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Caregiving among American Indians and Alaska Natives with Cancer

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Abstract

Purpose—Caregivers are an important source of support for oncology patients during cancer diagnosis and treatment, often helping patients manage barriers to care. Our study had three goals: to describe the characteristics of caregivers for American Indian and Alaska Native (AI/AN) oncology patients; to assess the similarities and differences between the perceptions of caregivers and patients regarding barriers to cancer care; and to compare AI/AN caregivers to non-AI/AN caregivers on perceived barriers to cancer care.

Methods—We conducted a structured interview that assessed perceived barriers to cancer care with a paired sample of 98 adult caregivers and 98 AI/AN oncology patients and to assess the degree of agreement between these two groups. We also investigated whether AI/AN and non-AI/AN caregivers had differing perceptions of barriers to cancer care.

Results—Caregivers reported that their role was very meaningful and not highly stressful. Caregivers and patients agreed 70% of the time on specific barriers to cancer care. Both groups overwhelmingly reported financial and family or work issues as major barriers to care, whereas trust in providers was the least frequently endorsed barrier. A comparison of AI/AN and non-AI/AN caregivers revealed that AI/AN caregivers identified confidentiality among clinical staff as a significant barrier, whereas non-AI/AN caregivers perceived financial barriers as more significant.

Conclusions—Finances, family, and work are perceived as the largest barriers to the receipt of cancer care for AI/AN oncology patients. Both patients and caregivers trusted health care providers. Assessing barriers to care early in the assessment process may result in better engagement with cancer treatment by patients and their caregivers.

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CONFLICT OF INTEREST STATEMENT

All authors declare that they have no competing interests and no financial conflicts of interest with the organization that sponsored the research. The authors do have full control of all primary data and agree to allow *Supportive Care in Cancer* to review this data if requested.

Keywords

American Indian; Alaska Native; cancer; caregivers; barrier to care

INTRODUCTION

Cancer remains the second-leading cause of death in residents of the U.S. [1], including American Indians and Alaska Natives (AI/ANs) [2]. Trends in cancer morbidity and mortality suggest that AI/ANs experience more barriers to receiving timely, high-quality screening and treatment than other racial/ethnic groups [3]. Several barriers that affect receipt of cancer care may be particularly relevant to AI/ANs, including distance to treatment centers, limited insurance coverage, transportation difficulties, and differences in cultural expectations and communication styles that may limit understanding between patients and providers.

Recent efforts have tried to illuminate and address these challenges. Patient navigation programs, for example, are effective in reducing delays and interruptions in cancer treatment for both majority [4,5] and AI/AN [6,7] populations. Caregivers are also increasingly recognized as central to the oncology treatment experience [8], since they often serve as liaisons between patients and their health care team. Caregiver duties and responsibilities are multifaceted and often involve logistical, functional, medical, physical, emotional, and even financial support [9]. Much of this support is crucial to surmounting barriers to cancer care.

Research with caregivers has documented both the positive and negative impact of the caregiving experience among medically ill and aging populations. In comparison to white caregivers, those of other racial or ethnic backgrounds tend to report a lower overall burden of stress [10], a higher level of personal meaningfulness [11], and more informal support in their caregiving duties [12]. However, non-white caregivers also tend to have lower annual incomes, provide higher levels of care, and report more unmet care needs than their white counterparts [10]. Caregivers may be at higher risk for incident depression than the general population and more likely to perceive their own physical health as less than optimal. Their immune systems are also more likely to be compromised [13–15]. For caregivers of oncology patients, such adverse mental and physical health outcomes are well-documented [16]. Few studies, however, have examined the caregiving experience in AI/AN communities [17–20]. Like other non-white populations, AI/ANs tend to regard their caregiving activities as highly meaningful and personally satisfying, and they report manageable levels of stress [19]. However, most research to date has focused on caregiving for elderly or other chronic disease populations and has applied diverse measures of stress and satisfaction, so that comparisons between AI/ANs and other demographic groups pose difficulties.

