

The Impact of Care Recipient Age among Caregivers in Florida, 2008

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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 disease.¹ These informal or family 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 estimated across known for all states and at the local level. State and federal agencies, as well as private organizations are concerned about issues surrounding caregiving and could employ these data to design needed programs and interventions to address an 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 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.

The Individuals with Disabilities Education Act (IDEA) ensures services to people with disabilities up until 21 years of age.² After this time, support is not ensured by law under this act, which may mean that caregivers of recipients under 21 and caregivers of recipients 21 and over may face different challenges. Thus, it is important to identify and address the potentially different challenges faced by these two groups.

During the past four years, the National Center on Birth Defects and Development Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC) has made a systematic attempt to adequately estimate prevalence, 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).³ 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.⁴ The Caregiver Module is designed to collect information about a population-based sample of adult caregivers (age 18 and older) 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 surveys represent the entire state of Florida based on age, gender, and race. As of 2008, six states had used the BRFSS module and have data on caregiver prevalence and outcomes (Hawaii, Florida, North Carolina, Washington, Kansas, and Michigan). The focus of this report is the state of Florida, specifically comparing caregiver issues for recipients under 21 to those who are adult (aged 21 and older).

Caregiving in Florida

According to US Census Bureau projections, the age profile of Florida will change considerably by the year 2030.⁵ 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 2030.⁵ Because the risk of disability increases with age, it is expected that as the population ages, the need for informal caregivers will also increase.

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).

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.

Results

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 recipients aged under 21 and caregivers of recipients 21 and over are presented in Table 1. The mean age of caregivers of recipients less than 21 years of age was 42.9 years old

compared to 48.0 years old in the group of caregivers of recipients aged 21 and over. Caregivers of younger recipients were more likely to be female than caregivers of older recipients (60.6% versus 54.4%). They were also less frequently married or coupled than caregivers of older recipients (57.4 % versus 62.1%). Caregivers of younger recipients were more frequently Black, non-Hispanic and Hispanic than caregivers of older recipients (22.8% versus 12.4% and 42.3% versus 13.2%, respectively). Similarly, 34.7% of caregivers of younger recipients reported being White, non-Hispanic versus 66.0% of caregivers of older recipients. Caregivers of younger recipients reported higher frequencies of not completing a high school education (20.6% versus 8.9%) and reported lower frequencies of having a college or university degree (22.1% versus 36.8%) than caregivers of older recipients. Caregivers of younger recipients (86.3%) and caregivers of older recipients (69.7%) were more likely to be employed.

The following health status and health behaviors of caregivers were examined: frequent mental distress (14 days or more of poor mental health based on the question, “Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past thirty days was your mental health not good?”); self-reported general health; disability (reporting either an activity limitation or use of special equipment); body mass index (BMI); ever being diagnosed with the chronic health conditions arthritis, asthma, diabetes (not including gestational and borderline diabetes), or heart disease; having had a stroke; smoking status; binge drinking status; and influenza vaccination (shot or spray in the previous 12 months). Younger recipients’ caretakers much more frequently reported having a BMI of over 30 than caregivers of older recipients (41.8% versus 26.4%). Caregivers of younger recipients more frequently reported ever having asthma than caregivers of older recipients (21.5% versus 11.6%). They also reported having had the influenza shot or spray in the previous 12 months less frequently than caregivers of older recipients (18.1% versus 34.7%). Other health behaviors were similar between the two groups.

The results of the thirteen-question Florida Caregiver Module based on the 1,461 identified caregivers are found in Table 2. Younger care recipients were less frequently female than older recipients (34.2% versus 61.1%). The overwhelming majority of younger care recipients were children of the caregivers (50.2%); while in the other group, this was the overwhelming minority (3.5%). The top 5 major health problem in each group with the exception of “other” that necessitated caregiving as reported by the caregiver were included in the table. Responses included cancer, diabetes, dementia/Alzheimer’s Disease, arthritis/rheumatism, stroke, depression, heart disease, developmental delays, cerebral palsy, Down’s syndrome, and heart disease among others). Because various conditions affect a person in different stages of their lives, responses varied widely between the two categories. 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 of younger recipient reported self care more frequently than caregivers of older recipients (69.7% versus 34.7%) and reported anxiety or depression less frequently (0.8% versus 19.8%). Caregivers of younger recipients reported having provided care for 0-3 months much less frequently than those of older recipients (3.8% versus 25.8%) and more frequently reported having provided care for 25-60 months (39.8% versus 18.9%). Younger recipients were more likely to be co-residing with the caregivers than older recipients (65.6% versus 40.1%).

