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## The Influence of Caregiving on Health-Related Quality of Life among American Indians

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### Abstract

Caregiving can have a profound effect on the health of the caregiver, yet research on caregiving among American Indians is limited. The purpose of this study was to examine the influence of caregiving on health-related quality of life (HRQoL) among American Indians enrolled in the Education And Research Towards Health (EARTH) study. Participants in the EARTH study represented three different tribes in the Northern Plains and Southwestern regions of the U.S. who completed self-administered, computer-assisted questionnaires between 2003 and 2006. Participants were classified as either non-caregivers ( $n = 3,736$ ) or caregivers if at least one adult relied on them for personal care. Caregivers were further classified by type; those caring for an adult with unspecified needs (CAU,  $n = 482$ ), or those caring for an adult with mental and/or physical difficulties (CAD,  $n = 295$ ). HRQoL was measured using the mental health and physical health component scores of the 12-Item Short-Form Health Survey. Regional differences emerged with regard to caregiver type. Across both regions, non-caregivers reported significantly better mental and physical health than CAD ( $p < 0.01$ ), and the health of participants classified as CAU did not differ from that of non-caregivers. The health of American Indian caregivers is dependent on the kind of care provided, but detailed measures of caregiving are necessary to understand how

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caregiving influences health. This has implications for the design of effective interventions in tribal communities.

### Keywords

caregiving; quality of life; American Indian; SF-12

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## INTRODUCTION

Caregiving has received significant attention in the gerontological literature. From a research perspective, the basis of this interest is two-fold. First, the aging of the population will require that informal caregivers play an increasingly important role in the U.S. long-term care system. According to the National Family Caregivers Association, more than 50 million people provide care for chronically ill, disabled or aged family members or loved ones during a given year. Although the average amount of time spent caring for an adult has declined since 2004, the intensity of this care had increased.<sup>1</sup> There is also an immense economic cost of services provided by informal caregivers in the U.S., reaching \$450 billion in 2009.<sup>2</sup> This value tends to rise as the care recipient's level of impairment increases.<sup>3</sup>

Although numerous studies exist on the physical and psychiatric effects of caregiving,<sup>4-5</sup> there are few papers on caregiving in racial/ethnic minority groups<sup>6</sup> and even less research on caregiving among American Indians.<sup>7-15</sup> Data from the 2000 Behavioral Risk Factor Surveillance System (BRFSS) indicated that approximately 17.6% of American Indians and Alaska Natives were caregivers to a person aged 60 years or older, compared with 16.4% of the general U.S. population.<sup>7</sup> Similar to other racial/ethnic groups, American Indian informal caregivers provide the majority of long-term care and can experience stress in the caregiving role.<sup>13</sup> The limited research on health outcomes in this population has focused on caregiver burden, using small samples and only a few tribes.<sup>9-10,12,14</sup> Indeed, it is difficult to fully understand the health of American Indian caregivers because most datasets either do not contain sufficient numbers of American Indians for analysis or fail to provide adequate information on caregiving among this population.

Much of the literature on caregiving has focused on the self-identified primary caregiver. This approach ignores the reality of the caregiving situation – that is, that caregiving is dynamic, systemic, and typically involves a network of individuals who provide support to the older adult.<sup>15-17</sup> In a mixed methods study of 19 American Indian caregivers, results indicated that a typical scenario was multiple family members providing care to an elder. This “collective caregiving” is one way that caregivers are able to share responsibility and decrease their overall feelings of burden.<sup>14</sup> Consistent with this more realistic caregiving paradigm, recent research has focused on variations in the level of assistance provided by caregivers. Specifically, investigators are recognizing that caregivers can be involved in a wide range of different activities to assist their loved ones, including the provision of routine personal assistance.<sup>18</sup> As more individuals become involved in care provision, the informal support network becomes increasingly complex; each individual's level of involvement in the caregiving process can vary and caregiver stress is often related to the degree of the care

recipient's dependency.<sup>19</sup> Thus, it is important to understand how different types of care provision, including more routine assistance, might contribute to stress-related health outcomes.