This study has three objectives. First, we provide a qualitative description of caregivers for AI/AN oncology patients with a focus on demographic characteristics, health-related quality of life, caregiving stress burden, and meaningfulness of care provision. Second, we assess the concordance between caregivers and AI/AN oncology patients on specific barriers to cancer care. Third, we compare AI/AN and non-AI/AN caregivers to determine if any cultural differences exist in perceived barriers.

METHODS

Study design

The Surveillance, Epidemiology, and End Results (SEER) program provided contact information for oncology patients aged 21–85 years, diagnosed with cancer between January 2009 and January 2012, who were living in 13 counties in northwest Washington State. SEER is a population-based database that assesses the incidence and outcomes of cancer in people residing across the U.S. We selected those patients who had been coded within the SEER as being AI/AN. Before any patients were contacted, all physicians listed in the SEER registry had the option of withdrawing their own patients from the study for any reason. SEER then mailed a letter to the remaining eligible patients to introduce the study, offering the option of calling a toll-free telephone number if they preferred to opt out.

After patients exercised their option to decline, research staff at the University of Washington contacted the remaining eligible respondents to obtain verbal consent to enroll in the study and to confirm AI/AN race/ethnicity. Interested AI/AN oncology patients completed a structured interview either by telephone or in person to assess their cancer care experiences. Patients were asked if they had a caregiver during their cancer treatment, and if research staff could contact caregivers for inclusion in the study. We used similar verbal consent procedures for caregivers. Patients were invited to participate even if their caregivers declined, however, only those patients and caregivers who agreed to be interviewed were included in the present study.

Culturally-competent research staff administered individual interviews with AI/AN patients and caregivers. All research staff, some of whom were of AI/AN race/ethnicity, involved in this project have extensive experience working with other AI/AN health promotion research programs through the University of Washington. Each interview lasted about 45 minutes and included several verbally-administered questionnaires. Each participant received \$50 on completion of the interview. Participants who completed the informed consent process but declined the interview received \$5 each. Study protocols and survey instruments were approved by the Fred Hutchinson Cancer Research Center Institutional Review Board. Interviews were conducted between September 2011 and May 2012.

Participants

A total of 427 AI/AN adults were identified from the SEER registry of western Washington. Fifty-eight patients were initially excluded because they had been misdiagnosed, misidentified in the SEER registry as AI/AN after being contacted by phone, removed from study eligibility by their physicians, or reported as deceased by their physicians. Of the remaining 369 patients, another 207 patients opted out, were deemed ineligible, could not be contacted, or were deceased. A total of 162 AI/AN patients were eligible for participation, of whom 143 completed the interview, for a participation rate of 88%. Approximately 80% (N = 114) of AI/AN cancer patients reported having a caregiver, of which, 98 caregivers consented to the study and completed the surveys. All study participants completed the interviews in English. The present study reports on the 98 matched-pair datasets that include

AI/AN oncology patients and their caregivers, for a combined total of 196 patients and caregivers.

Measures

Demographics—Self-reported demographic data on caregivers included sex, age, race/ethnicity, marital status, education level, annual income, and relationship to the oncology patient. Similar demographic variables were collected for patients. Age was measured continuously in years. The percentage of caregivers who self-identified as AI/AN was calculated. Marital status was dichotomized according to married or living with partner versus all other categories. Education was categorized as 12th grade or less, high school graduate, some college, or college graduate. Annual personal income was dichotomized as above or below \$15,000. We did not assess if caregivers were paid in their role. Caregiver relationship was categorized as spouse/partner, immediate family (e.g., child, sibling, parent), extended family (e.g., cousin, in-law), or “friend, companion, other.”

Health-related quality of life—The Veterans RAND 36 Item Health Survey (VR-36) was used to assess health-related quality of life across eight domains of functioning: physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, energy/vitality, social functioning, role limitations due to emotional problems, and mental health [21]. These eight subscales were combined into two higher-order scales, the physical component score (PCS) and the mental component score (MCS), which were used in the present study.

