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Medical Mistrust and Less Satisfaction With Health Care Among Native Americans Presenting for Cancer Treatment

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Abstract

Purpose—To assess barriers to cancer care among Native Americans, whose health outcomes compare unfavorably with those of the general U. S. population.

Methods and patients—We undertook a comparative community-based participatory research project in which newly-diagnosed cancer patients were prospectively surveyed using novel scales for medical mistrust and satisfaction with health care. Socio-demographic information was obtained. Mean scale scores for mistrust and satisfaction were analyzed by race. Multi-variable models were used to adjust for income, education level, and distance lived from cancer care institute.

Results—Participation refusal rate was 38%. Of 165 eligible patients, 52 were Native American and 113 were non-Hispanic White. Native Americans expressed significantly higher levels of mistrust ($p=.0001$) and lower levels of satisfaction ($p=.0001$) with health care than Whites. In multivariable analyses, race was the only factor found to be significantly predictive of higher mistrust and lower satisfaction scores.

Conclusion—Native Americans exhibit higher medical mistrust and lower satisfaction with health care.

Keywords

Native Americans; American Indians; medical mistrust; health disparities; health care; satisfaction

Cancer mortality rates for Native Americans are among the highest of all racial and ethnic groups in the United States.^{1–3} Investigators have also reported other cancer-related disparities among Native Americans, such as lower rates of screening utilization¹ and higher rates of advanced-stage disease at presentation.^{1,2,4–6} Furthermore, Native Americans in the Northern Plains region of the U. S. have age-adjusted mortality rates that are significantly higher than rates for Whites for certain cancers for which effective screening tests exist, such as cervical cancer (79% higher), colorectal cancer (58% higher), and prostate cancer (49% higher).⁷ A growing literature regarding health disparities has begun to illuminate causes for differences in health outcomes for various racial and ethnic groups.^{8,9} Root causes of such disparities are multiple. They arise from patient-, physician-, and health care system related factors. For Native Americans, patient-related factors may include mistrust of physicians or hospitals or lack of knowledge/health literacy concerning preventable diseases;^{10–12} physician-related factors may include lack of cultural competency in caring for this racial/ethnic group; and health-system-related factors may include issues related to the unique health care system (and its funding status) under which many Native Americans receive health care.^{13–15} However, scant literature focuses specifically on Native American health disparities and few studies have specifically sought to study causes of disparities disfavoring Native American cancer patients.

Patient-related factors contributing to disparities include socioeconomic status, cultural differences, and limited health care literacy. Many interventions aimed at overcoming these impediments require trust between health care providers and vulnerable populations. Mistrust of and dissatisfaction with the health care system have been most thoroughly investigated as barriers for African American patient populations.^{16–19} Evidence exists that Native Americans also feel mistrust of health care providers and dissatisfaction with their health care experiences.^{20,21} However, no studies have been conducted that examine these attitudes among Native American cancer patients. Data exploring trust and perceptions of health care are critical in helping to formulate interventions in this vulnerable population. Effective clinical care for Native Americans requires understanding and sensitivity regarding attitudes and beliefs about health care.

In 2003, a review of the Rapid City Regional Hospital (RCRH) (Rapid City, South Dakota) tumor registry (1990–2000) revealed that 50% of Native Americans presenting with breast, colorectal, prostate, cervical, or lung cancer presented with stage III–IV disease, compared with only 36% of non-Native Americans presenting with those cancers having the disease at an advanced stage.^{4,5} The RCRH is a regional facility that provides secondary and tertiary cancer care for approximately 60,000 adult Native Americans living on nearby reservations, in surrounding rural communities, and in Rapid City itself. In 2003, RCRH was awarded a Cancer Disparities Research Partnership (CDRP) grant to study the causes of cancer-related racial and ethnic disparities and to develop effective interventions to eliminate these disparities. Since that time, a multi-faceted, community-based participatory research and intervention effort has been forged to explore root causes of racial and ethnic disparities in Rapid City and surrounding areas, promote screening and prevention, enroll Native Americans in clinical trials, and provide patient navigation through cancer treatment.^{4,5,22} As part of this effort, we undertook a comparative study to examine mistrust and satisfaction with the health care system and to determine whether there are differences in these attitudes by race. We hypothesized that Native American cancer patients mistrust the health care system more and perceive the health care system more negatively than White patients.

