



Published in final edited form as:

J Prim Care Community Health. 2013 July 1; 4(3): 160–166. doi:10.1177/2150131912457574.

Views, Barriers, and Suggestions for Colorectal Cancer Screening Among American Indian Women Older Than 50 Years in the Midwest

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Abstract

Objective—Although colorectal cancer (CRC) mortality rates in the US population have shown a decline, American Indian (AI) CRC mortality rates appear to be increasing. CRC screening rates of AIs remain low when compared with other ethnic groups. The research team explored women's perceptions toward CRC screening, existing barriers, and suggestions to promote education and screening among AI women in Kansas and Missouri.

Methods—Using a community-based participatory research approach, the authors conducted 7 focus groups with AI women older than 50 years (N = 52) to better understand their perceptions of and attitudes toward CRC screening.

Results—Women recognized barriers to screening, such as embarrassment, privacy issues, fear, insurance, and cost. They countered perceived barriers through inventive suggestions for education and awareness via social support systems and intergenerational relationships.

Discussion—CRC screening interventions for AI must be culturally tailored.

Keywords

American Indian; colorectal cancer; colorectal cancer screening; community-based participatory research

In the United States, colorectal cancer (CRC) is the second leading cause of cancer death for men and women combined.¹ Some data sources, such as the Surveillance, Epidemiology, and End Results (SEER) program report that American Indians/Alaska Natives (AI/AN) have lower CRC incidence rates than both white and black Americans.² However, SEER data focus on AI/AN in selected geographic areas and increasingly suggest that there are wide variations in CRC incidence rates by region.³ Disproportionately higher rates of CRC

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Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

incidence have been reported for AN (102.6/100 000), and for AI in the Northern (54.9/100 000) and Southern Plains (49.1/100 000).^{3,4} Coupled with this, stage of CRC diagnosis is higher and survival is lower for AI/AN populations, even when adjusted for socioeconomic differences.⁵ Some reports show that CRC mortality rates are rising for the AI/AN population,⁶ opposite of a national trend of decreasing CRC mortality among the overall US population. The regional variation, substantial misclassification of AI/AN race in many cancer registries,⁷ and poorer survival once diagnosed demonstrate that CRC burden in AI/AN may be underestimated and represents a significant public health problem.

Screening for CRC is an effective strategy for reducing incidence and mortality.⁸⁻¹⁰ Screening can detect cancers at early stages when treatment is more effective (ie, improving survival and reducing mortality) and can lead to detection and removal of premalignant growths, thereby reducing CRC incidence. Screening is low in the general US population and lower still among AI/AN.¹¹⁻¹³ Lower screening rates among AI/AN are associated with later stage at diagnosis and poorer outcomes.¹⁴ Current CRC screening rates for all race/ethnic US women are reported around 11.7% for fecal occult blood test (FOBT), 42% for sigmoidoscopy or colonoscopy, and 45.8% for combined endoscopy/FOBT.¹ For AI/AN women, these rates are 5.8%, 31.7%, and 34.4%, respectively.¹ A number of well-established patient-level and system-level barriers to CRC screening exist, but few studies have investigated barriers to or facilitators of CRC screening among AI/AN. This is important because in addition to socioeconomic factors, there may be culturally specific barriers to and facilitators of screening, such as speaking a Native language¹⁵ or perceiving discrimination in medical settings.^{16,17} This study was designed to explore the perceptions of AI women older than 50 years toward CRC screenings, existing barriers, and suggestions to promote education and screening among AI in the Midwest.

Methods

To understand women's perceptions of CRC screenings, existing barriers, and suggestions to promote education and screening among AI women in Kansas and Missouri, we conducted a series of 7 focus groups with women 50 years and older (N = 52 participants). Participants were recruited primarily through word-of-mouth at local powwows and other cultural events. Additional recruitment was done through posters and flyers at locations AI women frequent, e-mail listservs from community organizations, and direct recruitment through our community advisory board. All study protocols were approved by the University of Kansas Medical Center Human Subjects Committee and local tribal councils, as needed.

