



Published in final edited form as:

J Community Health. 2023 February ; 48(1): 160–165. doi:10.1007/s10900-022-01156-7.

Informal Caregiving Among American Indians and Alaska Natives in the Pacific Northwest

Eric Strachan, PhD¹, Dedra Buchwald, MD²

¹University of Washington Department of Psychiatry and Behavioral Sciences

²Institute for Research and Education to Advance Community Health and Partnerships for Native Health Founding Director, Elson S. Floyd College of Medicine, Washington State University

Abstract

Unpaid or informal caregivers are people who provide assistance without compensation to adults and children who require care beyond typical needs. Although often rewarding, informal caregiving can be associated with high rates of depression, stress, anxiety, sleep and endocrine system disruption, immunosuppression, and general morbidity and mortality. Few recent studies of informal caregivers have included data from American Indians and Alaska Natives (AI/AN). Given this noteworthy gap in the literature, we surveyed a total of 225 AI/ANs attending two cultural, community functions in the Pacific Northwest to gain a general understanding of frequency of caregiving, caregiver and recipient characteristics, caregiving duties, support needs, and financial, emotional, and physical strains as a consequence of caregiving. Of the 225 participants who completed the survey, 90 (40%) indicated that they had been an unpaid caregiver for a month or more and 28 (12%) were current unpaid caregivers. Consistent with prior research, most caregivers (84%) reported satisfaction from providing help, but 84% of caregivers reported experiencing “increased stress,” 40% reported financial strain, and 34% reported decreased health “because of involvement with providing care.” Our data also suggested a disproportionate impact on AI/AN women given higher rates of being a caregiver compared to other populations and less support from others in their communities. Our data suggest similarities for AI/AN caregivers with other groups of caregivers but also emphasize the importance of including AI/AN populations in future research in order to understand ways to best serve their unique needs.

Unpaid caregivers – also known as “informal caregivers” or “family caregivers” – are people who provide assistance without compensation to adults who would otherwise be unable to live independently because of functional or cognitive deficits, or children who require care beyond what a typical healthy child needs.^[1] Recent estimates suggest more than 50 million Americans—possibly as many as 80 million—serve as informal caregivers.^[1, 2] The economic value they provide exceeds the total annual budget for Medicare or Medicaid and is more than four times the amount spent on formal home care services.^[1, 2] Although some informal caregivers report the care they provide to family or friends involves minimal or manageable adverse personal consequences, many feel burdened by relentless and inescapable duties, family problems, and such secondary consequences as lost work

and strained finances.^[3, 4] In addition, informal caregiving is associated with high rates of depression, stress, anxiety, sleep and endocrine system disruption, immunosuppression, and general morbidity and mortality.^[5–13] Although findings are mixed, the association between informal caregiving and poor health may be exacerbated by increases in behaviors that confer health risk, including smoking, alcohol use, as well as sedentary lifestyles and poor diet, which encourage obesity.^[14]

In 2020, the American Association of Retired People (AARP) and the National Alliance for Caregiving published a landmark study based on a nationally representative survey of 1,392 adults who had provided unpaid care in the prior 12 months.^[1] Unfortunately, that study—and nearly every other caregiving study like it—has a conspicuous shortcoming in that no data were collected or reported on caregiving in American Indian/Alaska Native (AI/AN) communities. A 2018 systematic review of the function of unpaid indigenous caregivers^[15] identified only 6 studies that qualified for inclusion; 3 were from the United States.^[16–18] Results suggested that poor health and a high burden of caregiving among indigenous caregivers was typical but the quality and strength of the studies was considered weak with numerous methodological limitations. In the single study published since then, interviews with 44 unpaid female Hopi caregivers revealed 89% had inadequate time for family and or friends, 75% encountered financial burdens, 61% lacked time for themselves, and 46% experienced stress.^[19]

Given this noteworthy gap in the literature, we surveyed AI/ANs attending two cultural, community functions in the Pacific Northwest. The purpose was to gain a general understanding of frequency of caregiving, caregiver and recipient characteristics, caregiving duties, support needs, and financial, emotional, and physical strains as a consequence of caregiving.

