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Caregiving on the Hopi Reservation: Findings from the 2012 Hopi Survey of Cancer and Chronic Disease

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Abstract

A family caregiver provides unpaid assistance to a family member/friend with a chronic disease, illness or disability. The caregiving process can affect a caregiver’s quality of life by reducing time for themselves, for other family members and for work. The 2000 Behavioral Risk Factor Surveillance Survey estimates that 16 % of adult American Indians (AIs) are caregivers. A 2012 survey collected knowledge and personal experience data from a random sample of Hopi men and women (248 men and 252 women). Self-identified caregivers answered questions on time spent

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

caregiving, caregiver difficulties and services requested. Approximately 20 % of the 500 Hopi participants self-identified as caregivers (N = 98), with 56 % female. Caregivers in contrast to non-caregivers had a lower percentage of ever having a mammogram (86, 89 %), a higher percentage of ever having had a Pap smear test (89.1, 85.6 %), a prostate specific antigen test (35, 30.6 %) and ever having had a colonoscopy (51.2, 44 %). Almost 21 % of caregivers reported difficulty with stress and 49 % reported it as their greatest caregiver difficulty. More males (28.6 %) identified financial burden as the greatest difficulty than females ($p = 0.01$). Training on patient care was the service that caregivers would like to receive most (18.2 %). The percentage of Hopi's providing caregiving was similar to national averages, although among men, was somewhat higher than national data (44 vs. 34 %). Stress was identified as a difficulty, similar to national studies.

Keywords

Caregiving; Caregiver; American Indian; Reservation; Health disparities; Cancer screening; Cancer

Introduction

Caregiving is an important part of societies, communities and families. With the ever-increasing costs of assisted living facilities, some families may be influenced by financial restrictions and choose to provide care for a family member or friend with a chronic illness, disability or advanced age in their homes [1]. However, family caregiving may not be related to the costs of professional assistance but chosen for cultural reasons, particularly in collectivist communities, such as American Indian (AI) communities [2, 3]. In native and non-native families, in-home care is often unpaid, but can have costs and rewards for the caregiver and the rest of the family. These rewards and costs are not always the same and can differ across populations.

The Family Caregiver Alliance, a national nonprofit organization, developed to address the needs of families and friends providing long-term care at home, defines a "caregiver" as someone that is unpaid who performs "daily living tasks" for the care recipient. These tasks may include cooking, doing laundry, cleaning, helping get in and out of bed, and "medical tasks" for the care recipient such as giving medications and making medical appointments [5]. In 2009, the National Alliance for Caregiving (NAC) and American Association of Retired Persons (AARP) conducted telephone-based surveys and found 30 % of people identified themselves as caregivers of adults within the past year [6]. In 2015, NAC/AARP reported 16.6 % were caregivers; this more recent survey was conducted exclusively with participants surveyed and this difference in methodology may explain the difference in estimates from 2009's telephone survey [6,7]. In 2009, 72 % of caregiver recipients lived with or near their caregiver within a 20-min commute [6]. The National Alliance for Caregiving, conducted multi-ethnic surveys and the majority of caregivers are female with a mean age of 49 years [6, 8, 9]. Northouse et al. [10] suggest that caregivers face various mental health and general health issues such as elevated levels of depression, anxiety, and sleep disturbance. The burden of caregiving is variable, depending on the recipient's needs. Caregivers that provide care for individuals with cancer or dementia report a more intense caregiving experience requiring many hours per week providing care (individuals with cancer caregivers 31.80, individuals with dementia caregivers 29.90, individuals with diabetes caregivers 23.37 and frail elderly caregivers providing 13.31 hours), increased physical demand, and stress versus caregivers of individuals with diabetes or the frail elderly [8]. To combat the specific health risks that caregivers face, feasibility studies and interventions have been developed and evaluated to decrease caregiver stress and enhance life management skills. These interventions have included self-efficacy building, mind-based stress reduction, and spirituality strengthening through the mediums of web-based video and teleconferences [11–15].

Recently, a community-wide survey of knowledge of and experience with chronic diseases was conducted with members of the Hopi Tribe of Arizona [4]. The survey included questions about caregiving and provided an opportunity to describe the caregiving experience within the community. The intent of the caregiver questions was to compare caregivers versus non-caregivers' reported health and use of the health care system for chronic disease prevention.

