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Effect of Tribal Language Use on Colorectal Cancer Screening among American Indians

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Abstract

American Indians have one of the lowest colorectal cancer (CRC) screening rates for any racial/ethnic group in the U.S., yet reasons for their low screening participation are poorly understood. Limited English language use may create barriers to cancer screening in Hispanic and other ethnic minority immigrant populations; the extent to which this hypothesis is generalizable to American Indians is unknown. We examine whether tribal (indigenous) language use is associated with knowledge and use of CRC screening in a community-based sample of American Indians. Using logistic regression to estimate the association between tribal language use and CRC test knowledge and receipt we found participants speaking primarily English were no more aware of CRC screening tests than those speaking primarily a tribal language (OR=1.16 [0.29, 4.63]). Participants who spoke only a tribal language at home (OR=1.09 [0.30, 4.00]) and those who spoke both a tribal language *and* English (OR=1.74 [0.62, 4.88]) also showed comparable rates of knowledge and receipt of CRC screening. Study findings failed to support the concept that primary use of a tribal language is a barrier to CRC screening among American Indians.

Keywords

American Indians; Native Americans; Culture; Language; Colorectal Cancer; Cancer; Screening

INTRODUCTION

Colorectal cancer (CRC) is the second leading cause of cancer-related deaths in the United States.¹ Survival from CRC is closely related to stage of disease at the time of diagnosis, with 5-year survival rates exceeding 90% for those with localized disease. In comparison, 5-

year survival is less than 10% for persons with distant metastases.^{2,3} A growing body of evidence indicates that CRC deaths could be greatly reduced through appropriate screening.⁴ However, CRC screening continues to be underused, particularly by racial/ethnic minorities.^{3,5–8}

Among American Indians, CRC is the second leading cause of cancer death in men and the third most common in women.⁹ Yet despite the efficacy and widespread availability of proven technologies to detect precancerous polyps, routine screening consistent with national guidelines continues to be underused by American Indians.^{10–12} For example, a recent study of almost 1,000 American Indians from several Northern Plain tribes found that only 44% of age-eligible respondents reported lifetime screening for any type of cancer, with rates for CRC screening especially low relative to the general population.¹¹ National data suggest similarly troubling patterns. Results from the 2000 National Health Interview Survey (NHIS) found only 30.6% of American Indians and Alaska Natives reported receiving either an fecal occult blood test (FOBT) in the preceding year or an endoscopy procedure (flexible sigmoidoscopy or colonoscopy), within the previous 5 years, compared to 39.4% for the total United States population.¹³ The 2010 National Healthcare Quality & Disparities Report found the percentage of AI/AN who reported ever being screened for CRC fell from about 49 percent in 2000 to roughly 37 percent in 2008.¹⁴ Such patterns may help to explain findings based on Surveillance, Epidemiology and End Results (SEER) data, which document that American Indians and Alaska Natives are more likely to be diagnosed with advanced-stage CRC than non-Hispanic whites (24.4% vs. 19.5%).^{15,16}

Understanding the factors associated with lower rates of CRC screening among American Indians is important for reducing cancer disparities, a major goal of Healthy People 2010.¹⁷ Several studies examining breast and cervical cancer screening among American Indian women foreground cultural characteristics, including Native language use, to explain screening disparities, but with mixed results.^{18–20} One population-based study of women on the Hopi reservation found a positive relationship between “traditionalism”—assessed as Native language use, Native cultural participation, and length of reservation residency—and protective health behaviors.¹⁹ A study of almost 1,000 Lumbees in North Carolina—a tribe that has not retained a Native language—nevertheless found better knowledge of cervical cancer screening among women who identified more strongly with other aspects of their Native American culture.²¹ Studies across many different tribes have commonly argued that themes, values, and symbols associated with tribal cultures can function as important resources for encouraging health knowledge and healthy behaviors, including behaviors relevant to cancer screening.^{22–24}

