

# Assessing Cancer Stage and Screening Disparities Among Native American Cancer Patients

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## SYNOPSIS

**Objective.** Disparities in cancer-related health outcomes exist among Native Americans. This article assesses barriers to timely and effective cancer care among Native American cancer patients.

**Methods.** We conducted a community-based participatory survey of newly diagnosed cancer patients to assess their basic knowledge of cancer screening and their beliefs about cancer management. Sociodemographic and cancer-related information was obtained from medical records. Mean scores for correct answers to the screening knowledge battery were tabulated and analyzed by race/ethnicity and sociodemographic characteristics. Multivariable regression models were used to adjust for sociodemographic characteristics in evaluating the association between screening knowledge and race/ethnicity.

**Results.** The survey response rate was 62%. Of 165 patients, 52 were Native American and 113 were white. Native Americans with cancers for which a screening test is available presented with significantly higher rates of advanced-stage cancer ( $p=0.04$ ). Native Americans scored lower on the cancer screening knowledge battery ( $p=0.0001$ ). In multivariable analyses adjusting for age, gender, income, education level, employment status, and geographic distance from the cancer center, Native American race/ethnicity was the only factor significantly predictive of lower screening knowledge. Native Americans expressed more negative attitudes toward cancer treatment in some of the items regarding impacts and burden of cancer treatment.

**Conclusions.** Native American cancer patients presented with higher rates of advanced-stage disease for screening-detectable cancers, lower levels of basic cancer screening knowledge, and more negative attitudes about cancer treatment than white patients. Public health interventions regarding screening and cancer education are needed.

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Population-based studies of cancer-related health outcomes have consistently identified that Native Americans have cancer mortality rates that are relatively high compared with other racial and ethnic groups.<sup>1-3</sup> Poorer cancer-related survival persists, even when adjustments are made for the influence of poverty.<sup>1</sup> In the most recent report to the nation on the status of cancer by the Centers for Disease Control and Prevention, analyses of cancer death rates from 1975 to 2004 revealed declining trends in cancer death rates for all racial/ethnic groups except American Indians and Alaska Natives, for whom cancer death rate trends remained level.<sup>4</sup> This suggests that advances in cancer screening, diagnosis, and treatment that are positively affecting cancer outcomes in the U.S. are not reaching this subset of the population. Furthermore, American Indians in the U.S. Northern Plains, where many large reservations are located, have age-adjusted mortality rates that are significantly higher than those for white Americans for cancers for which an effective screening test exists. Specifically, the cancer-specific mortality rates for Native Americans in that region are 79% higher for cervical cancer, 58% higher for colorectal cancer, and 49% higher for prostate cancer.<sup>5</sup>

Upstream of the cancer mortality disparity, investigators also have consistently shown lower rates of screening utilization among Native Americans,<sup>1,4,6-10</sup> and thus, not surprisingly, have found that Native Americans present with disparately high rates of advanced-stage cancer.<sup>1-3,11,12</sup> Root causes for these disparities are multiple, and a growing literature is dedicated to examining and solving the patient-, physician-, and health-care system-related factors that contribute to inequities in health outcomes by race/ethnicity.<sup>13-15</sup> However, relatively few studies focus specifically on Native American health disparities, and even more scant are reports on disparities among Native American cancer patients. More information is needed to understand and address disparate cancer-related health outcomes in this vulnerable population.

In 2003, a review of the tumor registry (from 1990 to 2000) of Rapid City Regional Hospital (RCRH) in Rapid City, South Dakota, revealed that 50% of Native American cancer patients presented with stage III or IV breast, colorectal, prostate, cervical, and lung cancer compared with 36% of non-Native Americans presenting with advanced-stage disease for those malignancies.<sup>12,16</sup> This regional facility provides secondary and tertiary cancer care for approximately 60,000 adult Native Americans living in nearby reservations, surrounding rural communities, and Rapid City itself. In 2003, RCRH was awarded a Cancer Disparities Research Partnership grant to study the causes of

cancer-related disparities and to develop effective interventions to eliminate these inequities. Since that time, a multifaceted, community-based participatory research and intervention effort has been undertaken to explore root causes of disparities, promote screening and prevention, enroll Native Americans in clinical trials, and provide patient navigation through cancer treatment.<sup>11,12,16,17</sup> As part of this effort, we prospectively surveyed patients presenting for cancer treatment to the RCRH Cancer Care Institute (CCI) to determine whether there were differences by race/ethnicity in cancer-related screening knowledge and attitudes about cancer treatment. We hypothesized that Native Americans would have persistent stage disparities for screening-detectable cancers, demonstrate less basic screening knowledge, and express more negative attitudes about cancer treatment and outcomes than their non-Native American counterparts.