Methods

Survey Development

Development of the 2012 Hopi Survey of Cancer and Chronic Disease was initiated September 2010 and completed February 2012 [16]. The survey was the effort of a community-based participatory research collaboration between the Hopi Tribe, The University of Arizona (UA) and Northern Arizona University (NAU). The survey was designed to document the health status and health care of Hopi Tribal members. This information could guide health services planning and future health education programming. The survey questions were based primarily on the Behavioral Risk Factor Surveillance Survey (BRFSS) [17] and modified by the research team (Hopi, NAU, UA) to assure the questions were culturally relevant and specific to the Hopi people. A pilot survey was field tested for comprehension and cultural appropriateness, with 11 Hopi males and 11 Hopi females.

Approvals

Before study initiation, Hopi Tribal Council approved this research on December 2010. Approvals were also received from the Institutional Review Board (IRB) from the UA Offices of Human Subject Research Compliance, the UA American Indian Studies Department, and the UA Cancer Center's Scientific Advisory Committee.

Data Collection

Eligible potential participants were randomly selected from the tribal enrollment, resulting in 1567 adults 18 years and older. Tribal members were excluded from potential participant pool if they were not residing on the Hopi reservation; thus, 802 of these 1567 were eligible to participate. Surveying began June 2012 and ended in December 2012.

Members of the Hopi tribe conducted home interviews. Hopi interviewers completed the University of Arizona's Collaborative Institutional Training Initiative (CITI) exam (both the Social and Behavioral module and the Native American research module) and received training (one and a half days) by the Hopi–UA–NAU research team on recruiting, consenting, confidentiality, participant refusal, and field monitoring. Interviewers were assigned a random list of participants to interview by the study coordinator. The tribal enrollment office provided a list that contained the phone number and address of the potential participant and was provided to the study coordinator by the tribal enrollment office. Interviewers then contacted potential participants a maximum of five times via phone or in person. At each survey interview, the interviewer would read the consent form to the participant, answer questions and obtain consent. After providing written consent, the participants then completed the survey questions verbally administered by the interviewers. Participants had the option of having the interview conducted in English or Hopi. All interviewers used a computerized script for consistency when contacting potential participants and interviews were conducted in the participants' homes. The Hopi interviewers administered the surveys and recorded responses on a laptop computer into the Epi Info based survey. Participants received a $40 gift card as compensation for their time and interviewers received $50 for each completed interview. The entire survey conducted by interviewers contained 206 questions. If participants perceived themselves as caregivers, additional questions based on being a caregiver were asked.

Focus on Caregivers and the Caregiving Experience

The following was asked of each participant: *People may provide regular care or assistance to a friend or family member who has a disease or disability. During the past month did you provide any such care? (Excludes care provided to young healthy children at home).*" Participants who responded "Yes" to this question were considered caregivers. If participants responded yes, nine additional questions were asked related to their experience as caregivers:

> Did/do you provide this care to someone with cancer?
>
> Did/do you provide this care to someone with a disease or disability other than cancer?
>
> (Any disease or disability other than cancer was not further probed to determine the condition or disability)
>
> For how long have you been providing care or assistance to the friend or family member?
>
> How often do you go with him/her to his/her medical appointments?
>
> Do you usually go into the room with the person you are assisting when he or she sees the doctor or another health care provider?
>
> Do you usually understand what the health care provider says?
>
> Please tell me if you have experienced any of these when caring for your friend or family member: stress, a financial burden, don't have enough time for yourself, don't

> have enough time for your family, interferes with your work, created or aggravated your own health problems, affects family relationships, no difficulty. Multiple responses allowed.
>
> Which ONE is the greatest difficulty you have faced: stress, a financial burden, don't have enough time for yourself, don't have enough time for your family, interferes with your work, created or aggravated your own health problems, affects family relationships, no difficulty.
>
> As a caregiver what type of services would you like to have to help you and/or the individual you are taking care of? The interviewer then read the following list and allowed multiple responses: counseling services, education on individuals illness/problem, transportation services, support group, pamphlets/brochures on illness/problem, help in filling out paperwork, i.e., enrollment forms, applications, etc., training on patient care such as physical therapy, proper nutrition, activities of daily living (ADL), or 'I don't need extra services'.

