



## Characteristics And Health Of Caregivers And Care Recipients -- North Carolina, 2005

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### Abstract

Approximately 53.4 million caregivers in the United States provide an estimated \$257--\$389 billion worth of unpaid care annually to persons of all ages with disabilities and chronic illness (1,2). The health of caregivers and their ability to continue their contributions have emerged as public health concerns (3). A 2004 study indicated that those persons who provided the most intense caregiving reported substantially poorer health than noncaregivers or those with modest caregiving responsibilities (2). A Healthy People 2010 objective calls for public health surveillance and health promotion programs for persons with disabilities and caregivers in every state and the District of Columbia (objective 6-13) (4). Although limited caregiver surveys have provided data at the national level, data have not been available at the state level to characterize the health of caregivers or health effects of caregiving. Such information could be useful to states for planning and policy decisions and the development and implementation of interventions to promote caregivers' health. To analyze the characteristics and health of caregivers and care recipients and to assess the effects of caregiving, data were analyzed from a caregiver module that was piloted in North Carolina in the 2005 Behavioral Risk Factor Surveillance System (BRFSS) survey. This report summarizes the results of that analysis, which determined that caregivers provided an average of 20.1 hours of care per week, and 72.2% of caregivers lived in the same household as (24.9%) or within 20 minutes of (47.3%) the care recipient. Caregivers were more likely to be women (59.5%) than men and averaged more days when their mental health was not good when compared with noncaregivers (4.3 days versus 3.0 days, of the preceding 30 days). Public health initiatives should be designed to promote the health and well-being of both care recipients and caregivers.

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# Characteristics and Health of Caregivers and Care Recipients --- North Carolina, 2005

Approximately 53.4 million caregivers in the United States provide an estimated \$257--\$389 billion worth of unpaid care annually to persons of all ages with disabilities and chronic illness (1,2). The health of caregivers and their ability to continue their contributions have emerged as public health concerns (3). A 2004 study indicated that those persons who provided the most intense caregiving reported substantially poorer health than noncaregivers or those with modest caregiving responsibilities (2). A *Healthy People 2010* objective calls for public health surveillance and health promotion programs for persons with disabilities and caregivers in every state and the District of Columbia (objective 6-13) (4). Although limited caregiver surveys have provided data at the national level, data have not been available at the state level to characterize the health of caregivers or health effects of caregiving. Such information could be useful to states for planning and policy decisions and the development and implementation of interventions to promote caregivers' health. To analyze the characteristics and health of caregivers and care recipients and to assess the effects of caregiving, data were analyzed from a caregiver module that was piloted in North Carolina in the 2005 Behavioral Risk Factor Surveillance System (BRFSS) survey. This report summarizes the results of that analysis, which determined that caregivers provided an average of 20.1 hours of care per week, and 72.2% of caregivers lived in the same household as (24.9%) or within 20 minutes of (47.3%) the care recipient. Caregivers were more likely to be women (59.5%) than men and averaged more days when their mental health was not good when compared with noncaregivers (4.3 days versus 3.0 days, of the preceding 30 days). Public health initiatives should be designed to promote the health and well-being of both care recipients and caregivers.

BRFSS is a state-based, random-digit--dialed telephone survey of the noninstitutionalized, U.S. civilian population aged  $\geq 18$  years. Questions related to caregiving were administered as part of the national BRFSS core survey (i.e., the survey questions administered in all states) in 2000 (5) but were not repeated. To improve caregiver surveillance, CDC provided funds to the University of Florida in 2004 to develop a caregiver module to collect data on the characteristics and health of caregivers. Module development was based on previous research (2) and influenced by key national stakeholders convened by AARP (formerly known as the American Association of Retired Persons) in February 2005. North Carolina was selected as the site for piloting the module because of the state's large BRFSS sample size and administrative capacity.

The following caregiver screening question was administered in the North Carolina 2005 BRFSS survey: "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?" Persons who responded "yes" to the question were classified as caregivers and completed the caregiver module by responding to questions about themselves and their primary care recipient. If the caregiver had more than one care recipient, the caregiver was asked to answer module questions in reference to the recipient who required the most care. Questions in the caregiver module related to the age and sex of the care recipient; relationship of the care recipient to the caregiver (e.g., parent, spouse, or child); care recipient's major diagnosis (e.g.,

heart disease, cancer, stroke, or diabetes); care recipient's functional limitations (e.g., moving around or self-care) as defined by the *International Classification of Functioning, Disability, and Health* (6); duration of caregiving; hours per week of caregiving; difficulties for the caregiver that were created by caregiving (e.g., stress, lack of time, and health problems); and travel time to reach the care recipient. Comparisons were tested using *t* tests for differences in means of continuous variables and chi-square or chi-square for trend tests among categorical variables.