## METHODS

### Study population

We surveyed Native American and non-Native American cancer patients presenting for cancer treatment at the RCRH CCI from February 2005 to October 2007. 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 at a subsequent visit). To minimize bias potentially incurred from contact with CCI staff and programs, 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 (except for non-melanoma skin cancers). All adult cancer patients presenting to the CCI were approached upon registration about whether they would be willing to participate. If a patient agreed to participate, the individual was then contacted by research staff to schedule an appointment for a survey interview.

All surveys were administered in a face-to-face interview with research staff trained in administration of the instrument. Patients received \$15 upon completion of the survey. Both the instrument and study protocol were approved by the following entities prior to initiation of this study: the Institutional Review Board of RCRH, the Institutional Review Board of the Aberdeen Area Indian Health Service (IHS), the Aberdeen Area IHS Tribal Chairman's Health Board, Tribal Councils and Health Departments (Cheyenne River Sioux Tribe, Oglala Sioux Tribe, and 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).

Informed consent was obtained from all participants prior to collecting any data.

**Data source**

The data for this analysis came from a novel instrument developed after reviewing the literature and exploratory meetings with focus groups of Native American cancer patients as well as research program staff of both Native American and non-Native American background. Use of a previously validated instrument was not possible because no instruments existed that were specific to Native Americans. Furthermore, community participation required that Native American community members have input into the development of the survey. The eight-item battery assessing basic screening knowledge was partially adapted from items in the 2003 National Health Interview Survey.<sup>18</sup> Eight items were included in the survey to assess beliefs and attitudes regarding cancer treatment and impact on the individual diagnosed with cancer. These items were developed from focus group meetings with community members, cancer patients, and research staff experienced with health-care literacy in the local Native American and non-Native American populations.

Novel items were generated using general principles of survey development,<sup>19,20</sup> as determined to be appropriate by the focus groups and research program staff.

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. The second focus group to pilot test and approve the survey consisted of eight Native American community members, four of whom were cancer survivors. Sociodemographic and medical information was obtained from the medical record as well as from items in the survey itself. Race/ethnicity and tribal enrollment status were self-reported by participants.

**Study measures.** The major dependent variables in the study were basic knowledge of cancer screening and attitudes toward cancer treatment as measured by the batteries and items described previously. Basic knowledge of cancer screening was measured by tabulating a score for an eight-item battery of basic screening questions. The score was determined by summing the number of correct answers to the four items shown in Table 1 and adding that to the number of “yes” answers to the items shown in Table 2. Attitudes toward cancer treatment were assessed using an eight-item battery, whereby respondents were asked to rate their agreement with items on a five-point scale of “strongly

**Table 1. Cancer screening knowledge, true/false battery for cancer patients surveyed at RCRH CCI, Rapid City, South Dakota, 2005–2007**

Screening knowledge statement	Native American (n=52) N (percent)	White (n= 113) N (percent)	P-value
Screening tests for cancer should only be done for people who have symptoms that might be caused by cancer.			
True	9 (17)	12 (11)	0.23
False/I don't know <sup>a</sup>	43 (83)	101 (89)	
Screening tests for cancer only need to be done once in a person's lifetime.			
True	4 (8)	0 (0)	0.003
False/I don't know <sup>a</sup>	48 (92)	113 (100)	
People who do not have a family history of cancer still need to be screened for cancer.			
True <sup>a</sup>	48 (92)	109 (96)	0.49
False/I don't know	3 (6)	4 (4)	
Prefer not to answer	1 (2)	0 (0)	
Only people who smoke need to be screened for cancer.			
True	5 (10)	1 (1)	0.005
False/I don't know <sup>a</sup>	46 (88)	112 (99)	
Prefer not to answer	1 (2)	0 (0)	

<sup>a</sup>Denotes the correct answer, which was given a score of 1 for tabulation of the scores for the battery for screening knowledge. All other answers were given a score of zero.