In addition to the caregiving questions, the participant were asked their age, gender, marital status, education level, employment, body weight and height, specific health behaviors such as smoking and exercise frequency, a history of self-health care such as cancer screening (mammogram, colonoscopy, PAP smear testing), dental visits, and a brief medical history. Participants were also asked to report current health status as 1 = a lot better than most and somewhat better than most, 2 = about the same as most and 3 = somewhat worse than most and a lot worse than most.

Data Analysis

Survey data were entered into EpiInfo 3.5.3 and later transferred to Stata 13 for analysis. Frequencies and percentages were calculated for the categorical variables for both caregivers and non-caregivers. Characteristic and behavior comparisons between caregivers and non-caregivers were evaluated with chi-square tests or the Fischer's exact test for categories that contained less than five observations. Statistical significance was defined as a p value of <0.05.

Results

As reflected in Table 1, a total of 500 Hopi men (248) and women (252) participated in the survey. From the eligible pool of participants or 802, the overall response rate was 62 %, (54 % for men and 74 % for women). 98 participants self-identified as caregivers, with 391 identifying as non-caregivers, 11 participants either did not answer/refused to answer or did not know. The average age was 44.5 years for caregivers and 45.8 years for non-caregivers (data not shown in Table 1). The highest percentage of caregivers was the age category of 50–59 (27.6 %) and for non-caregivers, it was under 30 years of age (24.6 %). Caregivers reported having a larger number of children in their household than non-caregivers with a mean of 1.82 children for caregivers and 1.46 children for non-caregivers, $p = 0.02$. A higher percentage of Hopi caregivers speak a language other than English (most often Hopi, Tewa or another AI language) in their homes (34 vs. 30 % for non-caregivers, not reported in Table 1). More caregivers consider themselves Hopi (94 %) than non-caregivers (88 %

Tewa, not reported in Table 1). More caregivers reported using a traditional healer (74 %) than non-caregivers (64 %, not reported in Table 1). More caregivers answered “yes” to having ever lived off the reservation (82 %) in comparison to non-caregivers (72 %, not reported in Table 1).

Table 2 shows the self-reported health screening behaviors of Hopi adult caregivers compared to those that did not identify as a caregiver. Caregivers reported slightly lower percentages of ever having had mammogram screening in comparison to non-caregivers (86.8 vs.%). Caregivers had a higher percentage than non-caregivers of having had a Papanicolaou Test (PAP) tests (89.1 vs. 85.6 %). Prostate Specific Antigen (PSA) tests among men were higher in caregivers than in non-caregivers (35 vs. 30.6 %). An almost identical percentage of caregivers and non-caregivers reported ever having a Fecal Occult Blood Test [FOBT (40.5 vs. 40.4 %)]. A higher percentage of caregivers versus non-caregivers reported ever having had a colonoscopy (51.2 vs. 44 %), these differences were not statistically significant. Of respondents, a higher percentage of caregivers versus non-caregivers reported ever visiting the dentist (78.6 vs. 69.7 %). All the differences between caregivers and non-caregivers were not significant.

Health Behavior and Perception of Health

Current cigarette smoking among caregivers was 20.4 % and 17.6 % for non-caregivers. Among current smokers that responded to how often they smoked, a non-significant higher percentage of caregivers reported being everyday smokers (31.6 %) in comparison to non-caregivers (17.9 %). For perceptions of personal health status, caregivers reported a non-significant lower perception of their health. Fifty-six percent (56.7 %) of caregivers versus % of non-caregivers whom rated their health as a one (1) the highest rating category of “A lot better than most and somewhat better than most” with means of 1.44 for caregivers and 1.46 for non-caregivers (means not reported in Table 2).

Questions Asked Only of Caregivers

Table 3 describes the characteristics of the 98 Hopi caregivers. Nine caregivers (9 %) reported caring for someone with cancer, with the rest caring for non-cancer patients. Almost half of the caregivers reported providing caregiving services for 3 or more years. Less than five caregivers provided more than 5 years of care. For female caregivers, the largest percentage, 27.8 % (N = 15) had provided caregiving services for 3–5 years. For males, the largest percentage, 35.7 % (N = 15) provided care for 6 years and over. Differences in the amount of time spent caregiving between females and males was statistically different ($p = 0.020$).

