities and chronic diseases.¹⁻³ These informal caregivers may be a family member, friend, or neighbor of a person with a disability or chronic health condition.

There are both positive and negative health outcomes and experiences associated with caregiving. The person providing care, or caregiver, may experience improved well-being when caring for another. However, she may also neglect her own health or feel added physical, emotional, and financial strain because of caregiving duties. Research on caregiving has been, and continues at multiple levels. On an individual level, investigators determine the risks for poor health outcomes and assess the effect of providing support to caregivers based on attributes of care such as the care recipient's diagnosis, the amount of time spent caring, or the relationship between caregiver and care recipient. At the population level, public health staff, agencies, and researchers are working to understand caregivers and their health outcomes. They also seek to answer questions such as how many caregivers there are in the U.S., what types of care they provide, and for how long they provide this care. Understanding caregiving across multiple levels allows us to understand the impact of caregiving, to plan for services and other needs to support caregivers and care recipients, and to deliver appropriate interventions to caregivers.

Alzheimer's Disease and Dementia in the United States

Alzheimer's disease, the most common type of dementia, is the 6th leading cause of death in the United States.⁴ It is estimated that 5.4 million people in the U.S. have Alzheimer's disease and that it costs approximately \$200 billion annually.⁴ Over 15 million Americans provide informal caregiving for people with Alzheimer's disease.⁴

Research suggests that caregivers for people with Alzheimer's disease or dementia spend more hours providing care than other types of caregivers and provide more intense care – like assistance with eating, bathing, dressing, or other so-called activities of daily living (ADLs) – than caregivers of persons without Alzheimer's disease or dementia.⁴ This may lead to more negative physical and mental health outcomes. Also, caregivers for people with cognitive impairment tend to be older than other caregivers, and potentially have more disability and are more frail themselves.⁵ Thus, this specific subgroup of caregivers is especially important for public health and health care planning and program development.

The BRFSS and the Caregiver Module

Currently, the prevalence of caregiving and the health impacts of caregiving are not known in all states or at the local level across the U.S. States. Federal and state agencies, as well as private organizations, are concerned about issues surrounding caregiving and could employ population-based data to design needed programming interventions to address this important public health issue. Many community and public health groups are interested in specific health conditions as they relate to caregiving—notably cancer, Alzheimer's disease and dementia, and developmental disabilities. Thus, there is an emerging and increasing audience requiring this information. Learning more about caregivers and how their caregiving activities impact their risk of poor health outcomes

will improve our understanding of how to provide support to them, in turn improving the ability of care recipients to maintain independence and experience an improved quality of life. Maintaining the health of caregivers and their ability to provide care also helps them to continue to contribute their important personal resources to the overall U.S. health care system.

Since 2004, the National Center on Birth Defects and Developmental Disabilities (NCBDDD) and the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) at the Centers for Disease Control and Prevention (CDC) have made a systematic attempt to identify and describe caregivers as part of the total health care system, and to identify public health dimensions of caregiving. One result of this work has been the development of the Caregiver Module, a series of questions about caregivers and their experiences that can be added to the Behavioral Risk Factor Surveillance System (BRFSS).⁶ The BRFSS is a state-based, random-digit-dialed (RDD) telephone survey of non-institutionalized U.S. adults aged 18 and older. In other words, only adults living in community settings who have a landline or cellular telephone may be sampled for this survey. (Institutions include places like group homes, college dormitories, military housing, and jails.) This survey is administered by state health agencies, territories, and in the District of Columbia with assistance from the CDC.⁷ Each state asks a common set of questions during a calendar year (known as the “core” questionnaire) and may choose to ask additional questions about specific topics of interest through the use of CDC-approved modules or through the addition of state-added questions (questions not part of a CDC-approved module).

The Caregiver Module, now one of the CDC-approved optional modules available to all states, is designed to collect information about adult caregivers who care for individuals with a disability or chronic condition regardless of the individual’s age, level of need, or diagnosis. The module is a series of ten questions that asks caregivers about the person for whom they provide care, the type of care they provide, the amount of care they provide, and difficulties they face in providing care. Data are weighted so that people who respond to the survey represent the entire community-based population of the state or territory from which respondents are sampled based on age, gender, and race.

Population Profiles

According to U.S. Census Bureau projections, the age profile of all states will change considerably by the year 2030: the United States population is aging.⁸ Table 1 displays the projected changes in the population structure of Connecticut, New Hampshire, New Jersey, New York, and Tennessee over the coming decades. In four states – Connecticut, New Hampshire, New Jersey, and New York – the proportion of the population under age 18 is expected to decrease slightly (by 0.5 to 1.0%) between 2010 and 2030. In Tennessee, the proportion of the population under age 18 is expected to increase slightly, from just under 24% to just over 24%. In all states, the proportion of the population aged 65 or older is expected to grow from just over one in ten (13-14%) to around one in five (19-21%). Because the risks of Alzheimer’s disease, dementia, and disability increase with age, it is expected that as the population ages, the need for informal caregivers will increase as well.