NOTE: The tabulated score of Table 1 was summed with the tabulated score of Table 2 to comprise the total score for screening knowledge.

RCRH CCI = Rapid City Regional Hospital Cancer Care Institute

**Table 2. Cancer screening knowledge/screening test familiarity battery for cancer patients surveyed at RCRH CCI, Rapid City, South Dakota, 2005–2007**

	Native American (n=52) N (percent)	White (n=113) N (percent)	P-value
A PSA test is a screening test of your blood that tests for prostate cancer in men. Before today, have you ever heard of a PSA test?			
Yes <sup>a</sup>	31 (60)	102 (90)	0.0001
No/I don't know	21 (40)	11 (10)	
A pap test is a screening test that tests for cervical cancer in women. Before today, have you ever heard of a pap test?			
Yes <sup>a</sup>	50 (96)	112 (99)	0.19
No/I don't know	2 (4)	1 (1)	
A mammogram is a screening test that tests for breast cancer in women. It is done by pressing the breasts between plastic plates while an x-ray of the breast is taken. Before today, have you ever heard of a mammogram?			
Yes <sup>a</sup>	52 (100)	113 (100)	No difference
No/I don't know	0 (0)	0 (0)	
A stool blood test can be used to screen for cancer in the bowels or rectum. This can be done by yourself at home using a kit or by your doctor in the hospital or clinic. Before today, have you ever heard of a stool blood test?			
Yes <sup>a</sup>	43 (83)	107 (95)	0.01
No/I don't know	9 (17)	6 (5)	

<sup>a</sup>A "yes" answer was given a score of 1 in tabulation of scores for battery for screening knowledge. All other answers were given a score of zero.

NOTE: The tabulated score of Table 1 was summed with the tabulated score of Table 2 to comprise the total score for screening knowledge.

RCRH CCI = Rapid City Regional Hospital Cancer Care Institute

PSA = prostate-specific antigen

agree," "agree," "I don't have an opinion about this," "disagree," or "strongly disagree." For this analysis, the responses to these eight items were collapsed into three categories: agree ("strongly agree" plus "agree"), neutral ("I don't have an opinion about this"), and disagree ("disagree" plus "strongly disagree").

The main independent variable was race/ethnicity. Other variables including gender, age, income, education level, employment status, and distance of the patient's home from the CCI were also collected.

**Statistical analysis.** Data analyses were performed using SPSS version 12.0.<sup>21</sup> The survey batteries showed good content validity, as determined by the focus group review by both non-Native American and Native American research staff and cancer patients. Mean scale scores for screening knowledge and continuous variables were compared using the nonparametric Mann-Whitney test.<sup>22</sup> Differences between proportions for categorical variables were analyzed using the Chi-square statistic or Fisher's exact test as appropriate. Multivariable analyses examining the effects on mean scale scores when adjustments were made for confounding

by variables other than race/ethnicity 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%) patients declined participation. There was a significant difference by race/ethnicity in the number of patients who declined to participate in the study. Only eight of 159 (5%) Native American patients declined participation, while 768 of 1,887 (41%) non-Native American patients declined participation ( $p < 0.0001$ ). Of the 1,270 patients who agreed to participate, 1,105 patients were determined to be ineligible due to a previous cancer diagnosis and treatment, having been under treatment for longer than two weeks for a current cancer diagnosis, or not planning to return to RCRH for further care. Thus, the study population comprised 165 patients—52 Native Americans and 113 non-Native Americans. All

52 Native Americans were enrolled members of a federally recognized tribe. All 113 non-Native Americans were identified as non-Hispanic white.