Methods

Study population

We prospectively surveyed Native American and non-Native American cancer patients presenting for cancer treatment at Rapid City Regional Hospital's Cancer Care Institute (CCI), in Rapid City, South Dakota, between February 2005 and May 2007. This research initiative was part of the greater Walking Forward Program, described elsewhere,^{5,22,23} which is a community-based participatory research and service initiative based at RCRH. The Rapid City Regional Hospital CCI and the Walking Forward Program serve patients living in the region surrounding Rapid City, South Dakota, and are major secondary and tertiary cancer services providers for the Oglala Sioux Tribe (Pine Ridge), Cheyenne River Sioux Tribe, Rosebud Sioux Tribe, and Rapid City Native American community. Patients from these tribal communities represent the majority of Native Americans treated at CCI.

For this study, all adult patients presenting to the clinic were asked upon registration by the hospital staff at CCI if they would consent to being approached by our research staff regarding participation in the survey. This consent was not informed consent for the survey administration, but rather a brief intake/patient-contact permission to have non-clinical/research staff contact the patient and have access to records to determine eligibility for the study. This step was necessary to bridge the clinical and potential research aspect of patients' experiences in this community/regional hospital that did not historically have research as part of its mission. If the patient refused to be approached, then no research staff accessed the demographic or clinical records of the patient as stipulated by the protocol approved by the hospital's institutional review board (IRB). If patients consented to be approached, then eligibility was determined by the research staff.

Patients were eligible to be surveyed if they were 18 years of age or older and planning to return to the CCI for further care (surveys were administered in a face-to-face interview at a subsequent visit). To minimize survivor bias and bias potentially incurred from contact with CCI staff, patients were surveyed prior to or within two weeks of the initiation of cancer treatment. Patients were excluded if they had a prior history of a malignancy (excepting non-melanoma skin cancers). If a patient agreed to be approached by research staff and was eligible to participate in the study, the individual was then contacted by research staff to schedule an appointment for a survey interview. Informed consent was obtained from all participants prior to any demographic or clinical data being collected.

All surveys were administered in a face-to-face interview with culturally competent research staff trained in administration of the instrument. Cultural competence was fostered by training received as part of the ongoing grant effort underway in at Rapid City CCI (the Walking Forward Program).^{4,22} Furthermore, most of the Walking Forward Program staff are closely connected with or are members of the Native American communities served by this program. Patients received \$15 upon completion of the survey. Both the instrument and the study protocol were approved by the following entities prior to initiation of this study: the IRB of RCRH, the IRB of the Aberdeen Area Indian Health Service (IHS), Aberdeen Area Indian Health Service (IHS) Tribal Chairman's Health Board, Tribal Councils and Health Departments (Cheyenne River Sioux Tribe, Oglala Sioux Tribe, Rosebud Sioux Tribe), and IHS Hospital Chief Executive Officers (Cheyenne River IHS Hospital, Pine Ridge (Oglala) IHS Hospital, Rapid City Sioux San IHS Hospital, and Rosebud IHS Hospital).