The current study examines the health-related quality of life (HRQoL) among different types of American Indian caregivers. Specifically, the goals were to: 1) describe American Indians who reported one of the following: not providing personal care to a child or adult, having an adult rely on them for personal care needs, or having an adult who has mental and/or physical difficulties rely on them for personal care needs; and 2) test for differences in the mental and physical dimensions of HRQoL across these three caregiver types while adjusting for demographic characteristics. The Education And Research Towards Health (EARTH) study provided the rare opportunity to examine HRQoL outcomes based on caregiver type in a large sample of reservation-based American Indians in the Northern Plains and Southwest regions of the U.S.

## METHODS

### Data Source

The EARTH study was a 5-year prospective cohort study of 5,207 American Indians between the ages of 18 and 95 years living in the Northern Plains and the Southwest regions of the U.S. All participants were enrolled and examined between December 2003 and April 2006. The initial purpose of the EARTH study was to determine whether it was feasible for three field centers to recruit and retain a cohort of American Indians to participate in health-related research.<sup>20</sup> The Northern Plains region included members of the Lakota Sioux Nation who reside on the Pine Ridge Indian Reservation ( $n = 2,025$ ) in southwestern South Dakota and the Cheyenne River Sioux Reservation ( $n = 1,528$ ) in north-central South Dakota. The Southwest region included the Pima and Maricopa Nations ( $n = 1,654$ ) who reside on the 372,000-acre Gila River Indian Community, located in southern Arizona between Phoenix and Tucson.

Different strategies were used to recruit participants from the two regions in response to the needs of the different American Indian communities.<sup>20</sup> Participants from the Northern Plains were initially recruited through print and radio advertising, community presentations, and word-of-mouth. After 18 months, age- and sex-specific targeted recruitment took place to ensure that a final sample was age-representative within 5-year age cohort categories to  $\pm 5\%$  of the 2000 U.S. Census for those reservations. Participants in the Southwest were recruited through a random, systematic household sampling, with detailed housing maps provided to the study team.<sup>20</sup>

All EARTH participants provided informed consent, underwent clinical examinations, and completed intake questionnaires. The self-administered, computer-assisted questionnaires collected information on demographics, dietary history, health history, lifestyle, physical activity, and cultural factors.<sup>21</sup> Approval from tribal and institutional review boards was obtained before data collection, including approval from both Aberdeen and Phoenix Area Indian Health Service institutional review boards. Additional information about the methods

of the EARTH Study are available elsewhere.<sup>20</sup> In addition, the university's institutional review board approved this cross-sectional analysis of the EARTH dataset.

## Measures

**Caregiver Types**—Participants were classified as caregivers if they were at least 18 years old and reported that at least one adult relied on them for personal care needs. This was determined from two survey items: “Do any children or adults usually rely on you as the main person responsible to help them with their personal care needs? For example, eating, bathing, dressing, or getting around the house.” If the respondent answered “yes,” they were then asked, “How many adults rely on you for personal care needs?” This follow up question allowed us to distinguish caregivers of adults from parents engaging in normative care of their children. The type of adult caregiver was based on their response to the follow-up question, “Does this adult have mental and/or physical difficulties?” Those who said “No” were classified as “caregivers of adults, unspecified” (CAU) and those who answered “Yes” were classified as “caregivers of adults with difficulties” (CAD). Participants who did not report that at least one adult relied on them for care, were classified as “non-caregivers.”

**Demographic Characteristics**—Demographic characteristics included geographic region, age, sex, educational attainment, household size, and marital status. Geographic region was categorized as either the Northern Plains or the Southwest. Age was a continuous variable measured in years. Sex was a categorical variable based on the participant's self-identification as male or female and highest education level was categorized as either less than high school, high school or equivalent, some college, or bachelor's degree or higher. Household size reflected the number of people living in household, which was treated as continuous. Finally, marital status was a binary variable, categorized as either “married/living as married” or “other.”