Sociodemographic characteristics of the patients who took the survey are shown in Table 3. Native Americans had a significantly lower median annual income ( $p=0.0001$ ) and lived significantly farther from the CCI compared with white patients ( $p=0.0001$ ). Also, a higher proportion of Native Americans had less than a high school or equivalent education compared with white patients ( $p=0.03$ ).

### Cancer-related characteristics of the study population

For the entire cohort, there was no significant difference by race/ethnicity in the proportion of patients presenting with advanced-stage disease (stage III or IV) as shown in Table 4. A separate analysis of cancer stage at presentation was performed for patients with cancers for which a screening test is available (i.e., breast, cervical, colorectal, and prostate.) A total of 88 patients—29 Native American and 59 white patients—presented with breast, prostate, colorectal, or cervical cancers. Of

**Table 3. Sociodemographic characteristics of cancer patients surveyed at RCRH CCI, Rapid City, South Dakota, 2005–2007**

Characteristic	Total sample (n=165) N (percent) <sup>a</sup>	Native American (n=52) N (percent) <sup>a</sup>	Non-Hispanic white (n=113) N (percent) <sup>a</sup>	P-value
Sex				
Male	73 (44)	19 (37)	54 (48)	0.18
Female	92 (56)	33 (64)	59 (52)	
Median age in years	64	59	66	0.009
Age range in years	27–86	34–86	27–84	
Education				
Less than high school	26 (16)	13 (25)	13 (12)	0.07
High school/GED	49 (30)	11 (21)	38 (34)	
Some college/associate's degree	50 (30)	18 (35)	32 (28)	
Bachelor's degree or higher	40 (24)	10 (19)	30 (27)	
Education (dichotomized)				
Less than high school	26 (16)	13 (25)	13 (12)	0.03
High school/GED or more	139 (84)	39 (75)	100 (89)	
Median annual income <sup>b</sup>	\$30,000	\$16,800	\$35,000	0.0001
Annual income range	\$0–\$150,000	\$0–\$100,000	\$6,000–\$150,000	
Annual income <sup>b</sup>				
<\$10,000	15 (10)	9 (21)	6 (6)	0.0001
\$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)	0.01
No	36 (22)	18 (35)	18 (16)	
Retired	81 (49)	18 (35)	63 (56)	
Distance from home to CCI in miles				
0–10	59 (36)	6 (12)	53 (47)	0.0001
11–50	31 (19)	2 (4)	29 (26)	
51–100	32 (19)	9 (17)	23 (20)	
101–150	22 (13)	17 (33)	5 (4)	
>150	21 (13)	18 (35)	3 (3)	

<sup>a</sup>Percentages may not equal 100% due to rounding.

<sup>b</sup>Only 145 patients supplied information regarding income.

RCRH CCI = Rapid City Regional Hospital Cancer Care Institute

GED = general educational development

**Table 4. Cancer-related characteristics of cancer patients surveyed at RCRH CCI by race/ethnicity, Rapid City, South Dakota, 2005–2007**

Characteristic	Total sample (n=165) N (percent) <sup>a</sup>	Native American (n=52) N (percent) <sup>a</sup>	Non-Hispanic white (n=113) N (percent) <sup>a</sup>	P-value
Primary site of cancer				
Bladder	1 (1)	0 (0)	1 (1)	NS
Breast	34 (21)	12 (23)	22 (20)	
Central nervous system	1 (1)	0 (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 (0)	1 (1)	
Lung	28 (17)	10 (19)	18 (16)	
Melanoma	1 (1)	0 (0)	1 (1)	
Pancreatic	1 (1)	0 (0)	1 (1)	
Prostate	28 (17)	6 (12)	22 (20)	
Seminoma	1 (1)	0 (0)	1 (1)	
Unknown primary site	5 (3)	1 (2)	4 (4)	
Other (atypical carcinoid)	1 (1)	0 (0)	1 (1)	
Stage at presentation				
Stage I–II (includes DCIS)	80 (48)	21 (40)	59 (52)	0.26
Stage III–IV	80 (48)	30 (58)	50 (44)	
Not staged	5 (3)	1 (2)	4 (5)	
Stage at presentation for breast, cervical, colorectal, and prostate <sup>b</sup>				
Stage I–II	61 (69)	16 (55)	45 (76)	0.04
Stage III–IV	27 (31)	13 (45)	14 (24)	

<sup>a</sup>Percentages may not equal 100% due to rounding.

