

RESILIENCE AND STRESS AMONG HOPI FEMALE CAREGIVERS

Felina M. Cordova-Marks, DrPH, James K. Cunningham, PhD, Robin B. Harris, PhD, Lynn B. Gerald, PhD, Beatrice Norton, Ann M. Mastergeorge, PhD, and Nicolette I. Teufel-Shone, PhD

Abstract: Resilience and stress are important factors in the caregiving experience, but research has yet to examine their association among American Indian (AI) caregivers. This study examines resilience and stress in a group of Hopi female caregivers. Data came from the Hopi Adult Caregiver Survey (2017), which conducted interviews with 44 Hopi women who were providing care without remuneration to an adult family member. Measures included the abbreviated Connor-Davidson Resilience Scale (CD-RISC-10), the Perceived Stress Scale (PSS-10), and questions about caregiver characteristics, care recipient characteristics, social support/community support, and cultural factors. Stress and resilience were looked at above the median (higher stress or higher resilience) and below the median (lower stress or lower resilience). Caregivers who reported relatively lower resilience were more likely to report that they lived separately from their care recipients and that all Hopis are expected to be caregivers. Caregivers who reported relatively higher stress reported a higher total number of caregiver difficulties, a poorer self-perception of their own health, use of a traditional healer in the past 5 years, and that females are expected to be caregivers. A regression analysis adjusting for age, education, and employment status indicated that higher resilience among the caregivers was significantly associated with lower stress. In light of these findings, programs working with AI caregivers may wish to explore whether supporting the resilience of these caregivers is a means towards limiting their stress.

INTRODUCTION

In the United States, informal caregivers provide unpaid care that amounts to paid care services that would cost between \$470-522 billion annually (Family Caregiver Alliance, 2019; Hopps et al., 2017). Maintaining the health of this ‘workforce,’ consequently, is important. That said, 38% of caregivers in the U.S. general population consider their situation to be stressful (National Alliance for Caregiving, 2015), a concern as stress can challenge a caregiver’s health

and threaten their ability to care for family, friends, and community members suffering from issues ranging from cancer to dementia. Caregiver stress and the factors affecting it has become an important area of analysis, particularly as the US population is now aging. But little such analysis has been conducted for one of the country's major racial/ethnic groups—American Indians (AI). A few studies that have examined stress among AI caregivers (specifically Southwestern and Northern Plains AI caregivers) report that stress is a caregiving difficulty (Jervis et al., 2010; Cordova et al., 2016; Cordova-Marks et al., 2018). But no caregiving studies have looked specifically at related factors such as resilience among AI caregivers, an important gap as resilience is thought to help counter stress among caregivers (Palacio et al., 2020).

Resilience has been defined as “[P]ositive psychological, behavioral, and/or social adaptation in the face of stressors and adversities” (Dulin et al., 2018, p.57), and similarly as “[T]he ability to successfully cope with change or misfortune” (Ahern et al., 2006, p.104). In a recent review of caregiving, Palacio et al. (2020) concluded that resilience can help limit the risk of stress and burden that caregivers often face. For example, in a study of caregivers for persons with Alzheimer's disease, Lopes da Rosa et al. (2020) found that resilience helped the caregivers manage and respond positively to the stressful demands of care. This is consistent with studies on resilience and stress in general, which have found, for example, that resilience is associated with lesser stress among university students, corporate level executives, medical patients and their spouses in the United States, and international medical patients (Bacchi & Licinio, 2017; Kermott et al., 2019; Lim et al, 2014; Tian et al., 2016).

While dozens of studies have reported on the association of resilience with stress (Palacio et al., 2020), no studies have yet examined these two variables among AI caregivers. Here, we examine resilience and stress as reported by Hopi female caregivers. This is the first study to examine both factors in an AI tribe. We also examine possible related factors such as the characteristics and experience of caregivers and the characteristics of the persons receiving care. Note that not all tribes are similar and the diversity among tribes can be substantial. This study on Hopi female caregivers will provide a starting point for other tribes to look at caregiver resilience and stress among their own populations.