Data source

The data were collected by means of a novel instrument developed after a review of the literature and meetings with focus groups of Native American cancer patients, as well as

research program staff of both Native American and non-Native American background. The domains established for this study were medical mistrust and satisfaction with health care. (The detailed scales and individual items are shown in tabular form in the results section.) The domains to be studied were established by a focus group of eight Walking Forward Program staff, which included Native Americans, non-Native Americans, physicians, nurses, and public health practitioners, as well as one individual trained as a Lakota medicine man. This focus group was lead by the lead author of this paper. Once the domains were identified, it was determined that use of a previously validated instrument was not possible since no instruments specific to Native Americans exist. Furthermore, community participation with this effort required that Native American community members have a say in the development and approval of the survey, which was accomplished through the initial focus group and a subsequent focus group of non-medically-trained/non-public health-trained Native American community members. Whenever possible, items from previously analyzed and reported surveys were included, modified if necessary, and vetted by focus groups. The 9-item battery constituting the scale for mistrust arose from modification of the Medical Mistrust Index developed by LaVeist and colleagues.^{17,19} The seven-item scale for measuring satisfaction with health care was derived from items reported by LaVeist and associates and Zheng and associates.^{17,19,24} Novel items exploring the domains of medical mistrust and satisfaction with health care were included, using general principles of survey development^{25,26} and as deemed appropriate by the focus groups and research program staff.

Focus group goals were to determine conceptual domains and formulate items as well as to eliminate or modify items when existing items in the literature were proposed for inclusion in the instrument. The initial focus group that developed the instrument met twice to assemble the preliminary instrument proposed for this study. A second focus group of eight Native American community members then vetted the proposed instrument. Efforts were made to ensure that community members from all three tribes and the Rapid City Native American community were part of this focus group. This group was co-led by the first author of this paper as well the fourth author, who is a registered nurse as well as a trained Lakota medicine man. This second focus group resulted in minor modifications to the wording of individual items. No items were added or removed as part of this second focus group's deliberations. After this second focus group approved the content of the instrument, tribal health boards and institutional review boards reviewed the instrument, suggested minor modifications to the wording, and approved the instrument as well.

Content validity of the instrument was determined by the focus groups. Two focus groups were enlisted to pilot-test the final survey. The first focus group consisted of eight Native American and non-Native American members of the community research staff, including some who were not a part of the original focus group that developed the survey, but rather who are community research representatives (CRRs). These CRRs have no formal medical/public health training but are members of communities of surrounding tribes (Oglala [Pine Ridge], Cheyenne River Sioux, Rosebud Sioux) and the Rapid City Native American community who are employed by Walking Forward to be trained liaisons between the program and the communities it serves. The second focus group to pilot-test and approve the survey consisted of eight Native American community members, four of whom were cancer survivors. This is the same focus group that is described above for vetting the assembled instrument. The vetting of the instrument described above and the assessment of content validity, cultural appropriateness, and relevance by this focus group was accomplished in one meeting of the group as necessitated by the logistical constraints of some traveling long distances to participate.

Demographic and medical information was obtained from medical record review as well as from non-scaled or descriptive items (such as tribal affiliation, income, employment

information, and education level) in the survey itself. Race and tribal enrollment status was self-reported by the participant.

Study measures

The dependent variables in this study were medical mistrust and satisfaction with health care. Mistrust was measured by a nine-item Likert-type²⁷ battery whereby respondents were asked to rate their agreement with items on a five-point scale including *strongly agree*, *agree*, *I don't have an opinion about this*, *disagree*, or *strongly disagree*. Scoring range was 1–5 (determined by the mean score for items in the scale) with a higher scale score corresponding to a higher level of mistrust. A seven-item battery using the same five-point scale described above was used to measure satisfaction with health care. A higher score corresponded to a higher level of satisfaction with health care. Categorized results are also presented in tabular form in the results section along with details of the scales and items to provide readers an evaluation of the crude data, but the collapsed categories do not reflect the five-point scales used to calculate scale scores.

The main independent variable was race, categorized as Native American or White. No explicit attempt to exclude other racial/ethnic groups was made; however, all non–Native American participants were non-Hispanic White (which is roughly in keeping with the population mix in the region). Other variables (including gender, age, income, educational attainment level, employment status, and distance from the CCI) were also collected.

