

Characteristics of Caregivers of Care Recipients with and without Memory or Thinking Problems – Florida, 2008

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Characteristics of Caregivers for Persons with and without Memory or Thinking Problems—Florida, 2008

These data are from the 2008 Florida Behavioral Risk Factor surveillance System (BRFSS) and are designed to provide estimates of the adult, non-institutionalized population in Florida.

Caregiving and the Caregiver Module

America's 53.4 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 These informal caregivers may be a family member, friend, or neighbor of a person with a disability or chronic health condition. Currently, the prevalence of caregiving and the health impacts of caregiving are not known at the state and local level. State and federal agencies, as well as private organizations are concerned about issues surrounding caregiving and could employ population-based caregiving data to design needed programs and interventions to address this increasingly important public health issue. Many community and public health groups also express interest in specific 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.

During the past four years, the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC) has 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).² The BRFSS is a state-based, random-digit-dialed (RDD) telephone survey of non-institutionalized U.S. adults aged 18 and older. This survey is administered by state health agencies, territories, and in the District of Columbia with assistance from the CDC.³ The Caregiver Module is designed to collect information about a population-based sample of adult caregivers who care for individuals with a disability or chronic condition regardless of the individual's age, level of need, or diagnosis. Data are weighted so that people who respond to the survey represent the entire state of Florida based on age, gender, and race.

Caregiving in Florida

According to US Census Bureau projections, the age profile of Florida will change considerably by the year 2030.⁴ In 2000, an estimated 3.6 million Floridians were under age 18, representing 22.8% of the population. By 2030, this number is expected to grow to 5.8 million people, but those under age 18 will represent a smaller percent (20.1) of Florida's population. In 2000, 17.6% of Floridians, or 2.8 million people, were age 65 or older. This age group is expected to grow to 7.8 million people, or 27.1% of Florida's population, by 2030.⁴ Because the risk of disability increases with age, it is expected that as the population ages, the need for informal caregivers will increase as well.

In addition to the risk of disability increasing with age, the risk of cognitive disorders like Alzheimer's disease and other dementias also increases with age. In 2000, an estimated 360,000 Floridians were living with Alzheimer's disease. By 2025, that number is expected to grow by 64% to 590,000.⁵ In some studies, caregivers for people with cognitive impairment or dementia spend more hours providing care than other types of caregivers.⁵ Also, caregivers for people with cognitive impairment tend to be older than other caregivers, and potentially have more disability and are more frail themselves.⁶ Thus, this specific subgroup of caregivers is of interest for planning and program development.

To study the characteristics and health of caregivers and their care recipients in the state of Florida, the thirteen question Caregiver Module was added to the 2008 Florida BRFSS (Appendix A). The 2008 Florida BRFSS not only allows 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 received, and self-reported general health status.

During 2008, 10,217 Florida BRFSS respondents were asked, "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?" A total of 1,461 people, or 13.4% (weighted) of these respondents said "yes" to this question. These respondents were classified as caregivers and answered the remaining Caregiver Module questions about themselves and their care recipient. (Note: if the caregiver reported providing care to more than one recipient, the caregiver was asked to answer the remaining questions based on the recipient who required the most care). A total of 1,395 caregivers answered the question, "Do you have concerns about your {care recipient's} memory or thinking?" Nearly half (47.3% or 651 caregivers) said "yes" to this question. These caregivers are considered to be caring for a person with a memory or thinking problem in this report.

Other questions on the Caregiver Module included the age and gender of the care recipient and their relationship to the caregiver. Module questions also assessed the major health problem of the care recipient, and up to two areas in which the care recipient required the most assistance. Other questions asked the caregiver how long they have provided care for the recipient, the average number of hours per week they provided care, how far they lived from their care recipient, and their greatest difficulty faced as a caregiver. Finally, the caregiver was asked not only whether she had any concerns about the care recipient's memory or thinking, but also whether memory or thinking problems interfered with the care recipient's daily activities or quality of life, and whether the care recipient's memory or thinking had ever been formally evaluated by a health care professional.