A focus group moderator's guide was developed in conjunction with a community advisory board, based on prior interviews with community leaders and providers¹⁸ (see the appendix). Focus groups were held in both urban areas and on reservations during both days and evenings to accommodate women with various work schedules. Groups lasted between 60 and 90 minutes and were audio-taped and transcribed verbatim. New groups were convened until data saturation was achieved on major themes. Text analysis was conducted using a community-based participatory research protocol developed by the team where 5 individuals are involved in analysis, 3 as coders (2 researchers and 1 community member) and 2 as reviewers of themes developed by the coders (the study principal investigator [PI] and 1 community member). Transcripts were coded independently by hand by 3 members of the research team using a codebook developed by both academic and community member researchers specifically for this study using an inductive approach. Approximately 10% of the codes were cross-checked by the PI of the overall study to ensure intercoder reliability; few to no differences were found. Coders identified preliminary themes that were then combined into thematic statements by the PI and checked by a community member

researcher. The entire team then met to ensure consensus on the final themes. Full details of the analytic process are described elsewhere.¹⁹

Results

We conducted 7 focus groups with AI women; demographic information is summarized in Table 1 and screening history in Table 2. Text analysis of focus group data revealed 7 discrete themes.

Women had general knowledge of CRC symptoms, screening methods, risk factors, and treatment. Sources of knowledge included TV personalities, Internet sites, providers, family and friends, and tribal newspapers. Some participants had been screened or had indirect experience with CRC, so they had knowledge of the process and knew more than those who had not. Other women said that their knowledge was superficial. For example, women may have heard of different screening tests but did not know their importance or the pros and cons of each.

Women described hearing about CRC screening via various media. Television personalities such as Oprah, Dr Oz, and Katie Couric, were cited as vehicles for providing information about CRC. Participants named other sources for CRC information, such as the Internet and print materials, though none referred to specific sources.

Health care providers and family members or friends were described as providing information from a clinical or experiential perspective. Most women stated that their health care providers had recommended and discussed screenings with them, providing basic information. Family and friends provided information about prior experiences with CRC screening. Even though women's exposure to CRC information varied, most agreed that the information they received from health care providers, family, and friends lacked details specific to AI.

Women felt that Native people do not get screened for CRC; barriers to screening included embarrassment, privacy issues, fear of the procedure and possible results, insurance, and cost. Embarrassment was mentioned by many women who explained that colonoscopy involves body parts that may not be discussed openly. Some participants suggested that the colon, and the colonoscopy, are somewhat taboo and are not talked about because of privacy.

Other participants discussed fear, both of the tests themselves and of the results, as factors that would inhibit them from getting screened. Women mentioned factors that influenced their uncertainty toward the process, such as not knowing what to expect, how the procedure would feel, and what to do beyond the screening (depending on the outcome). Others described hearing from friends about difficulties preparing for and receiving colonoscopies. However, most women who had received colonoscopies reported it was not a big deal or that although it may not have been pleasant, the benefits outweighed the uncomfortable or awkward process. The same was true for FOBT. Even though FOBT is noninvasive, some women felt that the collection of stool was disgusting and that they did not want to do it. Women who had an FOBT screening stated that the test may not be desirable, but the alternative of doing nothing was worse.

Finally, participants listed both lack of insurance and cost as barriers to screenings. Participants felt that if a screening detected something suspicious or abnormal, the necessary follow-up and treatment could be problematic in the absence of insurance. In addition, women reported that many AI do not have insurance outside of the Indian Health Service (IHS) and, therefore, would have difficulty accessing a colonoscopy. Participants stated that

the IHS in Kansas does not provide screening colonoscopies and that AIs without health insurance have to pay for colonoscopies out of pocket. Furthermore, participants reported that not all AIs have access to IHS services because of tribal enrollment standards.

Women felt that because less attention is paid to CRC than to breast cancer or diabetes, CRC is not seen as serious. Participants said other health conditions get more attention from mainstream media, whether specific to AI or to the general public, and that public health messages focus on other conditions. Participants agreed that the prominence of discussion about other diseases and conditions, for example, alcoholism and diabetes, by clinicians and through public health messages and popular media, deemphasizes CRC education. Participants noted that this results in low enthusiasm for staying current with screening guidelines.

Though most women reported discussing CRC with their health care providers and viewed the discussions in a positive light, women did not always adhere to provider recommendations for screening. Some women reported a sense of satisfaction with their provider's communication concerning CRC screening and appreciated conversations about screening; however, some women felt trepidation toward the topic.

Many women reported that their conversations with providers often did not result in actual screenings for several reasons. One woman described receiving an FOBT kit but she had yet to collect and send in her stool sample, saying she was, "just afraid to do it." For others, the price of the test was prohibitive, regardless of provider recommendation.