METHOD

Participants and Setting

We surveyed 196 AI/AN attendees at the Annual Indian Days Powwow in Seattle, Washington. First held in 1987, attendance over the 3-day event is estimated at 8,000 people, including visitors, dancers, musicians, vendors, and tourists. The powwow, which brings Native people of all tribes and cultures together to celebrate, showcases traditional Indian cooking, jewelry-making, music, and especially dancing. We also surveyed 29 AI/AN attendees at the Sealaksa Celebration, which has been held every other June since 1982 in Juneau, Alaska. The 4 day our biennial festival of Tlingit, Haida, and Tsimshian cultures features traditional song, dance, arts, crafts, and food. Celebration is the second-largest event sponsored by Alaska Natives in the State of Alaska, drawing about 5,000 Native and non-Native people.

Procedures

The caregiving questions were embedded in a larger survey that also asked questions about interpersonal relationships and care of and concern for elders in the community. An identical survey was administered at both community events. The introduction to the caregiving

section read: “Some people provide regular unpaid care or assistance to a family member or friend who has a health condition, long-term illness or disability. They provide this care so that their family member or friend can maintain an independent lifestyle. This family member or friend could be an adult or a child. Assistance can range from a few hours of shopping and cleaning to intensive medical or personal care. Tasks can include shopping, house cleaning, cooking, giving medications, toileting assistance and so forth.” Subsequent questions asked about caregiving status, number of care recipients, relationship to recipient, health conditions, duration of care, care tasks, hours per week of caregiving, and whether support was available from other members of the community. After these initial questions, the survey focused whether the caregiver might need information, education, or training about self-care, providing care for aging adults, understanding the care recipient’s medical condition, enlisting additional family members to assist with care, legal issues, and finding professional care (long-term inpatient or in-home support). Finally, the survey asked about personal stress, satisfaction, confidence, and financial strain.

Data Analysis

Because no significant differences were noted between respondents attending the two events, the samples were combined. A total of 225 individuals completed the survey, representing more than 45 tribal affiliations. Missing data (incomplete or ambiguous responses) on certain questions reduced the total sample available for comparisons and the number of missing varied by question. We also examined whether gender also impacted the types and consequences of caregiving that were provided. Specifically, we performed tests of gender by relationship, number of care recipients, duration, duties, time, location, support, and strain. All data analysis was conducted using IBM SPSS v.26 (Chicago, IL). For evaluations of difference between groups, the significance level was set to $p < 0.05$. For crosstabulations, in cases where expected cell counts were less than 5, 2-sided Fisher’s Exact Test is reported instead of Pearson χ^2 .

RESULTS

Participants

Table 1 shows the demographic variables that were available from the survey. Of the 225 participants who completed the survey, 90 (40%) indicated that they had been an unpaid caregiver for a month or more and 28 (12%) were current unpaid caregivers. Table 2 shows how caregivers compare to non-caregivers in the sample.

Relationship and Care Recipient Condition

Caregivers reported that they had provided (and in some cases still were providing) care for an extended family member ($n = 31$, 34%), parent ($n = 28$, 31%), adult child ($n = 10$, 11%), friend ($n = 5$, 6%), spouse/partner ($n = 3$, 3%), and other ($n = 13$, 14%). In the “other” category, the descriptions were primarily extended family (e.g. “Grandma,” “Nephew,” “Brother,” “Stepchild”). In terms of conditions, physical disability ($n = 29$, 32%) was the most frequent selection followed by cancer ($n = 25$, 28%), dementia ($n = 21$, 23%), heart or lung disease ($n = 10$, 11%), cognitive or developmental disability ($n = 9$, 10%),

brain injury ($n = 4$, 4%), and other ($n = 21$, 23%). Diabetes, stroke, and mental illness all had more than one mention in the “other” category.

