

## CHARACTERISTICS OF AMERICAN INDIAN AND ALASKA NATIVE ADULT CAREGIVERS, BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM, 2000

**Objectives:** We compared characteristics of American Indian and Alaska Native (AI/AN) adult caregivers (age  $\geq 18$  years) who were caring for an older adult (age  $\geq 60$  years) to those of other ethnic groups.

**Methods:** Participants ( $N=20,996$ ) were from the 2000 Behavioral Risk Factor Surveillance System. Caregivers provided regular care or assistance during the past month to a family member or friend who was  $\geq 60$  years of age. In addition, participants were asked to indicate whom they would call to arrange short- or long-term care in the home for elderly relatives or friends who were no longer able to care for themselves.

**Results:** A total of 16.4% of adults were caregivers to a person who was  $\geq 60$ . AI/AN were significantly more likely to report being caregivers than were people who were of Asian descent. Compared to AI/AN caregivers, Hispanic caregivers indicated that if a friend or relative needed short- or long-term care, they were more likely to provide care themselves (29.1% vs 46.6%) and that they were less likely to indicate that they would contact a professional resource (14.5% vs 25.2%).

**Conclusions:** Family caregivers provide a valuable service in the United States, particularly to chronically ill or disabled older adults. National, state, and local surveys should regularly collect information on caregiving. (*Ethn Dis.* 2008;18:477–482)

**Key Words:** AI/AN, Behavioral Risk Factor Surveillance System (BRFSS), Caregiving

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### INTRODUCTION

In 2030, the population of adults aged  $\geq 65$  years is projected to be 71 million (20% of the US population), up from 36 million in 2005.<sup>1</sup> Along with general trends for America's population, minority populations are living longer and getting older. Members of minority groups aged  $\geq 65$  are projected to increase from 5.7 million in 2000 (16.4% of the older adult population) to 8.1 million in 2010 (20.1% of the older adult population) and then to 12.9 million in 2020 (23.6% of the older adult population).<sup>1</sup> As the number of older adults of all races and ethnicities continues to increase, so will the need for caregivers.<sup>2</sup>

Understanding caregiving for older adults presents new challenges and opportunities for the field of public health.<sup>2</sup> Factors believed to have influenced the growing demand for caregivers in the United States include an increase in the number and proportion of older adults, medical advances, shorter hospital stays, limited discharge planning by hospitals, and the expansion of home care technology. The result is that a substantial portion of supportive care services are provided outside the formal medical care system; families are primarily responsible for caregiving,<sup>3</sup> which is now required for

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longer than ever.<sup>3</sup> Family caregivers represent the largest source of supportive care services in the United States.<sup>4</sup>

In a 2004 national survey by the National Alliance for Caregiving and AARP (NAC/AARP), approximately 44 million American family caregivers who were  $\geq 18$  years of age provided care to someone  $\geq 18$  years old, and 34 million provided care to someone  $\geq 50$  years old.<sup>5</sup> Unfortunately, the NAC/AARP survey did not examine American Indian and Alaska Native (AI/AN) caregivers.<sup>5</sup> In addition, most caregivers (83%) are family caregivers who are caring for a relative<sup>5</sup> or close friend; thus, this article focuses on family caregivers to adults aged  $\geq 60$  years.

Despite the attention to caregiving in the gerontology literature, little is known about AI/AN caregivers.<sup>6–8</sup> What is known about AI/AN caregivers is primarily from small focus groups<sup>9–11</sup> or regionally or tribally specific samples.<sup>12,13</sup> Moreover, AI/ANs may be more affected by caregiving, both as a caregiver and as a care recipient, than people from other ethnic groups for several reasons. First, the increasing life expectancy, high rates of disability, and

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poor health status may result in increased demand for long-term care services and for caregivers. Although life expectancy of AI/ANs has increased dramatically since the 1970s,<sup>14</sup> AI/ANs who are  $\geq 60$  years of age can expect to spend 50%–60% of their remaining life with a disability.<sup>15</sup> Also, AI/ANs who were  $\geq 18$  years had consistently one of the highest prevalences of self-reported fair-to-poor health compared with the general US population from 1991 to 2004.<sup>16</sup> The result of these factors is that the anticipated long-term care needs of AI/AN aged  $\geq 75$  years are expected to at least double during the next 25 years.<sup>17</sup> Second, the location of the caregiver and care recipient can compound the usual stresses and burdens associated with caregiving. Approximately 50% of AI/ANs live on reservations,<sup>18</sup> and most reservations have challenges related to high poverty rates and few, if any, long-term care services.<sup>6</sup>

The purpose of the present investigation was two-fold. First, we estimated the prevalence of family caregivers (herein referred to as caregivers) among ethnic groups who were caring for an older adult ( $\geq 60$  years of age) as well as characteristics of the caregivers. Second, we compared characteristics of AI/AN caregivers to caregivers of other ethnic groups by using national-level data from the 2000 Behavioral Risk Factor Surveillance System (BRFSS) survey.