**Health-Related Quality of Life (HRQoL)**—HRQoL was measured using the mental and physical health component summaries of the 12-Item Short-Form Health Survey (SF-12). The SF-12 is an abbreviated form of the 36-Item Short-Form Health Survey (SF-36) from the Medical Outcomes Study, which is one of the most widely-used measures of HRQoL. The SF-12 includes two items each for the following dimensions of health assessed with the SF-36: mental health, physical functioning, role-physical, and role-emotional. One item is used to measure each of the remaining four health dimensions: bodily pain, vitality, social functioning, and general health. We used the mental component summary (MCS) and physical component summary (PCS) scores from the SF-12 as our primary indicators of HRQoL. The MCS includes the domains of vitality, social functioning, role-emotional and mental health, while the PCS includes the domains of physical functioning, role-physical, bodily pain, and general health.<sup>22</sup> The scores on each of the component summaries range from 0 – 100, with higher scores indicating higher mental or physical health, respectively. The SF-12 was used in this study for both its brevity and because it has been shown to have high construct validity with American Indians;<sup>22</sup> the SF-12 items account for 91.8% of the variance in MCS and 91.1% of the variance in PCS, respectively, of the full SF-36.<sup>23</sup>

## Statistical Analyses

The goal of this study was to examine the influence of caregiving on HRQoL among American Indians in two geographic regions. First, contingency tables were used to examine variations by sex in caregiver type for each of the regions. Descriptive statistics,  $\chi^2$  for categorical variables, and t-tests or analyses of variance (ANOVA) for continuous variables, were used to describe and compare demographic characteristics by caregiver type.

A series of ANOVAs were then used to examine mental and physical health for the different types of caregivers – non-caregivers; caregivers of adults, unspecified (CAU); and caregivers of adults with difficulties (CAD) – stratified by geographic region. The outcomes of interest were the participant's scores on the MCS and PCS scales of the SF-12. These analyses were then adjusted for potential confounding factors of age, sex, household size, and marital status by using a series of analysis of covariance (ANCOVAs). Tukey-Kramer was used to do pairwise comparisons of adjusted means. For this study, complete case analysis required participants to have complete data for all covariates, which reduced the sample size to 4,513 of the original 5,207 participants. Participants who were dropped due to missing data did not differ significantly from those included in the analytic sample on any of the variables of interest, indicating that the data were missing at random. All analyses were conducted using the STATA 10 statistical package (StataCorp LP, College Station, TX).

## RESULTS

### Demographic Characteristics by Caregiver Type

Table 1 shows the demographic characteristics of the sample by caregiver type. In the overall sample, 83% were categorized as non-caregivers, 11% as CAU, and 6% as CAD. Regional differences by caregiver type were also observed. In the Northern Plains, 16% of the participants were categorized as caregivers of adults and of these, 68% were classified as CAU and 32% were CAD. In the Southwest, 19% of the participants were identified as caregivers, with 50% of these caregivers classified as CAU and 50% as CAD ( $p < 0.01$ ).

Across both regions, participants in the CAU group [*Mean (M) age* = 33.0 years, *SD (Standard Deviation)* = 10.9] tended to be younger than either CAD (*M age* = 37.0, *SD* = 11.9) or non-caregivers (*M age* = 37.6, *SD* = 14.7;  $p < 0.01$ ). In addition, 61% of CAU and 62% of CAD were female compared with 54% of non-caregivers ( $p < 0.01$ ). Both CAU (*M* = 5.9, *SD* = 2.7) and CAD (*M* = 5.2, *SD* = 2.8) reported more people in the household than did non-caregivers (*M* = 4.9, *SD* = 2.7;  $p < 0.01$ ). Finally, a greater proportion of CAU and CAD were married (40% and 38%) when compared with non-caregivers (33%;  $p < 0.01$ ).