At the same time, other analyses have identified no significant relationships between cancer screening and language use or related indicators of identification with tribal cultures.^{19,25,26} Indeed, at least one study, which collected data from about 200 American Indian women in northeastern Oklahoma, has found greater traditionalism as measured by tribal language fluency and use in home associated with reduced rates of screening for cervical cancer.²⁰ The single study that has examined primary language and screening specifically for CRC in Native populations likewise found significantly lower screening rates among persons who reported speaking a Native language.²⁷

The discordant results emerging from studies probing tribal language and related cultural characteristics as influences on cancer screening suggest that much remains to be learned. Disentangling the effects of language on health risks related to CRC is important because of the many ways in which language interacts with health behaviors and outcomes.²⁸ Studies among Hispanic and Asian subpopulations have found that preference and use of a language other than English is associated with limited access to and understanding of educational materials, as well as medical mistrust, poor patient-provider communication, and low socioeconomic status—all factors found to impede the use of screening.^{29–36} For example, in one study among Hispanics, no association was found between English fluency and screening receipt.³² However, other studies found a negative association between Spanish language use and CRC screening.^{37–41} Similarly, studies of Asian subgroups found that English preference and fluency were positively associated with higher rates of CRC screening.^{30,34,35,42} Other studies have found associations between limited English proficiency and lower quality of and access to health care,^{43–47} poor patient-provider communication,^{43–45} cultural differences in values, attitudes, and beliefs known to be related to cancer screening,⁴⁸ and lower socioeconomic status.

To examine the association between language use and CRC screening awareness and use, this study drew on a population-based sample of American Indians from a Southwestern tribe with especially high rates of Native language use and fluency, the Hopi. We investigated whether the primary language spoken at home was associated with awareness and receipt of the two most common CRC screening modalities, fecal occult blood test (FOBT) and colonoscopy.

METHODS

Study Setting

The Hopi Reservation is located in northeastern Arizona and encompasses approximately 1.6 million acres. Descendants of the prehistoric Anasazi people, the Hopi continue to occupy a portion of their *Tutsqua* or sacred ancestral homelands. This continuity of residence distinguishes them from many other tribes that were displaced and relocated to government-created reservations. Today the Hopi live in 12 village communities situated on or below three adjoining mesas in northeastern Arizona. In 2000, the U.S. Census reported more than 12,000 Hopis, 10,590 of whom were enrolled tribal members. In 2003, Hopi tribal enrollment records identified nearly 9,000 community-dwelling tribal members. The reservation is largely racially endogenous, with 94.6% of reservation residents identifying as Native American, 3.9% White, 1.9% Hispanic, and less than 1% each as Black, Asian, or Pacific Islander.⁴⁹ Considered one of the best-preserved Native cultures in North America, the Hopi retain and continue to practice their cultural traditions, including the use of the Hopi language. In 1990, it was estimated that over 5,000 people were fluent speakers of the Hopi language.⁵⁰ In addition, a small subgroup of the population speaks Tewa, a language introduced to the community in the 17th century when a group of Tewa speakers migrated from New Mexico during the second Pueblo Revolt.⁵¹

Data Collection

Data for this cross-sectional study were obtained from a random sample of 182 adult Hopi tribal members, between 40 and 87 years of age, residing on the Hopi Reservation. Given the expansive boundaries of the reservation, we selected just two villages, similar in size and population characteristics, from which to sample. Using tribal enrollment records, which provided the most current and comprehensive membership information, we randomly sampled community-dwelling tribal members from the two villages. All persons appearing on these records are eligible for health care through the U.S. Indian Health Service.

Eligibility criteria required each participant to be at least 40 years of age, a current reservation resident, mentally competent, and able to understand and speak English. Our participation rate was 84%; no one was excluded for lack of English fluency. Eligible participants were contacted either by telephone or in person. Data were collected through an interviewer-administered survey between July and September 2007. All study participants provided signed informed consent and received a \$15 gift card as compensation for their time. The study protocol was reviewed and approved by the Hopi Tribal Council and by the Cornell University Institutional Review Board.