## METHODS

To examine the characteristics of AI/AN caregivers ( $\geq 18$  years of age) compared with caregivers of other ethnic groups, we analyzed data from the 2000 BRFSS. It is a monthly, state-based, list-assisted, random-digit-dialed telephone survey of the noninstitutionalized US population aged  $\geq 18$  years. Used to monitor behaviors associated with the leading causes of morbidity and mortality, the BRFSS is in place in all 50 states, the District of Columbia, and the

three US territories of Guam, Puerto Rico, and the US Virgin Islands. Information about the quality of BRFSS data, history of survey questions, and module information can be obtained from the BRFSS website (<http://www.cdc.gov/brfss>). Of particular importance, the BRFSS is the only source of continuously collected state-based population data regarding the health of AI/AN adults.

Participants' race/ethnicity was based on their responses to two questions, "What is your race?" and "Are you of Spanish or Hispanic origin?" Those who indicated that their race was AI/AN, Asian, Black, or White on the first question were classified as such. Regardless of the participants' response to the first question, those who indicated on the second question that they were of Spanish or Hispanic origin were classified as Hispanic. Those who indicated that they were of another race were excluded from the analyses because of the small numbers of caregivers.

Two caregiver questions were included in the core of the BRFSS that was asked of the entire sample in 2000, and these questions were not repeated in subsequent years. These questions were aimed at understanding caregivers. Caregiver status was based on response to the following question: "There are situations where people provide regular care or assistance to a family member or friend who is elderly or 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 who is 60 years of age or older?" Respondents were categorized as a caregiver if they answered yes. All survey respondents also were asked: "Who would you call to arrange short- or long-term care in the home for an elderly relative or friend who was no longer able to care for themselves?" We classified responses into five categories (would provide care myself, relative/friend/clergy, professional, other, do not know who to call).

Health-related quality of life was measured through the following four questions: the number of days in the past 30 in which physical health was not good ( $<14$  days or  $\geq 14$  days); the number of days in the past 30 in which mental health was not good ( $<14$  days or  $\geq 14$  days); the number of days in the past 30 in which poor physical or mental health resulted in activity limitations ( $<14$  days or  $\geq 14$  days); and a general rating of overall health on a five-item scale ranging from poor to excellent, which we classified into three levels (excellent/very good, good, fair/poor). The validity of the health-related quality of life questions is reported elsewhere.<sup>19</sup>

In addition to health-related quality of life, the demographic factors of sex, age, income, marital status, education, employment status, number of adults in household, and the presence of children ( $\leq 17$  years of age) in the household were used to characterize the population of caregivers by ethnic group.

## Statistical Analyses

The present investigation combined 2000 BRFSS data from 50 states and the District of Columbia. The weighting method took into account the probability of selection of a telephone number, the number of adults in a household, and the number of telephones in a household. The data were then poststratified to adjust for nonresponse and noncoverage of households without telephones, weighted to each state's adult population, and aggregated for the analyses. To account for the split sample method used by Illinois in 2000, in which not all questions were administered to their entire sample, the appropriate adjustment was made to Illinois' sample weight and applied to the analytic data set.

To account for the complex sampling design, SUDAAN (RTI International, Research Triangle Park, NC) was used in all analyses. All prevalence estimates provided from our study have a numerator of at least 50 and a relative

standard error <30% to ensure that estimates were stable. We first estimated the prevalence rates of caregiving and specific demographic characteristic for caregivers by racial/ethnic groups (AI/AN, Asian, Black, Hispanic, and White). Then we compared characteristics of AI/AN caregivers independently to caregivers of other racial/ethnic groups. If the comparison contained an unstable estimate, no statistical testing was conducted. We reduced our  $\alpha$  level from .05 to .01 for significance testing, to account for the potential inflation of the type I error from the multiple comparisons.