Statistical analysis

Data analyses were performed using SPSS version 12.0 (SPSS, Inc., Apache Software Foundation, Chicago, IL, USA). The scales showed good content validity, as determined by focus group review by both non–Native American and Native American research staff and cancer patients. Internal reliability for each scale was evaluated by Cronbach's alpha.²⁸ The Cronbach's alpha for the mistrust scale was 0.84, and the Cronbach's alpha for the satisfaction scale was 0.85. These values suggest that the scales showed good internal consistency. Mean scale scores and continuous variables were compared using the non-parametric Mann-Whitney test.²⁹ Differences between proportions for categorical variables were analyzed using the chi-squared statistic or Fisher's exact test, as appropriate. Multivariable analyses examining the effects on mean scale scores when adjustments were made for variables other than race were conducted using multiple linear regression models.

Results

Participation and characteristics of the study population

Of 2,046 cancer patients who were approached to participate in the study, 776 (38%) declined to do so. There was a significant difference by race in the number of patients who declined to participate in the study. Only 8 of 159 Native American patients (5%) declined to participate, while 768 of 1,887 Whites (41%) did so ($p<.0001$). Of the 1,270 patients who agreed to participate, 1,105 were determined to be ineligible due to previous cancer diagnosis and treatment, having been under treatment for longer than two weeks for current cancer diagnosis, or not planning to return to RCRH for further care. Thus, 165 patients (52 Native Americans and 113 Whites) constitute the study population. All 52 Native Americans were enrolled members of a federally recognized tribe. All 113 non–Native Americans were non-Hispanic White.

Baseline characteristics of the patients who took the survey are shown in Table 1. Median annual individual income was significantly lower among Native Americans than among Whites ($p=.0001$), and Native Americans were found to live significantly further from the CCI than

Whites ($p=.0001$). More Native Americans had less than a high school education than their White counterparts ($p = .03$). Cancer-specific characteristics were analyzed by race. For the entire cohort, there was no significant difference by race in the proportion of patients presenting with advanced stage disease (Stage III–IV). A separate analysis of stage at presentation by race was performed on patients with cancers for which there is a screening test available (includes: breast, cervix, colorectal, prostate). When these 88 patients were selected, there was a higher proportion of Native Americans (45%) than of Whites (24%) presenting with Stage III–IV disease ($p = .04$). Details of cancer-related characteristics of the study population are shown in Table 2.

Mistrust of the health care and providers

There was a significant difference in mean scale scores for medical mistrust by race. In the univariate analysis, Native Americans exhibited higher mean scores for mistrust than Whites ($p=.0001$). Annual individual income below \$30,000 ($p=.04$) and residing more than 50 miles from CCI ($p=.009$) were also associated with a higher level of mistrust. Univariate analyses for mistrust mean scale scores are shown in Table 3. A multivariable regression model including race, age, gender, employment status, annual income, education level, and distance from CCI revealed that Native Americans exhibited a significantly higher level of mistrust ($p = .008$), even when adjusting for the other variables, as shown in Table 4. The adjusted increase in mean scale score for mistrust by race of 0.46 (95% CI 0.19 to 0.72) approximates the unadjusted difference in mean scale score, 0.40, as shown in the tables. No other variable was associated with a significant difference in mistrust scores in the multivariable model. Categorized responses to individual items in the mistrust scale are shown in Table 5.

Satisfaction with health care and providers

There was also a significant difference in mean scale scores by race for satisfaction with the health care system and providers. As shown in Table 3, Native American patients had lower mean scale scores for satisfaction than did White patients ($p=.0001$). In the univariate analysis, patients whose annual individual income was below \$30,000 ($p=.02$) and who resided further than 50 miles from CCI ($p = .001$) expressed lower levels of satisfaction with health care. The multivariable model analyzing satisfaction mean scale score also showed that Native Americans had significantly lower scores for satisfaction than Whites had ($p = .0001$) even when adjusting for age, gender, employment status, income, education level, and distance from CCI. The adjusted decrease in mean scale score for satisfaction with health care by race of -0.63 (95% CI -0.95 to -0.30) is similar to the decrease in satisfaction score shown in the univariate analysis. No other variable was associated with significantly different levels of satisfaction in the multivariable model (Table 4). Categorized responses to individual items in the satisfaction scale are shown in Table 6.

