

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 ≥ 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 ≥ 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 pro-

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)
Age group (yrs)				
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)
Race/Ethnicity				
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)
Sex				
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)
Marital status				
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)
Education¶				
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)
Annual income				
<\$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); $p < 0.05$.

vided 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 ≥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).

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

Characteristic	Care recipients (n = 895)	
	%	(95% CI†)
Age group (yrs)		
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)
Sex		
Male	32.8	(28.7–37.3)
Female	67.2	(62.7–71.3)
Relationship to caregiver		
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)
Major diagnosis		
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.

Reported by: B Neugaard, PhD, EM Andresen, PhD, EL DeFries, MPH, Univ of Florida. RC Talley, PhD, JE Crews, DPA, Div of Human Development and Disability, National Center on Birth Defects and Developmental Disabilities, CDC.

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 ≥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.

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

Characteristic	Caregiver (n = 895)	
	%	(95% CI†)
Duration of caregiving		
≤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)
Amount of caregiving (hrs per week)		
≤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)
Greatest difficulties resulting from caregiving§		
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)
Functional limitations for which caregiver provides the most help¶		
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)
Travel time to care recipient		
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).

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 ≥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.

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Acanthamoeba Keratitis — Multiple States, 2005–2007

On May 26, 2007, this report was posted as an MMWR Dispatch on the MMWR website (<http://www.cdc.gov/mmwr>).

In May 2006, the Illinois Department of Public Health (IDPH) informed CDC about a possible increase in *Acanthamoeba* keratitis (AK) at an ophthalmology center in Illinois during the preceding 3 years. The University of Illinois at Chicago (UIC) was investigating this possible increase. In October 2006, IDPH updated CDC about the ongoing UIC investigation. At that time, CDC informally contacted multiple ophthalmology centers in the United States to assess whether the potential increase in cases extended beyond Illinois. Responses from the ophthalmology centers were inconclusive. In January 2007, CDC initiated a retrospective survey of 22 ophthalmology centers nationwide to assess whether cases were increasing throughout the United States. In March 2007, data received from 13 centers demonstrated an increase in culture-confirmed cases of AK with wide geographic distribution. The increase in cases had begun in 2004 and continued to the present. On March 16, 2007, CDC initiated a multistate investigation to look for risk factors associated with this increase in AK cases. This report summarizes recent preliminary results of that investigation, which, indicated an association with AK in soft contact lens wearers who used

Advanced Medical Optics (Santa Ana, California) Complete[®] MoisturePlus[™] (AMOCMP) multipurpose cleaning solution. CDC and the Food and Drug Administration (FDA) are taking steps to notify the public and the medical and public health communities of this preliminary association. The manufacturer has undertaken a voluntary recall of the product.

AK, a rare but potentially blinding infection of the cornea, is caused by a ubiquitous, free-living amoeba (*Acanthamoeba*) that is found commonly in the environment, including water (e.g., tap and recreational water), soil, sewage systems, cooling towers, and heating/ventilation/air conditioning (HVAC) systems. AK primarily affects otherwise healthy persons who wear contact lenses; an estimated 85% of U.S. cases occur in contact lens wearers (including wearers who follow recommended contact lens-care practices) (1). Persons who improperly store, handle, or disinfect their lenses (e.g., by using tap water or homemade solutions for cleaning); swim, use hot tubs, or shower while wearing lenses; come in contact with contaminated water; have minor damage to their corneas; or have previous corneal trauma are at increased risk for infection (2). Based on an analysis of cases reported to CDC during 1985–1987, the incidence of AK in the United States has been estimated at one to two cases per million contact lens users (3,4). An estimated 30 million persons in the United States wear soft contact lenses (5).

Initial case finding for this investigation was facilitated through postings on the *Epidemic Information Exchange (Epi-X)*, on ophthalmology/optometry/infection control listservs and websites, and through queries of clinical microbiology laboratories. As of May 24, 2007, a total of 138 patients with onset of symptoms on or after January 1, 2005, and positive *Acanthamoeba* cultures from corneal specimens had been reported to CDC by public health authorities and ophthalmologists from 35 states and Puerto Rico. Standardized telephone interviews of patients, ophthalmologists, and primary eye-care providers are being conducted by state and local health officials and CDC. Laboratory testing of clinical specimens, contact lenses, bottles of solution, and contact lens cases received from AK patients, including typing of *Acanthamoeba* spp. isolates, is ongoing. An initial analysis was conducted using data from the first 46 completed patient interviews.

Among the 46 culture-confirmed patients who were interviewed, the median age was 40 years (range: 15–77 years); six (13%) were aged <18 years. Twenty-seven (59%) were female. Of the 37 of these patients for whom clinical data were available, medical therapy was unsuccessful for nine (24%), and they were required or expected to undergo corneal transplantation. Of the 46 patients, 39 (85%) wore soft contact lenses, three (7%) wore rigid lenses, and four (9%) reported no con-

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