## RESULTS

Of the 127,232 participants in the 2000 BRFSS survey with complete data, our study contained 20,996 people who indicated that they were caregivers to a family member or friend who was aged  $\geq 60$  years. A total of 16.4% (standard error [SE] .2%) of the US adult population considered themselves a caregiver. Caregiver status was reported by 17.6% (SE=1.6%) of AI/AN adults, 11.0% (SE=1.2%) of Asian adults, 18.1% (SE=.6%) of Black adults, 16.7% (SE=.5) of Hispanic adults, and 16.2% (SE=.2) of White adults. A larger proportion of AI/ANs reported that they were a caregiver than did people of Asian descent ( $P<.001$ ). No significant differences were observed between AI/ANs and other ethnic groups.

Compared with AI/AN caregivers, a significantly larger proportion of Black caregivers lived alone (Table 1). A larger proportion of White caregivers had two-person households, and fewer of them had four or more people living in their household. In comparison to other groups, a larger proportion of AI/AN caregivers had a child living in their household than did White caregivers.

Compared to AI/AN caregivers, Hispanic caregivers indicated that if a friend

or relative needed short- or long-term care that they were significantly more likely to provide care themselves. Furthermore, Hispanic caregivers were significantly less likely than AI/AN caregivers to indicate that they would contact a professional resource if short- or long-term care was needed for a friend or relative. Black caregivers were more likely than AI/AN caregivers to indicate that they would contact a relative, friend, or clergy if short- or long-term care was needed for a friend or relative.

## DISCUSSION

Based on the nationally representative 2000 BRFSS, we estimated that 16.4% of US adults self-identify as a caregiver to a family member or friend who was aged  $\geq 60$  years. AI/AN adults were significantly more likely to report being a caregiver than were people who were of Asian descent. Our estimate of caregivers was equivalent to the NAC/AARP estimate. However, the NAC/AARP study reported that 16% of US adults were caring for a person aged  $\geq 50$ ,<sup>5</sup> while our study determined the prevalence of caregivers for people aged  $\geq 60$ . In addition to the different age criteria of the care recipients, these studies used different operational definitions of a caregiver. The NAC/AARP study included caregivers who assisted with at least one activity of daily living or instrumental activity of daily living, whereas in the BRFSS caregivers self-identified.

The National Family Caregivers Association indicates that there may be three triggers in a caregiving situation that are most likely to get family caregivers to initially self-identify as caregivers.<sup>20</sup> These are: providing personal care (eg, dressing, transferring, toileting/continence), the gravity of their loved one's diagnosis, and interaction with the healthcare system. Caregiver self-identification improves the lives of family caregivers and their loved

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ones. Those who self-identified as caregivers indicated that they were more proactive in seeking resources and skills to assist the care recipient and that they had increased confidence when speaking with healthcare professionals about the care recipient's health care.<sup>20</sup>

One of the main issues among families preparing to provide care for a frail, older adult is the lack of knowledge about how to obtain outside help.<sup>21</sup> We found that 9.1%–16.7% of current caregivers did not know where to turn for caregiving resources if an elderly friend or relative could no longer care for themselves. Caregivers may provide care to older adults because they do not know where to turn for caregiving resources or because they already self-identify as a caregiver. In addition, the willingness of caregivers to give care themselves may be due to the lack of care options available, especially in rural and reservation areas, leaving families as the primary source of care to prevent institutional placement.<sup>7,9</sup> However, AI/ANs are not homogeneous; although half of AI/ANs do not live on reservations,<sup>18</sup> the research on urban American Indians is sparse.<sup>22</sup>

Despite the changes in living arrangements, American Indians provide the most care for family members in need.<sup>23</sup> Our research indicated that 29.1% of AI/AN caregivers indicated that they would provide care if an elderly friend or relative could no longer care for themselves. These caregivers

**Table 1. Unadjusted prevalence of characteristics of caregivers aged  $\geq 18$  years (N=20,996) by race/ethnicity, Behavioral Risk Factor Surveillance System, 2000**

