American Indian Community Leader and Provider Views of Needs and Barriers to Colorectal Cancer Screening

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Abstract

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Keywords

American Indian; Barriers to care; Cancer — Diagnosis; Cancer – Prevention; Colon (Anatomy) — Cancer; Colorectal cancer screening; Community-based participatory research; Health education; Indians of North America; Rectum — Cancer

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American Indian Community Leader and Provider Views of Needs and Barriers to Colorectal Cancer Screening

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ABSTRACT

Colorectal cancer is a great concern for the American Indian/Alaska Native (AI/AN) community, as incidence and mortality rates remain high and screening rates stay low. We conducted interviews with community leaders (n=13) and with providers from the Indian Health Service (IHS), tribal clinics, and urban safety-net clinics (n=17) in Northeast Kansas and the Kansas City Metro Area to determine their understanding of needs and barriers to colorectal cancer screening among American Indians. Using a community-based participatory research (CBPR) approach for this pilot study, community leaders and providers identified similar needs, including: culturally-appropriate education about colorectal cancer and screenings, the potential use of Native elders as patient navigators, and an emphasis on preventive care, particularly through the IHS. Barriers included culturally specific issues such as historic mistrust and gender roles. Other barriers are similar to members of other ethnic groups, such as cost, transportation, fear, and repulsion toward the screening process.

Key Words

American Indian, colorectal cancer screening, barriers to care, community-based participatory research

INTRODUCTION

Nationally, colorectal cancer is the second leading cause of cancer mortality. Several studies demonstrate that American Indians and Alaska Natives (AI/AN) have similar or higher rates of colorectal cancer incidence and colorectal cancer mortality than other racial/ethnic groups (Kelly, 2007; Lanier, 2008). The age –adjusted incidence rates of colorectal cancer for AI/AN are lower than for non-Hispanic Whites, at 46.0 per 100,000 and 41.2 per 100,000 among men and women, respectively, compared with 58.9 per 100,000 and 43.9 per 100,000 among White men and women, respectively (ACS, 2009). However, recent evidence illustrates incidence rates for AI/AN vary widely from region to region (up to 5-fold differences, from 21.0 per 100,000 in the Southwest to 102.6 per 100,000 in Alaska) (Perdue, 2008). Therefore, region specific data are necessary and important.

Colorectal cancer mortality rates have declined in the overall population with no significant change in the mortality rates among AI/AN, at 20.5 per 100,000 for men and 14.2 per 100,000 for women (ACS, 2009; D. K. Espey et al., 2007). Like incidence, the mortality rate varies in different regions of the country for AI/AN, with the highest rates in Alaska and the Northern Plains region (1.71 per 100,000 and 1.55 per 100,000, respectively) and lowest in the Southwest and Pacific coast regions (0.49 per 100,000 and 0.65 per 100,000, respectively) (D. Espey, Paisano, & Cobb, 2005).

United States colorectal cancer screening rates remain low in all populations, but rates remain disproportionately low for Native people compared with others in the United States (D. K. Espey, et al., 2007; Steele, Cardinez, Richardson, Tom-Orme, & Shaw, 2008). Because screening can reduce colorectal cancer incidence and mortality, these disparities in colorectal cancer screening among AI/AN warrant further research. Few studies have examined attitudes and knowledge of AI/AN about cancer screening and fewer have addressed colorectal cancer screening. Given the evidence that AI/AN are less likely than whites to report that their doctor recommended endoscopy for colorectal cancer screening (28.9% for AI/AN vs. 23.7% for whites) (Coughlin & Thompson, 2005) and the intricacies of the IHS healthcare system, it is important to examine both provider- and community-level views of colorectal cancer screening.

Using a community-based participatory research (CBPR) approach, we explored community leader and provider perspectives on colorectal cancer to obtain a more holistic understanding of colorectal cancer awareness, attitudes, barriers, and utilization among rural and urban AI/AN in Northeast Kansas and the Kansas City Metropolitan Area of Missouri.