Data Analysis:

In order to understand the best way to target and serve the needs of caregivers, it is necessary to understand who they are. Demographic and health behavior characteristics of caregivers of people with and without memory or thinking problems are presented in Table 1, pages 8-9. The majority of caregivers identified in the survey were women (58%), though

caregivers of people with memory problems were less likely to be female than were other caregivers (53% compared to 62%). The mean age of caregivers was 48 years, regardless of the caregiver's concern about the recipient's memory or thinking. Both types of caregivers similarly reported having at least one child under the age of 18 living in the household (32.9% compared to 31.9%). Educational attainment was similar across groups of caregivers, with 69% of caregivers for people with a memory or thinking problem and 64% of other caregivers having at least some education beyond high school. Caregivers of people with a memory or thinking problem were more likely to be employed than other caregivers (64% versus 53%) and less likely to be a student (0.8% compared to 7.5%) or retired (16.4% compared to 21.7%). Household income remained consistent within each bracket. 30.5% of caregivers concerned about their recipient's memory problems earned over \$75,000 compared to 26.2% of caregivers who are not concerned. Racial and ethnic distributions and marital status were similar regardless of caregiver type. The majority of caregivers were white, non-Hispanic (62% of caregivers of people with memory or thinking problems and 65% of other caregivers) and the member of a couple (61% of caregivers of people with memory or thinking problems and 62% of other caregivers).

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 people with memory or thinking problems was slightly higher (30%) than among other caregivers (24%).

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. 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; 4.0 and 3.2 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 similar for caregivers of people with memory or thinking problems (6.3 days) and other caregivers (5.1 days). More than 90% of caregivers in both groups rated their general life satisfaction as very satisfied or satisfied (92% of caregivers of people with memory or thinking problems and 93% of other caregivers). Emotional support of the respondents was assessed by the question: "How often do you get the social or emotional support you need?" Caregivers of people with memory or thinking problems reported always or usually receiving the social and emotional support needed less frequently than other caregivers (75% and 83%, respectively). Ratings of general health among both groups of caregivers were similar; 81% of caregivers of people with memory or thinking problems and 84% of other caregivers reported their general health was excellent, very good, or good. When it came to covering costs for medical needs, 23.1% of caregivers of people with memory or thinking problems reported not going to the doctor when needed to because of cost, compared to

18.8% of caregivers of people without memory or thinking problems. 8.5% of respondents taking care of persons with memory problems reported that they were told by a doctor that they had cancer, compared to 11.1% of caregivers not concerned with their recipient's memory problem.

Measures of health and health behaviors were very similar across the two caregiving groups. Seventy-six percent of caregivers of people with memory or thinking problems and 78% of other caregivers reported engaging in some form of physical activity outside of work. In each group, approximately 40% of caregivers had a body mass index (BMI) in the normal range (18.5-24.9), roughly 30% were considered overweight (BMI of 25.0-29.9), and the remaining 30% were obese (BMI of 30.0 or higher).

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. The prevalence of binge drinking in the last 30 days was 18% among caregivers of people with memory or thinking problems and 11% among other caregivers. Approximately 3% of caregivers of people with memory or thinking problems and 4% of other caregivers reported heavy alcohol consumption. Twenty percent of caregivers of people with memory or thinking problems and 22% of other caregivers were current smokers.

Only caregivers age 65 and older were asked whether they had received a flu shot in the past year or a pneumonia vaccine at any time. Caregivers of people with memory or thinking problems were less likely to have received either of these vaccinations; 59% of caregivers of people with memory or thinking problems reported receiving each shot and 65% of other caregivers reported receiving each shot.

More than one in ten caregivers surveyed reported they had fallen in the past 3 months (13% of caregivers of people with memory or thinking problems and 12% of other caregivers). Respondents who reported experiencing a fall also were asked whether they sustained an injury due to the fall. Caregivers of people with memory or thinking problems were more likely to have been injured in a fall (48%) than other caregivers (23%).