Among the 5,859 survey respondents interviewed during May--August 2005, a total of 895 (weighted prevalence: 15.5%; 95% confidence interval [CI] = 14.2%--16.9%) indicated they were caregivers. A greater percentage of caregivers (59.5%) were women than men (40.5%) (Table 1). A greater percentage of caregivers (21.2%) than noncaregivers (15.8%) were non-Hispanic blacks, but a smaller percentage of caregivers (2.3%) than noncaregivers (10.3%) were Hispanic (Table 1). On average, caregivers reported more days (4.3 days out of 30 days) that their mental health was not good than noncaregivers (3.0 days), although the number of days that physical health was reported not good was similar for caregivers (3.2 days) and noncaregivers (3.5 days).

Most care recipients (67.2%) were female and older than the general population; 64.3% of care recipients were aged  $\geq 65$  years, and 82.8% were cared for by a relative (Table 2). The major diagnoses of care recipients specified by caregivers were heart disease (12.8%), cancer (11.7%), stroke (9.1%), diabetes (9.0%), dementia (8.8%), arthritis/rheumatism (5.1%), lung disease/emphysema (3.0%), cerebral palsy (2.6%), and hypertension (2.4%). When asked to identify the functional limitations of their care recipients that required the most help, caregivers named moving around (41.7%); self-care (e.g., eating, dressing, bathing, and toileting) (41.0%); learning, memory, and confusion (17.0%); and anxiety or depression (16.4%) (Table 2). On average, caregivers had provided care for 42.5 months, with 26.4% providing care for  $>5$  years (Table 3). Although caregivers averaged 20.1 hours per week of care, 13.6% provided  $\geq 40$  hours per week. When asked to name the one or two greatest difficulties they experienced from caregiving, 29.9% of caregivers cited stress, 27.9% cited not enough time for themselves or their families, and 12.0% indicated that caregiving had created a financial burden (Table 3). In addition, 3.5% of caregivers said caregiving created or aggravated health problems. In response to a separate question, 3.7% (CI = 2.5%--5.4%) reported sustaining an injury while caregiving. Nearly half (47.3%) of caregivers lived within 20 minutes of the care recipient; 24.9% resided in the same household (Table 3).

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### **Editorial Note:**

These findings from the piloting of the BRFSS caregiver module reveal that an estimated 15.5% of adults in North Carolina were caregivers in 2005, compared with an estimated 21% of adults nationally, according to a study published in 2004 (2). In North Carolina, caregivers were more likely to be women than men, and one fourth of caregivers had been providing care for  $>5$  years.

Care recipients were most likely to be aged  $\geq 65$  years, and more than half had a major diagnosis of a chronic disabling condition, such as heart disease, cancer, stroke, diabetes, and dementia.

Recent data on the prevalence of disability indicated that variations occur from state to state (from 11% to 26% of the population) and persons with disabilities are likely to report overall poorer health (9). The extent to which the prevalence of caregiving mirrors these variations in disability is unknown and represents an area for future research.

The intensity and duration of caregiving has the potential to affect overall health among caregivers (7,8). Programs should be developed to address both the physical and mental health needs of caregivers and to relieve some of the difficulties they report (e.g., not enough time for self or family and financial burdens). Because 29.9% of caregivers indicate that stress, which can precipitate long-term physical or mental health problems, is one of the greatest difficulties resulting from caregiving, policies and preventive support should remove or mediate stressors. Also, given that 3.7% of caregivers report injuries, training and materials should be considered to prevent these injuries. In addition, because BRFSS data are collected only from adults aged  $\geq 18$  years, they do not reflect younger caregivers; alternative forms of national and state assessment should be developed to analyze the health needs and caregiving patterns for populations aged  $< 18$  years.

The caregiver module should be implemented in additional states to create national and state profiles of caregiving and caregiver health effects. By adopting the caregiver module, state officials, including policy makers and program planners in services for aging populations, children and youths, and persons with disabilities, will be able to develop and monitor data-driven state plans to support caregivers and care recipients.