METHODS

For this pilot study, we conducted 13 interviews with community leaders and 17 interviews with providers from the Oklahoma Area Office of the Indian Health Service (IHS), tribal clinic providers, and safety-net clinic providers in Kansas between fall 2006 and spring 2007. We audio-taped and transcribed all interviews verbatim. Provider interviews lasted between 20 and 60 minutes; community leader interviews lasted between 45 minutes and 2.5 hours. Two community members who were formally trained as interviewers conducted all community leader interviews and the majority of provider interviews. Because we conducted most of the provider interviews (n=12) on one day in one IHS facility, additional members of the research team who were trained interviewers, though not community members, also conducted interviews. No differences in provider answers based on whether or not the interviewer was a community member were identified. Our community partner organizations and our team members who were also members of the community identified “community leaders.” “Providers” included anyone working in the clinic with direct patient contact, including physicians and dentists, auxiliary medical personnel, and administrators.

Interviews followed a semi-structured format, with both open- and closed-ended questions. Prior to the start of each community member interview, participants provided demographic information and free-listed all barriers to colorectal cancer screening. Four participants declined to answer their marital status; three declined to answer where they received the majority of their healthcare. We did not ask participants to explain why they chose not to answer those questions. Providers were also asked to free list barriers, but we did not collect demographic information on them because we wanted to ensure their anonymity given the few providers serving AI/AN in Kansas. A medical anthropologist with over 10 years of experience conducting qualitative research related to cancer screening with American Indians (CMD) developed interview guides. Topics covered in the interviews included knowledge of colorectal cancer and its screening mechanisms, perceptions of community member/patient knowledge, barriers to colorectal cancer screening, and suggestions for education and improving screening rates.

We analyzed demographic information with summary statistics and basic measures of central tendency. We used the statistical program ANTHROPAC® to compute Smith’s Saliency Index, average rank, and frequency for free list data. Smith’s Saliency Index is based on the idea that when free listing, participants list items of greater salience first. The resulting weighted average takes into consideration the number of participants mentioning an item, the placement of an item on a participant’s list, and the total number of items on each individual list. It is commonly used to interpret free list data (Bernard, 2006). Once we completed our initial analysis, we condensed some terms that were used to describe the same thing (e.g., “education” and “educate”, “paying for test” and “cost of test”). All condensing was done through consensus with the research team (including community members), after which free lists were re-analyzed using the condensed terms.

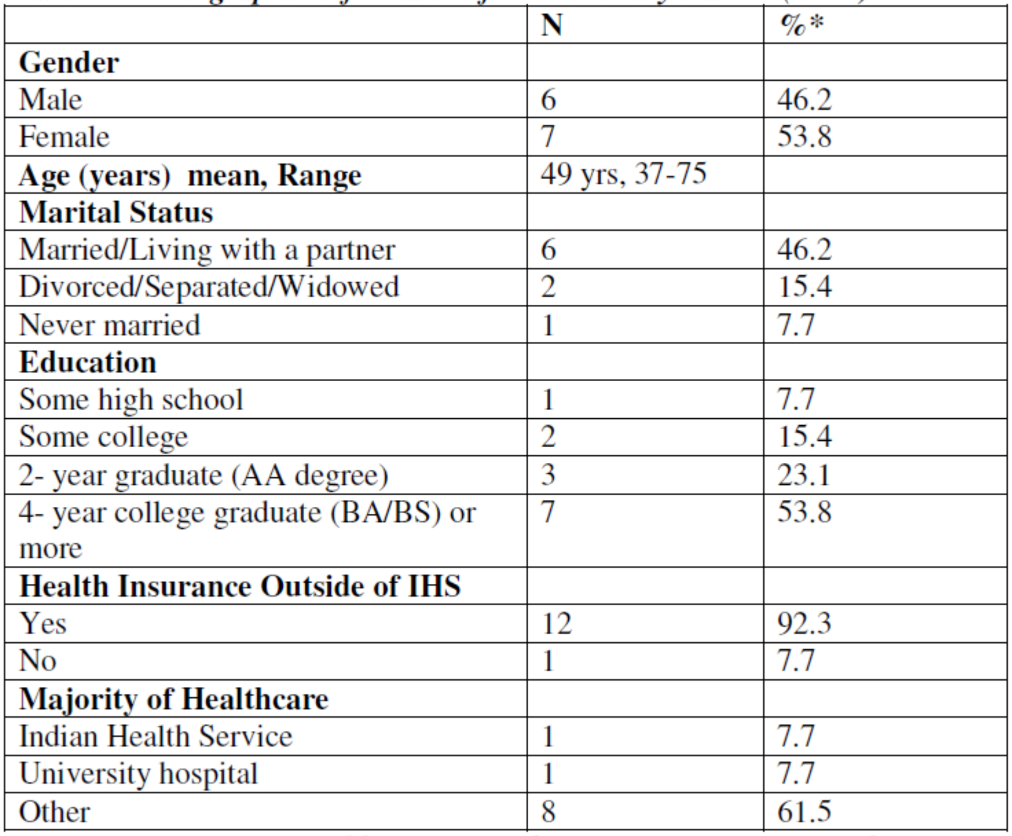
We analyzed qualitative data using a community-based participatory method involving five team members (both researchers and community members) in the process, developed by the study Principal Investigator (CMD), with input from the investigative team. It follows a combination of native and team ethnography, grounded theory, and the principles of CBPR, and is described in detail elsewhere (Daley et al., 2010). Initially, all analysts read through the transcripts and met to inductively develop an initial list of codes that was then compiled into a codebook through an iterative process. Coders deductively coded the transcripts by hand. We chose coding by hand rather than using a computer program because we wanted to make sure community members participated in coding.