<sup>b</sup>Cancers for which there is a screening test. For prostate cancer detection, screening method included either digital rectal examination, prostate-specific antigen testing, or both.

RCRH CCI = Rapid City Regional Hospital Cancer Care Institute

NS = not significant

DCIS = ductal carcinoma in situ

these 88 patients, 13 of the 29 Native Americans (45%) presented with advanced-stage disease compared with 14 of the 59 white patients (24%) ( $p=0.04$ ). Among these patients with screening-detectable cancers, data on the type of diagnostic test that identified their malignancy were available for 84 patients. (For prostate cancer, the screening detection method included digital rectal examination, prostate-specific antigen testing, or both.) The diagnostic test identifying the patient's cancer was a screening test for 39 of 57 (68%) white patients compared with 10 of 27 (37%) Native American patients ( $p=0.006$ ).

#### Cancer screening knowledge

There was a significant difference by race/ethnicity in the mean score for the battery of questions assessing basic screening knowledge, with Native American patients scoring lower than white patients ( $p=0.0001$ )

as shown in Table 5. On univariate analysis, no other factor was associated with significantly lower levels of screening knowledge. Multivariable analysis including race/ethnicity, gender, age, education level, employment status, income, and geographic remoteness from the CCI revealed that only Native American race/ethnicity was significantly associated with lower scores on the screening knowledge scale as shown in Table 6. Of note, the magnitude of the decrement in the unadjusted mean scale score by race/ethnicity (univariate analysis)—shown by a lower mean score of 7.0 for Native Americans compared with a mean score of 7.7 for white patients, a decrement of 0.7—was similar in magnitude to the difference in mean screening knowledge scores by race/ethnicity when adjustments were made for other variables (a decrement of 0.6 in mean scale score for Native Americans compared with white patients in the multivariate analysis). This suggests that

**Table 5. Univariate analysis of mean scale scores for screening knowledge among cancer patients surveyed at RCRH CCI, Rapid City, South Dakota, 2005–2007**

Characteristic	Screening knowledge score <sup>a</sup> (range of 0–8 possible)	P-value <sup>b</sup>
Entire cohort	7.5 (2–8)	—
Race/ethnicity		
Native American	7.0 (2–8)	0.0001
White	7.7 (6–8)	
Gender		
Male	7.6 (6–8)	0.19
Female	7.4 (2–8)	
Annual income <sup>c</sup>		
<\$30,000	7.3 (2–8)	0.06
≥\$30,000	7.6 (6–8)	
Education level		
<High school/GED	7.0 (2–8)	0.09
≥High school/GED	7.6 (4–8)	
Distance from home to CCI		
≤50 miles	7.6 (6–8)	0.06
>50 miles	7.3 (2–8)	

<sup>a</sup>A higher score represents a greater knowledge of cancer screening and screening rationale.

<sup>b</sup>P-values are derived from the Mann-Whitney nonparametric test.

<sup>c</sup>Twenty patients did not supply income information (n=145 for this characteristic; n=165 for all others).

RCRH CCI = Rapid City Regional Hospital Cancer Care Institute

GED = general educational development

the deficit in screening knowledge by race/ethnicity (i.e., lower scores for Native Americans) is not attributable to other sociodemographic characteristics such as income level, educational level, or geographic remoteness from the cancer center. Categorized responses to the individual items in this battery are shown in Tables 1 and 2.

**Attitudes and beliefs about cancer management and control**

The data presented in Table 7 show the differences in attitudes and beliefs about cancer control by race/ethnicity. The first four items probed attitudes regarding prevention, early detection, long-term benefits of cancer treatment, as well as willingness to sustain the rigors of cancer treatment. When asked whether there were things a person could do to lower the risk of getting cancer, there was no difference in the percentage of Native American (83%) and white (85%) patients who agreed with the statement (p=0.42). A high proportion of patients of both racial/ethnic groups agreed that there is a good chance of survival

if cancer is found and treated early (100% of Native Americans and 97% of white patients agreed, p=0.39). A high proportion of both Native American (94%) and white (98%) patients agreed that a good life was possible after surviving cancer (p=0.16). Patients from both races/ethnicities predominantly agreed that many people would undergo cancer treatment even with the considerable emotional and physical burden associated with such treatment (90% of Native Americans agreed and 96% of white patients agreed, p=0.43).

