

## PERCEIVED CANCER RISK AMONG AMERICAN INDIANS: IMPLICATIONS FOR INTERVENTION RESEARCH

**Objective:** Perceived risk of disease plays a key role in health behaviors, making it an important issue for cancer-prevention research. We investigate associations between perceived cancer risk and selected cancer risk factors in a population-based sample of American Indians.

**Study Design and Population:** Data for this cross-sectional study come from a random sample of 182 American Indian adults, aged  $\geq 40$  years, residing on the Hopi Reservation in northeastern Arizona.

**Outcome Measures:** Perception of cancer risk was ascertained with the 5-point Likert scale question, "How likely do you think it is that you will develop cancer in the future?" dichotomized into low perceived risk and high perceived risk.

**Results:** Participants reporting a family member with cancer were more likely, by greater than five times, to report the perception that they would get cancer (OR=5.3; 95% CI: 2.3, 12.3). After controlling for age and family history of cancer, knowledge of cancer risk factors and attitude about cancer prevention were not significantly associated with risk perception.

**Conclusions:** Perceived cancer risk was significantly associated with self-reported family history of cancer, supporting the importance of personal knowledge of cancer among American Indians. Further research is needed to obtain a more complete picture of the factors associated with perceptions of cancer risk among American Indians in order to develop effective interventions. (*Ethn Dis.* 2010;20:458–462)

**Key Words:** Indians, North America, Cancer, Health Belief Model, Risk Perception, Attitudes and Beliefs, Cancer Knowledge, Family History

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### INTRODUCTION

Cancer is the second leading cause of death among American Indians.<sup>1</sup> The number of deaths associated with cancer among American Indians aged  $\geq 45$  years exceeds the next three leading causes combined (diabetes, unintentional injuries, chronic liver disease/cirrhosis).<sup>2</sup> While overall cancer incidence and mortality rates in the United States have been decreasing, the age-adjusted incidence and mortality rates for many cancers have been increasing among American Indians.<sup>1,3,4</sup> The American Cancer Society estimates that more than half of all cancer deaths could be prevented by adopting health-protective behaviors and preventive screening.<sup>5</sup> However, according to the Health Belief Model,<sup>6</sup> an individual's perception of risk plays a significant role in adopting preventive health behaviors.<sup>7,8</sup>

Perceived risk of cancer – the subjective estimation of likelihood that one might be diagnosed with cancer in the future – has been used to predict cancer screening behaviors as well as to evaluate the effectiveness of interventions to promote screening and other health-protective behaviors.<sup>9–12</sup>

Perceptions of cancer risk vary widely among populations.<sup>2,13–18</sup> A study of risk perception in a nationally

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representative sample of Whites, Blacks, Hispanics, and Asians found that non-Whites reported lower perceptions of cancer risk than Whites.<sup>16</sup> A study of perceived risk for breast, cervical, and colon cancer found striking racial/ethnic differences, with Asian women reporting the lowest perception of risk for all three cancers and Latinas reporting the highest.<sup>15</sup> Studies have also found distinctive attributions of perceived risk in racial/ethnic minority populations.<sup>19,20</sup> One study using a predominantly African-American sample found that respondents more often attributed their risk to psychological causes, such as "just feeling like you could get it," than to medically established factors such as heredity or environmental causes.<sup>21</sup>

Variations in perception of cancer risk among racial/ethnic groups suggest that social and cultural characteristics may be significantly related to risk perception, and thus may pose a

potential barrier to screening and other preventive behaviors. To our knowledge, no studies have examined perception of cancer risk among American Indians. Given the cancer incidence and mortality rates in this population, understanding factors associated with risk perception has important implications for developing effective, culturally relevant interventions. In this study we assess whether knowledge of cancer risk factors, attitudes about cancer prevention, and family history of cancer are associated with perception of risk in a population-based study of American Indians.