Discussion

In this study of patients presenting for cancer treatment at a regional cancer center serving a large population of Native Americans, we found that Native Americans were significantly less likely to trust health care providers, clinics, and hospitals than non-Hispanic Whites. Native Americans also expressed lower levels of satisfaction with the health care system than non-Hispanic Whites. These differences in perceptions remain significant even when adjusting for other sociodemographic variables such as annual income, education level, and distance from the cancer care institute. Our data also show that Native Americans continue to present with advanced-stage cancer at significantly higher rates than their non-Hispanic White counterparts for cancers where there is an effective screening test available. We also show that the distribution of types of cancers is comparable to what is expected from national data, with breast, prostate, lung, and colorectal malignancies—three of these screen-detectable and one

possibly preventable through smoking cessation/prevention—being the most common malignancies in this region.^{30,31} These findings, along with other investigations documenting poorer cancer-related health outcomes among Native Americans,^{1–5,7} underscore the need for investigation of root causes of health disparities in this population.

Very few studies specifically examine Native American attitudes regarding the health care system; ours is the first looking specifically at Native American cancer patients. Hunt and colleagues²¹ compared levels of trust in and satisfaction with physicians among multiple racial groups in a community-based survey, and found that trust and satisfaction levels among Native Americans were among the lowest. The differences in attitudes persisted when adjustments were made for health plan type, suggesting that these issues go beyond restrictiveness of health plan coverage or provider choices. In an analysis of factors influencing health care utilization by Native Americans covered by a state-run public health care plan, Call and colleagues¹⁰ reported that low trust/confidence in health care providers was among barriers to receiving general medical care in their study population. Additionally, Roberson and associates¹¹ identified lack of trust in medical care among Native Americans in a study examining clinical trial participation among racial/ethnic groups. These data, along with our findings, demonstrate that trust and perceptions of quality of care are significant potential impediments to eliminating health disparities disfavoring this vulnerable population.

There are important clinical and public health implications of high levels of mistrust and low levels of satisfaction with health care providers and institutions among Native Americans. Trust is a linchpin in the provision of high-quality care,³² especially when healthy individuals are being asked to undergo screening or sick patients to adhere to complex treatment recommendations. Cancer treatment often involves multi-modal, protracted treatment regimens that can be overwhelming for even the most trusting and medical-savvy of patients. Native American patients represent a geographically isolated and socioeconomically marginalized population with historical reasons for mistrust of health care providers and institutions.^{13–15} Furthermore, the Indian Health Service (IHS), which provides free primary care and contract-care specialty services for approximately one-third of the over 4 million people in the U.S. who identify themselves as Native American, is perennially underfunded,^{13–15} thus hobbling a primary source of screening and timely cancer care. While increasing the flow of resources to the IHS and health programs for Native Americans is critical, engagement of Native communities in public health interventions and involvement of Native Americans in health care delivery are essential to efforts aimed at reducing cancer-related disparities.

We acknowledge limitations of our study, which include the significantly higher rate of Whites declining to participate compared with Native Americans. This could possibly be explained by the fact that the patient-contact literature inviting participation disclosed that the purpose of the study was to examine causes of cancer disparities disfavoring Native Americans. Non-Native American patients may not have felt their participation would be relevant or perhaps were not motivated to participate. We also used instruments that had not previously been validated to conduct our survey. However, in order to attain community engagement and approval for the study, it was necessary for Native American community members to participate in developing the instrument. Thus, while we did not use a previously validated instrument, we are confident that the instrument we used was culturally appropriate and acceptable based on focus group pilot-testing. Due to the small size of the study population, we were unable to assess whether medical mistrust and satisfaction were predictors for health outcomes such as cancer stage at presentation. However, our instrument showed good reliability and content validity such that further investigation with larger numbers of patients could be performed to examine the relationship of these attitudes to cancer-related health outcomes.