Measures

CRC Knowledge and Screening—Our two primary outcomes of interest were 1) self-reported awareness of FOBT or colonoscopy among all study participants and 2) self-reported receipt of FOBT or colonoscopy among participants 50 years and older. To assess awareness of FOBT or colonoscopy, participants were provided a description of each test and asked, “Have you ever heard of [this test]?” Those who replied “Yes” to either question were coded as being aware of a recommended CRC screening test. To assess lifetime receipt of FOBT or colonoscopy, participants were asked, “Have you ever had [this test]?” Participants who replied “Yes” to either question were classified as having been screened.

Language Use—Language use was assessed with a single measure: “What language do you primarily speak at home?” Response options included English, Hopi, and a combination of both. Because we knew that some Hopi speak Tewa, a language introduced to the community when a group of Tewa speakers from New Mexico came to live with the Hopis after the Pueblo Revolt in 1680, response choices also included this language. However, because none of our respondents reported speaking Tewa at home, we dropped this response option from analyses.

Covariates—We additionally measured sociodemographic variables, attitudes and perceptions about cancer, and health status. Sociodemographic variables included age, sex, education, household income, and marital status. “Cancer pessimism” was assessed with two items. The first item asked, “How frequently do you worry about colon cancer?” Those who responded “sometimes,” “often,” or “all the time” were categorized as “worried.” A second item invited participants to agree or disagree with the statement, “There’s not much people can do to lower their chances of getting cancer.” Responses of “strongly agree” and “agree” were categorized as “pessimistic.” Both items have been used in the Health Information National Trends Survey and the National Health Interview Survey Cancer Control

Supplement to assess mental models of cancer worry and risk perception.^{52,53} Health status variables included self-reported family history of cancer, body mass index (BMI, calculated from height and weight), and exercise frequency.

Statistical Analyses

Analyses of our first dependent variable, awareness of CRC screening tests, were conducted for the entire sample. Analyses pertaining to screening use, our second dependent variable, were restricted to the subsample of participants older than age 50, the age group for which annual screening is recommended. Our independent variable, language use, was characterized in 3 ways: (1) categorically as primary language spoken in the home (English, Hopi, or a combination of languages), (2) dichotomously, with those who spoke a Native language at home to *any* extent versus all others, and (3) dichotomously, with those who spoke only a Native language in the home versus all others.

BMI was categorized according to the Centers for Disease Control and Prevention's definitions for normal, overweight, and obese. Educational level was categorized as high school/GED or less; some college or Associate's degree; or Bachelors' or advanced degree. Annual household income was categorized into three levels: \$25,000 or less; \$25,001 to \$50,000; and \$50,001 or more. Where possible, other variables were assessed continuously as well as categorically in tertiles.

We assessed univariate associations between each outcome and participant characteristics using Pearson's chi-squared test for categorical variables and a t-test for continuous variables. We conducted a score test of trend for ordinal variables with more than two categories. Odds ratios (OR) and 95% confidence intervals (CI) were obtained from logistic regression models controlling for demographic characteristics and other covariates. Covariates were assessed for confounding effects on the primary association; those that did not importantly change estimates of association between language and CRC screening measures were not retained in final models. All tests were two-tailed, with p-values of less than 0.05 considered statistically significant. Analyses were performed using Stata v10.1 (StataCorp LP, College Station, TX).

RESULTS

A total of 182 individuals participated in the study, of whom 111 (60%) were female. Participants ranged from 40 to 87 years of age, with an average age of 54 (standard deviation = 11.2). Thirty-eight percent had a high school education or equivalent. More than half (52%) had received some college education or attained an Associate's degree, while the remaining 10% had received a Bachelor's or advanced degree. More than half were married, and almost 79% were employed or self-employed. About 22% of respondents spoke only English at home, with a slightly lower percentage (19%) speaking only Hopi. More than half of respondents (60%) indicated that they spoke both languages at home.