Table 1. Number and percent of residents in Connecticut, New Hampshire, New Jersey, New York, and Tennessee who are under age 18 and age 65 or older in 2010 and 2030 according to U.S. Census Projections.

State	Population under age 18				Population age 65 and older			
	2010		2030 (projected)		2010		2030 (projected)	
	No.	%	No.	%	No.	%	No.	%
Connecticut	814,008	22.8	823,436	22.3	515,621	14.4	794,405	21.5
New Hampshire	304,164	22.0	355,531	21.6	178,823	12.9	352,786	21.4
New Jersey	2,088,224	23.2	2,175,752	22.2	1,231,585	13.7	1,959,545	20.0
New York	4,420,876	22.7	4,325,477	22.2	2,651,655	13.6	3,916,891	20.1
Tennessee	1,478,915	23.7	1,791,281	24.3	829,023	13.3	1,417,708	19.2

Source: [8]

Methods

To study the characteristics and health of caregivers and their care recipients in Connecticut, New Hampshire, New Jersey, New York, and Tennessee, the Caregiver Module was added to the 2010 BRFSS in each of these states. The BRFSS allows not only for the analysis of demographic differences among caregivers and non-caregivers but also assesses health behaviors, such as exercise frequency, smoking status, and alcohol use. In addition, through the use of this module, caregivers can be compared to non-caregivers on quality of life measures such as general life satisfaction, the amount of emotional and social support they receive, and their self-reported general health status. Because of the complex sampling design used on the BRFSS, all results presented in this report are weighted using SAS 9.3. These weights are used so that BRFSS respondents represent the entire state’s non institutional population by age, race, and gender.

During 2010, a total of 23,158 BRFSS respondents in Connecticut, New Hampshire, New Jersey, New York, and Tennessee provided a valid response (yes or no) to the question, “People may provide regular care or assistance to someone who has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend?” Of these, 4,338 or 19.7% (weighted) said “yes” to this question. These respondents were classified as caregivers and answered the remaining Caregiver Module questions about themselves and their care recipient. (If a caregiver reported providing care to more than one recipient, the caregiver was asked to answer the Caregiver Module questions based on the recipient to whom he or she provided the most care). A total of 3,582 caregivers provided a valid response (a specific health condition) to the question, “What do you think or what has a doctor said is the major health problem that your [care recipient] has?” Among those caregivers, 370 or 7.5% (weighted) said Alzheimer’s disease or dementia to this question. In this report, these respondents are considered to be caregivers of persons with Alzheimer’s disease or dementia. In Tables 3 and 4, the percentages and 95% confidence intervals (95% CI) are based on the number of valid responses for each item; in other words, individuals who did not answer a question were not excluded from the overall analysis so the denominator varies slightly for each variable. In all cases other than income, fewer than 5% of the responses were missing and are not reported in the results. For income there is a separate row for missing/refused

respondents since there were a substantial number of surveys in which this question was not answered. We also provide statistical significance of comparisons, and note where these differences have a p-value less than 0.05 (by chi-square tests).

Results

Information about the recipient and the caregiving experience of caregivers of people with and without Alzheimer's disease or dementia appears in Table 2. We present the results for caregivers of people without Alzheimer's disease or dementia in two separate columns: the first includes care recipients of all ages (n=3,212) and the second includes only care recipients age 60 and older (n=2,546). Because most care recipients with Alzheimer's disease or dementia were age 60 or older (361/370 or 97.5%), we present only the single column since the results did not change appreciably.

Most care recipients were women (61% of care recipients with Alzheimer's disease or dementia and 63% of care recipients without Alzheimer's disease or dementia). Care recipients with Alzheimer's disease or dementia were significantly older than care recipients without Alzheimer's disease or dementia (mean ages: 84 for care recipients with Alzheimer's disease or dementia and 65 for care recipients without Alzheimer's disease or dementia). Care recipients were most commonly a family member of the caregiver in both groups. Among caregivers of persons with Alzheimer's disease or dementia, 59% were providing care for a parent, 12% cared for a spouse or partner, and 22% cared for some other family member (sibling, grandparent, etc.). Similarly, among caregivers of persons without Alzheimer's disease or dementia 43% provided care for a parent, 12% for a spouse or partner, and 28% for another family member. As noted above, caregivers were asked to identify the care recipient's major health condition that led to their need for care. Among caregivers of persons without Alzheimer's disease or dementia, the most common diagnoses reported were cancer (16%), heart disease (9%), diabetes (8%), and stroke (4%). Most caregivers of persons with Alzheimer's disease or dementia reported their care recipients experienced a change in thinking or remembering in the past year (95%). These caregivers were significantly more likely to report a cognitive change than were caregivers of persons without Alzheimer's disease or dementia, although nearly half (47%) of other caregivers also reported a cognitive change.