In conclusion, our study is the first to document significantly higher levels of medical mistrust and dissatisfaction among Native American cancer patients, a population with known and persistent cancer-related health disparities. Our findings underscore that successful clinical or public health interventions will require full engagement with and involvement of Native American communities in order to establish trust and deliver culturally competent care. More resources are, of course, needed to eliminate cancer disparities in this vulnerable population. However, an infusion of funding alone will not suffice to improve health care access in a population with demonstrated mistrust of and wariness towards the health care system. We assert, based on our findings and experience, that Native American community members must be recruited and trained to serve as liaisons to the health care system. Culturally responsive programs and interventions should be developed and expanded in health care systems serving Native American patients.

Notes

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Table 1
SOCIODEMOGRAPHIC CHARACTERISTICS OF THE STUDY POPULATION

Characteristic	Total sample (N=165) number (%)	Native American (n=52) number (%)	non-Hispanic White (n=113) number (%)	p-value
Sex				
Male	73 (44)	19 (37)	54 (48)	.18
Female	92 (56)	33 (64)	59 (52)	
Median age	64 yrs	59 yrs	66 yrs	.009
Range	27–86 yrs	34–86 yrs	27–84 yrs	
Education				
Less than high school	26 (16)	13 (25)	13 (12)	.03
High school/GED or more	139 (84)	39 (75)	100 (89)	
Median annual income ^a	\$30,000	\$16,800	\$35,000	.0001
Range	0–\$150,000	0–\$100,000	\$6000–\$150,000	
Annual income ^a				
<\$10,000	15 (10)	9 (21)	6 (6)	.0001
\$10,000–\$24,999	46 (32)	21 (48)	25 (25)	
\$25,000–50,000	51 (35)	7 (16)	44 (44)	
>\$50,000	33 (23)	7 (16)	26 (26)	
Employment status				
Yes	48 (29)	16 (31)	32 (28)	.01
No	36 (22)	18 (35)	18 (16)	
Retired	81 (49)	18 (35)	63 (56)	
Distance lived from CCI				
0–10 miles	59 (36)	6 (12)	53 (47)	.0001
11–50 miles	31 (19)	2 (4)	29 (26)	
51–100 miles	32 (19)	9 (17)	23 (20)	
101–150 miles	22 (13)	17 (33)	5 (4)	
> 150 miles	21 (13)	18 (35)	3 (3)	

^aOnly 147 patients supplied information regarding income.

Percentages may exceed 100%, due to rounding.

Yrs = years

GED = General Education Development high school equivalency test

CCI = Cancer Care Institute

Table 2
CANCER-RELATED CHARACTERISTICS OF THE STUDY POPULATION

Characteristic	Total sample (N=165) number (%)	Native American (n=52) number (%)	non-Hispanic White (n=113) number (%)	p-value
Primary site of cancer				
Bladder	1 (1)	0	1 (1)	NS
Breast	34 (21)	12 (23)	22 (20)	
Central nervous system	1 (1)	0	1 (1)	
Colorectal	23 (14)	9 (17)	14 (12)	
Gastric	7 (4)	2 (4)	5 (4)	
Gynecologic	10 (6)	6 (12)	4 (4)	
Head and neck	4 (2)	2 (4)	2 (2)	
Hematologic	19 (12)	4 (8)	15 (13)	
Hepatobiliary	1 (1)	0	1 (1)	
Lung	28 (17)	10 (19)	18 (16)	
Melanoma	1 (1)	0	1 (1)	
Pancreatic	1 (1)	0	1 (1)	
Prostate	28 (17)	6 (12)	22 (20)	
Seminoma	1 (1)	0	1 (1)	
Unknown primary site	5 (3)	1 (2)	4 (4)	
Other (atypical carcinoid)	1 (1)	0	1 (1)	
Stage at presentation				
Stage I–II (includes DCIS)	80 (48)	21 (40)	59 (52)	.26
Stage III–IV	80 (48)	30 (58)	50 (44)	
Not Staged	5 (3)	1 (2)	4 (5)	
Stage at presentation for breast, cervix, colorectal, prostate ^a				
Stage I–II	61 (69)	16 (55)	45 (76)	.04
Stage III–IV	27 (31)	13 (45)	14 (24)	

^aCancers with screening test

Percentages may not equal 100%, due to rounding.