The results of the thirteen question Florida Caregiver Module for caregivers of people with and without memory or thinking problems are found in Table 2. Most care recipients were women (63% of care recipients with memory or thinking problems and 59% of care recipients without memory or thinking problems). The mean age of care recipients with memory or thinking problems was 69 and the mean age of other care recipients was 71. Approximately 4% of care recipients were under age 17 in both the group of care recipients with memory or thinking problems and in the other group. Nearly 65% of care recipients with memory or thinking problems and more than 60% of care recipients without memory or thinking problems were age 65 or older. Care recipients were most commonly a family member of the caregiver, with a parent or parent-in-law being the most frequently reported relationship (36% of care recipients with memory or thinking problems and 27% of care recipients without memory or thinking problems). Nearly 11% of caregivers of people with memory or thinking problems reported they were caring for their child or child-in-law, 11% said they cared for a friend, and 5% reported being the care recipient's spouse. Among caregivers of people without a memory or

thinking problem, 18% reported they were caring for their child or child-in-law, 4% cared for a friend, and 6% cared for a spouse. Caregivers were asked to identify the care recipient's major health condition that led to their need for care. The most common diagnosis reported by both groups was cancer (17% of care recipients with memory or thinking problems and 21% of other care recipients). Alzheimer's disease or dementia was reported much more frequently among care recipients with memory or thinking problems compared to other care recipients (14% and 1%, respectively).

Caregivers reported providing the most help in a variety of areas. When asked to choose up to two areas in which their care recipient needed the most help, caregivers reported self-care and moving around, both representing activities of daily living (ADL), most frequently. However, because "learning, remembering, and confusion" was also an option, fewer caregivers of people with memory or thinking problems reported ADL areas as the major areas in which they provided help. Specifically, 37% of caregivers of people with memory or thinking problems reported moving around; 33% said self care; and 31% said learning, remembering, and confusion were the two areas in which they provided most care. This is in contrast to the 48% of caregivers of people without memory or thinking problems who reported assisting with moving around; the 40% who said self care; and the 8% who said learning, remembering, and confusion as the two major areas in which they assisted. When asked the greatest difficulties faced personally, caregivers most often said that caregiving created stress (57% of caregivers of people with memory or thinking problems and 53% of other caregivers). Caregivers also reported caregiving created a financial burden (22% of caregivers of people with memory or thinking problems and 26% of other caregivers) and did not leave enough time for themselves (23% of caregivers of people with memory or thinking problems and 26% of other caregivers). Caregivers of people with memory or thinking problems were more likely to report caregiving did not leave enough time for their families than were other caregivers (17% compared to 7%).

Most caregivers lived near the care recipient. Among caregivers of people with memory or thinking problems, 43% lived with the care recipient and another 36% lived within twenty minutes of the care recipient. Similarly, 41% of caregivers of people without memory or thinking problems lived in the same house and 43% lived within 20 minutes of the care recipient. The hours of care provided in an average week were similar across caregiving groups, though caregivers of people with memory or thinking problems were somewhat more likely to be in higher categories of care per week. Forty-four percent of caregivers of people with memory or thinking problems and 39% of other caregivers provided at least 20 hours of care in an average week. The duration of care tended to be longer among caregivers of people with memory or thinking problems, with 27% providing care for more than five years.

References

1. Talley RC, Crews JE. Framing the public health of caregiving. *Am J Public Health* 2007; 97:224-228.
2. 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]
3. Remington PL, Smith MY, Williamson DF, Anda RF, Gentry EM, Hogelin GC (1988). Design, Characteristics, and Usefulness of State-Based Behavioral Risk Factor Surveillance: 1981-1987. *Public Health Reports* 103(4) 366-375.
4. 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>.
5. Alzheimer's Association. 2009 Alzheimer's Disease Facts and Figures. Available at http://www.alz.org/national/documents/report_alzfactsfigures2009.pdf.
6. DeFries EL, McGuire LC, Andresen EM, Brumback BA, Anderson LA. Caregivers of older adults with cognitive impairment. *Prev Chronic Dis* 2009;6(2). [http://www.cdc.gov/pcd/issues/2009/apr/08_0088.htm.]

Table 1

Table 1: Weighted demographic and health behavior characteristics of caregivers of persons with memory or thinking problems and caregivers of persons without memory or thinking problems, Florida Behavioral Risk Factor Surveillance System (BRFSS), 2008.