After coding, coders individually formulated summary statements, which were then reviewed by the PI and a community member or provider, as appropriate. Thematic statements were written by the PI based on the summary statements and were modified by the community member or provider reviewing them. All analysts then met to finalize the wording of the themes through consensus. Approximately 10% of the codes were cross-checked for inter-coder reliability and few to no differences were noted. We analyzed community leader and provider data separately and then we compared themes across groups. All study protocols were approved by the Institutional Review Board of University of Kansas Medical Center and the Oklahoma Area Office of the Indian Health Service prior to conducting the study.

RESULTS: COMMUNITY LEADERS

We interviewed 13 community leaders from Kansas and Missouri; demographic information is summarized in table 1. We asked participants to free list barriers to colorectal cancer screening; 7 community leaders provided free lists, the others they were unsure or that they could not list them specifically. The most salient items listed for community leaders were fear, cost, and transportation (see table 2 for full listing). The list contains ideas that coincide with seven major themes that emerged across the interview data.

Table 1: Demographic information for community leaders (n=13)



	N	**%***
Gender		
Male	6	46.2
Female	7	53.8
Age (years) mean, Range	49 yrs, 37-75	
Marital Status		
Married/Living with a partner	6	46.2
Divorced/Separated/Widowed	2	15.4
Never married	1	7.7
Education		
Some high school	1	7.7
Some college	2	15.4
2- year graduate (AA degree)	3	23.1
4- year college graduate (BA/BS) or more	7	53.8
Health Insurance Outside of IHS		
Yes	12	92.3
No	1	7.7
Majority of Healthcare		
Indian Health Service	1	7.7
University hospital	1	7.7
Other	8	61.5