Table 3
UNIVARIATE ANALYSIS OF MEAN SCALE SCORES FOR MISTRUST SCALE AND SATISFACTION SCALE

Characteristic	Mistrust score ^a (range)	p-value	Satisfaction Score ^b (range)	p-value
Entire cohort	2.1 (1.0–4.7)	—	4.2 (1.0–5.0)	—
n=	161		164	
Race				
Native American	2.4 (1.1–4.7)	.0001	3.7 (1–5)	.0001
White	2.0 (1–4.3)		4.4 (2.7–5)	
Gender				
Male	2.1 (1.1–4.7)	.31	4.2 (1–5)	.58
Female	2.1 (1–4.3)		4.2 (2.3–5)	
Annual Income				
n=	142		144	
<\$30,000	2.2 (1–4.7)	.04	4.1 (1–5)	.02
≥\$30,000	2.0 (1–3.9)		4.4 (2.6–5)	
Education level				
<High school/GED	2.2 (1–3.6)	.36	4.3 (3.3–5)	.94
≥High school/GED	2.1 (1–4.7)		4.2 (1–5)	
Distance from CCI				
≤50 miles	2.0 (1–3.3)	.009	4.4 (2.6–5.0)	.001
> 50 miles	2.3 (1–4.7)		4.0 (1–5)	

^a A higher score corresponds to a higher level of mistrust of the health care system and health care providers.

^b A higher score corresponds to a higher level of satisfaction with the health care and health care providers.

n = number of respondents with scale completed

GED = General Educational Development high school equivalency

CCI = Cancer Care Institute

Table 4
MULTIVARIABLE ANALYSIS SHOWING CHANGES IN MEAN SCALE
SCORES AND 95% CONFIDENCE INTERVAL (CI)

Predictor	Mistrust		Satisfaction	
	Adjustment in mean score (95% CI) ^a	p-value	Adjustment in mean score (95% CI) ^b	p-value
Race				
Native American	0.46 (0.19 to 0.72)	.001	−0.63 (−0.95 to −0.30)	.0001
White	reference		reference	
Gender				
Female	−0.190 (−0.39 to 0.01)	.06	0.12 (−0.12 to 0.36)	.95
Male	reference		reference	
Age (linear)	−0.01 (−0.01 to 0.0001)	.07	0.01 (−0.001 to 0.02)	.08
Education (ordinal)	0.08 (−0.03 to 0.18)	.15	0.01 (−0.11 to 0.14)	.82
Employment status				
No/Retired	0.13 (−0.13 to 0.38)	.32	0.002 (−0.30 to 0.30)	.99
Yes	reference			
Annual Income				
<\$30,000	reference	.16	reference	.29
≥\$30,000	−0.16 (−0.38 to 0.06)		0.14 (−0.12 to 0.40)	
Distance from CCI				
≤50 miles	reference	.96	reference	.83
>50 miles	−0.01 (−0.24 to 0.23)		0.03 (−0.25 to 0.31)	

Note: Eighteen patients did not supply income information. Multivariable analysis was also performed excluding income from the model to see if the absence of these participants in the model influenced the model results. The models not including income showed similar results to the analysis above and thus are not presented here.

^a The influence of each variable on mean scores is adjusted for confounding by other variables using multiple linear regression. An increase in Mistrust mean scale score represents an increase in medical mistrust as measured by this scale.

^b A decrease in Satisfaction mean scale score represents a decrease in satisfaction with health care as measured by this scale.