The findings in this report are subject to at least five limitations. First, BRFSS is a telephone-based survey and excludes households without landline telephones or with cellular telephones only. Second, data are self-reported and subject to recall bias; therefore, prevalence estimates might be underestimated or overestimated. Third, no question specifically asked whether caregivers were paid or unpaid; the 1.2% of caregivers recorded as paid represents only those who provided that information without being asked, and therefore likely underestimate the proportion of caregivers who were paid. Further research might determine whether differences exist in the characteristics of paid and unpaid caregivers and the implications of these differences. Fourth, assessment of the greatest difficulties resulting from caregiving was asked only of caregivers, and no comparison can be made between caregivers and noncaregivers with regard to these difficulties (e.g., stress and not enough time for self or family). Finally, information on the relationship between the caregiver and the care recipient was limited (i.e., spouse, relative other than spouse, non-relative, and paid). Future surveys will more fully describe this relationship (e.g., parent, sibling, or child).

The data presented in this report are the first CDC-sponsored state-level data to assess the characteristics and health of caregivers and care recipients and their caregiving situations. CDC plans to support further testing to develop an optional BRFSS caregiver module for adoption by more states in 2009. Participation by all states would enable CDC to report caregiver health status, using population-based data, for the first time nationally and by state. Additionally, states

would have the surveillance results needed to create benchmarks, document and prioritize caregiver needs among their residents, and plan interventions to address those needs.

## **Acknowledgments**

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## **Table 1**

**TABLE 1. Characteristics of caregivers compared with noncaregivers\* — Behavioral Risk Factor Surveillance System, North Carolina, 2005**

Characteristic	Caregiver (n = 895)		Noncaregiver (n = 4,964)	
	%	(95% CI†)	%	(95% CI)
<b>Age group (yrs)</b>				
18–34	26.9	(21.8–32.8)	32.1	(29.7–33.9)
35–44	19.3	(16.2–22.9)	21.0	(19.6–22.6)
45–54	21.4	(18.2–24.9)	17.0	(15.7–18.4)
55–64	17.4	(14.7–20.6)	13.1	(12.4–14.5)
≥65	15.0	(12.5–17.8)	16.7	(15.6–17.9)
<b>Race/Ethnicity</b>				
White, non-Hispanic	71.5	(66.1–76.3)	69.6	(68.4–72.2)
Black, non-Hispanic§	21.2	(16.6–26.6)	15.8	(13.8–16.4)
Other, non-Hispanic	5.0	(3.1–8.0)	4.2	(3.5–5.0)
Hispanic§	2.3	(1.4–3.9)	10.3	(8.9–12.2)
<b>Sex</b>				
Men	40.5	(35.6–45.7)	48.8	(45.8–50.7)
Women§	59.5	(54.3–64.4)	51.1	(49.3–53.2)
<b>Marital status</b>				
Married/Coupled	64.8	(59.6–69.7)	63.9	(62.4–66.2)
Divorced/Separated	11.2	(9.2–13.6)	11.7	(10.6–12.6)
Widowed	5.1	(3.8–6.9)	7.1	(6.4–7.8)
Never married	18.8	(14.0–24.8)	17.3	(15.3–19.0)
<b>Education¶</b>				
No formal/Eighth grade or less	2.9	(1.6–5.2)	7.4	(6.2–8.7)
Some high school	9.9	(6.2–15.5)	10.4	(9.1–11.6)
High school graduate	28.3	(24.4–32.6)	29.3	(27.4–31.0)
Beyond high school	58.8	(53.8–63.7)	52.9	(51.2–55.1)
<b>Annual income</b>				
<\$25,000	30.3	(26.0–35.0)	34.0	(31.8–36.0)
\$25,000–\$34,999	17.4	(14.0–21.4)	14.0	(12.6–15.5)
\$35,000–\$49,999	16.3	(11.8–22.1)	15.0	(13.8–16.5)
\$50,000–\$74,999	15.9	(13.0–19.4)	16.1	(14.8–17.7)
≥\$75,000	20.1	(16.7–24.0)	21.0	(19.2–22.5)

\* Percentages are weighted according to state population estimates; groupings do not all add to 100.0% because of rounding.