Variable	Categories	Caregivers Concerned about Recipient's Memory or Thinking (n = 651)	Caregivers Not Concerned about Recipient's Memory or Thinking (n = 744)
		Percent (95% CI)	Percent (95% CI)
Age	18-24	12.2 (5.1-26.4)	10.2 (5.3-18.8)
	25-34	10.6 (6.2-17.6)	21.4 (15.0-29.7)
	35-44	16.8 (11.8-23.2)	12.2 (8.7-16.8)
	45-54	25.6 (19.4-33.1)	16.9 (12.9-21.7)
	55-64	18.6 (14.4-23.7)	17.2 (13.5-21.7)
	65 and older	16.2 (12.4-20.9)	22.0 (17.9-26.8)
Gender (% Female)	Female	52.6 (43.7-61.5)	61.7 (54.2-69.2)
Education status	Less than high school	10.6 (6.4-17.1)	8.5 (5.6-12.7)
	High school degree or equivalent	20.5 (15.2-27.1)	27.5 (22.2-33.5)
	Some college or technical School	30.9 (22.7-40.6)	30.5 (24.0-38.0)
	College degree or higher	37.9 (30.4-46.0)	33.5 (27.0-40.7)
Employment status	Employed	64.5 (51.8-78.7)	52.6 (42.1-65.2)
	Out of work	6.5 (2.5-16.5)	5.4 (2.8-10.1)
	Homemaker	7.4 (4.1-12.9)	7.3 (5.0-10.7)
	Student	0.8 (0.3-2.2)	7.5 (2.9-18.0)
	Retired	16.4 (12.8-20.8)	21.7 (17.6-26.5)
	Unable to work	4.4 (2.4-7.9)	5.5 (3.0-9.6)
Race/ethnicity	White only, non-Hispanic	62.0 (52.2-70.8)	65.5 (57.1-73.0)
	Black only, non-Hispanic	11.3 (7.2-17.4)	15.9 (10.8-22.7)

	Other only, non-Hispanic	6.7 (3.7-11.6)	5.4 (2.5-11.2)
	Multiracial, non-Hispanic	3.1 (1.1-8.8)	0.9 (0.3-2.9)
	Hispanic	16.9 (9.1-29.3)	12.4 (6.7-21.7)
Marital status	Married/Coupled	61.1 (51.8-69.7)	61.8 (54.2-68.9)
	Divorced/Widowed/Separated	20.6 (15.5-26.8)	20.3 (15.5-26.3)
	Never married	18.2 (10.3-30.1)	17.9 (11.6-26.4)
Disability status	Respondent has a disability	29.9 (23.5-37.3)	24.4 (19.1-30.7)
General life satisfaction	Very Satisfied/Satisfied	91.6 (86.6-94.9)	93.0 (88.7-95.7)
Emotional support	Always or usually receive support needed	75.0 (67.7-81.1)	83.4 (77.6-88.0)
General health	Excellent, very good, or good	81.3 (74.7-86.4)	84.4 (79.8-88.1)
Physical activity	Engage in physical activity outside of work	76.0 (69.1-81.8)	78.1 (71.7-83.4)
Body Mass Index (BMI)	Neither overweight nor obese	39.6 (30.8-49.1)	41.0 (33.9-48.5)
	Overweight	31.3 (24.8-38.6)	32.1 (25.9-39.0)
	Obese	29.1 (22.4-36.9)	26.9 (21.5-33.1)
Smoking status	Current Smoker	19.6 (14.1-26.6)	22.0 (17.0-28.0)
	Former Smoker	25.1 (19.3-32.0)	22.5 (18.2-27.6)
	Never Smoked	55.2 (46.9-63.3)	55.4 (48.5-62.1)
Alcohol consumption	Heavy drinkers (adult men having more than two drinks per day and adult women having more than one drink per day)	3.4 (2.1-5.5)	3.7 (2.2-6.2)
Binge drinking	Binge drinkers (Men having five or more drinks on one occasion, women having four or more drinks on one occasion)	17.6 (11.0-27.1)	11.1 (7.7-15.5)
Flu shot	Adults age 65+ who have had flu shot within the past year	58.7 (45.5-70.8)	65.4 (55.5-74.1)
Pneumonia vaccine	Adults age 65+ who have ever had a pneumonia vaccination	58.7 (45.5-70.8)	65.4 (55.5-74.1)
Veteran status	Caregiver is a veteran	9.8 (7.0-13.6)	11.5 (7.7-16.7)
Fall experience	Caregiver has fallen within the past 3 months	12.8 (9.2-17.5)	11.8 (8.6-16.1)
Fall-related injury	Among caregivers who fell in the past 3 months, those who were injured	47.8 (32.1-63.9)	23.1 (13.2-37.3)