Other priorities (or logistical realities) were described as taking precedence over screening as well, that is, child care duties, work schedules, long wait periods, and lack of transportation. Depending on location, contract health services was described as posing another issue for women living outside of the county with services. For example, a woman who lives in a different county than that of the IHS facility to which she goes, will not be able to use contract health for a colonoscopy because the contractual services are only provided in-county.

Colorectal cancer was not widely discussed with the exception of family and friends who have a history of or known risk factors associated with CRC. Women explained that some topics are not discussed in the Native community; CRC is not discussed due to the nature of screening procedures and the body parts involved. CRC was described as not coming up in casual conversation unless someone had experienced or been affected by it. Most participants acknowledged that current attitudes and behaviors concerning CRC needed to change to increase awareness and screenings.

However, some women reported engaging in conversations regarding CRC with others. These situations occurred usually because they or someone they knew had been affected by CRC. Conversations about CRC knowledge were described as being based on personal experience and when these experiences were shared, others were encouraged to get screened. Women said they try to influence others to get screened by focusing on the detrimental effects if people go unscreened.

Women described a need for a comprehensive approach to CRC education and screening, similar to what has been done for breast cancer. They felt education must include information specific to Native people, should be tied to social support networks, and should be inter-generational. They suggested an aggressive campaign for CRC screening that acknowledged cultural views about CRC and certain key components. First, women believed that education should contain information specific to Native people and culturally tailored so that it would be more relevant to them. Participants thought women would be

better able to make informed decisions if they had appropriate information about screening methods and in the context of familial risk for CRC. Second, women thought that education should be tied to social support networks because education and screenings may be facilitated through family and friends. Third, women suggested that education be intergenerational. Women felt that involving younger people represented a critical channel for promoting health because younger generations can learn from elders and make changes to decrease mortality and improve screening.

Participants were frustrated with screening, referrals, and follow-up in both the IHS and other health care settings. Many of the complaints stemmed from systematic challenges within the health care system. The problems reported range from accessing IHS services to IHS not having the necessary screening services. For example, IHS may not provide colonoscopies; therefore, individuals may need to rely on contract health. Participants reported that referrals through contract health do not imply a speedy, worry-free process. It can be confusing and frustrating for both providers and patients, with problems in scheduling appointments, long waits for appointments once they are scheduled, and poor tracking and reporting of test results. These problems make it less likely for patients to follow through with any appointments using contract health. However, the descriptions about contract health and IHS were not specific to CRC. Problems were described when someone needs a test and when coordination of care is necessary.

Participants described how screenings needed coordination on several levels. In the following example, a woman described a typical experience with health services:

Well, but my Nation would cover it except I'd have to go down there and live in a motel room while everything is being done and if you don't have the money to do that . . . [the test will not happen].

This experience illustrated the point that even if health services are available, patients may not use them because of unanticipated costs.

Discussion

Participants offered insights into exploring and testing new strategies for increasing screenings among AIs. They described CRC knowledge among AIs as inadequate and expressed concern that more was not being done to raise awareness and spread the word. Women incorporated an underlying narrative into the structure of their responses: a lack of dialogue concerning CRC among the AI community. A relationship between basic knowledge and lack of communication was described. Women reiterated that lack of knowledge may feed into a cycle of inadequate communication among community members.

Participants' concerns around knowledge led to discussions and suggested strategies for improving screening rates. A culturally tailored approach to education was suggested. Current screening and informational messages were described as lacking culturally appropriate detail. Intergenerational approaches for education were also suggested.

Another important concept described by participants related to use of IHS and the complexity of dealing with the health care system. The unique problems and challenges of dealing with IHS and contract health were seen as a major barrier to expanding uptake of CRC screening. Specific suggestions for improving this situation were not generally offered, but it was clear that current inadequate access to screening could be improved.

Study conclusions are limited by our use of a regionally recruited sample. Themes may be unique to AI in the Central Plains. Also, the majority of information given during the focus

groups concerned IHS or contract health. Few conversations addressed the influence of private health insurance. Finally, even though all participants self-identified as Native, the groups contained a heterogeneous population. Not all Native populations are the same, though most recognize some shared cultural identity. Therefore, the process of reaching consensus may have been more difficult because of the diversity of participants.

In sum, our research findings provide discrete areas of concern and suggestions for future approaches to enhance CRC screening. These results informed a research grant (R01 CA158238-01, PI: KAG) that focuses on CRC screening among AI communities via a tailored touch screen computer intervention. In addition, these results are being incorporated into culturally appropriate brochures that target AI and CRC screening (P20 MD004805, PIs: CMD, KAG). These brochures will be designed to meet the needs of the local population based on the information participants provided. Additional future interventions are under development.