Caregiver stress index—We generated 16 items to assess the burden of stress on caregivers across multiple domains, including reductions in personal time, strain on the relationship with the patient, neglect of other important relationships, financial hardship, anxiety, and ability to attend to one’s own personal medical needs. Caregivers rated the degree of perceived stress attributable to their caregiving activities on a 4-point scale, ranging from 1 = “not at all” to 4 = “a lot.” We calculated a total caregiver stress burden score by summing all responses (possible range 16–64). The internal consistency for the caregiver stress index in the present study was .93.

Caregiver meaningfulness index—We generated two items on caregiver meaningfulness to assess the degree to which they found caregiving rewarding and the degree to which they felt that they were doing something important. Responses in this area used the same scale as responses to the items used in the caregiver stress index. We calculated a total caregiver meaningfulness score by adding these responses together (possible range 2–8). The internal consistency for the caregiver meaningfulness index in the present study was .70.

Barriers to cancer care—The Barriers to Care questionnaire used in the present study is a 24-item measure based on a 19-item Barriers to Care measure used in a previous investigation of AI/AN health [22]. Before beginning this study, we conducted focus groups with AI/AN patients and their caregivers. Focus group participants recommended including five additional concerns in the original barriers questionnaire: too much paperwork is

required; doctors do not explain things in an understandable way; lack of privacy as an important concern; clinic staff might talk to other people about patients' health problems; and other people might have negative perceptions of cancer patients. We classified the resulting 24 items into five barrier domains: finances, access, privacy/trust, language/communication, and family/work responsibilities. Caregivers and AI/AN patients reported whether each barrier item was "not a problem," "a small problem," or "a big problem" in obtaining needed cancer care. As in previous research [22], we combined "a small problem" and "a big problem" into a single category to identify self-reported barriers to care.

Statistical analyses

We calculated descriptive statistics for caregivers, including demographics, health-related quality of life (PCS and MCS), stress index, and meaningfulness index. Frequencies among caregivers and patients were calculated for each barrier item and each barrier domain. Proportions tests with Yates' continuity correction were applied to assess homogeneity. Survey items with heterogeneous problem frequencies were counted as either problematic or not problematic. For marginal inference on domains, responses were treated as independent and aggregated item-wise.

To determine agreement between caregiver-patient dyads, we calculated conditional odds ratios by using McNemar's test for paired responses. AI/AN and non-AI/AN caregivers were then compared with proportions tests for frequencies of barrier responses.

RESULTS

Participant characteristics

Table 1 outlines the means and frequencies for demographic and behavioral variables in our paired sample of patients and caregivers. The average age of caregivers was 52 years, and most were female, married or partnered, college educated, and earning more than \$15,000 per year. Slightly over half of caregivers were AI/AN. The vast majority were either spouses (54%) or immediate family members (30%) of the patients for whom they cared. In general, patients were slightly older than their caregivers, but otherwise the two groups were similar. Most patients were female, married or partnered, and college educated, with an annual income above \$15,000.

Health-related quality of life, stress, and meaningfulness

The mean PCS and MCS scores for caregivers were 46.4 (SD ± 11.5) and 47.5 (SD ± 12.2), respectively. These scores are consistent with national averages among individuals of the same age and sex. The mean PCS and MCS scores for patients were 37.7 (SD ± 11.4) and 45.8 (SD ± 13.0), respectively. These values fall near the lowest quartile of national population-based scores, indicating more self-reported physical and emotional distress in patients than in their caregivers. Caregiver stress was rated in the low range, while caregiver meaningfulness was in the high range.