### Mental Health by Caregiver Type

Table 2 presents the unadjusted and adjusted mean scores and standard errors for the MCS and PCS by caregiver type, stratified by geographic region ( $\alpha$  level = 0.05 for all analyses). In the Northern Plains, results indicated that non-caregivers had significantly higher scores [*M* = 51.3, *Standard Error (SE)* = 0.2] on the MCS than did either type of caregiver. Participants classified as CAU and CAD reported similar scores on the MCS, although CAU reported slightly higher MCS scores than CAD (*M* = 49.1, *SE* = 0.6 vs. 48.0, *SE* = 0.8). This

finding held in both the unadjusted and adjusted analyses. A similar trend was found for participants in the Southwest, where participants categorized as CAU had a mean MCS score that was intermediate ( $M = 48.2$   $SE = 0.9$ ) and non-caregivers had significantly higher scores ( $M = 49.9$   $SE = 0.3$ ) on the MCS than CAD ( $M = 47.0$ ,  $SE = 0.9$ ).

### Physical Health by Caregiver Type

Table 2 displays the results from both the unadjusted model and the model that was adjusted for age, sex, household size, and marital status. In the Northern Plains, PCS scores were significantly higher for non-caregivers than CAD ( $M = 46.8$ ,  $SE = 0.2$  vs.  $44.5$ ,  $SE = 0.7$ ). PCS scores for CAU did not differ significantly from the other two caregiver types ( $M = 46.1$   $SE = 0.5$ ). The same trend was found in the Southwest; PCS scores for CAD ( $M = 42.3$ ,  $SE = 0.8$ ) were significantly lower than the scores for non-caregivers ( $M = 45.4$ ,  $SE = 0.3$ ), but the PCS scores for CAU ( $M = 43.6$ ,  $SE = 0.8$ ) did not differ from the other two caregiver types.

## DISCUSSION

The current examination of EARTH study participants indicated that non-caregivers, CAU, and CAD were distinct groups in both their demographic profile and health status. Unique differences by geographic region also emerged. Approximately 2/3 (68%) of caregivers in the Northern Plains were classified as CAU, while caregivers in the Southwest represented a more even distribution by caregiver type (50% CAU and 50% CAD). Across both regions, non-caregivers consistently reported better mental health than participants classified as CAD. Similar results were found for physical health; only CAD experienced significantly poorer physical health than the non-caregivers. These results suggest that difficulties experienced by the care recipient possibly made a difference in the mental and physical health of caregivers; CAU participants were comparatively less affected by care provision than CAD. In other words, participants who reported caring for an adult with physical and mental difficulties were the ones who exhibited the poorest health of the three caregiver types.

Our results, while not surprising, underscore the importance of obtaining detailed information about the caregiving situation before making broad, sweeping claims about the health effects of caregiving. Research has shown that factors such as cognitive status, behavioral problems, and daily dependencies act as primary stressors on the caregiver.<sup>24–25</sup> However, the EARTH data do not provide insight into the activities conducted by participants who reported that an adult relies on them for “personal care needs,” nor does it provide information on the care recipient – which was particularly problematic for the CAU group. Previous research with the SF-36 demonstrated that among 1,594 caregivers of veterans, the inverse relationship between caregiving and mental health was stronger than the relationship between caregiving and physical health.<sup>26</sup> A similar trend was observed in this study, but in the EARTH sample, providing personal care to an adult who did not have mental or physical difficulties was less detrimental across both health outcomes. By including three caregiver types, the current study revealed that American Indians who reported that an adult relies on them for personal care were different from those who would



be classified as caregivers under more traditional definitions. Indeed, group differences appeared to be primarily driven by the perceived difficulties experienced by the care recipient.