Caregivers of persons with Alzheimer's disease or dementia had provided care for a significantly longer period than had caregivers of persons without Alzheimer's disease or dementia. Fifteen percent of caregivers of persons with Alzheimer's disease or dementia had been providing care for 3 months or less compared to 31% of caregivers of persons without Alzheimer's disease or dementia. More than one in five caregivers in both groups had provided care for 5 years or longer (25% of caregivers of persons with Alzheimer's disease or dementia and 22% of other caregivers). The hours of care provided in an average week were similar across caregiving groups, with 57% of caregivers in both groups providing 0-8 hours of care in an average week. Fifteen percent of caregivers of persons with Alzheimer's disease or dementia and 11% of caregivers of persons without Alzheimer's disease or dementia provided 40 hours of care per week or more.

Caregivers reported providing the most help to the care recipient in a variety of areas. When asked to identify the area in which their care recipient needed the most help, more than one quarter of all caregivers reported household care, regardless of the care

recipient's diagnosis (27% of caregivers of persons with Alzheimer's disease or dementia and 30% of other caregivers). Nearly one quarter of caregivers of persons with Alzheimer's disease or dementia reported providing the most help with self-care, like eating, bathing or dressing (23%) compared to 16% of other caregivers; this difference was not statistically significant.

When asked the greatest difficulties faced personally, caregivers of persons with Alzheimer's disease or dementia most often said that caregiving created stress (27%). Caregivers of persons without Alzheimer's disease or dementia most often said that caregiving did not create any difficulties (36%; significantly higher than the 19% of caregivers of persons with Alzheimer's disease or dementia). Nonetheless, a similar proportion of caregivers of persons without Alzheimer's disease or dementia reported that caregiving created stress (24%). Caregivers of persons with Alzheimer's disease or dementia were significantly more likely to report that caregiving created or aggravated their own health problems (7% compared to 2% of other caregivers) and significantly less likely to report that caregiving created a financial burden (3% compared to 8% of caregivers of persons without Alzheimer's disease or dementia).

Demographic and health behavior characteristics of caregivers of people with and without Alzheimer's disease or dementia are presented in Table 3. As in Table 2, the first column includes caregiver for people of all ages with Alzheimer's disease or dementia, the second column includes caregivers for people of all ages without Alzheimer's disease or dementia, and the third column includes caregivers for people age 60 and older without Alzheimer's disease or dementia. The majority of all caregivers were women and a similar proportion of caregivers of persons with Alzheimer's disease or dementia and other caregivers were women (62% of caregivers of persons with Alzheimer's disease or dementia and 65% of caregivers of persons without Alzheimer's disease or dementia). Caregivers of persons with Alzheimer's disease or dementia were older than caregivers of persons with other diagnoses (mean ages: 54 for caregivers of persons with Alzheimer's disease or dementia and 48 for caregivers of persons without Alzheimer's disease or dementia). Caregivers of persons with and without Alzheimer's disease or dementia had similar levels of educational attainment. For example, roughly 25% of caregivers in both groups had earned a high school degree and more than 40% had attended college or had a degree beyond high school. Most caregivers were employed (59% of caregivers of persons with Alzheimer's disease or dementia and 71% of other caregivers), though caregivers of persons with Alzheimer's disease or dementia were significantly more likely to be retired than other caregivers (26% compared to 15%). Racial and ethnic distributions of caregivers were similar. The majority of caregivers reported their race as white and ethnicity as non-Hispanic (83% of caregivers of persons with Alzheimer's disease or dementia and 81% of caregivers of persons without Alzheimer's disease or dementia). Twelve percent of caregivers of persons with Alzheimer's disease or dementia and 9% of other caregivers reported their race as black and their ethnicity as non-Hispanic. Hispanic ethnicity was uncommon in both groups of caregivers: 2% of caregivers of persons with Alzheimer's disease or dementia and 6% of caregivers of persons without Alzheimer's disease or dementia reported Hispanic ethnicity. Annual household income was similar for both groups of caregivers and around half of respondents reported \$50,000 or more (54% of caregivers of persons with Alzheimer's disease or dementia and 52% of caregivers of persons without Alzheimer's disease or dementia). Most caregivers were married or living

as a couple (nearly 70% of both groups). More than one in three caregivers reported having at least one child under the age of 18 living in the household (34% of caregivers of persons with Alzheimer's disease or dementia and 41% of caregivers of persons without Alzheimer's disease or dementia).

Respondents were categorized as having a disability according to the BRFSS definition: If respondents answered "yes" to either of two questions: "Are you limited in any way in any activities because of physical, mental, or emotional problems," or "Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone," they were classified as having a disability. The prevalence of disability among caregivers of persons with Alzheimer's disease or dementia was similar to the prevalence of disability among caregivers of persons with Alzheimer's disease or dementia (28% and 25%, respectively).