There were significant differences by race/ethnicity in beliefs about the immediate impact of a cancer diagnosis and treatment on a person’s daily life. Sixty-four percent of Native American patients agreed that cancer treatment “always takes many weeks of daily treatment” compared with 41% of white patients who

**Table 6. Multivariable analysis showing changes in mean screening knowledge scores and 95% CIs among cancer patients surveyed at RCRH CCI, Rapid City, South Dakota, 2005–2007**

Predictor	Adjustment in mean score (95% CI) <sup>a</sup>	P-value
Race/ethnicity		
Native American	−0.62 (−1.0, −0.25)	0.001
White	Ref.	
Gender		
Female	−0.18 (−0.47, 0.11)	0.23
Male	Ref.	
Age (linear)	0.01 (−0.01, 0.02)	0.45
Education (ordinal)	0.05 (−0.11, 0.20)	0.54
Employment status		
Not employed/retired	−0.10 (−0.47, 0.27)	0.60
Employed	Ref.	
Annual income <sup>b</sup>		
<\$30,000	Ref.	0.32
≥\$30,000	0.16 (−0.16, 0.49)	
Distance from home to CCI		
≤50 miles	Ref.	0.69
>50 miles	0.07 (−0.27, 0.40)	

<sup>a</sup>The influence of each variable on mean scores is adjusted for confounding by other variables using multiple linear regression. An increase in screening knowledge mean scale score represents an increase in knowledge of cancer screening tests and rationale as measured by this scale.

<sup>b</sup>Twenty patients did not supply income information. Multivariable analyses were 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 are thus not presented here.

CI = confidence interval

RCRH CCI = Rapid City Regional Hospital Cancer Care Institute

Ref. = reference group

agreed with this statement ( $p=0.009$ ). Twenty-nine percent of Native Americans agreed with the statement that cancer treatments “always make people so sick that they are unable to go about their daily lives,” while only 1% of white respondents agreed with this statement ( $p=0.0001$ ). Native American patients (39%)

expressed a belief that cancer treatment “always causes a person’s hair to fall out” in much higher proportions compared with white patients (1%) ( $p=0.0001$ ). A significantly higher proportion of Native American (40%) compared with white (16%) patients also expressed a belief that a cancer diagnosis can result in other people

**Table 7. Beliefs about cancer management and control among cancer patients surveyed at RCRH CCI by race/ethnicity, Rapid City, South Dakota, 2005–2007**

Belief	Native American (n=52)	White (n=113)	P-value
	N (percent)	N (percent)	
There are things a person can do to lower the risk of getting cancer.			
Agree <sup>a</sup>	43 (83)	96 (85)	0.42
Neutral	3 (6)	10 (9)	
Disagree <sup>b</sup>	6 (11)	7 (6)	
If you have cancer and it is found and treated early, there is a very good chance that you will survive.			
Agree <sup>a</sup>	52 (100)	109 (96)	0.39
Neutral	0 (0)	3 (3)	
Disagree <sup>b</sup>	0 (0)	1 (1)	
Many people who have survived cancer after undergoing treatments are able to live a good life.			
Agree <sup>a</sup>	49 (94)	111 (98)	0.16
Neutral	3 (6)	2 (2)	
Disagree <sup>b</sup>	0 (0)	0 (0)	
Many people would go through cancer treatments even though the treatments can be emotionally or physically uncomfortable.			
Agree <sup>a</sup>	47 (90)	108 (95)	0.43
Neutral	4 (8)	4 (4)	
Disagree <sup>b</sup>	1 (2)	1 (1)	
Cancer treatment always takes many weeks of daily treatment.			
Agree <sup>a</sup>	33 (63)	46 (41)	0.009
Neutral	5 (10)	31 (27)	
Disagree <sup>b</sup>	14 (27)	36 (32)	
Cancer treatments always cause a person’s hair to fall out.			
Agree <sup>a</sup>	20 (38)	1 (1)	0.0001
Neutral	5 (10)	17 (15)	
Disagree <sup>b</sup>	27 (52)	95 (84)	
Cancer treatments always make people so sick that they are unable to go on about their daily lives.			
Agree <sup>a</sup>	15 (29)	1 (1)	0.0001
Neutral	8 (15)	9 (8)	
Disagree <sup>b</sup>	29 (56)	103 (91)	
Once someone is diagnosed with cancer, people in the community will treat that person in a way that makes him or her uncomfortable.			
Agree <sup>a</sup>	21 (40)	18 (16)	0.001
Neutral	11 (21)	18 (16)	
Disagree <sup>b</sup>	20 (39)	77 (68)	