Household Income	Less than \$10,000	1.9 (0.8,3.0)	3.4 (0.0,7.3)
	\$10,000-\$20,000	15.9 (9.8,21.9)	12.2 (7.3,17.0)
	\$20,000-\$35,000	18.6 (12.2,24.9)	22.2 (17.0,27.3)
	\$35,000-\$50,000	17.1 (9.6,24.7)	19.2 (12.7,25.7)
	\$50,000-\$75,000	16.1 (10.6,21.5)	16.9 (10.0,23.8)
	More than \$75,000	30.5 (21.3,39.6)	26.2 (20.5,31.8)
Children in Household	At least one child under age 18 lives in household	32.9 (25.2,40.5)	31.9 (25.4,38.4)
Medical Costs	Needed to see a doctor but could not because of cost	23.1 (16.2,30.0)	18.8 (13.4,24.2)
Cancer	Respondent ever told by a doctor that they had cancer	8.5 (5.5,11.5)	11.1 (8.0,14.1)

Table 2

Table 2: Weighted caregiving experience characteristics of caregivers of persons with memory or thinking problems and caregivers of persons without memory or thinking problems, Florida Behavioral Risk Factor Surveillance System (BRFSS), 2008.

Variable	Category	Caregivers Concerned about Recipient's Memory or Thinking (n = 651)	Caregivers Not Concerned about Recipient's Memory or Thinking (n = 744)
		Percent (95% CI)	Percent (95% CI)
Care recipient gender	Female	62.5 (54.5-70.5)	58.6 (51.3-66.0)
Care recipient age	0-5	3.2 (0.0-6.7)	2.4 (0.0-5.1)
	6-17	1.2 (0.0-2.8)	2.0 (0.4-3.7)
	18-34	4.5 (1.5-7.5)	6.9 (3.8-9.9)
	35-44	6.4 (2.9-9.9)	5.7 (3.2-8.2)
	45-54	6.3 (2.6-10.1)	9.8 (4.9-14.7)
	55-64	13.9 (8.0-19.8)	12.7 (7.7-17.6)
	65-74	18.7 (10.3-27.0)	23.5 (17.5-29.5)
	75-84	20.7 (14.7-26.6)	19.5 (13.1-26.0)
	85+	25.1 (17.9-32.3)	17.5 (13.5-21.5)
Care recipient's relationship to caregiver	Parent or Parent-in-law	36.4 (28.7-44.1)	26.5 (19.8-33.1)
	Friend	10.7 (5.5-15.9)	4.2 (2.1-6.2)
	Spouse or Partner	5.3 (2.1-8.5)	6.0 (2.9-9.0)
	Child or Child-in-law	10.5 (7.0-14.0)	17.9 (13.5-22.4)
	Sibling or Sibling-in-law	2.5 (0.6-4.3)	6.2 (3.9-8.4)
	Grandparent	7.9 (1.1-14.7)	8.8 (2.3-15.2)
	Neighbor	2.0 (0.0-4.3)	0.3 (0.0-0.7)
	Client or patient	4.4 (1.9-6.9)	8.3 (3.6-13.0)
	Other family member	20.2 (11.7-28.8)	21.9 (16.6-27.2)