METHODS

Data for this study were drawn from the 2017 Hopi Adult Caregiver Survey, which has been previously described (Cordova-Marks et al., 2018). This 58-item survey included questions

about caregiver characteristics, caregiver experience, and the persons receiving care (care recipients). Caregiver characteristics included age, education, employment status, marital status, number of adults in the home, and number of children in the home. Questions related to the caregiving experience included their reason for becoming a caregiver, types of caregiving duties, amount of time devoted to caregiving (total years and hours/week), caregiver difficulties, and the caregivers' perceived health status, resilience, and stress. Caregivers also answered questions about the care recipients, including their age, health conditions, relationship, and aspects of culture they participate in. Questions related to culture and tradition (language spoken at home, use of traditional healer, attending ceremonies) were also asked, as culture and tradition can bear on familial/community behavior in AI tribes.

As part of the Hopi Adult Caregiver Survey, resilience and stress were assessed using the abbreviated Connor-Davidson Resilience Scale (CD-RISC-10) and the Perceived Stress Scale (PSS-10; Campbell-Sills & Stein, 2007; Connor & Davidson, 2003; Cohen et al., 1983). The CD-RISC-10 and the PSS-10 have both been used in prior research with AIs. Goins and colleagues (2013) used the CD-RISC-10 with AIs and found it to be reliable. Other studies with mixed samples have assessed the validity of the PSS-10 (Bersamin et al., 2014). Both instruments have ten items. For each instrument, individual items are scored from 0-4 and summed to a final score with a possible range of 0-40. (In the present study, one modification was made to the CD-RISC-10: "humorous" was changed to "funny" for Question 3 of the CD-RISC-10 per a suggestion from a member of the Hopi tribal council. Higher scores on the CD-RISC-10 and PSS-10 indicate greater resilience or greater stress, respectively.

Eligible participants were self-identified Hopi caregivers 18+ years of age who lived on the Hopi reservation (located in northeastern Arizona) and provided care without pay to an adult family member due to that member's health condition, disability, or older age. Persons that provided care for a child only were not included. Participants were recruited from the Hopi Office of Aging and Adult Services' (HOAAS) list of caregivers and via an advertisement placed in the local newspaper, the Hopi Tutuveni (inclusion and exclusion criteria were included in this advertisement). A Hopi interviewer that has conducted surveys on past Hopi-related survey projects, such as the 2012 Hopi Cancer and Chronic Disease survey, was trained by the project's principal investigator to administer the questions. This interviewer conducted all surveys in person at participants' homes or the Hopi Nutrition Center, depending on the participant's preference. Participants were given the option of having the survey conducted in Hopi or English (the

interviewer was fluent in both); all participants chose English. A \$20 gift card or \$20 cash was provided to participants for their time at the end of their interviews.

From a set of 64 self-identified caregivers that met inclusion criteria, 46 (71.9%) responded. Those that did not respond were unable to be reached by phone or did not go to their scheduled survey time(s). Less than five were recruited from the newspaper advertisement with the rest being recruited from the HOAAS. Only two of the respondents were males. They were not included in this study's analysis as the male experience would not be adequately represented with only two individuals, leaving a total sample of 44 participants. Complete data were available for all of the study's respondents, except for two questions. The question asking the number of children living in the home of the caregiver was missing from one respondent and the question asking how has caregiving affected your health had one participant respond "Don't know/unsure" (see Table 1). The average amount of time to complete the entire survey was 45 minutes.

Approvals

Approval from the University of Arizona Human Subjects Protection Program and the Hopi Tribal Council was obtained prior to initiation of surveying, and a letter of approval was also received from the Chairman for publishing this manuscript. All members of the research team completed CITI training as well.

Analysis

Stata 13 data analysis software was used for all analyses (Stata, 2018). Cronbach's alphas were calculated for the resilience scale and the perceived stress scale. Per the Hopi tribe's request, any counts less than five were reported as "< 5." Frequencies and percentages were calculated for categorical values. Group means ($\pm SD$) were calculated using the summary resilience and stress scale scores from each participant. To examine the association of resilience and stress with the caregiver and care recipient characteristics, participants were first classified as being below or above the median for resilience and being below or above the median for stress (indicators that resilience and stress were relatively lower or higher). Fisher's Exact Test was then used to compare the caregiver and care recipient characteristics with their higher/lower resilience and stress classifications. A regression analysis that adjusted for age, education, and employment status was

performed to assess whether caregiver resilience was associated with stress. Data was calculated by number of complete responses for each question.