<sup>a</sup>Agree = strongly agree plus agree

<sup>b</sup>Disagree = strongly disagree plus disagree

RCRH CCI = Rapid City Regional Hospital Cancer Care Institute



treating them in a way that makes them uncomfortable ( $p=0.001$ ).

## DISCUSSION

This study of cancer patients presenting to a regional cancer center serving a large population of Native Americans showed that Native Americans demonstrated persistent stage disparities for cancers for which a screening test is available, and it documented that there is a concomitant screening disparity by race/ethnicity among patients with certain screening-detectable malignancies. Furthermore, we found that Native Americans presenting for cancer treatment have less basic knowledge about cancer screening. This disparity in screening knowledge remained significant even when adjustments were made for income, education level, and geographic remoteness from the CCI. While both Native American and white patients expressed positive attitudes regarding the benefits of prevention and early detection of cancer, their willingness to undergo cancer treatment, and beliefs about long-term outcomes of treatment, we found more negative attitudes about cancer's immediate impact upon an individual among Native American patients. We assert that these data showing a lack of screening knowledge and negative attitudes toward cancer care may present barriers to screening utilization as well as timely and effective cancer treatment in this vulnerable population.

Our finding of a significantly higher rate of presentation with advanced-stage disease for certain screening-detectable cancers among Native American cancer patients was consistent with population-based studies analyzing trends in stage at cancer presentation by race/ethnicity.<sup>1-3,5</sup> Also, the disparity we observed in proportions of cancers that were screening-detected among Native Americans compared with white patients was consistent with reports published by other investigators showing lower screening prevalence among Native Americans.<sup>6-10</sup> While limited access to preventive care could explain this inequity in some subpopulations of Native Americans,<sup>7</sup> all of the Native American patients in this study were enrolled members of federally recognized tribes and thus eligible for free primary care and contract-care specialty services through the IHS in our region.<sup>23</sup> Therefore, other explanations for lower rates of screening and higher rates of presentation with advanced-stage disease must be explored. Our findings that Native Americans demonstrated less basic screening knowledge and expressed more negative attitudes toward some, perhaps culturally sensitive, aspects of cancer treatment could partially explain the cancer-related health disparities observed in this analysis.

Other investigators have sought to examine predictors of screening utilization among Native Americans and have found that basic knowledge of cancer screening was poor<sup>6</sup> and that higher rates of screening were associated with more basic knowledge of cancer screening recommendations and rationale.<sup>7</sup> Paskett and colleagues<sup>24</sup> evaluated knowledge and beliefs of breast carcinoma in a multiracial population and showed that Native Americans exhibited the lowest levels of accurate knowledge regarding breast cancer when compared with white and African American respondents. While lower educational levels, which may translate to lower levels of health literacy, have been associated with decreased use of preventive services and cancer screening specifically in vulnerable populations,<sup>8,25,26</sup> we found that the lower scores on a screening knowledge assessment were independent of educational attainment level in this investigation. Because the Native Americans in our study did live farther from the CCI in higher proportions than white patients, it could be postulated that geographic isolation may account for the observed disparate levels of cancer knowledge. However, when we adjusted for geographic remoteness in the multivariable analysis, race/ethnicity remained highly significantly associated with lower screening knowledge. The implication from our study is that appropriate education regarding cancer screening has not been accomplished in this population.