Comparing caregivers and patients on barriers to cancer care

Table 2 compares caregivers of any race and AI/AN oncology patients on the frequency of endorsing each questionnaire item as a barrier. Patients tended to report slightly more items (28%) as barriers than caregivers (26%), although 70% of the time, both caregivers and patients agreed that a particular item was a barrier. Finances were equally regarded as the principal barrier domain by caregivers (37%) as well as patients (37%). In particular, worry that patients could not afford to pay for medical care was the most frequently endorsed financial barrier for both caregivers (42%) and patients (53%). However, caregivers tended to express more concern over financial issues less directly related to care, such as prescription medication and insurance, whereas patients were more concerned by financial uncertainties, such as which services were covered by insurance and where to ask questions. Responsibilities for family and work were frequently endorsed as a barrier, at 44% for caregivers and 48% for patients. Lack of trust in providers was least likely to be endorsed as a barrier by caregivers and patients; however, patients were more likely than caregivers to consider it a barrier ($p < .01$). Caregivers, on the other hand, tended to report logistical issues as major barriers, including clinic hours and transportation difficulties.

Comparing AI/AN and non-AI/AN caregivers on barriers to cancer care

Table 3 compares AI/AN to non-AI/AN caregivers on the frequency of endorsing each item in the Barriers to Care questionnaire as a barrier. AI/AN caregivers considered financial issues to be barriers less often than non-AI/AN caregivers ($p < .01$). In particular, worry about unexpected charges ($p < .04$) and worry about the cost of prescription medications ($p < .02$) were rated as a barrier significantly more often by non-AI/ANs than by AI/ANs. Non-AI/AN caregivers were less likely to endorse gossip among clinic staff as a barrier than were AI/AN caregivers ($p < .05$), although both groups showed a similar level of concern over providers' respect for AI/AN culture.

DISCUSSION

Cancer is a prevalent and often chronic condition for which a great deal of effort is needed to orchestrate and deliver optimal care. Paid and unpaid caregivers play a central role in supporting cancer patients, managing the logistics of their treatment, and assisting in treatment delivery. Although studies increasingly recognize both the positive and negative implications of the caregiving experience [9,16], few have investigated these outcomes among caregivers for AI/AN oncology patients. Our study examined the characteristics of such caregivers, the concordance between caregivers and AI/AN patients regarding their perceptions of barriers to medical care, and the patterns of similarities and differences among AI/AN and non-AI/AN caregivers regarding such perceptions.

As in the existing literature [10–12], our sample of cancer caregivers had mixed ethnic and racial origins. Most were middle-aged, female, and the spouse of the patient for whom they cared. In contrast to studies that focused exclusively on AI/AN caregivers and chronically ill AI/AN patients [17,19], our caregivers tended to be older and were more likely to be college-educated. These demographic differences may be due to geographic sampling effects, as our study drew from a largely urban population, whereas earlier studies have

sampled rural AI/ANs. Furthermore, it is possible that urban AI/ANs with some college education may have been more willing to participate in the study as they may be more familiar with completing questionnaires and have greater phone availability of phone contact than rural AI/ANs.

Previous research suggests that the burden of stress among oncology caregivers is not only high but comparable to the burden among dementia caregivers [9]. Nevertheless, caregivers in the present study reported that their care brought relatively low stress and was highly meaningful. These characteristics may help to sustain their health and engagement in caregiving over the long term. Other studies have documented the negative impact of care provision, noting compromised immune system functioning [15] and higher rates of clinical depression [12–14] among caregivers than non-caregivers. Therefore, we recommend the use of structured clinical interviews to assess objective health outcomes and to diagnose mood and anxiety disorders in future research with AI/AN caregivers. We also note that caring for oncology patients is typically a commitment lasting for months or years. Longitudinal examination of stress biomarkers over the duration of caregiving may therefore yield important insights into the effect of care on caregivers' health.

Our association of caregiving with low stress and great personal meaning closely corresponds to the results of other studies with caregivers from minority populations [10–12], including AI/ANs [17–20]. Non-white caregivers typically find the caregiving experience to be positive. Although our caregiver sample included both AI/ANs and non-AI/ANs, all cared for AI/ANs. Traditional cultural values in AI/AN communities, such as promoting honor, maintaining dignity, cultivating spirituality, and upholding family responsibilities and intergenerational support [17], may partially explain these results in the context of an objectively stressful commitment to care.