Providing care to a loved one can act as a stressor through a variety of pathways, which can differentially influence caregiver health outcomes.<sup>25</sup> Although the EARTH data do not provide details on the kinds of physical or mental difficulties experienced by the care recipients described in the CAD type, it is possible that the differences in outcomes could be explained by differences in the intensity of care that was provided by these participants. The physical health differences among caregiver types might have been due to greater physical exertion, negative effects on health behaviors, physical manifestations of stress, and physiological changes<sup>4</sup> among CAD compared with CAU. It is possible that participants who were classified as CAU are members of a more extensive network of care providers, which might explain why their health was so similar to that of non-caregivers. Consistent with previous research with American Indian caregivers, a more extensive caregiving network can lead to a greater diffusion of caregiving tasks, which can then decrease the feelings of burden experienced by caregivers.<sup>14–15</sup> Alternately, participants who reported that at least one adult relies on them for personal care needs might be describing activities that are part of a different familial role, such as preparing meals for the entire family unit. Future research with American Indian and other communities should be careful to distinguish caregiving of dependent adults from other forms of caregiving.

Although the results of the current study support the notion that American Indian caregivers experience stress-related health consequences – at least those who are caring for adults with physical and/or mental difficulties – the sources of this stress might vary. For example, a focus group study with 33 American Indian caregivers found four major sources of burden: 1) anxiety about managing severe disease conditions, 2) problems with difficult psychosocial aspects of care, 3) strains on family relations, and 4) negative effects on personal health and well-being.<sup>9–10</sup> These same researchers surveyed 169 American Indian primary caregivers and identified four additional dimensions of caregiver burden: 1) role conflict, 2) negative feelings, 3) lack of caregiver efficacy, and 4) guilt.<sup>27</sup> Although data from the EARTH study do not permit a more in-depth exploration of the observed differences in the SF-12, it is likely that the level of difficulty experienced by the care recipient would influence caregiver coping and perceived burden.

Stratifying by caregiver type was a unique aspect of the current analyses, even in light of the limitations in the EARTH measures of caregiving. The observed differences between CAU and CAD types suggest that American Indians may have a broad definition of what constitutes “caregiving.” Caregiving may be defined according to the tasks performed by the person, the duration of time that he/she has provided assistance, or based on the dynamics of the family members. Due to the limitations in the EARTH data, it is unclear what participants meant when they indicated that they provided personal care to an adult *without physical or mental difficulties*. This might reflect a reluctance to discuss the care recipient’s limitations, or an overall tendency to avoid looking at caregiving from a burden perspective.<sup>10,27</sup> The latter explanation is consistent with previous observations<sup>28</sup> that even the word “caregiver” might carry negative connotations among American Indians. The

regional variations noted in this study also underscore the diversity of the caregiving experience among American Indians, both between and within tribal communities.

There are several limitations of this study. First, the EARTH data are cross-sectional, which limits the ability to capture the dynamics of caregiving. Specifically, we cannot make any causal inferences regarding the relationship between caregiving and health outcomes (i.e., unclear whether differences are due to caregiving or some other variable). Second, the data rely on a fairly crude classification of participants as caregivers with limited probing questions. It was assumed that the CAD type was providing a higher intensity of care because the adult who relied on them had physical or mental difficulties. However, without more detailed information on the caregiving situation, the ability to compare across caregiver types is hindered by a lack of information on care recipient factors such as age or level of disability, intensity of care provision, and duration of caregiving. Finally, EARTH data were obtained from three tribes across two U.S. geographic regions. Given the heterogeneity among the 566 federally recognized American Indian tribes and Alaska Natives in the U.S.,<sup>29</sup> these results cannot be generalized to all American Indians.

Data from the EARTH study provided an opportunity to examine caregiving among a relatively large sample of American Indians. In addition, the information gathered for the EARTH study was collected using an innovative computer-assisted approach, which limited the amount of missing data.<sup>21</sup> Finally, this study permitted comparison between the Northern Plains and Southwestern American Indians, who represent distinct geographic and cultural groups. Future efforts should include additional American Indian tribes and more detailed questions about cultural influences on the caregiving situation. The cultural context of caregiving cannot be overlooked;<sup>8</sup> many of the traditional notions of caregiving, such as classifying caregivers as either primary or secondary, do not adequately reflect the collective nature of caregiving among American Indians.<sup>15</sup> Such information could be used to not only contribute to the literature on caregiving, but also to tailor intervention and respite programs to the diverse needs of American Indian caregivers.