## METHODS

Data for this cross-sectional study were obtained from a random sample of 182 adult Hopi tribal members, aged 40 to 87 years, residing on the Hopi Reservation in northeastern Arizona. The Hopi Reservation encompasses ~1.6 million acres. Given the size of the reservation and geographic dispersal of village communities, we drew our sample from two villages similar in size and population characteristics. Using tribal enrollment records, we randomly selected a sample of community-dwelling tribal members. Tribal records provide the most current and comprehensive participant information, thereby enhancing the representation of our sample. Eligibility criteria required participants to be aged  $\geq 40$  years, current reservation resident, and able to understand and speak English.

People eligible for inclusion were contacted either by telephone or in person. Data were collected through an interviewer-administered survey between July and September 2007. All 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 Cornell University's Institutional Review Board.

## Measures

### *Dependent Variable*

Our outcome of interest was the perception of one's overall risk for developing cancer. To ascertain perception of cancer risk we used an item from the National Cancer Institute's 2004 Health Information National Trends Survey. Participants were asked to indicate their level of perceived risk on a 5-point Likert scale question: "How likely do you think it is that you will develop cancer in the future? Would you say your chance of getting cancer is very low / somewhat low / moderate / somewhat high / very high?" Responses were dichotomized into low perceived risk (very low or somewhat low) and high perceived risk (moderate, somewhat high, or very high).

### *Independent Variables*

We assessed three primary predictors of interest: 1) knowledge of cancer risk factors, 2) attitude about cancer prevention, and 3) family history of cancer. To measure risk factor knowledge, respondents were presented with a list of cancer risk factors including smoking, a high-fat diet, sun exposure, pesticides and food additives, lack of dietary fiber, a diet low in fruits or vegetables, alcohol intake, number of sexual partners, family history of cancer, race or ethnicity, lack of exercise, and obesity. They then responded to the question: "How much do you think (individual risk factor) increases a person's chance of getting cancer?" (a lot/a little/not at all). Responses to each item were dichotomized (not at all = 0; a little or a lot = 1). Answers to individual questions were summarized into a single continuous score for cancer risk factor knowledge with strong inter-item correlation (Cronbach's  $\alpha = .77$ ).<sup>22</sup> Fatalistic attitude about cancer prevention was assessed by agreement or disagreement with the statement, "There's not much people can do to lower their chances of getting cancer." People who agreed with

the statement were considered to have a fatalistic attitude about cancer prevention. Family history of cancer was measured by the question, "Have any members of your biological family ever had cancer?" (yes/no).

### *Control Variables*

Because we wanted to control for characteristics that might confound associations, we measured sociodemographic variables and health characteristics, including age, sex, educational level (high school/GED or less; some college or associate's degree; bachelor's or advanced degree), employment status, household income ( $\leq \$25,000$ ,  $\$25,001$ – $\$50,000$ , and  $\geq \$50,001$ ), marital status, body mass index (from height and weight), and frequency of exercise. Family history of cancer served as a covariate in models that used cancer knowledge and attitudes about cancer prevention as predictors.

## Statistical Analyses

We assessed univariate associations between perceived cancer risk and all other measures using Pearson's chi-squared test for categorical variables and the *t*-test for continuous variables. Knowledge of risk factor scores was categorized into three levels using inter-quartile values as cutoffs. We additionally conducted a score test of trend for ordinal variables with more than two categories. Multivariate associations were assessed by using unconditional logistic regression models that controlled for demographic characteristics and other covariates. Covariates were assessed for their confounding effects on the primary association; only those that significantly changed the estimates of association were retained in the final models. Odds ratios (OR) and 95% confidence intervals (CI) were used to assess the strength and significance of associations.

A preliminary examination of our data indicated that the summary knowl-

edge score was missing for a large number of participants ( $n=92$ ). To account for these missing values, we singly imputed responses to missing questions using the mean value of non-missing responses within each participant. An imputed knowledge score was created by summing responses across questions after imputation. We also created two other knowledge scores for a sensitivity analysis in which we substituted missing values of individual questions with 0, and then with 1, and summed across risk factor questions. We repeated our statistical analyses using knowledge scores that were created for our sensitivity analyses. All tests were two-tailed, with  $P$  of less than .05 considered statistically significant. Analyses were performed by using Stata v10.1 (StataCorp LP, College Station, TX).