Caregivers may also serve the unique role of re-connecting AI/AN patients to important cultural beliefs, values, and practices that were interrupted during medical treatment [17]. Future studies may wish to explore these and other factors involved in resiliency, because they could help caregivers and their patients cope with the physical and emotional stress of cancer management.

Concern over finances was the most frequently reported barrier to cancer care among caregivers and patients. Financial instability for both caregivers and patients can stem from work absences, loss of employment, limited insurance coverage, and expenses incurred by travel to treatment centers. Finances are a common source of worry for oncology patients of all races [24], among whom high levels predict delays in seeking care for colorectal cancer symptoms [25] and follow-up medical treatments among cancer survivors [26]. In a nationally representative sample of cancer survivors, about one-third reported significant financial problems that predicted delay or omission of follow-up medical care, including filling prescriptions and seeking mental health treatment [27]. Relative to the general U.S. population, cancer patients are much more likely to forgo medical appointments and prescription medications because of cost [24]. Delaying cancer screening, treatment, and follow-up for any reason can place patients and their caregivers at higher risk of disease burden. Assessing financial concerns early and often in the course of cancer treatment and

follow-up may be essential to mitigate problems arising from delaying or forgoing care. Social workers might play an important role in future efforts to help patients and their caregivers connect with social service programs and other resources.

Family and work responsibilities were also frequently endorsed as a barrier by our sample, consistent with previous research in other cancer populations [28–30]. An earlier study with general medical patients noted that AIs were more likely than Whites to report family and work responsibilities as a significant barrier to medical care [22]. In that study, only 13% of caregivers and 20% of patients identified lack of childcare as a barrier, while 44% of caregivers and 48% of patients identified work or family responsibilities as a significant barrier. Unfortunately, our measure assessed family and work only at a generic level. A more precise analysis of specific familial barriers, such as caring for family members, doing housework, and preparing meals, as well as specific work barriers, such as reductions in working hours, reductions in wages, and changes in job responsibilities, would be needed to determine which barriers are most relevant to caregivers and patients. It is possible that these two groups differ considerably regarding the relative roles of family and work in presenting barriers to care. It is also possible that disruptions in family and work responsibilities are intertwined with financial pressures, such that family and work barriers predict the onset of financial problems over time.

Like previous studies comparing AI and white medical patients [22], we found that trust was less frequently endorsed than other domains as a barrier to care. Our focus groups with AI/AN caregivers and patients before beginning the present study recommended adding three items on privacy and trust to the Barriers to Care questionnaire. In this domain, lack of trust in one's doctor and perceiving that the doctor did not understand Native culture were the most frequently endorsed barriers by our sample, yet relatively few participants shared these perceptions. We find it encouraging that both caregivers and patients rarely reported that doctors did not respect Native religious and cultural beliefs, or that they worried about inappropriate discussions of patients' health problems, that they were concerned by what other people might think of their illness, and that cancer centers were not welcoming. Positive perceptions in all these areas are likely to help patients engage better with their treatment. Culturally appropriate education for provider teams who work with AI/AN oncology patients might further help to alleviate these concerns, and thereby to facilitate the navigation and treatment process.

Additional items on the Barriers to Care questionnaire differentiated AI/AN patients from caregivers. For example, caregivers tended to rate retention concerns over their healthcare coverage and having transportation available higher than patients. Likewise, patients reported greater concerns over not knowing where to go for help and not having trust in their doctor than caregivers. Although these between-group differences were not statistically significant, the relative magnitude of these differences may deserve further investigation with a larger sample.