RESULTS

A slight majority of the caregivers were over the age of 60 (54.5%). Most (69.8%) had more than a high school education; 52.3% reported that they were currently working; 68.2% were single, widowed, separated, or divorced; 81.8% spoke English at home, and 52.3% of participants spoke Hopi at home (the question allowed more than one answer for language spoken at home). All had an adult living in the same home, and more than half (58.1%) had a family member under the age of 18 living in the same home.

Caregiver Resilience

Scores on the resilience scale (CD-RISC-10) ranged from 16-40. Cronbach's alpha (a measure of internal consistency) for the CD-RISC 10 was 0.78, which is acceptable. The mean score was 28.7 ($SD = 6.2$).

Resilience and Caregiver/Care Recipient Characteristics

To help examine whether the resilience of the caregivers was associated with their characteristics or the characteristics of their care recipients, the caregivers were classified as being below or above their group median resilience score (< 29 or ≥ 29), and this classification was then compared with the characteristics (Table 1). Two comparisons were statistically significant. Participants with lower resilience (scores below the median) were more likely to report that caregiving was an expectation of all Hopis. Participants with higher resilience were more likely to live together with their care recipient.

Mean resilience scores of caregivers by care recipient health condition were as follows: disability ($M = 29.0$, $SD = 8.7$; $n < 5$), cancer ($M = 29.0$, $SD = 3.2$; $n = 8$), and other (non-cancer) diseases ($M = 28.7$, $SD = 3.3$; $n = 30$); among these other diseases were Alzheimer's disease/dementia ($M = 25.9$, $SD = 1.2$; $n = 12$) and diabetes ($M = 29.7$, $SD = 2.5$; $n = 6$).

Table 1
Association of Caregiver Characteristics and Perceptions with Lower/Higher Resilience and Stress^a

	Resilience		Stress			
	Lower N = 21	Higher N = 23		Lower N = 22	Higher N = 22	
	n (%)	n (%)	FET ^b	n (%)	n (%)	FET ^b
Adults living in home of caregiver						
1-2	11 (52.4)	9 (39.1)		10 (45.5)	10 (45.5)	
3 or more	10 (47.6)	14 (60.9)		12 (54.5)	12 (54.5)	
Children living in home of the caregiver ^c						
0	10 (47.6)	8 (36.4)		10 (47.6)	8 (36.4)	
1 or more	11 (52.4)	14 (63.6)		11 (52.4)	14 (63.6)	
Years caregiving						
<3	8 (38.1)	11 (47.8)		10 (45.5)	9 (40.9)	
3 or more	13 (61.9)	12 (52.2)		12 (54.5)	13 (59.1)	
Reasons for Caregiving						
Wanted to care for the elder						
Yes	13 (61.9)	17 (73.9)		16 (72.7)	14 (63.6)	
No	8 (38.1)	6 (26.1)		6 (27.3)	8 (36.4)	
Only family that can take care of the elder						
Yes	10 (47.6)	5 (21.7)		8 (36.4)	7 (31.8)	
No	11 (52.4)	18 (78.3)		14 (63.6)	15 (68.2)	
Elder preferred to live together instead of assisted living facility						
Yes	11 (52.4)	9 (39.1)		8 (36.4)	12 (54.5)	
No	10 (47.6)	14 (60.9)		14 (63.6)	10 (45.5)	
Hopi expected to be caregivers						
Yes	17 (81.0)	10 (43.5) **		15 (68.2)	12 (54.5)	
No	<5	13 (56.5)		7 (31.8)	10 (45.5)	
Females expected to be caregivers						
Yes	10 (47.6)	9 (39.1)		6 (27.3)	13 (59.1) *	
No	11 (52.4)	14 (60.9)		16 (72.7)	9 (40.9)	
Not employed so have time						
Yes	8 (38.1)	7 (30.4)		5 (22.7)	10 (45.5)	
No	13 (61.9)	16 (69.6)		17 (77.3)	12 (54.5)	
Caregiving Experience						
Hours per week caregiving						
≤ 20	9 (42.9)	9 (39.1)		9 (40.9)	9 (40.9)	
21-40	<5	<5		<5	<5	
> 40 hours	8 (38.1)	12 (52.2)		10 (45.5)	10 (45.5)	
Physical strain						
High	<5	<5		<5	5 (22.7)	
Moderate	10 (47.6)	12 (52.2)		11 (50.0)	11 (50.0)	
Low	7 (33.3)	8 (36.4)		9 (40.9)	6 (27.3)	
Number of difficulties						
<2	7 (33.3)	6 (26.1)		10 (45.5)	<5 *	
3 or more	14 (66.7)	17 (73.9)		12 (54.5)	19 (86.4)	
Caregiver/Care recipient living situation						
Living apart	11 (52.4)	4 (17.4) *		9 (40.9)	6 (27.3)	
Living together	10 (47.6)	19 (82.6)		13 (59.1)	16 (72.7)	