Awareness of FOBT and colonoscopy varied according to several demographic characteristics (Table 1). Those who had heard of these screening tests tended to be younger, female, more educated, and less likely to have a pessimistic attitude about cancer. A total of

49.6% (58 out of 117 respondents 50 and older) reported CRC screening by either FOBT or colonoscopy.

Screening receipt was positively associated with education and self-reported family history of cancer (Table 1). In contrast, primary language spoken in the home was not significantly associated with awareness of FOBT or colonoscopy or with lifetime screening. Participants who spoke only Hopi in the home (OR=1.16; 95% CI: 0.29, 4.63) or a combination of Hopi and English (OR=1.02; 95% CI: 0.32, 3.25) did not differ from English-only respondents in their awareness of FOBT or colonoscopy, after adjusting for covariates (Table 2). Actual receipt of screening in the age-eligible subsample was similarly not associated with language spoken in the home; respondents aged 50 years or older reported FOBT or colonoscopy at rates similar to English-only speakers, regardless of whether they spoke only Hopi at home (OR=1.09; 95% CI: 0.30, 4.00) or a combination of Hopi and English (OR=1.74; 95% CI: 0.62, 4.88) (Table 3).

DISCUSSION

Studies in some racial/ethnic populations have found that individuals whose home language is not English tend to have reduced prevalences of cancer screening. However, scarcity and inconsistency in available research obscures the extent to which similar relationships may characterize American Indian populations. The present study examines the associations between language use, awareness of two common CRC tests (FOBT and colonoscopy), and screening behavior in a population-based sample of reservation-dwelling Hopi adults.

Primary language spoken in the home did *not* influence CRC screening behavior in our sample. Compared to respondents who spoke only English in the home, those who spoke Hopi did not significantly differ in their awareness of FOBT or colonoscopy or in their likelihood of receiving these tests. Our findings contrast with those of the only comparable study examining primary language and CRC screening in Native populations. Focusing on American Indians and Alaska Natives living in Arizona and Alaska, the earlier study found significantly lower screening rates among persons who reported speaking a Native language.²⁷

These findings are consistent with the conclusion that any association between language use and healthcare use may be conditioned by the sociocultural context in which the preferred language is spoken. Therefore, we cannot assume that non-English language preference or fluency is a barrier to health knowledge and use. Instead, the role of language may vary for different ethnic groups with different histories. In some groups—especially immigrants—non-English preference may imply lack of English fluency, but for Hopis, and perhaps for other American Indian communities, it may not.

Our finding of a lack of association between Hopi language use and receipt of CRC screening may relate to the complexity of Hopi language learning and related assumptions around language use. For many Hopis, English is not a second language but a language acquired in childhood, simultaneously with Hopi. This raises the possibility that bilingual Hopis have internalized two implicit linguistic knowledge systems, giving them access to

knowledge and information in two distinct cultural systems.^{54,55} Thus, fluency in English, rather than being subtractive (i.e., replacing Hopi language) might better be understood as additive, insofar as it provides bilingual speakers with the ability to shift between languages as situation and needs dictate.

Implicit in most models of traditionalism or traditionality that use Native language as a proxy for culture is an assumption of two different, identifiable cultural orientations – Native and non-Native or White.^{19,2056} Fundamentally, the notion of such a dichotomy is premised on the perceived existence of two distinct, homogeneous cultures. Such models do not consider the possibility of biculturalism—two cultures are operative in one person. Instead traditionalism is seen as a distinctive outcome rather than a complex multidimensional experience. Such dichotomous conceptualizations of Native cultural identity do not account for tribally distinct historical experiences of contact and colonization, as well as reservation location and degree of isolation, which have resulted in highly variable cultural traditions and practices. Such models conceptualize traditionalism and traditionality as ideal and static, rather than recognizing culture as vital and syncretistic. Syncretism, even in more traditional Native cultures such as the Hopi, is inescapable and contributes to a culture's resilience, survival and viability.⁵⁷