* Care recipient's major health problem	Cancer	16.7 (10.4-23.1)	21.5 (15.4-27.6)
	Arthritis/Rheumatism	7.9 (0.0-16.3)	8.7 (2.2-15.3)
	Alzheimer's disease or dementia	14.4 (9.7-19.0)	1.1 (0.2-1.9)
	Stroke	5.3 (2.1-8.6)	2.6 (1.2-4.0)
	Heart disease	5.6 (2.9-8.3)	7.1 (4.1-10.1)
	Diabetes	5.8 (2.3-9.4)	7.7 (4.0-11.5)
Areas in which care recipient needs most help (respondent could choose up to 2)	Learning, remembering, confusion	30.6 (23.7-37.5)	7.9 (3.1-12.7)
	Seeing or hearing	12.8 (4.3-21.3)	7.6 (3.1-12.1)
	Self-care	32.7 (25.1-40.4)	40.0 (32.6-47.3)
	Communicating with others	11.9 (7.3-16.5)	8.3 (4.9-11.6)
	Moving around	37.0 (27.4-46.7)	48.4 (40.4-56.4)
	Getting along with people	7.7 (2.9-12.5)	5.3 (2.3-8.3)
	Feeling anxious or depressed	23.5 (16.3-30.7)	14.5 (10.4-18.6)
Greatest difficulty faced by caregiver (respondent could choose up to 2)	Financial burden	21.7 (14.7-28.8)	26.4 (18.6-34.3)
	Not enough time for him/herself	22.9 (16.1-29.7)	26.4 (18.3-34.4)
	Not enough time for family	17.3 (10.9-23.7)	7.4 (6.4-16.0)
	Interferes with work	9.5 (4.6-14.3)	16.7 (10.3-23.2)
	Creates or aggravates health problems	4.7 (1.3-8.1)	3.6 (1.0-6.2)
	Affects family relationships	6.2 (3.0-9.4)	4.0 (1.8-6.3)
	Creates stress	56.8 (47.5-66.2)	53.2 (43.8-62.5)
	Another difficulty	6.0 (3.2-8.9)	13.0 (3.5-22.5)
Care recipient's distance from caregiver	Same house	43.1 (34.1-52.1)	40.6 (33.7-47.5)
	Less than 20 minutes away	36.3 (28.6-44.1)	42.8 (35.5-50.2)
	20-60 minutes away	12.9 (8.0-17.8)	7.7 (5.1-10.4)
	1-2 hours away	1.7 (0.6-2.9)	1.5 (0.4-2.5)
	More than 2 hours away	5.9 (3.1-8.6)	7.4 (4.4-10.3)
Hours of care provided per week	0-8	37.9 (30.1-45.7)	42.3 (35.0-49.6)

	9-19	18.3 (10.8-25.8)	19.2 (14.1-24.4)
	20-39	15.4 (9.8-20.9)	14.6 (10.5-18.7)
	40+	28.4 (20.5-36.4)	23.8 (17.9-29.8)
Length of care	0-3 months	17.4 (11.6-23.2)	29.5 (23.1-35.9)
	4-12 months	24.6 (15.0-34.2)	23.5 (17.3-29.6)
	13-24 months	9.5 (5.9-13.2)	7.0 (4.3-9.6)
	25-60 months	21.5 (15.2-27.8)	16.2 (11.3-21.2)
	More than 5 years	26.9 (20.0-33.9)	23.8 (17.2-30.4)
Impact of memory or thinking problems	Interferes with everyday activities or quality of life	70.8 (62.4-79.2)	9.2 (5.5-12.9)
Memory or thinking evaluation	Evaluated by health care professional	74.3 (65.9-82.8)	38.5 (30.8-46.2)

* Note: The responses of 25.5% of caregivers of persons with memory or thinking problems (n=188) and 34.9% of caregivers of persons without memory or thinking problems (n=261) were classified as “other” for this question.

Appendix A

Caregiver Module – 2008 Florida BRFSS

FL3.1 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?

IF NEEDED: If recipient has died in the past 30 days, say “I’m so sorry to hear of your loss” and go to the next section.

- 1 Yes
- 2 No [Go to next module]
- 7 Don't know / Not sure [Go to next module]
- 9 Refused [Go to next module]

FL3.2 What age is the person to whom you are giving care?

IF NEEDED: If more than one, ask, “What is the age of the person to whom you gave the most care in the past 30 days?”

- ___ Age in years [0-115]
- 998 Don't know
- 999 Refused

FL3.3 What is the gender of the person you are caring for?

- 1 Male
- 2 Female
- 7 Don't know / Not sure
- 9 Refused

FL3.4 (Program for gender based on response to question FL3.3) What is his/her relationship to you? For example is he/she your (mother/daughter or father/son)?

DO NOT READ ANSWER CHOICES. Let the respondent name the relationship, but probe to fit if it isn't clear. PROBE for relationship – If more than one, ask “What is the relationship of the person to whom you gave the most care in the past 30 days?”

IF NEEDED – If more than one relationship applies, say “I can only record ONE answer choice”, or something similar to ensure respondent chooses only one option.