Assisting in Health Care

Of the participants that answered the question (N = 97) “How often do you go to their medical appointments?,” 40 participants reported “seldom or never,” 37 participants reported “always or most of the time” and 20 participants reported, “about half the time.” When they do go to medical appointments with the care recipient, 49 caregivers reported that they “Always or most of the time” go into the doctor’s room with the care recipient, 16 caregivers go “seldom or never” and 10 caregivers go “about half the time.” When it comes to understanding the health care provider of the care recipient, 65 caregivers responded that they "Always or most of the time" understand the health care provider, 6 "seldom or never" understand the provider and less than five understand "about half the time."

Looking at differences between female and male caregivers, a higher percentage of female (40 %) than male caregivers (35.7 %) "Always or most of the time" go to medical appointments with the care recipient. A higher percentage of female caregivers than male caregivers (73.3 vs. 53.3 %) "Always or most of the time" went into the doctor's room with the care recipient. More female caregivers (91.1 %) than male caregivers (82.8 %) reported that they "Almost or most of the time" understand the care recipient's health care provider.

Caregiver Burden

Table 4 illustrates that 43 caregivers reported "No Difficulty" with the caregiving experience. Participants were allowed to respond "no difficulty" as well as reporting experiencing other difficulties. For difficulties, caregivers reported difficulty with stress, 20.9 % (N = 39) and 11.2 % (N = 21) reported that caregiving "interferes with work." The most frequently reported "greatest difficulty" for all caregivers was "stress," 48.8 % (N = 21).

For male participants, more responded as having experienced "no difficulty" in comparison to female participants (35.4 % males, 16.4 % females). Results were statistically different between males and females for "stress", with 21.3 % of female caregiver reporting difficulty with stress versus 20 % for males ($p = 0.034$). Results were also significantly different for "don't have enough time for self" (13.1 % females, 6.2 % males; $p = 0.007$), "don't have enough time for family" (10.7 % females, 6.2 % males; $p = 0.029$), "created or aggravated own health problems" (6.6 % females, 1.5 % males; $p = 0.037$) and "affects family relationships" (12.3 % females, 3 % males, $p = 0.002$). Although not significant, more males than females reported their greatest difficulty as stress, 50 versus 48.3 %. For males, their greatest difficulty was "stress" followed by "financial hardship" (28.6 %), and then followed by "interferes with work" (14.3 %). For females their greatest difficulty was "stress," then "don't have enough time for self" (20.7 %) and then "affects family relationship" (13.9 %). The only "greatest difficulty" that was statistically significant between males and females was "financial burden" ($p = 0.01$) (Table 5).

Caregiver Services

For caregiver services, 16.6 % of responses were "I don't need extra services." The caregiver services most requested by caregivers for themselves and for the person they provide care for (multiple responses allowed) was "training on patient care" (18.2 %), "education on individuals' medical condition" (14.4 %), and the third requested service was "help in filling out paperwork" (13.3 %). For the open-ended "other" category, the following services were requested: building a ramp inside the caregivers home, financial supplement for caregiving, need for handicap accessories, new programs for the elderly, therapy rehabilitation, toiletry items, and traditional practices as a support mechanism (N < 5 for each response).

In contrast to males, more female caregivers would like counseling services (9.1 % females, 4.2 % males), education on individual's illness/problem (14.5 % females, 14.1 % males), support groups (7.3 % females, 5.6 % males), pamphlets/brochures on illness/problem (12.7 % females, 8.5 % males), help in filling out paperwork (13.6 % females, 12.7 % males). A higher percentage of responses from males (21.5 %) reported they “don’t need extra services” in comparison to females (13.6 %). More males would like “transportation services” than females (11.3 % males, 7.3 % females). No statistically significant differences were found between males and females.

Discussion

Based on results from this self-report survey, Hopi caregivers are most often middle-aged females. They also have higher percentages of current smokers and everyday smokers than their non-caregiver Hopi peers. A total of 98 or 20 % of the total 500 participants identified themselves as caregivers. This figure is higher than reported by Goins et al.’s [18], which reported 17 % of 5207 AI participants from three different reservations (Southwest region, Plains region) self-identified as caregivers. Of the Hopi caregiver group, 56 % were female, slightly lower than the 66 % reported nationally [6]. Male and female caregivers’ use of non-English (predominantly Hopi) and traditional medicine is similar to the findings of Goins et al. [18].