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Table 1 Continued
Association of Caregiver Characteristics and Perceptions with Lower/Higher Resilience and Stress^a

	Resilience		Stress			
	Lower N = 21 n (%)	Higher N = 23 n (%)	FET ^b	Lower N = 22 n (%)	Higher N = 22 n (%)	FET ^b
Caregiver Personal Health						
Caregiver's health						
Excellent or Very good	7 (33.3)	11 (47.8)		13 (59.1)	5 (22.7)	*
Fair or Poor	14 (66.7)	12 (52.2)		9 (40.9)	17 (77.3)	
Has caregiving affected your health ^d						
No impact	13 (61.9)	14 (63.6)		15 (68.2)	12 (57.1)	
Made it better	<5	<5		<5	<5	
Made it worse	8 (38.1)	5 (22.7)		5 (22.7)	8 (38.1)	
Have exercise habits changed since becoming a caregiver						
No change	6 (28.6)	11 (47.8)		10 (45.5)	7 (31.8)	
Exercise more	<5	<5		<5	<5	
Exercise less	12 (57.1)	9 (39.1)		9 (40.9)	12 (54.5)	
Days of exercise per week						
0-2 days	8 (38.1)	7 (30.4)		9 (40.9)	6 (27.3)	
3-4 days	5 (23.8)	12 (52.2)		9 (40.9)	8 (36.4)	
5-7 days	8 (38.1)	<5		<5	8 (36.4)	
Social Support						
Informal-Family over 18 years of age						
Yes	15 (71.4)	18 (78.3)		16 (72.7)	17 (77.3)	
No	6 (28.6)	5 (21.7)		6 (27.3)	5 (22.7)	
Informal-Family under 18 years of age						
Yes	6 (28.6)	11 (47.8)		6 (27.3)	11 (50.0)	
No	15 (71.4)	12 (52.2)		16 (72.7)	11 (50.0)	
Formal caregiving assistance						
Yes	10 (47.6)	7 (30.4)		6 (27.3)	11 (50.0)	
No	11 (52.4)	16 (69.6)		16 (72.7)	11 (50.0)	
Aspects of Culture						
Caregiver use of traditional healer or medicine person in past 5 years						
0	10 (47.6)	10 (43.5)		14 (63.6)	6 (27.3)	*
1+ times	11 (52.4)	13 (56.5)		8 (36.4)	16 (72.7)	
Caregiver takes part in cultural ceremonies						
Yes	16 (76.2)	21 (91.3)		18 (81.8)	19 (86.4)	
No	5 (23.8)	<5		<5	<5	
Care recipient goes to a traditional healer or medicine person						
Yes	11 (52.4)	11 (47.8)		10 (45.5)	12 (54.5)	
No	10 (47.6)	12 (52.2)		12 (54.5)	10 (45.5)	

Note. Percentages may not total to 100% due to rounding error, or to responses <5 that were not included in the percentage calculations.

^aHigher and lower defined as being above or below the median resilience or stress score for the sample.

^bFET = Fisher's Exact Test.

^cOne participant did not respond to this question.

^dOne participant "did not know/was unsure" for this question.

*p<0.05

**p<0.01

Caregiver Stress

Scores on the stress scale (PSS-10) ranged from 4-28. Cronbach's alpha for the PSS-10 was 0.75 (acceptable). The mean score on this scale was 17.9 ($SD = 6.2$).