- 1 Parent
- 2 Parent-in-law
- 3 Child
- 4 Spouse
- 5 Sibling
- 6 Grandparent
- 7 Grandchild
- 8 Other Relative
- 9 Friend or client
- 77 Don't Know / Not Sure
- 99 Refused

FL3.5 What do you think or what has a doctor said is the major health problem that your ____ {Insert response question FL3.4} has?

CHECK ONE CONDITION ONLY. DO NOT READ ANSWER CHOICES.

- | | |
|-----------------------------------|-------------------------------------|
| 1 ADD/ADHD | 15 Hearing problems (deafness) |
| 2 AIDS/HIV | 16 Heart disease |
| 3 Alzheimer's Disease or dementia | 17 Hypertension/high blood pressure |
| 4 Anxiety or emotional problems | 18 Lung disease/emphysema |
| 5 Arthritis/rheumatism | 19 Multiple Sclerosis |
| 6 Asthma | 20 Muscular Dystrophy |
| 7 Cancer | 21 Osteoporosis |
| 8 Cerebral Palsy | 22 Parkinson's |
| 9 Chromosomal anomaly | 23 Spinal Cord Injury (SCI) |
| 10 Depression | 24 Stroke |
| 11 Down's syndrome | 25 Traumatic Brain Injury (TBI) |
| 12 Developmental delays | 26 Other: |
| Specify _____ | |
| 13 Diabetes | 77 Don't know/Not sure |
| 14 Eye/vision problem (blindness) | 99 Refused |

FL3.6 Which TWO of the following areas does your ____ {Insert response question FL3.4} most need your help?

PLEASE READ ANSWER CHOICES 1-7. CHECK UP TO TWO. MULTIPLE RESPONSE.

- 1 Learning, remembering, & confusion;
 - 2 Seeing or hearing;
 - 3 Taking care of oneself, such as eating, dressing, bathing, or toileting;
 - 4 Communicating with others;
 - 5 Moving around;
 - 6 Getting along with people;
- or
- 7 Feeling anxious or depressed
- Please do not read:
- 77 Don't Know
 - 99 Refused

FL3.7 For how long have you provided care for your ____ {Insert response question FL3.4}?
DO NOT READ. Code using respondent's unit of time.

- 1 __ Days
- 2 __ Weeks
- 3 __ Months
- 4 __ Years
- 7 Don't know/Not sure
- 9 Refused

FL3.8 In an average week, how many hours do you provide care for your ____ {Insert response question FL3.4} because of his/her long-term illness or disability?

DO NOT READ

- __ Hours per week
- 77 Don't Know
- 99 Refused

FL3.9 I am going to read a list of difficulties you may have faced as a caregiver. Please indicate which TWO of the following is the greatest difficulty you have faced in your caregiving:
PLEASE READ ANSWER CHOICES 1-8. CHECK UP TO TWO

- 1 Caregiving creates a financial burden;
 - 2 Caregiving doesn't leave enough time for yourself;
 - 3 Caregiving doesn't leave enough time for your family;
 - 4 Caregiving interferes with your work;
 - 5 Caregiving creates or aggravates health problems;
 - 6 Caregiving affects your family relationships;
 - 7 Caregiving creates stress;
 - or
 - 8 Another difficulty
- Please do not read:**
77 Don't know/Not sure
99 Refused

FL3.10 How far away do you live from your ____ {Insert response question FL3.4}? Do you live...
PLEASE READ ANSWER CHOICES 1-5.

- 1 In the same house
- 2 Less than 20 minutes away
- 3 Between 20 & 60 minutes away
- 4 Between 1 & 2 hours away,
- or
- 5 More than two hours away?
- 7 Don't know/Not sure
- 9 Refused

FL3.11 Do you have concerns about your ____ {Insert response question FL3.4}'s memory or thinking?

- 1 Yes
- 2 No
- 7 Don't know / Not sure
- 9 Refused

FL3.12 Does your ____ {Insert response question FL3.4}'s memory or thinking interfere with everyday activities or quality of life?

- 1 Yes
- 2 No
- 7 Don't know / Not sure
- 9 Refused

FL3.13 Has a physician or other health care professional ever evaluated your relative's memory or thinking problems?

- 1 Yes
- 2 No
- 7 Don't know / Not sure
- 9 Refused