** Percentages may not add up to 100% because participants could answer multiple options or leave the question blank.*

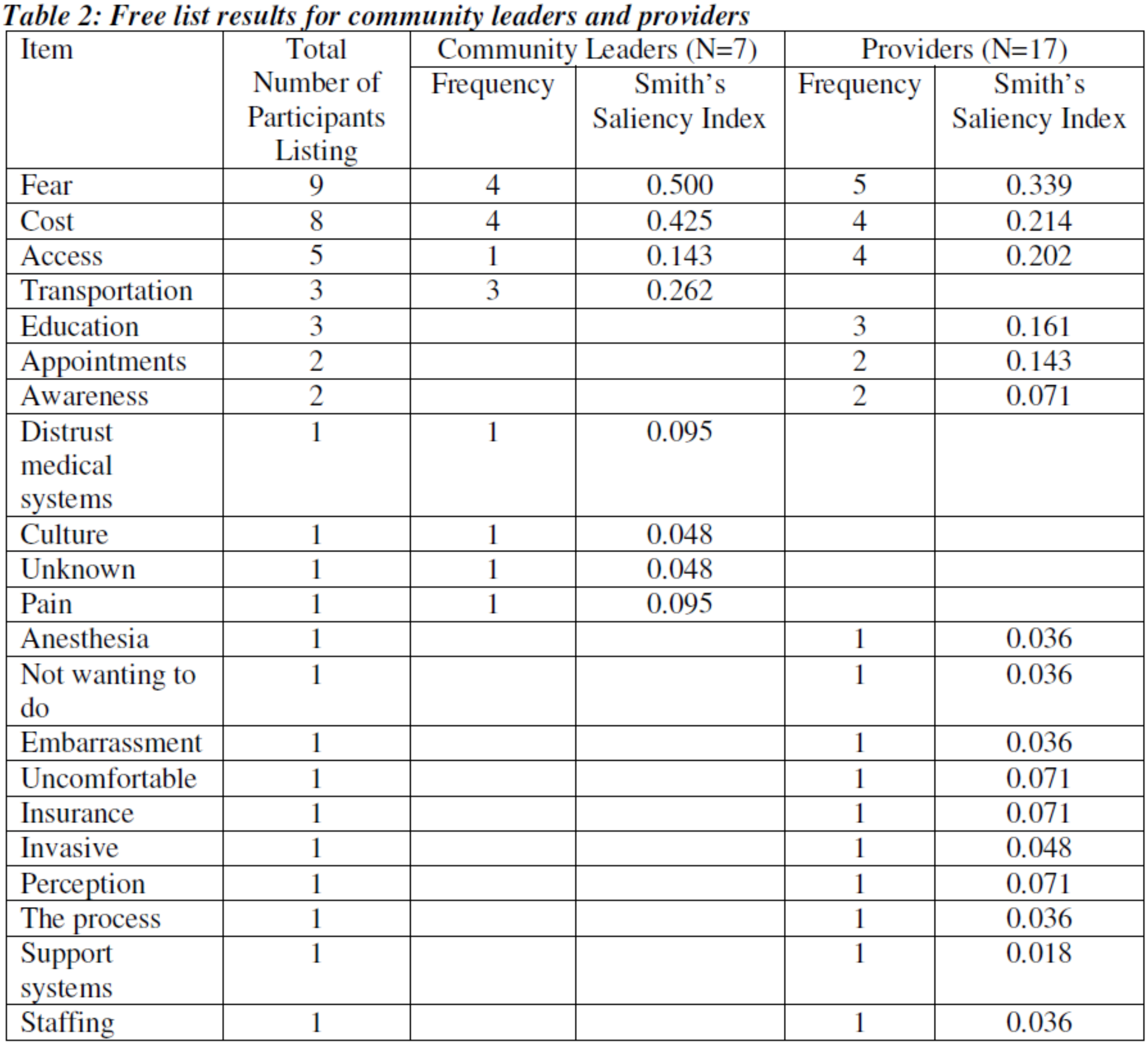


Table 2: Free list results for community leaders and providers

Item	Total Number of Participants Listing	Community Leaders (N=7)		Providers (N=17)	
		Frequency	Smith's Saliency Index	Frequency	Smith's Saliency Index
Fear	9	4	0.500	5	0.339
Cost	8	4	0.425	4	0.214
Access	5	1	0.143	4	0.202
Transportation	3	3	0.262		
Education	3			3	0.161
Appointments	2			2	0.143
Awareness	2			2	0.071
Distrust medical systems	1	1	0.095		
Culture	1	1	0.048		
Unknown	1	1	0.048		
Pain	1	1	0.095		
Anesthesia	1			1	0.036
Not wanting to do	1			1	0.036
Embarrassment	1			1	0.036
Uncomfortable	1			1	0.071
Insurance	1			1	0.071
Invasive	1			1	0.048
Perception	1			1	0.071
The process	1			1	0.036
Support systems	1			1	0.018
Staffing	1			1	0.036

1. Lack of Knowledge.

All community leaders interviewed felt that people in their community do not know much about general facts about colorectal cancer, risk factors, or screening guidelines. Many leaders think that community members do not regard colorectal cancer as an important issue and; therefore, do not get screened. In addition, lack of interest on the part of community members reinforces erroneous beliefs. For example, one reportedly widespread belief among community members is that colorectal cancer only affects men. Community leaders felt that misinformation stems from a lack of culturally-appropriate education.