Stress and Caregiver/Care Recipient Characteristics

To help examine whether the stress of the caregivers was associated with their characteristics or the characteristics of their care recipients, caregivers were classified as being above or below their group median stress score (< 19.5 or ≥ 19.5), and this classification was then compared with the characteristics (Table 1). Some significant associations were indicated. In particular, caregivers who reported relatively higher stress (above the median) also reported a higher total number of caregiver difficulties, a poorer self-perception of their own health, use of a traditional healer in the past 5 years, and that females were expected to be caregivers.

Mean stress scores by care recipient health condition were as follows: disability ($M = 18.8$, $SD = 5.1$; $n < 5$), cancer ($M = 20.0$, $SD = 1.8$; $n = 8$), and diseases other than cancer ($M = 17.0$, $SD = 1.1$; $n = 30$); among these other diseases were diabetes ($M = 18.0$, $SD = 1.7$, $n = 6$) and Alzheimer's/dementia ($M = 18.8$, $SD = 1.5$, $n = 12$).

Table 2
Association of Stress with Resilience, Age, Education and Employment Status

	Unadjusted <i>b</i> (CI)	Adjusted <i>b</i> (CI)
Resilience score	-0.41 (-0.69, -0.12)**	-0.41 (-0.70, -0.12)**
Demographics		
Age	-0.06 (-0.22, 0.09)	-0.08 (-0.25, 0.10)
Education ^a	0.60 (-3.61, 4.80)	1.02 (-3.40, 5.44)
Employment ^b	0.48 (-3.36, 4.32)	-0.21 (-4.67, 4.26)

b = unstandardized regression coefficient. CI = 95% confidence interval.

^aEducation coding: 0 = high school graduate or less; 1 = education beyond a high school education.

^bEmployment coding: 0 = student, retired, disabled or not currently working; 1 = working full-time or part time or self-employed.

* $p < 0.05$

** $p < 0.01$

Association of Resilience with Stress

A regression analysis that adjusted for the participants' age, education, and employment status was performed to examine whether resilience was associated with stress. A statistically significant association was found (Table 2). The adjusted regression coefficient for resilience

indicated that every 1-unit increase in the resilience score was associated with a decrease in the stress score of 0.41 ($p < 0.01$). Age, education, and employment status were not found to be significantly associated with stress.

DISCUSSION

Although resilience and stress are known to be important factors in the caregiving experience of the general population (Jervis et al., 2010; Ong et al., 2006), this study, to our knowledge, is the first to examine resilience and stress among AI caregivers. Forty-four female caregivers on the Hopi reservation were surveyed regarding resilience and stress. The mean resilience score found for these caregivers was 28.7 ($SD = 6.2$), somewhat lower than that reported for females in a large general community-based survey that administered the CD-RISC-10 ($M = 31.1$, $SD = 5.6$; Campbell-Sills et al., 2009). The mean PSS-10 stress score found for the Hopi caregivers ($M = 17.9$, $SD = 6.2$) was slightly higher than that reported for females in a national survey that administered the PSS-10 ($M = 16.1$, $SD = 7.5$; Cohen & Janicki-Deverts, 2012).

Caregiver resilience was found to be associated with some of the measured caregiver characteristics. In particular, caregivers who reported that they lived with their care recipient had significantly higher resilience scores. A possible explanation is that caregivers who live in the same home as their care recipients experience higher resilience partly in association with family connectedness (Coser et al., 2018). The AI family unit itself has been found to be associated with resilience in several non-caregiver AI studies (Teufel-Shone et al., 2018). Many AI families have more than one generation in the same household. In comparison to other racial/ethnic groups in Arizona, AIs have the highest percentage of multigeneration (three or more generations) households and is an aspect of AI culture (Lofquist, 2012). In contrast, caregivers who felt that caregiving was a cultural expectation of all Hopis had lower resilience scores. This suggests that caregivers with lower resilience may perceive less choice as to the performance of their caregiver role. If one considers that resilience entails “[Q]ualities that enable one to thrive in spite of stressful events” (Schure et al., 2013 p.27), choice might be one of these qualities. In general, resilience scores of the Hopi caregivers differed little by whether the care recipient’s health condition involved disability, cancer, other (non-cancer) diseases, or diabetes. The care recipient condition associated with the largest difference from the general mean resilience score of 28.7 was that found for caregivers providing care to persons with Alzheimer’s/dementia ($M = 25.9$).