Characteristic*	AI/AN (n=481) % (SE)	Asian (n=412) % (SE)	Black (n=1,587) % (SE)	Hispanic (n=2,493) % (SE)	White (n=16,023) % (SE)
Sex					
Men	43.6 (4.7)	40.6 (5.8)	38.5 (1.9)	39.4 (1.8)	40.1 (.6)
Women	56.4 (4.7)	59.4 (5.8)	61.5 (1.9)	60.6 (1.8)	59.9 (.6)
Age, years					
18–39	48.6 (4.7)	47.3 (5.6)	43.1 (1.9)	48.6 (1.8)	30.9 (.6)‡
40–59	39.3 (4.6)	41.8 (5.7)	41.7 (1.9)	37.0 (1.7)	44.8 (.6)
$\geq 60$	NA†	10.9 (2.2)	15.2 (1.4)	14.4 (1.2)	24.3 (.5)
Income, US \$1,000					
<15	11.9 (2.6)	NA†	15.3 (1.3)	24.0 (1.4)§	7.3 (.3)
$\geq 15$ to <25	21.2 (4.3)	11.2 (2.8)	22.4 (1.5)	26.3 (1.5)	14.3 (.4)
$\geq 25$ to <35	21.2 (4.1)	NA†	16.4 (1.3)	13.1 (1.2)	14.0 (.4)
$\geq 35$ to <50	18.0 (3.5)	16.4 (3.7)	15.7 (1.3)	10.9 (1.1)	18.7 (.5)
$\geq 50$	14.8 (3.3)	37.2 (5.1)§	21.0 (1.6)	15.7 (1.4)	33.9 (.6)§
Did not respond	12.8 (2.8)	NA†	9.2 (1.4)	10.0 (.9)	11.9 (.4)
Marital status					
Married/couple	56.8 (4.7)	67.6 (5.0)	42.2 (1.9)‡	60.6 (1.7)	67.3 (.6)
Previously married	23.5 (3.9)	NA†	29.0 (1.7)	17.5 (1.3)	17.8 (.5)
Never married	19.7 (4.0)	22.8 (4.5)	28.8 (1.7)	22.0 (1.5)	14.9 (.5)
Education					
Less than high school	16.3 (3.6)	NA†	12.9 (1.2)	23.1 (1.6)	8.7 (.4)
High school	32.3 (4.2)	16.3 (3.2)§	33.8 (1.8)	29.4 (1.6)	32.2 (.6)
More than high school	51.4 (4.7)	77.4 (4.3)§	53.3 (1.9)	47.5 (1.7)	59.1 (.6)
Employment status					
Employed	67.3 (4.5)	72.9 (4.7)	68.5 (1.8)	58.5 (1.7)	63.4 (.6)
Retired	NA†	6.4 (1.2)	11.4 (1.2)	8.9 (0.8)	18.2 (.5)
Not employed	24.7 (4.2)	20.7 (4.6)	20.2 (1.6)	32.6 (1.7)	18.4 (1.8)
Self-rated health					
Excellent/very good	43.8 (4.7)	57.7 (5.5)	43.5 (1.9)	39.0 (1.8)	54.6 (.6)
Good	34.2 (4.2)	27.6 (4.7)	36.0 (1.9)	33.1 (1.6)	30.8 (.6)
Fair/poor	22.1 (4.6)	NA†	20.5 (1.4)	27.9 (1.5)	14.6 (.4)
Mentally unhealthy days in past 30 days					
<14	77.1 (3.8)	93.2 (2.5)§	83.8 (1.3)	82.3 (1.5)	84.6 (.5)
$\geq 14$	22.9 (3.8)	NA†	16.2 (1.3)	17.7 (1.5)	15.4 (.5)
Physically unhealthy days in past 30 days					
<14	85.1 (3.3)	95.0 (2.7)	88.4 (1.1)	87.9 (1.2)	89.0 (.4)
$\geq 14$	14.9 (3.3)	NA†	11.6 (1.1)	12.1 (1.2)	11.0 (.4)
Activity limitation days in past 30 days					
<14	NA†	NA†	NA†	NA†	50.6 (2.3)
$\geq 14$	NA†	NA†	51.9 (7.3)	49.5 (7.7)	49.4 (2.3)
Number of adults in house					
1	10.8 (2.1)	10.6 (2.1)	21.9 (1.2)§	10.8 (.8)	15.8 (.4)
2	44.8 (4.7)	48.0 (5.6)	46.2 (1.9)	44.8 (1.7)	59.3 (.6)‡
3	27.5 (4.9)	22.5 (4.8)	19.4 (1.5)	26.9 (1.7)	17.3 (.5)
$\geq 4$	16.9 (3.1)	19.0 (3.9)	12.5 (1.9)	17.6 (1.6)	7.7 (.4)‡
Children aged $\leq 17$ years in house	47.9 (4.7)	45.0 (5.7)	52.3 (1.9)	50.1 (1.8)	34.5 (.6) ‡
Resource to contact					
Care myself	29.1 (4.5)	32.5 (4.8)	24.8 (1.7)	46.6 (1.7)§	25.2 (.5)
Relative/friend/clergy	22.9 (3.7)	28.2 (5.0)	34.5 (1.8) ‡	26.9 (1.7)	21.9 (.5)
Professional	25.2 (3.9)	19.2 (3.9)	23.7 (1.6)	14.5 (1.2)‡	30.5 (.5)
Other	NA†	NA†	4.8 (.8)	NA†	5.7 (.3)
Do not know	16.4 (3.6)	12.5 (3.0)	12.2 (1.2)	9.1 (1.0)	16.7 (.5)

AI/AN, American Indian/Alaska Native; SE, standard error; NA, estimate not available because of unstable estimate.