Roughly 90% of caregivers in both groups reported they were satisfied or very satisfied with their lives in general (89% of caregivers of persons with Alzheimer's disease or dementia and 93% of caregivers of persons without Alzheimer's disease or dementia). Emotional support of the respondents was assessed by the question: "How often do you get the social or emotional support you need?" Around eight in ten caregivers reported always or usually receiving the social and emotional support needed (83% of caregivers of persons with Alzheimer's disease or dementia and 79% of other caregivers).

Ratings of general health among both groups of caregivers were also similar; 81% of caregivers of persons with Alzheimer's disease or dementia and 85% of caregivers of persons without Alzheimer's disease or dementia reported their general health was excellent, very good, or good. Health-related quality of life (HRQOL) was assessed using the following variables: physical unhealthy days in the last 30 days, mental unhealthy days in the last 30 days, general life satisfaction, emotional support, and general health status (data not shown). The number of physical unhealthy days was assessed in the question: "Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?" Both types of caregivers had similar average number of days in the past month that their physical health was not good; 3.7 and 3.5 respectively. Mentally unhealthy days were assessed as: "Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?" The mean number of days of poor mental health days was significantly higher for caregivers of people with Alzheimer's disease or dementia (4.8 days) than other caregivers (3.1 days). The question about poor mental health days also can be used to create a variable called "frequent mental distress," defined as reporting 14 or more days of poor mental health in the past 30 days. This measure was similar across the two groups of caregivers with 14% of caregivers in each group being classified as having frequent mental distress. Measures of health and health behaviors were very similar across the two groups of caregivers. Among caregivers of persons with Alzheimer's disease or dementia, about one in three were classified as being neither overweight nor obese (body mass index [BMI] of 18.5-24.9). All caregivers were most commonly classified as being overweight (BMI of 25.0-29.9; 45% of caregivers of persons with Alzheimer's disease or dementia and 37% of caregivers of persons without Alzheimer's disease or dementia). Half of caregivers reported they had never smoked (51% of caregivers of persons with Alzheimer's disease or dementia and 54% of caregivers of persons without Alzheimer's disease or dementia). A

small proportion of all caregivers reported they currently smoked at the time of the survey (15% of caregivers of persons with Alzheimer's disease or dementia and 19% of other caregivers). Eighty percent of caregivers reported engaging in some form of physical activity outside of work. The CDC defines heavy drinking as more than two drinks per day for men and more than one drink per day for women. Binge drinking is defined as men having five or more drinks on one occasion, and women having four or more drinks on one occasion. Three percent of caregivers of people with Alzheimer's disease or dementia and 6% of caregivers of persons without Alzheimer's disease or dementia were classified as having heavy alcohol consumption while 7% of caregivers of persons with Alzheimer's disease or dementia and 14% of caregivers of persons without Alzheimer's disease or dementia were classified as binge drinking in the past month.

Most caregivers had some form of health insurance coverage; 92% of caregivers of persons with Alzheimer's disease or dementia and 90% of caregivers of persons without Alzheimer's disease or dementia said they had some type of health plan. Nonetheless, 19% of caregivers of persons with Alzheimer's disease or dementia and 14% of other caregivers reported that there was a time in the past year when they did not go to the doctor when they needed to because of cost.

When we restricted the age of care recipients to 60 or older, the differences in the caregiver experiences between caregivers of persons with Alzheimer's disease or dementia and caregivers of persons without Alzheimer's disease or dementia changed very little. For example, caregivers of persons with Alzheimer's disease or dementia still reported providing more assistance with self-care tasks and had provided care for a longer duration than other caregivers. However, in some ways the two caregiver groups became more similar. Age, of course, was more comparable, with 22% of caregivers of people with Alzheimer's disease or dementia and 20% of caregivers of people without Alzheimer's disease or dementia being age 65 or older. Care recipients with Alzheimer's disease or dementia still tended to be older than other care recipients, but the difference was smaller with the age restriction. Nearly 60% of both caregiver groups reported caring for a parent or parent-in-law (59% of caregivers of people with Alzheimer's disease or dementia and 57% of other caregivers). With the older average age of caregivers, some associated demographics changed as well: caregiver education level increased slightly (46% of caregivers had some college education or higher after restricting care recipient age to 60 or older, compared to 42% before age restriction), a larger proportion of caregivers were retired (19% compared to 15%), and a smaller proportion of caregivers reported having a child under age 18 in the household (35% compared to 40%). When restricted to older care recipients without Alzheimer's disease or dementia, all chronic health conditions were reported more frequently with the exception of cancer (16% of all ages and 13% of age 60+).

Table 2. Caregiving experience characteristics by Alzheimer’s disease or dementia presence among care recipients (weighted). Data from the Connecticut, New Hampshire, New Jersey, New York, and Tennessee Behavioral Risk Factor Surveillance System (BRFSS), 2010.