Acknowledgments

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Funding for this study was provided by the National Institutes of Health, National Institute for Minority Health and Health Disparities (P20 MD004805, PIs: CMD, KAG) and National Institutes of Health, National Cancer Institute (R03CA121828, PI: CMD).

Appendix

Focus Group Moderator's Guide

1. First, what comes to mind when I say colon cancer? What have you heard about it, if anything?
 - Who might be more likely to get it?
 - What kinds of symptoms should you look for?
 - Is it preventable?
 - Is it more or less deadly than other cancers?
 - Do you feel like you're at risk for it?
2. Have you ever talked about colon cancer with anyone besides your doctor or other health care provider? Who? What did you say?
3. Do you think people talk about colon cancer much?
 - What about compared to other cancers?
 - Is this even something people think about?
 - Would it be useful to have some educational materials? What kind(s)?
4. Have you ever talked with your doctor about colon cancer? What did s/he say?
5. *If unscreened:* Were you ever told to be screened or tested for colon cancer? What kind of testing?
 - FOBT/stool cards, sigmoidoscopy, colonos-copy, double-contrast barium enema?

6. *If screened*: What kind of testing did your doctor recommend you have? What kind of testing did you have? Why did you choose that one?
7. Do you know anyone who has been tested (other than you)? Have you talked with him/her about it? What did s/he say?
8. Do you think a lot of Native people get screened for colon cancer? About how many people in this area get screened? (*nobody, few, half, most, everybody*)
9. Where do people get screened?

Biography

Melissa K. Filippi, PhD is a research instructor in the Departments of Family Medicine and Preventive Medicine and Public Health and the Center for American Indian Community Health at the University of Kansas Medical Center. Her research interests are community-based participatory research, community health, and health disparities.

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Table 1

Demographic Information

American Indian Elder Women (N = 52)		
	Frequency	Percentage
Current living situation		
Married/partner	24	46.2
Divorced/widowed	23	44.2
Never married	5	9.6
Education ^a		
Some high school	3	5.9
High school graduate/GED	11	21.6
Some college	17	33.3
AA degree	6	11.8
BA/BS degree or higher	14	27.4
Health insurance outside of Indian Health Service		
No	7	13.5
Yes	45	86.5
Where do you receive the majority of your health care? ^a		
Indian Health Service	21	42.9
Other health care facility	28	57.1
Have you ever talked with your doctor about colon cancer testing? ^a		
No	15	29.4
Yes	35	68.6
Not sure	1	2.0
Have you ever been told by a doctor or nurse that you had a cancer other than colorectal cancer? ^a		
No	36	72.0
Yes	14	28.0
Have you or any of your blood relatives ever been diagnosed with colon polyps by a doctor or nurse? ^a		
No	22	48.9
Yes	19	42.2
Not sure	4	8.9
Have you or any of your blood relatives ever been diagnosed with colorectal cancer?		
No	27	51.9
Yes	19	36.5
Not sure	6	11.5
Did you or your family member receive treatment for colorectal cancer? ^a		
No	8	42.1
Yes	7	36.8
Not sure	4	21.1

^aNot all participants responded.

Table 2

Screening History

	Women 50+ Years Old (N = 52)	
	n	Percentage
Discussed colorectal cancer testing		
No	15	30
Yes	35	70
<i>Fecal occult blood test (FOBT)</i>		
Ever had a FOBT		
No	22	44
Yes	28	56
Most recent FOBT		
1 year	7	25
1-2 years	4	14.2
2-5 years	11	39.2
>5 years	6	21.4
Reason for most recent FOBT		
Routine exam	22	78.5
Symptom/follow-up	6	21.4
<i>Sigmoidoscopy</i>		
Ever had a sigmoidoscopy		
No	36	72
Yes	14	28
Most recent sigmoidoscopy		
1 year or less	1	8.3
1-2 years	2	16.6
2-5 years	2	16.6
>5 years	7	58.3
Reason for most recent sigmoidoscopy		
Routine exam	9	75
Symptom/follow-up	3	25
<i>Colonoscopy</i>		
Ever had a colonoscopy		
No	22	43.1
Yes	29	56.8
Most recent colonoscopy		
<2 years	9	32.1
2-5 years	13	46.4
5-10 years	5	17.8
>10 years	1	3.5
Reason for most recent colonoscopy		
Routine exam	18	64.2

Women 50+ Years Old (N = 52)		
	n	Percentage
Symptom/follow-up	10	35.7