When caregivers were asked, “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.” Answer choices were: caregiving creates a financial burden; caregiving doesn’t leave enough time for yourself; caregiving doesn’t leave enough time for your family; caregiving interferes with your work; caregiving creates or aggravates health problems; caregiving affects your family relationships; caregiving creates stress; another difficulty; or no difficulties. If respondents chose “caregiving creates a financial burden” as either of the two greatest difficulties, they were considered to have a financial burden. The same was done for all other options. Out of these options, the difficulties most often chosen by caregivers of younger recipients were financial burden (56.9%) and interference with work (43.3%). In the group of caregivers of older recipients, the difficulties most often chosen were that caregiving creates stress (55.8%) and that it does not allow for enough time for the caregiver (24.6%).

References

1. Talley RC, Crews JE. Framing the public health of caregiving. *Am J Public Health* 2007; 97:224-228.
2. Building The Legacy of IDEA 2004. (n.d.). *IDEA - Building The Legacy of IDEA 2004*. Retrieved May 3, 2010, from <http://idea.ed.gov/>
3. 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]
4. 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.
5. 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>.

Table 1**Weighted demographic & health behavior characteristics of caregivers who reported providing care for a recipient under 21 vs. 21 & older, Florida BRFSS, 2008**

Variable	Care Recipient Age	
	Under 21 (n=45)	21 and over (n=1386)
	% or mean (95% confidence intervals)	
Age (mean years)	42.9 (36.6, 49.2)	48.0 (45.8, 50.3)
Age groups		
18-34	34.6 (9.3, 59.9)	27.2 (20.7, 33.8)
35-54	52.8 (27.3, 78.2)	34.7 (29.7, 39.6)
55-64	9.2 (0.0, 18.4)	17.8 (14.8, 20.8)
65+	3.4 (0.0, 7.4)	20.3 (17.1, 23.4)
Female	60.6 (36.4, 84.8)	54.4 (52.1, 64.4)
Married or coupled	57.4 (32.4, 82.3)	62.1 (56.2, 68.0)
White only, non Hispanic	34.7 (13.7, 55.7)	66.0 (30.2, 71.9)
Black only, non Hispanic	22.8 (0.4, 45.2)	12.4 (8.6, 16.2)
Other/Multiracial, non Hispanic	0.2 (0.0, 0.5)	8.4 (5.0, 11.7)
Hispanic	42.3 (16.6, 68.1)	13.2 (7.1, 19.4)
Body mass index (BMI)		
Not overweight/obese (<25.0)	26.9 (4.3, 49.5)	41.8 (35.9, 47.7)
Overweight (25.0-29.9)	31.3 (11.0, 51.7)	31.8 (26.9, 36.6)
Obese (≥30.0)	41.8 (15.4, 68.2)	26.4 (22.0, 30.9)
<High school	20.6 (0.0, 44.6)	8.9 (5.9, 11.9)
High school graduate	22.4 (2.0, 42.8)	24.2 (20.1, 28.3)
Technical school	34.9 (13.0, 56.8)	30.1 (24.3, 36.0)
College or university	22.1 (0.0, 44.5)	36.8 (31.5, 42.0)
Employed/homemaker/student	86.3 (70.6, 100.0)	69.7 (65.6, 73.8)
Retired	2.2 (0.0, 5.1)	19.4 (16.5, 22.4)
Not working/unemployed/unable to work	11.5 (0.0, 27.0)	10.8 (7.7, 14.0)
Annual household income		
Less than \$15,000	15.6 (0.0, 32.8)	7.3 (4.6, 10.1)
\$15,000-24,999	28.5 (4.4, 52.7)	16.4 (13.0, 19.7)
\$25,000-34,999	2.0 (0.0, 5.0)	9.9 (7.0, 12.7)
\$35,000-49,999	22.8 (0.0, 47.2)	15.6 (11.1, 20.2)
\$50,000 or more	31.1 (9.8, 52.4)	41.6 (36.0, 47.2)
Missing	0.0 (0.0, 0.1)	9.2 (6.3, 12.0)
Frequent mental distress [^]	85.6 (76.4, 96.7)	71.2 (65.4, 77.0)
Fair/poor general health	33.7 (8.1, 59.3)	16.6 (13.3, 19.9)
Disability status*	34.2 (8.4, 60.0)	27.1 (22.7, 31.5)
Ever had asthma	21.5 (5.8, 37.1)	11.6 (8.7, 14.4)
Ever had diabetes	5.7 (0.0, 12.2)	9.6 (7.5, 11.8)
Ever had heart disease	0.1 (0.0, 0.2)	6.8 (4.3, 9.2)
Ever had stroke	13.6 (0.0, 37.4)	5.0 (2.8, 7.3)
Current smoker	17.5 (4.8, 30.2)	21.3 (17.0, 25.6)
Former smoker	14.5 (2.44, 26.6)	25.2 (21.1, 29.2)
Non smoker	68.0 (49.1, 86.8)	53.5 (48.2, 58.9)
Binge drinker §	15.7 (3.0, 28.3)	14.2 (9.7, 18.7)
Influenza vaccine/spray	18.1 (1.3, 34.9)	34.7 (30.1, 39.2)