AI/AN and non-AI/AN caregivers in our study tended to endorse barrier items in a similar manner. The principal exception to this generalization is that non-AI/ANs reported more concerns about finances, while AI/ANs reported more concerns about gossip among clinic

staff. Nevertheless, the high level of concordance between caregiver groups is encouraging, because such concordance will allow cancer treatment programs to adopt standardized screening protocols for barrier concerns. Identifying caregiver- and patient-specific barriers at the point of care is essential to maximize problem-solving and identify resources that will improve cancer treatment outcomes.

Our study has several limitations. First, we assessed an urban population of AI/AN patients and caregivers. Perceived barriers to care may be quite different for rural residents. Second, both patients and caregivers may have experienced recall bias, given a lapse as long as 3.5 years between the initial cancer diagnosis and our study activities. Furthermore, our recruitment process may have been biased towards capturing longer-term cancer survivors and their caregivers. Thus, it is possible that patient-caregiver dyads who experienced substantial barriers to care are not fully represented in our data. Finally, our findings are based solely on self-report, so we have no objective way to validate any reported barriers. It would be especially useful to determine whether care barriers are associated with other relevant factors involved in cancer management, such as treatment satisfaction, perceived social support, delays or interruptions in care, and long-term treatment outcomes.

Despite these limitations, the present study contributes to the emerging literature on the cancer experience among AI/ANs, a historically underserved and understudied population. Persistent barriers to cancer care may place patients at risk for delayed assessment, interruptions in treatment, incomplete treatment, and inadequate follow-up. We recommend screening oncology patients and their caregivers for potential barriers to care, especially financial, family, and work barriers, as an integral part of the initial assessment for patient navigation programs. Tailoring such programs to meet the cultural needs of Native people, to educate caregivers, and to reduce barriers to cancer treatment is imperative to reducing population health disparities.

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Table 1

Means, standard deviations (SD), and frequencies for study variables among paired caregivers (N = 98) and patients (N = 98).

Variable	Caregiver (N=98)	Patient (N=98)
Female, % (N)	67.3 (66)	59.2 (58)
Age, mean (SD)	51.5 (13.1)	56.2 (13.2)
Married/living with partner, % (N)	76.3 (74)	70.4 (69)
American Indian/Alaska Native, % (N)	52 (51)	100 (98)
Education, % (N)		
Less than 12 years	15.3 (15)	30.6 (30)
High school graduate	21.4 (21)	14.3 (14)
Some college	41.8 (41)	36.7 (36)
College graduate	21.4 (21)	18.4 (18)
Annual income above \$15,000, % (N)	77.2 (71)	77.1 (74)
Relationship to patient, % (N)		
Spouse	54.1 (53)	
Immediate family	29.6 (29)	
Extended family	5.1 (5)	
Friend, companion, other	11.2 (11)	
VR-36, mean (SD)		
Physical component score	46.4 (11.5)	37.7 (11.4)
Mental component score	47.5 (12.2)	45.8 (13)
Caregiver stress index, mean (SD)	30.3 (11.6)	
Caregiver meaningfulness index, mean (SD)	7.43 (1.11)	

VR-36 = Veterans RAND 36-Item Health Survey.

Table 2

Percentage reporting problems among patient and caregiver dyads (N=98) on the 24-item Barriers to Care questionnaire.