## RESULTS

A total of 182 individuals participated in the study, of whom 109 (60%) were female. Participants ranged in age from 40 to 87 years, with an average age of 56 (standard deviation = 11.0). Thirty-eight percent of respondents reported completing high school, and more than half (52%) had received at least some college education and most (68%) were employed (data not shown). Almost one third (29%) of respondents believed that they had a moderate to high likelihood of getting cancer. Participants who reported a greater perception of cancer risk were younger than those who did not ( $P=.03$ ), but did not significantly differ on other measured characteristics (Table 1).

As shown in Table 2, family history of cancer was associated strongly with perceived cancer risk; participants who reported a family member with cancer were over five times more likely than others to report the perception that they would also get cancer (OR=5.3; 95% CI: 2.3, 12.3). In contrast, knowledge

**Table 1. Demographic and lifestyle characteristics stratified by perceived risk of cancer among 182 Hopi Indians, Arizona, 2007**

Characteristic	High Perceived Risk		Low Perceived Risk		P*
Age, n (%)					.08
40-49	18	(41.9)	35	(32.7)	
50-59	17	(39.5)	34	(31.8)	
≥60	8	(18.6)	38	(35.5)	
Age, mean (SD)	52.1	(9.1)	56.2	(10.6)	.03
Male, n (%)	41	(38.3)	19	(43.2)	.58
Educational level, n (%)					.14
≤High school or GED	11	(25.0)	42	(39.6)	
Some college or AA	28	(63.6)	54	(50.9)	
≥Bachelor's or advanced	5	(11.4)	10	(9.4)	
Household income					.27
≤\$25,000	13	(34.2)	46	(50.6)	
\$25,001-\$50,000	19	(50.0)	30	(33.0)	
≥\$50,001	6	(15.8)	15	(16.5)	
Employed, n (%)	31	(70.5)	77	(72.0)	.85
Married, n (%)	22	(50.0)	57	(53.3)	.63
Body mass index, n (%)					.28
≤24	5	(11.6)	12	(11.5)	
25-29.9	17	(39.5)	27	(26.0)	
≥30	21	(48.8)	65	(62.5)	
Frequency of exercise, n (%)					.41
0-2 times per week	19	(43.2)	42	(39.3)	
3-4 times per week	11	(25.0)	21	(19.3)	
≥5 times per week	14	(31.8)	44	(41.1)	

\* score test for trend for ordinal variables; Pearson chi-squared test for independence for categorical variables and t test for continuous variables.

**Table 2. Association between knowledge, attitude, family history, and perceived cancer risk among 182 Hopi Indians, Arizona, 2007**

Exposure	High Perceived Risk		Low Perceived Risk		OR †	95% CI	P ‡
	n	(%)	n	(%)			
Family history of cancer							
No	11	(25.6)	54	(62.1)	1.0	Reference	
Yes	32	(74.4)	39	(37.9)	5.3	(2.3, 12.3)	
Knowledge* of risk factors							.56
≤10	14	(31.8)	25	(23.4)	1.0	Reference	
11-12	8	(18.2)	32	(29.9)	.3	(.1, 1.1)	
≥13	22	(50.0)	50	(46.7)	.7	(.3, 1.7)	
Fatalistic attitude §							
Disagree	33	(72.7)	68	(65.4)	1.0	Reference	
Agree	12	(27.3)	36	(34.6)	.8	(.3, 2.0)	

\* After single imputation of missing individual questions.  
 † Adjusted for age, knowledge of family history; model for knowledge of family history additionally adjusted for employment.  
 ‡ Test for linear trend in odds ratio.  
 § Question: "There's not much people can do to lower their chances of getting cancer".

of cancer risk factors was not significantly associated with risk perception, after controlling for age and family history of cancer. A sensitivity analysis using summary knowledge scores did not change our results. Similarly, a fatalistic attitude about cancer prevention, as indicated by agreement with "there is not much one can do to prevent cancer," was not related to perceived risk.