Caregiver characteristics were found to be associated with caregiver stress as well. Caregivers who felt that caregiving was an expectation of females instead of males reported higher stress. Again, this might be an issue of choice. Longacre et al. (2014) found that, among those providing cancer care to family members (general population study), a perceived lack of choice in providing care was significantly associated with greater stress (also see National Alliance for Caregiving, 2015). In the present study, caregivers who reported a greater number of difficulties reported significantly higher stress as well as caregivers who reported only poor/fair health. Consistent with this, Luchesi et al. (2016) found that higher stress was associated with poorer health in a study of Brazilian caregivers aged 60+ years. Finally, Hopi caregivers that used a traditional healer at least once in the past five years reported higher stress. It might be that caregivers with higher stress sought out a traditional healer to help deal with what may be contributing to their stress, such as poorer health. In general, stress scores of the Hopi caregivers differed little by whether the care recipient's health condition involved disability, diabetes, or Alzheimer's/dementia. The care recipient condition associated with the largest difference from the general mean stress score of 17.9 was that found for caregivers providing care to persons with cancer ($M = 20.0$).

Finally, our study's regression analysis indicated that higher Hopi caregiver resilience scores were associated with lower stress. This finding is consistent with studies that have found higher resilience to be associated with lesser stress in several other populations (Bacchi & Licinio, 2017; Kermott et al., 2019; Lim et al., 2014; Tian et al., 2016).

Implications

Given the inverse association between resilience and stress found here among female Hopi caregivers, programs working with AI caregivers may wish to explore whether supporting the resilience of caregivers is a means towards limiting their stress. Although there is limited published research on AI resilience, some programs currently exist with the goal of promoting resilience among AIs. For example, the Center for American Indian Resilience partners with AI communities in an effort to support resilience-building education, programs, and activities (Northern Arizona University, n.d.). Programs, however, that support resilience and its correlates (e.g., lesser stress) among AIs have not typically focused on caregivers. This study's findings will hopefully help bring more attention to AI caregivers and thus more research and programs designed to support them and the important work that they do, both on the Hopi reservation and among other tribes in the United States.

Limitations

This study examined data from a convenience sample of female Hopi caregivers. Generalizability of the findings to male AI caregivers, other tribes, and urban AI populations is unknown. Due to the small sample size ($N = 44$), the study may have lacked statistical power to identify some associations. The ability to compare and contrast this study's findings with other work on resilience and stress among AI caregivers was limited due to a general absence of research on the topic.

CONCLUSION

This is the first study to look at the relationship between resilience and stress in AI caregivers. It found that higher resilience was associated with lesser stress among Hopi female caregivers. In light of this finding, programs working with AI caregivers may wish to explore whether supporting the resilience of these caregivers is an avenue towards limiting their stress.

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AUTHOR INFORMATION

Dr. Felina M. Cordova-Marks is a postdoctoral research fellow at the University of Arizona Cancer Center in Tucson, Arizona. Dr. James K. Cunningham is an associate professor in the Department of Family and Community Medicine, Mel and Enid Zuckerman College of Public Health and Western Region Public Health Training Center at the University of Arizona in Tucson, Arizona. Dr. Robin B. Harris is a Professor of Epidemiology at the Mel and Enid Zuckerman College of Public Health and co-director of the Skin Cancer Institute, Arizona Cancer Center at the University of Arizona in Tucson, Arizona. Dr. Lynn B. Gerald is a professor and the Canyon Ranch Endowed Chair at the Mel and Enid Zuckerman College of Public Health and Associate Director for Clinical Research at the Asthma and Airway Disease Research Center at the University of Arizona in Tucson, Arizona. Ms. Beatrice Norton is director of the Office of Aging and Adult Services in the Department of Health and Human Services for the Hopi Tribe. Dr. Ann M. Mastergeorge is Chair and Rockwell Endowed Family and Child Professor in the Department of Human Development and Family Sciences at Texas Tech University in Lubbock, Texas. Dr. Nicolette I. Teufel-Shone is a professor in the Department of Health Sciences and associate director of the Center of Health Equity Research at Northern Arizona University in Flagstaff, Arizona.