With respect to attitudes about cancer care, the data suggest differences that may have sociocultural implications for this population. Responses to the first two questions shown in Table 7 suggest that messages regarding benefits of prevention and early detection have reached Native Americans served by this regional cancer center; however, knowledge necessary to advocate for the necessary screening to realize these benefits is still lacking, as shown and discussed previously. Table 7 suggests some misconceptions may exist among Native Americans regarding the immediate impact of a cancer diagnosis on one's daily life. This may present a barrier among Native Americans in this region who live remote to the cancer center or who have limited resources to travel back and forth for treatments.

This is an educational point to be addressed because while some cancer treatment regimens are quite complex and involved, treatment for many early-stage cancers can involve single-modality therapies such as surgery, brachytherapy, or short-course radiation therapy on trials that have recently opened in the region.<sup>11,12</sup> Furthermore, not all cancer treatment regimens are associated with visible hair loss, nor do they necessarily result in side effects that impede activities of daily living. Culturally loaded beliefs regarding hair

loss and community response to an individual's cancer diagnosis may exist, as possibly reflected in Table 7, and these considerations must be incorporated into any educational intervention or comprehensive clinical care effort that serves this population.

While Native Americans represent a heterogeneous population with unique sociocultural considerations with respect to health care,<sup>27–31</sup> culturally competent programs can successfully improve health-care utilization in this population.<sup>28,32</sup> Burhansstipanov and colleagues developed an educational intervention among Native American women in the Denver metropolitan area and showed increased recruitment to mammography after implementation of their program.<sup>28</sup> Similarly, Dignan and associates implemented a culturally specific cancer screening education program in a rural Native American community in North Carolina with similar sociodemographic barriers to cancer care as that seen in our study population. They demonstrated that the educational program resulted in greater knowledge of cervical cancer (the target malignancy for the educational intervention) and greater proportions of Native American women obtaining Pap tests.<sup>32</sup> Furthermore, comprehensive patient navigation and outreach programs have demonstrated improved cancer-related health outcomes in similar vulnerable populations.<sup>33,34</sup> These types of interventions help to bridge gaps in the health-care system throughout (e.g., screening accession to follow-up, and cancer diagnosis to specialty care initiation) and generally serve as liaisons between community members and the continuum of cancer care.<sup>17,35</sup>

### Limitations

Our study had limitations that must be considered, including the fact that significantly higher rates of non-Native American patients declined participation in our study than Native Americans. This could possibly be explained by the fact that the patient-contact literature inviting participation in the study specifically stated that the purpose of the study was to examine causes of cancer disparities among Native Americans. Perhaps non-Native American patients felt their input was not relevant or were potentially not motivated to participate. We also used survey instruments that had not been previously validated to conduct our survey. However, to obtain community approval and engagement, it was necessary for Native American community members and patients to have input into developing the instrument. We also conducted focus groups to pilot test and approve the survey. Therefore, while we did not use a previously validated instrument, we are

confident in our survey's cultural appropriateness and acceptability.

### CONCLUSIONS

This study identified lower levels of basic screening knowledge and more negative attitudes toward some aspects of cancer treatment among Native Americans, both factors that can impede preventive care utilization or accession of timely cancer treatment. We also found stage disparities for certain screening-detectable cancers among Native American cancer patients presenting for cancer treatment to the CCI. While causes of Native American health disparities are, no doubt, multifactorial, our investigation offers one definite point of focus for addressing poor cancer-specific health outcomes in this population.

Our findings that Native Americans have less basic knowledge of cancer screening and more negative attitudes toward the immediate impacts of cancer treatment underscore the need for culturally appropriate public health interventions in this vulnerable population. While Native Americans enrolled in a federally recognized tribe are eligible for free primary care at IHS facilities, public health interventions play a critical complementary role in ensuring that this population receives necessary preventive care. Education programs, screening program interventions, and patient navigation outreach are needed to provide Native Americans with the information they need to advocate for and access available screening tests as well as timely and effective cancer care.

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