Hopi caregivers’ perceived quality of health were aligned with the 2009 national survey on caregiving, with more than half of these caregivers reporting “excellent/very good” health [6]. For Hopi caregivers in this survey, the most commonly mentioned difficulty was stress. In the National Alliance for Caregiving’s study (2009), 30 % of caregivers nationally reported stress versus the approximate 20.9 % of Hopi caregivers reporting stress as a difficulty [6]. Female caregivers on Hopi experienced stress slightly more than males; this was echoed in this same national survey also found that a higher percentage of females experienced stress than males [6]. Sixty-six (66 %) of caregivers nationally report that caregiving has an impact on their work compared to 11.2 % of Hopi caregivers who responded they experienced this difficulty [6]. More than half of the national sample reported caregiving affecting family and friend relationships [6]. A much lower percentage (9.1 %) of Hopi caregivers responded to having experienced caregiving as affecting their family relationships and not having enough time for family.

For male and female caregivers, “training on patient care” was the service most requested (18.2 %). This need for training on patient care could be related to the finding from this survey that male caregivers reported that they often do not understand the health care provider when they go to appointments with their care recipient. The desire for more information is similar to the 2009 National Alliance for Caregiving’s survey on Caregiving, 78 % of caregivers nationally wanted additional information on caregiving [6]. The findings on caregiver difficulties and greatest caregiver difficulty point to a need for caregiver interventions and additional caregiver services. There have been few interventions directed towards caregiving in AI communities. In one randomized trial with AI caregivers of family members with dementia, looking at AI caregivers that received stress reduction touch therapy reported that the intervention decreased their levels of stress, depression, pain and health in comparison to those assigned to received “respite care” for their family member [19].

For AI, families are often expected to provide care at home and not seek care from outside professionals or in formal care institutions [3, 20]. There is also few to no families in formal care institutions on reservations and Alaska Native villages. However, the literature describing caregivers or the caregiving experience within AI communities is limited. In AI communities, there are additional considerations. Jervis et al. [2] found that additional family members other than the primary caregiver provide care-giving services. The family caregiver unit as a whole also needs to be looked at for a more comprehensive holistic approach to AI caregiving.

Limitations

Although the goals of conducting and analyzing this survey on the Hopi Reservation were met, the overall partnership itself was not evaluated by all partners involved. In addition, the limited number of caregiver questions yields a restricted insight into AI caregivers. The survey had a broad scope, was not caregiver specific and to reduce the respondent burden, did not focus on more in-depth aspects of caregiving. The highest percentage of caregivers chose “no difficulty” for the question on greatest caregiver difficulty as well as “I don’t need extra services” for the question on what services they would like. The nature of a survey methodology does not provide additional insight into the perceptions of why caregivers may believe they have no difficulty as a caregiver. A mixed methods approach such as structured interviews or focus groups after the analysis of the survey could reveal additional information on the resilience of Hopi caregivers.

The specific ways that caregivers are providing care was not examined in this survey. In a small study of Northern Plains American Indian caregivers (N = 19) who provided care to elders, caregivers most frequently helped with housekeeping, food preparation, shopping, transportation and doing laundry [2]. The motivation for becoming a caregiver was also not asked; in the 2009 National Alliance for Caregiving’s National Survey, 43 % of the caregivers reported caregiving due to not having any other choice, with Asians and Whites most frequently reporting this reason [6].