Variable	Category	Caregivers of persons with Alzheimer’s disease or dementia (care recipients of all ages; n=370)	Caregivers of Persons without Alzheimer’s disease or dementia	
			Care recipients of all ages (n=3,212)	Care recipients age ≥60 only (n=2,546)
		Percent (95% CI)+	Percent (95% CI)+	Percent (95% CI)+
Care recipient gender	Female	60.5 (48.4-72.6)	62.6 (59.0-66.2)	62.9 (58.7-67.1)
Care recipient age* [§]	0-64	3.0 (0.3-5.7)	42.1 (38.3-45.9)	12.9 age 60-64 (9.8-15.9)
	65-74	7.8 (3.7-11.8)	19.3 (16.2-22.5)	29.1 (24.8-33.3)
	75-84	33.0 (22.3-43.7)	19.7 (17.0-22.3)	29.6 (25.9-33.3)
	85 or older	56.3 (45.2-67.3)	18.9 (16.2-21.6)	28.5 (24.6-32.3)
Care recipient’s relationship to caregiver* [§]	Parent or Parent-in-Law	59.4 (47.9-70.8)	44.0 (40.3-47.8)	57.1 (52.9-61.3)
	Spouse	12.0 (6.2-17.8)	12.4 (10.1-14.8)	11.1 (8.9-13.3)
	Other relative	21.5 (9.9-33.2)	27.7 (24.6-30.9)	18.9 (15.6-22.2)
	Non-relative	7.0 (3.5-10.6)	15.8 (13.0-18.5)	12.9 (10.1-15.6)
Care recipient’s major health problem as identified by the caregiver	Alzheimer’s disease or dementia	100.0	--	--
	Cancer	--	16.3 (13.2-19.3)	12.8 (10.0-15.6)
	Heart disease	--	8.8 (7.0-10.6)	12.5 (10.0-15.1)
	Diabetes	--	8.1 (6.2-10.0)	9.5 (7.1-12.0)
	Arthritis	--	7.0 (5.0-9.0)	8.1 (5.6-10.6)
	Stroke	--	4.2 (3.1-5.3)	6.0 (4.4-7.6)

Variable	Category	Caregivers of persons with Alzheimer's disease or dementia (care recipients of all ages; n=370)	Caregivers of Persons without Alzheimer's disease or dementia	
			Care recipients of all ages (n=3,212)	Care recipients age ≥60 only
		Percent (95% CI)+	Percent (95% CI)+	Percent (95% CI)+
Cognitive status change* [§]	Care recipient experienced a change in thinking or remembering in the past year	94.6 (91.3-97.8)	46.5 (42.8-50.3)	53.1 (48.7-57.6)
Length of care* [§]	0-3 months	15.1 (5.2-25.0)	31.5 (27.9-35.2)	29.3 (25.2-33.5)
	4-12 months	12.3 (7.2-17.5)	18.5 (15.8-21.3)	18.8 (15.7-21.9)
	13-24 months	21.4 (12.8-30.1)	11.7 (9.5-14.0)	11.8 (9.1-14.5)
	25-60 months	26.5 (17.3-35.6)	15.8 (13.0-18.7)	19.2 (15.7-22.8)
	More than 5 years	24.7 (13.2-36.1)	22.3 (19.1-25.6)	20.8 (17.0-24.5)
Hours of care provided per week	0-8	57.0 (45.0-)	57.4 (53.4-61.4)	59.9 (55.3-64.5)
	9-19	15.0 (6.9-23.2)	16.9 (14.1-19.8)	16.5 (13.3-19.8)
	20-39	13.1 (6.8-19.3)	14.2 (11.2-17.2)	15.0 (11.4-18.6)
	40 or more	14.9 (7.0-22.8)	11.4 (8.9-14.0)	8.6 (6.2-10.9)
Area in which care recipient needs most help	Self-care	23.4 (10.7-36.0)	16.1 (12.8-19.3)	15.0 (11.2-18.7)
	Household care	26.8 (14.8-38.8)	30.0 (25.4-34.7)	31.4 (25.8-36.9)
	Communicating with others	6.1 (0.0-12.3)	5.0 (2.8-7.1)	4.4 (2.3-6.6)
	Learning, remembering, confusion* [§]	14.1 (3.7-24.4)	3.1 (1.2-5.0)	3.9 (1.1-6.7)
	Seeing or hearing	0.3 (0.0-0.7)	0.7 (0.3-1.1)	0.7 (0.2-1.2)
	Moving around	3.1 (0.0-6.9)	5.5 (2.9-8.0)	5.4 (3.0-7.9)