Although we did not find an association between language use and CRC knowledge and screening, our analysis did reveal an important finding: study participants aged 50 and older had a CRC screening participation rate of 49.6%. Not only did this rate essentially meet the Healthy People 2010 goal of 50%, surpassing the modified mid-year goal of 33%,⁵⁸ it was considerably higher than the 30.6% of American Indians in the 2000 National Health Interview Survey who reported having had either an FOBT in the preceding year or an endoscopy procedure in the past 5 years, or both.¹³ It is also much higher than the 12% CRC screening rate reported for Native people in southwestern tribes.²⁷

The high screening rates that we observed could be attributed to the success of the Hopi Office of Prevention and Intervention (HOPI) Cancer Support Services (formerly the Hopi Women's Health Program). This community-based resource emphasizes cancer education and prevention. As a tribally operated program, it employs health professionals knowledgeable about Hopi culture, many of whom are fluent speakers of the Hopi language. The program has a positive reputation among reservation residents, and outreach events and activities promoting cancer awareness and prevention are well attended.^{19,26} The high rate of reported CRC screening might also be attributed to participant access to federally-funded Indian Health Services healthcare provided by the Hopi Healthcare Center. The Indian Health Service, an agency within the Department of Health and Human Services, is responsible for providing federal health services to American Indians and Alaska Natives. As members of a federally-recognized Indian tribe, Hopi participants are eligible to receive healthcare through the two Indian Health Service facilities that serve the reservation. This study has several limitations that merit comment. Although we examined language preference as a predictor of health knowledge and behavior, this variable may function as an indicator of a larger set of cultural practices and beliefs. Our decision not to inquire specifically about such variables respected the privacy of our respondents but may have obscured important influences on health behavior for which language preference is a proxy

measure. Our sample size of a rarely studied population was modest, creating broad confidence intervals. This circumscribed sample size is a marker for the unique challenges of working with American Indian tribes, which may be geographically isolated and commonly express concern about researchers' motivations.⁵⁹ As well, our inability to discern whether colonoscopies were performed for diagnostic or screening purposes overestimate CRC screening. Moreover, our estimate of CRC screening was based on self-report. Nevertheless, prior studies in non-Hispanic whites have found good agreement between self-report data and medical records for colonoscopy.⁶⁰ A final caveat, although our study was limited to participants able to speak and understand English, we did not identify or exclude anyone for this reason. The paucity of monolingual speakers of the Hopi language in our sample is consistent with a 1997 tribal that found fewer than 5% of reservation residents unable to speak or understand English and thus provides assurance of sample representativeness.⁶¹ By contrast, our sample embraced high percentages of employed respondents with relatively high educational attainment—patterns that may reduce representativeness. Readers undertaking to generalize our findings should do so only with caution, remembering that both language vitality and sociodemographic patterns vary considerably both across tribes and between urban and reservation-based populations. Future research would thus do well to consider whether language variables translate into different dynamics in tribal communities with characteristics that distinguish them from our Hopi sample.

CONCLUSIONS

Prior to contact with Europeans, hundreds of tribal languages were spoken among indigenous groups in North America. Today, even though many of these traditional indigenous languages have become critically endangered, Native language use persist in a number of tribal communities, including the Hopi. This study is one of very few to examine the association between tribal language use and cancer prevention among American Indians. Accordingly, it makes an important contribution to scientific research into the role of language in cancer prevention knowledge and screening use in an ethnic minority population. It also provides evidence that among American Indians, use of a tribal language may not function as a barrier to cancer knowledge or screening as suggested by studies among Hispanics and other ethnic minority immigrant populations. Identifying the barriers that *do* contribute to low CRC screening among American Indian is important for understanding and developing culturally-sensitive interventions that take into account the use of traditional language in efforts to increase screening among American Indian communities.