[^] Defined as experiencing 14 or more days of poor mental health in the past 30 days

* Defined as either having an activity limitation or using of special equipment

§ Men having 5 or more drinks on one occasion, women having 4 or more drinks on one occasion

Table 2**Weighted characteristics of care recipient and caregiving experience characteristics based on reported care recipient age, Florida BRFSS, 2008**

Variable	Care Recipient Age	
	Under 21 (n=45)	21 and over (n=1386)
	% or mean (95% confidence intervals)	
Female recipient	34.2 (8.3, 60.1)	61.6 (56.1, 67.1)
Relationship to recipient		
Parent	14.2 (0.0, 38.0)	32.2 (27.1, 37.2)
Child	50.2 (24.7, 75.8)	3.5 (1.9, 5.0)
Spouse	0	15.0 (12.1, 18.0)
Other family	28.8 (7.4, 50.2)	27.5 (22.1, 32.9)
Non-family	6.8 (1.6, 11.9)	21.8 (16.8, 26.8)
Recipient health problem		
Alzheimer's Disease or dementia	0	7.9 (5.6, 10.2)
Arthritis/rheumatism	0	8.8 (3.4, 14.2)
Cancer	4.1 (2.0, 6.1)	19.1 (14.7, 23.5)
Cerebral Palsy	33.7 (7.8, 59.7)	0.8 (0.0, 1.6)
Down's syndrome	1.4 (0.0, 4.3)	0.01 (0.0, 0.02)
Developmental delays	3.9 (0.0, 10.7)	0.5 (0.2, 0.9)
Diabetes	18.2 (0.0, 42.8)	6.3 (3.9, 8.7)
Eye/vision problem (blindness)	2.0 (0.0, 6.0)	0.3 (0.0, 0.5)
Heart disease	0.2 (0.0, 0.6)	6.6 (4.5, 8.7)
Stroke	3.0 (0.0, 9.0)	3.9 (2.2, 5.6)
Other	32.7 (9.7, 55.8)	30.1 (25.4, 34.8)
Areas recipient needs most help		
Learning/Memory	18.6 (0.7, 36.5)	20.0 (15.8, 24.3)
Seeing or Hearing	17.0 (0.0, 41.8)	10.0 (5.0, 15.0)
Self-care	69.7 (44.2, 95.3)	34.7 (29.2, 40.1)
Communicating with Others	11.2 (0.5, 21.9)	10.4 (7.4, 13.4)
Moving Around	36.5 (9.6, 63.4)	42.8 (36.5, 49.1)
Getting Along with People	0.1 (0.0, 0.2)	6.9 (3.9, 9.9)
Anxious/Depressed	0.8 (0.0, 1.7)	19.8 (15.5, 24.2)
Length of care		
0-3 months	3.8 (1.9, 5.8)	25.8 (21.0, 30.6)
4-12 months	17.0 (0.0, 35.7)	25.3 (19.4, 31.3)
13-24 months	1.7 (0.0, 4.8)	9.1 (6.7, 11.5)
25-60 months	39.8 (13.4, 66.1)	18.9 (14.9, 22.9)
60+ months	37.7 (14.5, 60.9)	20.8 (16.1, 25.6)
Hours per week of care		
0-8 hours	16.0 (2.3, 29.6)	40.6 (35.1, 46.0)
9-19 hours	5.0 (0.0, 11.6)	15.8 (11.3, 20.3)
20-39 hours	32.6 (6.7, 58.4)	15.8 (12.6, 19.0)
40+ hours	46.4 (20.8, 72.1)	27.8 (22.8, 32.9)
Co-Residence	65.6 (43.3, 87.9)	40.1 (34.3, 45.8)
Greatest difficulty faced by caregiver		
Not enough time for caregiver	23.5 (0.0, 53.9)	24.6 (19.4, 29.8)
Not enough time for family	11.4 (0.0, 23.7)	15.1 (10.47, 19.4)
Interferes with work	43.3 (10.8, 75.9)	11.6 (8.2, 14.9)
Creates/aggravates health problems	0	4.4 (2.2, 6.7)
Affects family relationships	11.7 (0.0, 32.9)	5.4 (3.4, 7.4)
Creates stress	33.0 (9.6, 56.4)	55.8 (49.0, 62.6)
Creates financial burden	56.9 (25.8, 88.1)	22.2 (16.9, 27.5)