Variable	Category	Caregivers of persons with Alzheimer's disease or dementia (care recipients of all ages; n=370)	Caregivers of Persons without Alzheimer's disease or dementia	
			Care recipients of all ages (n=3,212)	Care recipients age ≥60 only
		Percent (95% CI)+	Percent (95% CI)+	Percent (95% CI)+
Area in which care recipient needs most help (continued)	Transportation outside the home	16.4 (3.3-29.5)	29.6 (24.9-34.3)	32.6 (27.1-38.1)
	Getting along with people*	0.1 (0.0-0.3)	1.3 (0.0-2.7)	0.4 (0.0-1.0)
	Feeling anxious or depressed	12.6 (0.0-29.3)	9.9 (6.8-13.0)	7.7 (4.8-10.5)
Greatest difficulty faced by caregiver	Financial burden*§	3.3 (0.9-5.7)	7.6 (5.3-9.9)	6.1 (3.3-8.8)
	Not enough time for him/herself	6.9 (3.1-10.7)	8.0 (6.1-9.9)	8.7 (6.2-11.1)
	Not enough time for family	15.6 (3.3-27.9)	6.8 (4.7-8.9)	7.9 (5.0-10.8)
	Interferes with work	2.9 (0.0-7.3)	3.8 (2.0-5.6)	3.5 (1.8-4.9)
	Creates or aggravates health problems*§	7.3 (0.9-13.6)	1.6 (0.8-2.4)	1.4 (0.5-2.3)
	Affects family relationships	8.9 (0.2-17.5)	5.4 (3.5-7.3)	5.9 (3.7-8.1)
	Creates stress	27.4 (18.5-36.3)	24.3 (21.4-27.5)	23.9 (20.7-27.2)
	Another difficulty	8.4 (3.0-13.8)	6.3 (4.6-7.9)	5.7 (4.0-7.3)
	No difficulty*§	19.3 (11.8-26.9)	36.1 (32.5-39.8)	37.1 (32.8-41.3)

+ 95 % confidence interval for the proportion

* Statistically significant difference (p<0.05) between the proportion of caregivers of persons with Alzheimer's disease or dementia reporting the variable compared to other caregivers of people of all ages(chi-square test)

§ Statistically significant difference (p<0.05) between the proportion of caregivers of persons with Alzheimer's disease or dementia reporting the variable compared to other caregivers of people age 60 and older(chi-square test)

Table 3. Demographic and health behavior characteristics of caregivers by Alzheimer’s disease or dementia presence among care recipients (weighted). Data from the Connecticut, New Hampshire, New Jersey, New York, and Tennessee Behavioral Risk Factor Surveillance System (BRFSS), 2010.

Variable	Category	Caregivers of persons with Alzheimer’s disease or dementia (care recipients of all ages; n=370)	Caregivers of Persons without Alzheimer’s disease or dementia	
			Care recipients of all ages (n=3,212)	Care recipients age ≥60 only
		Percent (95% CI)+	Percent (95% CI)+	Percent (95% CI)+
Gender	Female	62.3 (50.6-74.0)	65.5 (61.7-69.3)	67.2 (62.8-71.6)
Age*	18-34	7.7 (1.2-14.2)	19.9 (16.2-23.6)	11.7 (8.2-15.3)
	35-44	20.7 (7.7-33.7)	23.8 (20.5-27.2)	24.0 (19.7-28.3)
	45-54	21.3 (13.1-29.5)	23.6 (20.7-26.5)	24.0 (20.5-27.4)
	55-64	27.5 (18.5-36.5)	16.9 (14.6-19.2)	20.0 (16.9-23.0)
	65+	22.8 (15.3-30.3)	15.7 (13.6-17.9)	20.3 (17.4-23.3)
Education	Less than high school	26.2 (16.8-35.6)	32.5 (29.0-36.1)	28.9 (24.9-32.9)
	High school degree or equivalent	24.1 (14.3-34.0)	25.5 (22.3-28.8)	25.2 (21.5-28.9)
	Some college or beyond	49.7 (38.4-61.0)	41.9 (38.3-45.6)	45.9 (41.6-50.2)
Employment status*	Employed, student, or homemaker	59.2 (48.7-69.8)	70.7 (67.5-73.9)	67.9 (64.0-71.8)
	Retired	26.1 (17.7-34.4)	14.7 (12.7-16.7)	18.7 (15.9-21.5)
	Out of work or unable to work	14.7 (6.9-22.5)	14.6 (11.8-17.3)	13.3 (10.1-16.6)
Marital status	Married/Coupled	69.9 (60.5-79.4)	68.5 (64.9-71.9)	71.9 (68.2-75.7)
Children in household	At least one child under age 18 lives in household	34.4 (21.9-46.8)	40.5 (36.8-44.3)	34.9 (30.7-39.2)
Disability status	Respondent has a disability	27.8 (18.6-36.9)	25.3 (22.1-28.5)	26.1 (22.4-29.9)