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*Overall, we found that higher perceived cancer risk was associated with self-reported family history of cancer and younger age, but not with knowledge of cancer risk factors or with a fatalistic attitude about cancer prevention.*

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## DISCUSSION

This study examined a population-based sample of American Indians for factors known to be associated with perceptions of cancer risk in other US populations. Overall, we found that higher perceived cancer risk was associated with self-reported family history of cancer and younger age, but not with knowledge of cancer risk factors or with a fatalistic attitude about cancer prevention. To our knowledge, this is the first study to examine factors associated with perceived cancer risk among American Indians. The absence of similar studies in this population make comparisons difficult, but racial/ethnic variability in cancer risk perception suggests that cultural factors may influence individual perceptions of risk.

In studies of the general population, knowledge of family history of cancer has been found to increase individuals' sense of vulnerability through a personalizing process influenced by the emotional impact of witnessing a family member's illness, especially when the illness is sudden, premature, or fatal.<sup>23,24</sup> In a close-knit cultural community such as the Hopi Reservation, personalizing processes may extend beyond the immediate family to include extended kin and clan relatives as well as non-biologically related individuals. In such communities, knowledge of a community member's battle with cancer can increase individual awareness of the disease and possibly heighten perceptions of personal risk. To increase participation in cancer preventive behaviors, healthcare providers in these communities need to understand the relevant cultural and community dynamics in order to overcome potential barriers associated with risk perceptions.

A family history of cancer places one at increased risk for many cancers, including breast, ovarian, prostate, and colorectal.<sup>25,26,27</sup> With the increasing prevalence of cancer among American Indians, knowledge of family health history has become an important component of prevention.<sup>28</sup> Our finding therefore has important clinical implications. Health professionals need to consider cultural factors when collecting family medical history from American Indian patients. For example, while most Americans understand family as biogenetically determined, in many American Indian cultures the concept of family can be quite broad, including fictive, non-blood related kin. In certain tribes, however, the notion of family may be quite narrow, limited to either matrilineal or patrilineal blood-related relatives.

The diversity of ways in which family can be understood among American Indians underscores the need for culturally informed educational interventions that emphasize the significance of family history for certain hereditary cancers, as

well as the importance of sharing personal health history with family members. Likewise, the increased risk of developing hereditary cancers for individuals with a family history calls for culturally competent health professionals; understanding and using kinship terms that are specific to individual tribes during the collection of medical histories can help to ensure comprehensive information on all biologically related kin.

In addition, recognizing the multiplicity of cultural beliefs among American Indian tribes is important for understanding how cultural factors may influence individual health behaviors and perceptions of cancer risk. For example, in some American Indian cultures, talking about an illness is thought to invite it,<sup>29,30</sup> and this belief may hamper participation in educational programs that raise awareness of cancer risk factors and encourage preventive screening. Such beliefs highlight the need for culturally competent healthcare professionals who are sensitive to the unique cultures of American Indian tribes and the different ways in which tribal members may think about cancer prevention and treatment.

Several aspects of our study merit comment. First, our results are based on self-reported data, which can be unreliable. Second, because data for this study are cross-sectional, we cannot establish causality; longitudinal studies would be needed to track changes in risk perception associated with changes in cancer prevention strategies. Third, because of the diversity of beliefs, traditions, and practices among American Indian tribes, our findings can be generalized to other tribes and to urban American Indian populations only with considerable caution. Fourth, we lacked data on lifestyle behaviors and risk factors for cancer, such as smoking status, consumption of fruit, vegetables, and alcohol. Finally, although it is important to understand perceptions of general cancer risk while developing educational and clinical interventions, more

specifically targeted interventions will require further efforts to identify factors associated with specific cancers.

It is clear that individual preventive behaviors such as eating healthful foods, exercising regularly, using alcohol in moderation, and avoiding tobacco products can reduce the risk of cancer. However, racial and ethnic variations in perception of cancer risk suggest that social and cultural factors play a key role in perception. Our finding that perception of cancer risk was significantly associated with self-reported family history of cancer underscores the need for further research to obtain a more complete picture of cancer risk perceptions among American Indians.

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