Number of Care Recipients and Duration

Although most caregivers ($n = 54$, 63%) reported caring for 1 person, 15 (17%) reported caring for 2, and 17 (20%) reported caring for 3 or more people. The most common durations of unpaid caregiving categories were less than one year ($n = 29$, 33%) and 1 to 3 years ($n = 37$, 42%); a smaller number of people indicated 4 to 10 years ($n = 12$, 14%) and more than 10 years ($n = 10$, 11%).

Caregiving Duties, Time, and Location

Participants were asked about the kinds of care that they provided and the majority endorsed personal care ($n = 75$, 87%), homemaker chores ($n = 73$, 88%), transportation ($n = 64$, 77%), health care ($n = 69$, 77%), supervision ($n = 58$, 73%), and emotional support ($n = 80$, 89%). Only managing finances ($n = 44$, 49%) and other ($n = 17$, 19%) were performed by less than 50% of respondents. However, many of the “other” responses were homemaker chores (“childcare,” “cooking,” “laundry”). In terms of time spent providing unpaid care per week, the responses were divided among less than 5 hours ($n = 17$, 20%), 6–20 hours ($n = 29$, 34%), 21–40 hours ($n = 15$, 17%), and 40+ hours ($n = 25$, 29%). Approximately 63% ($n = 57$) of unpaid caregivers indicated that they provided care in the care recipient’s home while 25% ($n = 25$) provided care in their own home. The remainder were divided between someone else’s home and other facilities.

Caregiving Support

The plurality ($n = 41$, 46%) of unpaid caregivers endorsed receiving “some help” from members of their community, but many received “no help” ($n = 34$, 39%) while a smaller number received “a lot of help” ($n = 13$, 14%). Consistent with this finding, 54 (66%) of respondents endorsed that providing care is stressful. However, 60–71% did not believe they needed information on topics such as hands-on skills for personal care, legal and financial issues, home safety/modifications/equipment, and self-care. In contrast, 49% of participants wanted more information on how to get other family members to help.

Caregiving Strain

When asked about the mental and emotional strain of caregiving, participants “agreed” or “strongly agreed” with feeling “a sense of satisfaction helping” ($n = 75$, 84%), feeling “a sense of obligation to provide care” ($n = 66$, 74%), and being “confident about providing care” ($n = 73$, 83%). However, using the same scale, some also reported experiencing “increased stress” ($n = 75$, 84%), decreased health “because of involvement with providing care” ($n = 30$, 34%), and financial strain ($n = 36$, 40%). Many also agreed that they “could do a better job of providing care” ($n = 37$, 41%).

Differences by Gender

In our examination of gender by relationship, number of care recipients, duration, duties, time, location, support, and strain, the only significant findings were that males (56%) were

less likely than females (82%) to provide transportation as one of the caregiving duties, $X^2(1) = 4.89$, $p = 0.027$, and females were less likely to receive help in caregiving from members of their community (no help = 46%) compared to males (no help = 11%), *Fisher's Exact* = 8.13, $p = 0.016$. Caregiving financial strain did not differ by gender.

DISCUSSION

This study describes compelling new information regarding unpaid caregivers in Native communities with two striking findings related to the high prevalence of caregiving. First, nearly 40% of survey respondents reported having been a caregiver for at least 1 month or more. This compares with an estimate of 19% (caring for adults) from the AARP study and 17% in Spencer's 2013 study of AI/AN caregivers.^[18] Although differences in phrasing of the question (e.g., the AARP study limited responses to the past 12 months) may account for some of the difference, the prevalence among AI/ANs in our sample is nonetheless remarkable. Second, 80% of our caregivers were female compared with 61% in the AARP study, 62% in the Spencer study, and 74% in a 2010 study of reservation-dwelling AIs^[16]. The high percentage of female caregivers in our study is noteworthy because they were significantly less likely than their male counterparts to receive caregiving help from others in their community. Our findings were not surprising in terms of caregivers' relationship to the care recipients or the latter's diagnosis. While most caregivers reported satisfaction and confidence in caregiving, many nonetheless reported emotional, physical, and financial strain.