Conclusions

This study provides much-needed information on AI caregivers due to the limited published research available and can be used to inform tribes of caregiver experiences and needs. This project was a successful partnership between the Hopi Tribe and the University entities, with a survey being administered, analyzed and results provided to Hopi. This survey subsection on caregiving provides support for additional research to be completed looking at resilience in AI caregivers as well as the differences in caregivers related to the medical condition of recipients (cancer, diabetes, old age, etc.) and stress. Most importantly, the Hopi Tribe will use the survey information to influence and modify the services they provide currently and in the future for those living on the Hopi reservation

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Table 1

Comparison of demographic characteristics between Hopi caregivers and non-caregivers, 2012 Hopi cancer and chronic disease survey

	Caregivers N (%)	**Non-caregivers N (%)**	***P***
Total	98	391	
Age, years			
>30	24 (24.5)	96 (24.6)	0.130[+]
30–39	15 (15.3)	56 (14.3)	
40–49	15 (15.3)	67 (17.1)	
50–59	27 (27.6)	68 (17.4)	
60–69	12 (12.2)	55 (14.1)	
70+	5 (5.1)	49 (12.5)	
Gender			
Female	54 (55.7)	190 (48.6)	0.183
Male	43 (44.3)	201 (51.4)	
Education			
Less than 12th grade	17 (17.4)	54 (13.8)	0.071 +
Trade, technical, vocational beyond High school	40 (40.8)	142 (36.3)	
High School graduate/GED	7 (7.1)	49 (12.5)	
Some college but no degree	24 (24.5)	74 (19)	
2-year college graduate or more	10 (10.2)	72 (18.4)	
Marital status			
Single	45 (45.9)	194 (49.7)	0.528
Married (cohabitating/common law/married traditional)	38 (38.8)	126 (32.3)	
Widowed, separated, divorced	15 (15.3)	70 (18)	
Number of children living in home[*]			
None	36 (36.7)	156 (40.2)	0.019[+*]
One	14 (14.3)	72 (18.6)	
Two	14 (14.3)	74 (19.1)	
Three	22 (22.5)	37 (9.5)	
Four or more	12 (12.2)	49 (12.6)	

[*] $p < 0.05$

[+] p value calculated by Fischers exact

Table 2

Self-reported health screening behavior and perception of health among Hopi adults by their caregiving status, 2012 Hopi cancer and chronic disease survey

	Caregivers N (%)	**Non-caregivers N (%)**	***P***
Female cancer screening tests			
Ever had pap smear test performed (over 18 years of age)			
Yes	49 (89.1)	161 (85.6)	0.656[+]
No	6 (10.9)	27 (14.4)	
Ever had mammogram (over 40 years of age)			
Yes	33 (86.8)	99 (89.2)	0.769[+]
No	5 (13.2)	12 (10.8)	
Male cancer screening tests			
Ever had a PSA test? (over 45 years of age)			
Yes	7 (35)	30 (30.6)	0.700
No	13 (65)	68 (69.4)	
Other cancer screening tests			
Ever had a FOBT? (over 50 years of age)			
Yes	16 (40.5)	59 (40.4)	0.350
No	22 (59.5)	87 (59.6)	
Ever had a colonoscopy? (over 50 years of age)			
Yes	22 (51.2)	74 (44)	0.403
No	21 (48.8)	94 (56)	
Other regular screening			
Ever visit dentist?			
Yes	77 (78.6)	271 (69.7)	0.081
No	21 (21.4)	118 (30.3)	
Other health behaviors and health perceptions			
Current smoker			
Yes	20 (20.4)	69 (17.6)	0.873 (for yes vs. no)
How often smoke			
Everyday	6 (31.6)	12 (17.9)	0.213[+]

	Caregivers N (%)	Non-caregivers N (%)	*P*
Somedays	13 (68.4)	55 (82)	
No	78 (79.6)	322 (82.4)	
Current perceived health status			
A lot better than most and somewhat better than most	55 (56.7)	227 (59.3)	0.269 [+]
About the same as most	41 (42.3)	136 (35.5)	
Somewhat worse than most and a lot worse than most	N <5	20 (5.2)	

FOBT Fecal occult blood test

[+] *p* value calculated by Fischers

Table 3

Caregiver demographics and assistance in health care, 2012 Hopi cancer and chronic disease survey