CCI=Cancer Care Institute

Table 5
MISTRUST SCALE (CATEGORIZED RESULTS)

	Native American N (%)	White N (%)	p-value
Hospitals and clinics often want to know more about your personal business than they really need to know.			.036
Agree ^a	11 (28)	11 (11)	
Neutral	4 (10)	14 (14)	
Disagree ^b	24 (62)	78 (76)	
In the past, clinics and hospitals have done harmful things to patients without their knowledge.			.0001
Agree	24 (62)	26 (25)	
Neutral	8 (21)	27 (26)	
Disagree	7 (18)	50 (49)	
At hospitals and clinics rich patients receive better care than poor patients do.			.523
Agree	13 (33)	25 (24)	
Neutral	5 (13)	18 (17)	
Disagree	21 (54)	59 (57)	
Missing	0	1 (1)	
I worry that doctors and nurses will do experimental studies on me without telling or asking me.			.0001
Agree	11 (28)	5 (5)	
Neutral	3 (8)	3 (3)	
Disagree	25 (64)	95 (92)	
I have put off getting medical care when I have had health problems because I do not trust doctors and nurses.			.008
Agree	8 (21)	5 (5)	
Neutral	2 (5)	2 (2)	
Disagree	29 (74)	96 (93)	
I have put off getting medical care in the past because I felt that I would be treated disrespectfully.			.0001
Agree	9 (23)	2 (2)	
Neutral	3 (8)	1 (1)	
Disagree	27 (69)	99 (96)	
Missing	0	1(1)	
I usually trust doctors.			.195
Agree	33 (85)	96 (93)	
Neutral	2 (50)	2 (2)	
Disagree	4 (10)	4 (4)	
Missing	0	1(1)	
Hospitals are places where people go to die.			.051
Agree	4 (10)	2 (2)	
Neutral	2 (5)	2 (2)	
Disagree	33 (85)	98 (95)	
Missing	0	1	

	Native American N (%)	White N (%)	p-value
People should always follow the advice given to them at hospitals.			.149
Agree	27 (69)	80 (78)	
Neutral	7 (18)	7 (7)	
Disagree	5 (13)	14 (14)	
Missing	0	2 (2)	

^a Agree = strongly agree + agree.

^b Disagree = strongly disagree + disagree.

Table 6
SATISFACTION SCALE (CATEGORIZED RESULTS)

	Native American N (%)	White N (%)	p-value
The hospital or clinic I usually go to provides me with good health care over all.			.0001
Agree ^a	22 (56)	92 (89)	
Neutral	4 (10)	4 (4)	
Disagree ^b	13 (33)	7 (7)	
The medical care providers I usually see treat me with dignity and respect.			.001
Agree	30 (77)	100 (97)	
Neutral	3 (8)	1 (1)	
Disagree	6 (15)	2 (2)	
I feel comfortable talking to doctors when I have a health problem.			.006
Agree	32 (82)	98 (95)	
Neutral	0	2(2)	
Disagree	7 (18)	3 (3)	
The first doctor or nurse that told me I had cancer made sure I understood what to do next to get treatment for my cancer.			.097
Agree	33 (85)	93 (90)	
Neutral	0	4 (4)	
Disagree	6 (15)	6 (6)	
The first doctor or nurse that told me I had cancer listened carefully to my concerns.			.067
Agree	31 (79)	91 (88)	
Neutral	1 (3)	6 (6)	
Disagree	7 (18)	6 (6)	
Before my first visit to the Cancer Care Institute, there was a doctor or nurse available by phone or in person to answer my questions about cancer.			.0001
Agree	24 (62)	78 (76)	
Neutral	1(3)	18 (17)	
Disagree	14 (36)	7(7)	
If I have a question, my doctor will give me a straight answer.			.0001
Agree	25 (64)	96 (93)	
Neutral	4(10)	3(3)	
Disagree	10 (26)	4(4)	

^a Agree = Strongly agree + agree.

^b Disagree = strongly disagree + disagree.