Risk factors for colorectal cancer were largely unknown to our community leaders and, they believed, to other community members. Among our interviewees, there was little knowledge of screening guidelines and the different screening tests available. Most participants recognized colonoscopy as a test for colorectal cancer and knew more about it than Fecal Occult Blood Test (FOBT), and none knew of other methods (e.g., sigmoidoscopy, fecal immunochemical testing, and double contrast barium enema).

Another common misconception among Native community members, according to our community leaders, is the belief that Native people are not at risk or are less at risk for colorectal cancer than other people. As one participant explained,

> "I've never thought of it this way, but I've been told that many Native American populations just don't think that Native Americans get cancer, because the statistics are so low…and I don't think that a lot of times their healthcare providers or their rural locations have all the information necessarily to provide."

Therefore, community leaders said that many Native people do not believe they need to be screened and are unlikely to complete any of the screening tests available.

In addition, there may be cultural reasons why screening is not completed. One participant explained that, "Indian people kind of hang together and a lot of them do their own doctoring and (have) their own way of doing things." This sentiment was echoed in many interviews; many of our community leaders sought help from traditional healers or family members before or instead of going to see Western doctors. Reasons included a mistrust for Western doctors and the Indian Health Service and strong beliefs in the benefits of traditional healing.

Community leaders also believed that colorectal cancer is simply not a topic that is often discussed among members of their community due to cultural restraints regarding talking about bodily functions, health issues in general, or cancer in particular.

2. Culturally-Specific Education.

Culturally-specific education about colorectal cancer screening tests is imperative to increase screening rates because Native people want to make informed decisions. To alleviate the lack of knowledge prevalent in the community, interviewees would like to see culturally-specific oral and print health education materials available. The information should contain the specifics of all colorectal cancer screening modalities, including what the guidelines are, what to expect for each test, where to get them, and how to pay for them. They emphasized that just having pictures of Native people on brochures was inadequate to make the materials culturally-specific. In fact, most believed that print materials in general are inappropriate for their community due to the strong influence of oral tradition in most Native cultures.

Interviewees told us that it is just as important to ensure detailed explanations of testing procedures as it is to explain why a person should complete them. A full description of what to expect for each test, preferably explained by a Native elder who had completed the test, should be included. In addition, the intricacies of the health care system, including the IHS, tribal clinics, and public clinics, need to be explained in detail. Special attention should be given to access issues and navigating the system, i.e., where to get the tests and how to pay for them.

3. Screening Method.

Most community leaders see colonoscopy as the primary screening. test for colorectal cancer; many feel that FOBT will not be completed by Native people. Though most of our participants knew that the local IHS would not provide screening colonoscopies, they said their community would not complete FOBT because most people would find it to be distasteful and a series of stool samples are required. They believed that IHS should provide screening colonoscopy.

4. Low Screening Rates.

A sense of pride and independence, as well as privacy, regarding health issues may play a role in the low screening rates, particularly among Native men and Native people living in rural areas. Pride, independence, and privacy are by no means limited to Native people and are important when addressing health disparities, particularly for colorectal cancer screening. One participant noted that privacy and the personal nature of the tests would be more difficult to overcome than other barriers. Several participants talked about Native people living in rural communities and their sense of priorities,

> "We live in a rural area, so it's not a high priority as far…you know, if a person doesn't get sick to where they can't work, they typically don't go to the doctor. You know we just don't run…preventative maintenance is not done here."

and privacy,

> "You know, our people, we just…we're not real public. You know, we like to keep a lot of things to ourselves. And I don't know too many that would just jump up and say, hey, I want to go to the doctor and have this thing shoved up my butt, you know?"