Variable	Category	Caregivers of persons with Alzheimer's disease or dementia (care recipients of all ages; n=370)	Caregivers of Persons without Alzheimer's disease or dementia	
			Care recipients of all ages(n=3,212)	Care recipients age ≥60 only
		Percent (95% CI)+	Percent (95% CI)+	Percent (95% CI)+
Race/ethnicity	White only, non-Hispanic	82.6 (74.7-90.5)	80.8 (77.9-83.8)	84.7 (81.4-88.1)
	Black only, non-Hispanic	11.9 (5.0-18.8)	9.2 (7.1-11.2)	7.6 (5.5-9.7)
	Other race only, non-Hispanic	3.2 (0.0-6.8)	2.6 (1.4-3.7)	1.8 (0.7-2.9)
	Multiracial, non-Hispanic	0.0 (0.0-0.1)	1.1 (0.4-1.8)	0.7 (0.0-1.4)
	Any race, Hispanic	2.3 (0.0-4.7)	6.3 (4.3-8.3)	5.1 (2.5-7.7)
Household annual income	Less than \$15,000	3.5 (0.1-6.9)	5.2 (3.2-7.1)	5.3 (2.5-8.1)
	\$15,000-\$24,999	11.9 (5.0-18.7)	10.8 (8.9-12.8)	10.6 (8.4-12.7)
	\$25,000-\$34,999	4.8 (2.0-7.6)	9.8 (7.6-12.1)	8.6 (6.3-11.0)
	\$35,000-\$49,999	13.5 (6.3-20.7)	10.4 (8.4-12.5)	10.8 (8.3-13.4)
	\$50,000 or more	54.4 (43.4-65.4)	52.3 (48.7-56.0)	54.1 (49.8-58.4)
	Not reported or missing	11.9 (5.9-17.8)	11.3 (9.1-13.6)	10.6 (8.2-12.9)
General life satisfaction	Very Satisfied/Satisfied	88.9 (82.1-95.7)	92.7 (90.7-94.7)	93.2 (91.0-95.4)
Frequent mental distress	14 days or more of poor mental health in the past 30 days	14.1 (7.9-20.3)	13.9 (11.3-16.6)	11.9 (8.8-15.1)
Body Mass Index (BMI)	Neither overweight nor obese	32.2 (22.7-41.7)	33.9 (30.3-37.6)	32.8 (23.1-42.4)
	Overweight	45.1 (33.6-56.7)	37.5 (33.9-41.2)	45.8 (34.2-57.5)
	Obese	22.6 (14.9-30.4)	28.5 (25.0-32.0)	21.4 (13.8-29.0)

Variable	Category	Caregivers of persons with Alzheimer's disease or dementia (care recipients of all ages; n=370)	Caregivers of Persons without Alzheimer's disease or dementia	
			Care recipients of all ages (n=3,212)	Care recipients age ≥60 only
		Percent (95% CI)+	Percent (95% CI)+	Percent (95% CI)+
Emotional support	Always or usually receive support needed	83.0 (76.1-89.9)	79.2 (76.3-82.0)	80.3 (77.1-83.6)
Smoking status	Current Smoker	15.1 (6.8-23.4)	19.3 (16.2-22.4)	15.6 (12.2-18.9)
	Former Smoker	33.7 (23.4-43.9)	26.6 (23.5-29.7)	28.7 (25.0-32.4)
	Never Smoker	51.3 (40.0-62.5)	54.1 (50.4-57.8)	55.8 (51.5-60.1)
Physical activity	Engage in physical activity outside of work	79.6 (72.0-87.2)	80.4 (77.7-83.1)	80.3 (77.0-83.7)
Heavy alcohol consumption	Men having >2 drinks per day; women having >1 drink per day	3.2 (0.0-6.4)	6.1 (3.7-8.5)	3.7 (2.3-5.1)
Binge drinking	Men having ≥5drinks on one occasion; women having ≥4 drinks on one occasion	7.7 (1.6-13.9)	14.2 (1.6-13.9)	10.4 (7.7-13.1)
Veteran status	Ever served on active duty	6.7 (2.7-10.8)	6.9 (5.3-8.5)	7.7 (5.6-9.7)
General health	Excellent, very good, or good	80.6 (72.6-88.5)	84.8 (82.4-87.3)	85.0 (82.1-87.9)
Health care plan	Any coverage	91.9 (86.0-97.9)	90.3 (88.3-92.3)	91.9 (89.8-93.9)
Medical costs	Needed to see a doctor in the past year but could not because of cost	18.7 (9.4-27.9)	14.4 (11.9-16.8)	12.2 (9.6-14.8)

+ 95 % confidence interval for the proportion

* Statistically significant difference (p<0.05) between the proportion of caregivers of persons with Alzheimer's disease or dementia reporting the variable compared to other caregivers of people of all ages(chi-square test)

§ Statistically significant difference (p<0.05) between the proportion of caregivers of persons with Alzheimer's disease or dementia reporting the variable compared to other caregivers of people age 60 and older(chi-square test)