† Confidence interval.

§ Significant difference between caregivers and noncaregivers by chi-square test;  $p < 0.05$ .

¶ Significant difference between caregivers and noncaregivers across categories of education (rather than between education levels);  $p < 0.05$ .

**Table 2**

**TABLE 2. Characteristics of care recipients\* — Behavioral Risk Factor Surveillance System, North Carolina, 2005**

Characteristic	Care recipients (n = 895)	
	%	(95% CI†)
<b>Age group (yrs)</b>		
0–5	1.6	(0.7–3.8)
6–17	5.5	(3.6–8.3)
18–29	3.1	(1.8–5.3)
30–49	10.5	(7.9–13.9)
50–64	15.1	(12.4–18.2)
65–74	19.2	(15.9–22.9)
75–84	25.5	(22.0–29.3)
≥85	19.6	(15.2–24.8)
<b>Sex</b>		
Male	32.8	(28.7–37.3)
Female	67.2	(62.7–71.3)
<b>Relationship to caregiver</b>		
Relative other than spouse	72.0	(66.9–76.6)
Nonrelative	16.0	(11.8–21.4)
Spouse	10.8	(8.6–13.5)
Paid caregiver	1.2	(0.6–2.4)
<b>Major diagnosis</b>		
Heart disease	12.8	(10.3–15.8)
Cancer	11.7	(9.3–14.6)
Stroke	9.1	(6.8–12.0)
Diabetes	9.0	(6.5–12.4)
Dementia	8.8	(6.5–11.7)
Arthritis/Rheumatism	5.1	(3.6–7.3)
Lung disease/Emphysema	3.0	(1.8–4.9)
Cerebral palsy	2.6	(1.2–5.3)
Hypertension	2.4	(1.3–4.5)
Other disease or condition	35.5	(31.4–39.9)

\* Percentages are weighted according to state population estimates; groupings do not all add to 100.0% because of rounding.

† Confidence interval.

### Table 3

**TABLE 3. Characteristics of caregivers\* — Behavioral Risk Factor Surveillance System, North Carolina, 2005**

Characteristic	Caregiver (n = 895)	
	%	(95% CI†)
<b>Duration of caregiving</b>		
≤3 mos	22.1	(18.5–26.3)
4–12 mos	22.0	(18.6–25.8)
13–24 mos	17.6	(13.0–23.5)
25 mos–5 yrs	11.8	(9.4–14.8)
>5 yrs	26.4	(22.7–30.4)
<b>Amount of caregiving (hrs per week)</b>		
≤8	52.1	(47.1–57.2)
9–19	18.1	(14.8–22.0)
20–39	16.1	(13.0–19.8)
≥40	13.6	(10.9–16.9)
<b>Greatest difficulties resulting from caregiving§</b>		
Creates stress	29.9	(26.1–34.0)
Not enough time for self or family	27.9	(22.4–34.7)
Financial burden	12.0	(9.7–14.9)
Interferes with work	6.9	(4.9–9.7)
Affects family relationships	5.6	(4.1–7.6)
Causes or aggravates health problems	3.5	(2.4–5.0)
Creates other difficulties	4.0	(2.5–6.2)
<b>Functional limitations for which caregiver provides the most help¶</b>		
Moving around	41.7	(37.2–46.3)
Self-care (e.g., eating, dressing, bathing, and toileting)	41.0	(36.2–45.9)
Learning, remembering, and confusion	17.0	(14.0–20.4)
Feeling anxious or depressed	16.4	(13.6–19.6)
Communicating with others	8.7	(6.8–11.1)
Seeing or hearing	7.0	(5.2–9.4)
Getting along with others	6.1	(4.4–8.5)
<b>Travel time to care recipient</b>		
Same house	24.9	(21.2–29.0)
<20 min	47.3	(42.5–52.1)
20–59 min	18.4	(13.9–23.9)
1–2 hrs	2.9	(1.9–4.3)
>2 hrs	6.6	(4.9–8.9)

\* Percentages are weighted according to state population estimates; groupings do not all add to 100.0% because of rounding.

† Confidence interval.

§ Respondents were asked to name one or two.

¶ Respondents were asked to name the top one or two activity limitations of the care recipient as defined by the World Health Organization's *International Classification of Functioning, Disability, and Health*. Available at <http://www.who.int/classifications/icf/en> (6).

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