Our participants indicated that elders believed little could be done to prevent cancer; and, if they get it, they will eventually die from it. Colorectal cancer is generally seen as a death sentence, particularly if it is found after symptoms are seen. People living on reservations or in rural areas are more likely to have a fatalistic view of cancer in general, as well as colorectal cancer specifically,

> "I don't know what I'd do if I walked in and (the doctor) said I had cancer. I'd probably try to figure out how many days I had left, you know, what I could do with those days…. And if you know you're going to die anyway, an Indian's more apt to just say, okay, I'm going to die anyway, so why do I need to do anything?"

5. Ethnicity- and Gender-Specific Health Providers or Patient Navigators.

Ethnicity and gender-specific health providers or patient navigators would help to improve screening rates. These are not requests unique to Native people; many people of minority ethnic groups have had personal experiences or have heard of experiences that leave them mistrustful of the medical profession. Community leaders believed that these feelings are particularly strong among American Indians living in the urban areas because there are no IHS providers in Kansas City. They felt the use of the urban safety-net clinics ensured that there would be no Native providers, which was at least a possibility in the IHS.

Though our participants emphasized the need for Native providers, they recognized that there are few AI/AN in medical professions, leaving it difficult to staff clinics. They felt patient navigators would be a good compromise, though the term "patient navigator" was not used by many participants. A common request was to, "Let them know what to expect. Partner them up with someone who's had testing and they can go all the way with them until the exam." The following description explains how a patient navigator could alleviate fears associated with the exam:

> "Just kind of someone to help them along. Because I know for myself my first experiences was not pleasant. No one told me what to expect and that kind of

> thing. So I think if you have someone who….can talk to people about, 'this is what it will be like', 'This is how it happens.' So that eliminates some of the fears."

6. Other Barriers.

Cost, transportation, and fear of screening tests accompanied by test results are major barriers to increasing rates of screening, particularly for colonoscopy. Our participants focused on colonoscopy and stated that cost would be an issue for both reservation and urban populations. Because the IHS in the area represented by our study does not provide screening colonoscopies, AI/AN without health insurance or Medicaid would have to pay for a colonoscopy out-of-pocket and the cost is prohibitive. Community leaders believed that many AI/AN do not have health insurance outside of the IHS and, consequently, would not be able to get a colonoscopy. In addition, not all members of the Native community have access to the HIS due to tribal enrollment standards.

Transportation is another issue both on the reservation and in urban areas. On reservations, people often have to travel a significant distance to obtain a colonoscopy. Given other barriers, motivation to travel great distances is low. Though screening is available closer to home in the urban areas, the need for another person to take someone to and from a colonoscopy can still be prohibitive.

Fear of the screening test and the results can also be a problem. Though no one felt community members would have a fear of FOBT, there was definitely a sense of fear surrounding colonoscopy due to the invasive nature of the test. Fear of the results of either test was more commonly discussed than fear of the test itself.

7. Lack of Preventive Care.

Community leaders believe that the IHS or other health care providers who serve poorer communities, such as the Native community, fails to emphasize preventive care. They feel this is shown through the local IHS policy. Current policy designates colonoscopy as only a diagnostic tool, rather than a possible preventive measure through screening. Our participants also emphasized the need for providers to talk to their patients more about preventive care because preventing disease is preferable to treating it and in many tribes traditional medicine focuses on prevention rather than cure.

Participants spoke at length about getting appointments for urgent care or waiting months for primary care visits. They said this need for primary care and preventive health visits is one of the major problems within the IHS. One community leader explained the overall frustration:

> "Yeah, so that's a barrier right there. I think people get so frustrated with that system that they just…they probably don't seek help when they really need it because of the difficulty there is to access the help you really need because of their funding problems and the referral process and then them not following through with paying when they say they're going to pay."

Another interviewee talked about the referral process for colonoscopy itself,

> "I'm thinking barriers (to getting a colonoscopy)…when you go through IHS it's like there's always that referral process. And just to get a referral is just so time consuming. And then after you get the referral and then you see the physician,

> you know, then getting IHS to follow through with paying the bill that they say they're going to pay is almost next to impossible sometimes."

Participants also spoke of the de-emphasis on prevention of providers outside of the IHS, particularly for people without health insurance. They believe Western medicine focuses on treating people who are sick.