\* Weighted population estimate.

† Unstable estimate has a residual standard error  $> 30$  or cell size  $< 50$ . No statistical testing was conducted for comparisons that contained an unstable estimate.‡  $P < .01$  for comparison to AI/AN.§  $P < .001$  for comparison to AI/AN.



commonly report stresses associated with caregiving comparable to the stress experienced by caregivers of other ethnic groups.<sup>23</sup> In addition to competing demands with work and family, rural caregivers' stress and burden can be exacerbated by the general lack of services, lack of indoor plumbing, and needing wood for heating and cooking.<sup>23</sup> Caregiving may not stem solely from a lack of available services; it also may be consistent with tribal values that emphasize familial obligations and interdependence.<sup>24-26</sup>

The notion persists that AI/ANs live in multigenerational, extended family arrangements, as they once did; however, 60% of American Indian older adults (mean age: 58 years) indicated that they lived alone or with their spouse.<sup>27</sup> Those who lived in extended or multigenerational families could no longer live alone because of limitations.<sup>27</sup> Unfortunately, our data did not allow us to evaluate this notion by investigating the care recipients' degree of limitation. American Indians strongly value giving back to those who have provided for them in the past.<sup>10</sup>

Our findings are subject to several limitations. First, because the BRFSS is a telephone survey, the results may not be generalizable to people who do not have telephones or who use cellular telephones exclusively. In 1998, the percentage of households with a telephone was estimated as 83.4% for all AI/ANs and 95.6% for Whites.<sup>28</sup> However, in 2000, only 67.9% of AI/ANs who lived on reservations or on off-reservation trust lands lived in a household with a telephone.<sup>29</sup> AI/AN adults who do not have telephones have lower levels of formal education, have lower incomes, and are less likely to be employed.<sup>30</sup> Accordingly, our findings may overestimate or underestimate the prevalence of caregivers among AI/ANs.

Second, BRFSS interviews are conducted in English or Spanish. Not conducting interviews in AI/AN languages might mean that potential

respondents are missed. Third, despite the similarities between AI/ANs,<sup>6</sup> the aggregation of this diverse population may mask differences between tribes, as well as between those living on and off reservations; therefore, our findings are not generalizable to all AI/ANs. The US Census and the BRFSS rely on ethnic self-identification. Thus, our results may not reflect the more narrowly defined population of patients served by the Indian Health Service, virtually all of whom are tribally enrolled.<sup>31</sup> In addition, differences exist between rural and urban AI/ANs;<sup>6</sup> unfortunately the data do not allow us to tease apart these issues or allow us to determine which respondents live on reservations. Fourth, even though AI/ANs have a high prevalence of disability,<sup>31-33</sup> we could not evaluate the effect of disability on caregivers. Future research should examine the correspondence between disability and caregiver status for AI/ANs as well as other racial/ethnic groups. Despite these limitations, the large sample size of the BRFSS, with its proven reliability and validity,<sup>34</sup> allowed us to investigate characteristics of community-dwelling AI/AN adult caregivers who were caring for an older adult who previously had not been examined.

Caregiving benefits society as a whole, as well as individual recipients and their families. Unfortunately, comprehensive information about the characteristics of caregivers and recipients of care is lacking. Surveys should regularly collect information on caregiving. In order to obtain reliable estimates for AI/AN and Asian caregivers, because of the small numbers, oversampling or multiple years of data are needed. To fill this gap, a proposed set of caregiver questions are under consideration for inclusion as an optional BRFSS module in 2009 to address *Healthy People 2010* objectives 6-13.<sup>35</sup> These questions will yield information on characteristics of caregivers and care recipients and determine caregiver activities and burden. Two additional questions assess whether

care is provided to a person with a cognitive impairment. Tracking the characteristics of caregivers and their well-being over time would provide local, state, and federal public health officials with information for decision making and planning for an aging America.

#### ACKNOWLEDGMENTS

We thank the state Behavioral Risk Factor Surveillance System coordinators for their help in collecting the data used in this analysis and the members of the Centers for Disease Control and Prevention's Behavioral Surveillance Branch for their assistance in developing the database.

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*Design concept of study:* McGuire, Goins, Anderson

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*Manuscript draft:* McGuire, Okoro, Goins, Anderson

*Statistical expertise:* McGuire, Okoro, Goins

*Acquisition of funding:* Goins

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