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**Table 1**

**Demographic Characteristics of EARTH Study Participants by Caregiver Type (N=4,513)**

	Non-Caregivers	Caregiver of an Adult - Unspecified <sup>†</sup>	Caregiver of an Adult with Physical and/or Mental Difficulties <sup>‡</sup>	<i>p</i> -value <sup>§§</sup>
Caregiver type, overall, % (n) ¶ by Tribe, % (n) ¶	83% (3736)	11% (482)	6% (295)	<0.01
Northern Plains	83% (2494)	11% (336)	5% (158)	
Southwest	81% (1242)	10% (146)	9% (137)	
Age, in years, mean (SD) * by age group, % (n)	37.6 (14.7)	33.0 (10.9)	37.0 (11.9)	<0.01
17–25	26% (979)	31% (150)	22% (64)	<0.01
26–35	23% (875)	31% (148)	24% (72)	
36–45	23% (855)	25% (119)	29% (85)	
46 and older	27% (1027)	13% (65)	25% (74)	
Females, overall, % (n) ¶ by Tribe, % (n) ¶	54% (2006)	61% (295)	62% (184)	<0.01
Northern Plains	51% (1283)	59% (198)	62% (98)	<0.01
Southwest	58% (723)	66% (97)	63% (86)	0.11
Education, % (n)				0.82
Less than High school	36% (1311)	37% (177)	34% (97)	
High school or equivalent	36% (1300)	35% (165)	36% (105)	
Some college	26% (942)	26% (123)	27% (78)	
Bachelor's degree or higher	3% (102)	2% (8)	3% (8)	
Number in household, mean (SD) *	4.9 (2.7)	5.9 (2.7)	5.2 (2.8)	<0.01
Married/living as married, % (n)	33% (1246)	40% (191)	38% (113)	<0.01

\* SD = standard deviation.

<sup>†</sup> Participants who reported that an adult relies on them for personal care.

<sup>‡</sup> Participants who reported that an adult who has physical and/or mental difficulties relies on them for personal care.

<sup>§</sup> Used chi-square tests for categorical variables and analysis of variance for continuous variables to compare difference by caregiver type.

<sup>¶</sup> Values add to 100% across rows because information is presented across caregiver type (e.g., 83% of participants in the Northern Plains are non-caregivers).

**Table 2**  
Unadjusted and Adjusted SF-12 Mental and Physical Health Component Scores of EARTH Participants by Caregiver Type (N=4,513)

Northern Plains					
	Non-Caregivers	Caregiver of an Adult – Unspecified <sup>†</sup>	Caregiver of an Adult with Physical and/or Mental Difficulties <sup>‡</sup>	Unadjusted p-value <sup>§</sup>	Adjusted p-value <sup>¶</sup>
Mental Component Score, mean (SE)*	51.3 (0.2)	49.1 (0.6)	48.0 (0.8)	<0.01	<0.01
Physical Component Score, mean (SE)*	46.8 (0.2)	46.1 (0.5)	44.5 (0.7)	0.01	<0.01
Southwest					
Mental Component Score, mean (SE)*	49.9 (0.3)	48.2 (0.9)	47.0 (0.9)	<0.01	<0.01
Physical Component Score, mean (SE)*	45.4 (0.3)	43.6 (0.8)	42.3 (0.8)	<0.01	<0.01

Note. Significant differences between groups ( $p < 0.05$ ) based on follow-up pairwise comparisons are indicated by horizontal brackets.

\* All means and standard errors (SE) were adjusted for age, sex, household size, and marital status.

<sup>†</sup> Participants who reported that an adult relies on them for personal care.

<sup>‡</sup> Participants who reported that an adult who has physical and/or mental difficulties relies on them for personal care.

<sup>§</sup> Used analysis of variance to compare scores by caregiver type.

<sup>¶</sup> Used analysis of covariance to compare scores by caregiver type. Covariates include age, sex, household size, and marital status.