Few other studies have examined informal or unpaid caregiving in Native communities but research on caregivers acknowledges the toll that caregiving can take in underserved populations.^[15] In a randomized trial of complementary medicine for stress reduction among 42 AI/AN caregivers of individuals living with dementia, 90% of caregivers were women (52% daughters) with most (62%) reporting 6 to 36 months of providing care.^[20] Although not directly comparable to the present study due to differences in study design (survey vs. treatment trial), the caregivers in the treatment trial reported high stress, considerable depressive symptoms, and lower quality of life compared to the general population. In another study, we assessed perceived barriers to cancer care with a paired sample of 98 adult caregivers and 98 AI/AN oncology patients.^[21] Overall, caregivers reported that their role was very meaningful and not highly stressful. The 51 AI/AN caregivers considered financial issues to be barriers significantly less often than non-AI/AN caregivers; in contrast, worries about unexpected charges and the cost of prescription medications were rated as a barrier significantly more often by AI/AN caregivers than their non-AI/AN peers. Both groups showed a similar level of concern over providers' respect for AI/AN culture.

Key findings from the AARP and National Alliance for Caregiving study include the number of caregivers is increasing; women continue to comprise the majority of caregivers; the health problems of care recipients are getting more severe; and unpaid caregivers are assuming this role with insufficient resources and support (e.g. physical, emotional, financial) and lack affordable services.^[1] In addition, the impact of caregiving tends to extend beyond the primary caregiver to other members of the family or community who may

be enlisted to help. And while many caregivers express positive feelings about their role, in one national survey, physical, emotional, and financial stress were prominent.^[20] Although the present study did not include longitudinal data, our outcomes were consistent with the AARP study. We found that women are the primary group of caregivers, the number of people caring for more than one person was substantial, and that most caregivers looked to other community members for help in caregiving. In addition, the vast majority of caregivers noted increased stress from caregiving and many reported decreased personal health and financial strain.

Although this study offers important new information about AI/AN unpaid caregivers, it has several limitations. First, people attending community pow-wows are a convenience sample and biases may be present. However, urban AI/ANs do not live in circumscribed neighborhoods and cannot be identified by surnames, thus creating sampling frames is difficult. Nonetheless, pow-wows are an efficient way to survey a large, hard-to-reach population of both urban and rural AI/AN community members. Second, participants completed the survey on clipboards at tables, hindering our ability to monitor the completion of all questions. Third, these data are not generalizable to other AI/AN populations, which may view caregiving differently. Future studies should investigate differences in responses between socially engaged, AI/AN pow-wow attendees and AI/AN caregivers who do not or are unable to participate in such cultural events. Similarly, almost all our participants had at least a high school education; but according to the National School Boards Association's 2020 report (<https://www.nsba.org/ASBJ/2020/December/condition-native-american-students>), AI/ANs complete high school at rates ranging from 50% in South Dakota to 90% in Alabama, Maryland, and Tennessee. Likewise, a majority of our sample endorsed some college/college degree compared with <1% completion of a bachelor's degree across the U.S.^[22] Efforts to include participants who are less educated than will shed light on actual numbers of AI/AN caregivers, their needs, and needs of the broader AI/AN population.

In conclusion, the aging of the U.S. population and the associated morbidity and disability, along with improvements in the detection of developmental disorders and other potentially disabling conditions in children, have led many investigators^[4] and stakeholders^[2] to project a "caregiving crisis." This crisis will come about when critically overloaded public health systems push additional responsibilities onto people who already provide informal care, at the same time as a new generation of informal caregivers begins to shoulder the physical, emotional, and financial burdens of caring for a family member. This may be especially true for AI/AN populations given the high rate of disabilities and unintentional injuries among AI/AN^[23] (almost double the rate for children compared to the general population) and the significant expected increases in the proportion of older AI/ANs (individuals aged 85+ will increase 7 fold by 2050 and those aged 65+ 3-fold).^[24–25] The view that caregiving is a duty and not a burden^[26–28] might be protective in the face of some of the stress-related negative outcomes of caregiving, but it also means that a lot of AI/AN individuals will be affected by informal caregiving. At the very least, the specifics of AI/AN caregiving should be a focus of specific future research and AI/AN caregivers should be included in future national surveys and studies.