Conclusions

The results presented above demonstrate there are some differences between caregivers of persons with Alzheimer's disease or dementia when compared to other caregivers, both in demographic characteristics and the attributes of care that they provide. Their care recipients tended to be older than care recipients without Alzheimer's disease or dementia and more frequently need the most help with self-care like moving around or eating, bathing, or dressing compared to caregivers of persons without Alzheimer's disease or dementia, though this difference was not statistically significant ($p=0.21$). These self-care activities indicate caregivers of persons with Alzheimer's disease or dementia may be providing more intense care than other caregivers. Although both groups of caregivers spent a similar amount of time each week providing care, caregivers of persons with Alzheimer's disease or dementia had provided care for a longer duration than other caregivers. They also were more likely to report that caregiving created or aggravated health problems compared to other caregivers. All caregivers had similar levels of stress and frequent mental distress, though caregivers of persons with Alzheimer's disease or dementia averaged slightly more days of poor mental health in the past 30 days. Caregivers of persons without Alzheimer's disease or dementia were more likely to report that caregiving created a financial burden than were caregivers of persons with Alzheimer's disease or dementia. Although care recipients with Alzheimer's disease or dementia tend to be older than other care recipients, the differences in caregiver experiences persisted even after we restricted the care recipients to those age 60 and older, indicating that these differences are not attributable to differences in age alone.

Like their care recipients, caregivers of persons with Alzheimer's disease or dementia tended to be older than other caregivers. On most other demographic and health characteristics, caregivers were similar regardless of the diagnosis of the person to whom they provided care. For example, both groups of caregivers had similar levels of education and household income, though caregivers of persons with Alzheimer's disease or dementia were more likely to be retired. Disability, emotional support, life satisfaction, and general health ratings were similar across all caregivers. The two groups of caregivers did not report significantly different levels of physical activity, overweight or obesity, or heavy or binge drinking. One in three caregivers of persons with Alzheimer's disease or dementia reported having a child living in the household in addition to providing care to an older adult. These caregivers represent what has been called the "sandwich generation," in which adults are simultaneously providing care to both young children and aging family members.

The 2010 BRFSS data provide a population-based snapshot of caregiving in Connecticut, New Hampshire, New Jersey, New York, and Tennessee, and suggest that there are important differences between caregivers based on whether their care recipients have been diagnosed with Alzheimer's disease or dementia. Based on these data, caregivers of persons with Alzheimer's disease or dementia may need interventions to prevent health problems related to caregiving more than other caregivers. They also may need support for a longer period than other caregivers. All caregivers are likely to benefit from interventions to reduce stress. Also, cognitive changes were nearly universally reported by caregivers of persons with Alzheimer's disease or dementia and reported by nearly half of caregivers of persons with other chronic conditions, suggesting that most caregivers would also benefit

from education and intervention programs focused on caregiving issues related to cognitive impairment.

Overall, caregivers of persons with Alzheimer's disease and dementia were similar across the five states. Individual state data are not included in this report because of the small number of individuals who responded within each state.

Some caution should be exercised when interpreting the data presented in this report, particularly when the percentages are small. In some cases a relatively small number of people are used to represent all caregivers within a state and their experiences may not in fact be representative of the underlying population. The questions used in the Caregiver Module underwent cognitive testing, which is done to assure that the meaning of questions is clear to potential respondents and the wording is changed as needed if not, according to standard CDC protocol. It is not clear, however, whether the questions or the phrase "provided care" is interpreted similarly across racial or ethnic groups. Nonetheless, the BRFSS is a useful data source that is designed to provide state-level information.

If you are interested in having the Caregiver Module added to the BRFSS in your state, contact your state BRFSS coordinator. A complete listing, along with more information about the BRFSS and other topics covered by the survey, is available on the CDC's BRFSS website, <http://www.cdc.gov/brfss>.

References

1. Arno PS, Levine C, Memmott MM. The economic value of informal caregiving. *Health Affairs* 1999;18:182--8.
2. National Alliance for Caregiving and AARP. *Caregiving in the U.S.* Washington, DC: National Alliance for Caregiving and AARP; 2009. Available at http://www.caregiving.org/pdf/research/Caregiving_in_the_US_2009_full_report.pdf.
3. Talley RC, Crews JE. Framing the public health of caregiving. *American Journal of Public Health* 2007;97:224-228.
4. Alzheimer's Association. *2012 Alzheimer's Disease Facts and Figures*. Available at http://www.alz.org/downloads/facts_figures_2012.pdf.
5. DeFries EL, McGuire LC, Andresen EM, Brumback BA, Anderson LA. Caregivers of older adults with cognitive impairment. *Preventing Chronic Disease* 2009;6(2). [http://www.cdc.gov/pcd/issues/2009/apr/08_0088.htm.]
6. Neugaard B, Andresen EM, DeFries EL, Talley RC, Crews JE. The characteristics of caregivers & care recipients: North Carolina, 2005. *MMWR* 2007; 56(21):529 – 532. [http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5621a3.htm?s_cid=mm5621a3_e]
7. Remington PL, Smith MY, Williamson DF, Anda RF, Gentry EM, Hogelin GC. Design, Characteristics, and Usefulness of State-Based Behavioral Risk Factor Surveillance: 1981-1987. *Public Health Reports* 1988; 103(4):366-375.
8. US Census Bureau. *US Population Projections*, Table 5: Interim Projections: Population under age 18 and 65 and older: 2000, 2010, and 2030. Available at <http://www.census.gov/population/projections/PressTab5.xls>.