	Patient Problem (%)	Caregiver Problem (%)	% discordant
OVERALL	27.6	26.0	29.8
Financial			
<i>Total</i>	37.0**	36.7**	37.8
Medical care is unaffordable	52.6**	41.8**	43.3
Insurance won't cover medical care	32.7	38.8**	34.7
Costs are higher than expected	40.6**	43.9**	37.5
Medications cost too much	34.7	38.8**	28.6
Retention concerns over health care program	20.2	30.5	41.7
Unsure which procedures are covered	41.2**	38.9**	40.0
Unsure where to go for help	35.7	24.0	39.6
Access			
<i>Total</i>	22.6**	23.7	28.5
Having transportation	23.5	31.6	22.4
Knowing where to go	18.4	25.5	31.6
Clinic or office hours	15.5*	22.9	30.5
Paperwork	23.5	23.7	27.8
Provider choice	21.6	12.5**	29.5
Timely appointments	33.0	25.8	29.2
Trust			
<i>Total</i>	20.1**	14.1**	23.6[†]
Concerns about privacy	20.4	15.3	27.6
Confidentiality among staff	12.2**	11.2**	21.4
Perceptions of other people	32.7	14.3*	30.6 [†]
Doctors don't understand Native culture	28.1	24.0	33.0
Doctors don't understand Native religious beliefs	13.5**	7.2**	15.8
Care center is not welcoming	8.2**	7.1**	11.2
No trust in doctor	25.8	19.4	25.8
Language			
<i>Total</i>	27.7	20.7	31.2

	Patient Problem (%)	Caregiver Problem (%)	% discordant
OVERALL	27.6	26.0	29.8
Doctors speak different languages	21.6	11.3 **	19.8 †
Doctors don't explain things in understandable ways	33.7	30.2	42.7
Access			
Total	37.3 **	29.7	30.1
Work or family responsibilities	48.0 **	43.9 **	36.7
Childcare	20.0	13.1 *	19.0

1: p-values were calculated from tests of homogeneity by using the total of 24 item responses as proportions, significance levels *: p<0.05, ** p<0.01. In patients, the average frequency of problems was 27.6% and in caregivers, it was 26.0%. P-values were also calculated from McNemar's paired test for dichotomous data, significance levels †: p<0.05

Table 3

Percentage reporting problems among American Indian and Alaska Native (AI/AN) caregivers (N=51) non-AI/AN caregivers (N=47) on the 24-item Barriers to Care questionnaire.

	AI Caregiver Problem (%)	Non-AI Caregiver Problem (%)	% difference
Financial			
Total	31.1 **	42.8 **	-11.7 ††
Medical care is unaffordable	33.3	51.1 **	-17.8
Insurance won't cover medical care	39.2 *	38.3	0.9
Costs are higher than expected	33.3	55.3 **	-22.0 †
Medications cost too much	27.5	51.1 **	-23.6 †
Retention concerns over health care program	28.6	32.6	-4.0
Unsure which procedures are covered	36.7	41.3 *	-4.6
Unsure where to go for help	18.4	29.8	-11.4
Access			
Total	24.3	23.1	1.2
Transportation	31.4	31.9	-0.5
Knowing where to go	25.5	25.5	0.0
Clinic or office hours	26.5	19.1	7.4
Paperwork	24.0	23.4	0.6
Provider choice	14.0	10.9 *	3.1
Timely appointments	24.0	27.7	-3.7
Trust			
Total	16.1 **	11.9 **	4.2
Concerns about privacy	19.6	10.6 *	9.0
Confidentiality among staff	17.6	4.3 **	13.3 †
Perceptions of other people	19.6	8.5 *	11.1
Doctors don't understand Native culture	24.5	23.4	1.1
Doctors don't understand Native religious beliefs	4.0 *	10.6 *	-6.6
Care center is not welcoming	9.8 *	4.3 **	5.5
No trust in doctor	17.6	21.3	-3.7
Language			
Total	23.0	18.3	4.7
Doctors speak different languages	12.0	10.6 *	1.4
Doctors don't explain things in	34.0	26.1	7.9

	AI Caregiver Problem (%)	Non-AI Caregiver Problem (%)	% difference
understandable ways			
Access			
Total	26.8	32.9	-6.1
Work or family responsibilities	39.2	48.9	-9.7
Childcare	13.0	13.2	-0.2

1: p-values were calculated from tests of homogeneity by using the total of 24 item responses as proportions, significance levels *: p<0.05, **: p<0.01. In patients, the average frequency of problems was 27.6% and in caregivers, it was 26.0%. P-values were also calculated from test for proportions data, significance levels †: p<0.05, †† p<0.01.