REFERENCES

1. AARP and National Alliance for Caregiving, Caregiving in the United States 2020. 2020, AARP: Washington, DC.
2. Rosalynn Carter Institute for Caregiving, Averting the Caregiving Crisis: Why We Must Act Now. 2010, Americus, GA.
3. Marks NF, Lambert JD, and Choi H, Transitions to caregiving, gender, and psychological well-being: A prospective U.S. national study. *Journal of Marriage and Family*, 2002. 64(3): p. 657–667.
4. Shahly V, et al. , Cross-national differences in the prevalence and correlates of burden among older family caregivers in the World Health Organization World Mental Health (WMH) Surveys. *Psychological Medicine*, 2012. 9: p. 1–15.
5. Grunfeld E, et al. , Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal*, 2004. 170(12): p. 1795–1801. [PubMed: 15184333]
6. Russo J, et al. , Psychiatric disorders in spouse caregivers of care recipients with Alzheimer's disease and matched controls: a diathesis-stress model of psychopathology. *Journal of Abnormal Psychology*, 1995. 104(1): p. 197–204. [PubMed: 7897043]
7. Vitaliano PP, et al. , Psychophysiological mediators of caregiver stress and differential cognitive decline. *Psychology and Aging*, 2005. 20(3): p. 402–11. [PubMed: 16248700]
8. Vitaliano PP, et al. , Predictors of burden in spouse caregivers of individuals with Alzheimer's disease. *Psychology and Aging*, 1991. 6(3): p. 392–402. [PubMed: 1930756]
9. Vitaliano PP, et al. , Psychological distress, caregiving, and metabolic variables. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 1996. 51B: p. P290–P299.
10. Vitaliano PP, Zhang J, and Scanlan JM, Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, 2003. 129: p. 946–972. [PubMed: 14599289]
11. Dura JR, Stukenberg KW, and Kiecolt-Glaser JK, Anxiety and depressive disorders in adult children caring for demented parents. *Psychology and Aging*, 1991. 6(3): p. 467–73. [PubMed: 1930763]
12. Damjanovic AK, et al. , Accelerated telomere erosion is associated with a declined immune function of caregivers of Alzheimer's Disease patients. *Journal of Immunology*, 2007. 179: p. 4249–4254.
13. Schulz R and Beach SR, Caregiving as a risk factor for mortality - The caregiver health effects study. *JAMA*, 1999. 282(23): p. 2215–2219. [PubMed: 10605972]
14. Hoffman GJ, Lee J, and Mendez-Luck CA, Health behaviors among baby boomer informal caregivers. *Gerontologist*, 2012. 52(2): p. 219–230. [PubMed: 22391873]
15. Hokanson L, et al. , A systematic review of Indigenous caregiver functioning and interventions. *Qual Life Res*, 2018. 27(8): p. 2007–2017. [PubMed: 29564712]
16. Jervis LL, Boland ME, and Fickenscher A, American Indian family caregivers' experiences with helping elders. *J Cross Cult Gerontol*, 2010. 25(4): p. 355–69. [PubMed: 21063902]
17. John R, et al. , Toward the conceptualization and measurement of caregiver burden among Pueblo Indian family caregivers. *Gerontologist*, 2001. 41(2): p. 210–9. [PubMed: 11327487]
18. Spencer SM, et al. , Influence of caregiving on health-related quality of life among American Indians. *J Am Geriatr Soc*, 2013. 61(9): p. 1615–20. [PubMed: 24001320]
19. Cordova-Marks FM, et al. , Characteristics of American Indian Female Caregivers on a Southwest American Indian Reservation. *J Community Health*, 2019. 44(1): p. 52–60. [PubMed: 30056488]
20. Korn L, et al. , A randomized trial of a CAM therapy for stress reduction in American Indian and Alaskan Native family caregivers. *Gerontologist*, 2009 49(3): p. 368–77. [PubMed: 19377083]
21. Sawchuk CN, et al. , Caregiving among American Indians and Alaska Natives with cancer. *Support Care Cancer*, 2015 23(6): p. 1607–14. [PubMed: 25416095]
22. Rochat A Fostering Empowerment: Supporting Student Success at Native American Serving, Non-tribal Institutions. Retrieved from <http://www2.gse.upenn.edu/smsi/content/reports>.
23. Committee on Native American Child Health and Committee on Injury and Poison Prevention. American Academy of Pediatrics. The prevention of unintentional injury among American Indian