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Table 1

Characteristics of Hopi Indians according to screening awareness and screening history by FOBT and colonoscopy, Arizona, 2007

Characteristic	Awareness of FOBT or colonoscopy		Screened by FOBT or colonoscopy*		p-value [†]
	Yes (n=143)	No (n=38)	Yes (n=58)	No (n=58)	
Age, n (%)					0.58
<50	51 (35.9)	13 (34.2)			
50–59	47 (33.1)	7 (18.4)	26 (44.8)	29 (50.0)	
60	44 (31.0)	18 (47.4)	32 (55.2)	29 (50.0)	
Age, mean (SD)	54.8 (10.3)	58.7 (10.3)	62.2 (8.5)	61.0 (8.5)	0.49
Male, n (%)	49 (34.3)	24 (63.2)	18 (31.0)	25 (42.4)	0.20
Educational level, n (%)					0.009
High school or GED	43 (30.3)	23 (60.5)	13 (22.4)	31 (53.5)	
Some college of AA	82 (57.8)	14 (36.8)	37 (63.8)	20 (34.5)	
Bachelors or Advanced	17 (12.0)	1 (2.6)	8 (13.8)	7 (12.1)	
Household income					0.30
\$25,000	54 (44.6)	20 (64.5)	25 (48.1)	28 (60.9)	
\$25,001 – \$50,000	48 (39.7)	7 (22.6)	20 (38.5)	12 (26.1)	
\$50,001	19 (15.7)	4 (12.9)	7 (13.5)	6 (13.0)	
Employed, n (%)	102 (71.3)	22 (57.9)	33 (56.9)	35 (59.3)	0.79
Married, n (%)	80 (55.9)	18 (47.4)	32 (55.2)	29 (49.2)	0.52
Body mass index, n (%)					0.94
<24	20 (14.2)	6 (16.7)	10 (17.2)	9 (15.3)	
25–29.9	36 (25.5)	15 (41.7)	16 (27.6)	18 (30.5)	
30	85 (60.3)	15 (41.7)	32 (55.2)	32 (54.2)	
Frequency of exercise, n (%)					0.58
0–2 times per week	57 (39.9)	15 (39.4)	24 (41.4)	25 (42.4)	
3–4 times per week	57 (25.9)	5 (13.2)	13 (22.4)	9 (15.3)	
5 times per week	49 (34.3)	18 (47.4)	21 (26.2)	25 (42.4)	
Worried about getting colon cancer	58 (86.6)	83 (76.2)	25 (56.8)	32 (47.1)	0.31
Fatalistic attitude about cancer	39 (28.1)	19 (51.4)	20 (36.4)	20 (35.7)	0.94
Family history of cancer	13 (9.1)	2 (5.3)	33 (58.9)	22 (38.6)	0.03

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* Among 121 subjects 50 years old.
† Score test for trend for ordinal variables; Pearson chi-squared test for independence for categorical variables; Fisher exact test for small expected numbers.
‡ Continuous awareness score summed across 13 questions and categorized.

Table 2

Association between language and awareness of the FOBT or colonoscopy tests among Hopi Indians, Arizona, 2007

Exposure	Yes		No		Unadjusted		Adjusted*	
	n	(%)	n	(%)	OR	95% CI	OR	95% CI
Primary Language								
English	35	(24.7)	5	(13.2)	1.00	Reference	1.00	Reference
Hopi	24	(16.9)	10	(26.3)	0.34	(0.10, 1.13)	1.16	(0.29, 4.63)
Hopi and English	83	(58.5)	23	(60.5)	0.52	(0.18, 1.47)	1.02	(0.32, 3.25)

* Adjusted for age, gender, education, and pessimistic attitude about cancer.

Table 3

Association between language and FOBT or colonoscopy receipt among Hopi Indians aged 50 years and older, Arizona, 2007

Exposure	Yes		No		Unadjusted		Adjusted*	
	n	(%)	n	(%)	OR	95% CI	OR	95% CI
Primary Language								
English	13	(22.8)	12	(20.3)	1.00	Reference	1.00	Reference
Hopi	9	(15.8)	14	(23.7)	0.59	(0.19, 1.87)	1.09	(0.30, 4.00)
Hopi and English	35	(61.4)	33	(55.9)	0.98	(0.39, 2.45)	1.74	(0.62, 4.88)

* Adjusted for education, family history, and awareness of FOBT and colonoscopy.