	All N (%)	F	M	*P*
Type of Caregiver				
Provide care to someone with cancer	9 (10.1)	N <5	6 (14.6)	0.291[+]
Provide care to someone with disease or disability other than cancer	80 (89.9)	45 (93.7)	35 (85.4)	0.646
How long provided care				
1–3 months 98	17 (17.4)	9 (16.7)	8 (19.1)	0.020[*+]
4—6 months	5 (5.1)	N <5	N <5	
More than 6 months-1 year	9 (9.2)	N <5	5 (11.9)	
More than 1–2 years	17 (17.3)	10 (18.5)	N <5	
3—5 years	25 (25.5)	15 (27.8)	11 (26.2)	
More than 5 years	25 (25.5)	14 (25.9)	15 (35.7)	
Assisting in health care				
How often do you go to their medical appointments?				
Always or most of the time	37 (38.1)	22 (40)	15 (35.7)	0.782
About half the time	20 (20.6)	12 (21.8)	8 (19)	
Seldom or never	40 (41.3)	21 (38.2)	19 (45.3)	
Do you usually go into the doctor’s room?				
Always or most of the time	49 (65.4)	33 (73.3)	16 (53.3)	0.188[+]
About half the time	10 (13.3)	5 (11.1)	5 (16.7)	
Seldom or never	16 (21.3)	7 (156)	9 (30)	
Do you understand the health care provider?				
Always or most of the time	65 (87.8)	41 (91.1)	24 (82.8)	0.554[+]
About half the time	N <5	N <5	N <5	
Seldom or never	6 (8.1)	N <5	N <5	

[*] $p < 0.05$

[+] p value calculated by Fischers exact

Table 4

Caregiver burden, 2012 Hopi cancer and chronic disease survey

	All **N = 187**	**M** **N = 65**	**F** **N= 122**	***P***
No difficulty	43 (23)	23 (35.4)	20 (16.4)	0.594
Have experienced difficulty with				
Stress	39 (20.9)	13 (20)	26 (21.3)	0.034[*]
Financial burden	17 (9.1)	7 (10.8)	10 (8.2)	0.48
Don’t have enough time for self	20 (10.7)	N <5	16 (13.1)	0.007[*]
Don’t have enough time for family	17 (9.1)	N <5	13 (10.7)	0.029[*]
Interferes with work	21 (11.2)	10 (15.4)	11 (9)	0.853
Created or aggravated own health problems	9 (4.8)	N <5	8 (6.6)	0.037 +[*]
Affects family relationships	17 (9.1)	N <5	15 (12.3)	0.002 +[*]
Other	N <5	N <5	N < 5	0.624+
	All N = 43	M N = 14	F N = 29	*P*
Greatest difficulty				
Stress	21 (48.8)	7 (50)	14 (48.3)	0.919
Financial burden	N <5	N <5	N <5	0.01[+*]
Don’t have enough time for self	6 (14)	N <5	6 (20.7)	0.08[+]
Don’t have enough time for family	N <5	N <5	N <5	1[+]
Interferes with work	5 (11.6)	N <5	N <5	1[+]
Created or aggravated own health problems	N <5	N <5	N <5	-
Affects family relationships	N <5	N <5	N <5	0.282[+]
Other	N <5	N <5	N < 5 (3.4)	1

[+] *p* value calculated by Fischer’s exact

[*] $p < 0.05$

Table 5

Caregiver Services, 2012 Hopi cancer and chronic disease survey

	All **N= 181**	**F** **N = 110**	**M** **N = 71**	***P***
As a caregiver, what type of services would you like for yourself and/or the person you are taking care of? N (%)				
I don't need extra services	30 (16.6)	15 (13.6)	15 (21.1)	0.964
If services, I would like				
Counseling services	13 (7.2)	10 (9.1)	N <5	0.053 [+]
Education on individuals illness/problem	26 (14.4)	16 (14.5)	10 (14.1)	0.243
Transportation services	16 (8.8)	8 (7.3)	8 (11.3)	0.974
Support group	12 (6.6)	8 (7.3)	N <5	0.254 [+]
Pamphlets/brochures on illness/problem	20 (11)	14 (12.7)	6 (8.5)	0.074
Help in filling out paperwork	24 (13.3)	15 (13.6)	9 (12.7)	0.224
Training on patient care	33 (18.2)	20 (18.2)	13 (18.3)	0.225
Other—see below	7 (3.9)	N <5	N <5	

Other—build ramp inside the home (f), finance supplement for caregiving (m), need handicap accessories (f), new program for the elderly (f), therapy rehab (m), toiletry (f), traditional practices as support mechanism (m)

[+] *p* value calculated by Fischer's exact