- and Alaska Native children: a subject review. *Pediatrics*. 1999 104(6): p. 1397–1399. [PubMed: 10585996]
24. National Congress of American Indians. Demographics. Retrieved from <http://www.ncai.org/about-tribes/demographics>.
 25. Ortman J, Velkoff V, Hogan H An Aging Nation: The Older Population in the United States. Washington, DC. 2014.
 26. Goins RT, Spencer SM, McGuire LC, Goldberg J, Wen Y, Henderson JA Adult caregiving among American Indians: the role of cultural factors. *Gerontologist*. 2010 51(3): p. 310–320. [PubMed: 21148253]
 27. Hennessy CH, John R The interpretation of burden among Pueblo Indian caregivers. *Journal of Aging Studies*. 1995. 9(3): p. 215–229.
 28. John R, Hennessy CH, Dyeson TB, Garrett MD Toward the conceptualization and measurement of caregiver burden among Pueblo Indian family caregivers. *Gerontologist*. 2001. 41(2): p. 210–219. [PubMed: 11327487]

Table 1.

Demographics of AI/AN participants

		Daybreak Star	Sealaska
Total Participants, <i>N</i>		196	29
Female, <i>n</i> (%)		128 (65%)	25 (86%)
Age, <i>M</i> (<i>SD</i>)		44.9 (15.5)	55.4 (14.2)
Some College/College Degree, <i>n</i> (%)		134 (67%)	21 (74%)
Location, <i>n</i> (%)	Reservation	42 (21%)	0 (0%)
	Rural not Reservation	42 (21%)	10 (35%)
	Large Metropolitan	111 (58%)	18 (65%)
Marital Status, <i>n</i> (%)	Never Married	75 (38%)	3 (11%)
	Married/Partnered	72 (38%)	12 (43%)
	Divorced/Separated	38 (19%)	12 (43%)
	Widowed	10 (5%)	1 (3%)

Note: One participant from each event chose not to complete the demographic questions.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 2.

Characteristics of caregivers

		Caregiver (<i>n</i> = 90)	Non-caregiver (<i>n</i> = 86)	Test	<i>p</i> -value
Age, <i>M</i> (<i>SD</i>)		46.9 (14.4)	44.0 (16.0)	<i>t</i> (172) = -1.26	.211
HS Degree or higher, <i>n</i> (%)		83 (92%)	80 (93%)	χ^2 (2) = 11.2	.875
Gender, <i>n</i> (%)	Female	72 (80%)	49 (57%)	χ^2 (2) = 11.2	.004
	Male	18 (20%)	37 (43%)		
Location, <i>n</i> (%)	Reservation	15 (17%)	15 (17%)	χ^2 (2) = 3.3	.191
	Rural	16 (18%)	25 (29%)		
	Large Metro	58 (65%)	46 (54%)		
Marital Status, <i>n</i> (%)	Never Married	27 (30%)	34 (40%)	χ^2 (5) = 3.5	.619
	Married/Partner	36 (40%)	30 (35%)		
	Divorced/Separated	23 (26%)	18 (21%)		
	Widowed	4 (4%)	3 (4%)		