RESULTS: PROVIDERS

We did not collect demographic information on providers to maintain anonymity. However, within the provider group, we interviewed clinicians including primary care providers, radiologists, and dentists, clinical staff such as dental assistants, nurse practitioners, diabetic program coordinators, radiology technicians, and administrative coordinators. All providers free listed barriers to screening and gave lengthier free lists than those of community leaders, but both groups shared some ideas. Fear and cost were the two most salient items. Other prominent items listed include: access, education, appointments, and awareness (see table 2 for full free list results). Providers had some similar beliefs to community leaders (e.g., limited knowledge) but some beliefs were very different (e.g., limited resources for screening).

1. Limited Knowledge of Colorectal Cancer Screening.

Similar to community leaders, providers felt that the community at large has little knowledge of colorectal cancer and its risk factors and screening guidelines. They also recognized the same prevalent misconception that colorectal cancer only affects men, but they felt that the larger fallacy was patients believed that colorectal cancer does not affect Native people to any great degree. Compounding the issue, providers also believe that many staff members have little knowledge of colorectal cancer and less knowledge of the IHS policies surrounding screening options. Without educating all providers and staff who deal directly with patients about the policies, providers do not believe screening rates will improve.

2. Limited Health Resources.

Limited health care resources preclude colorectal cancer screening. Providers identified several categories of limited resources that impact their ability to provide screening. First, providers have large numbers of patients to see in limited time due to *staff shortages*, particularly of physicians. One administrator from an IHS facility noted,

> "I know they need to have more recruiting to get physicians…to get more staff in here. I think they need to support the medical staff that's here, you know, when we say we can't see any more patients today. You know, we've got this many to deal with already, there's a lack of support for…it's just that they keep being overrun by patients."

The limited time available to spend with each patient leads to less time for education about preventive care. One provider explained,

> "I think it comes down to enough staff…enough staff to take the time to make it (education about preventive care) a priority again. Because if it's a priority with us and it's important to us and we demonstrate that to the patient, then it becomes more important to them. But, you know, if we're not asking about it or taking the

> time or having the time to give that education…It's very rare that a patient comes in and says, 'hey, I need to have my rectal screening done, I'm over 50'."

Limited time to spend with patients also leads to less desire to educate patients about services that are difficult to get anyway because of additional limited resources. Providers believed their time would be better spent dealing with acute problems for which resources are available. Participants said that patient education must be coupled with an increase in services that requires an increase in the number of providers. Educating patients is further complicated by low health literacy rates. These issues complicate the problem because more education is needed in the time allotted per patient.

A second category of limited resources is *funding for preventive care*. In our research area, preventive care is tertiary priority within the IHS. It is only available if other services are covered by the end of the fiscal year. This prioritization is not the case in other parts of the country. A clinic administrator explained,

> "I know we should do it (screening colonoscopy)…but it comes down to monies and availability and when you have a certain amount to work off of…you have a catastrophe happen right after you get your monies and then it might take six months to get that money back. You have no funding along the way… When we get into a fix like that, everything goes on hold, only life threatening would be taken care of until we either were reimbursed that money."

The use of colonoscopy solely for diagnostic examination exemplifies the issues surrounding priority decision-making and budgets. Because IHS funding is through area offices and the federal government, it can take a long time for individual service units to be reimbursed. The fact that patients normally seek care when they are symptomatic further complicates the underutilization of available preventive care.

Finally, most facilities do not have the *resources to provide colonoscopy in-house* and use contract health services to do so. Contract health services are often tied to a county or state, leaving patients who live outside of the area without coverage. Without contract health, cost can become prohibitive for patients not covered with private health insurance. Many patients do not have private insurance and those who do are often reticent to tell their providers for fear that they will be sent elsewhere.

3. Culturally Appropriate Health Education.

Education for patients should be both targeted and tailored in terms of culture and literacy level. Like community leaders, providers identified broad-spectrum education as critical to increasing screening rates, including: basic colorectal cancer information, options for screening, and steps to access available services. Providers believe that education should include three general components. First, the materials must contain culturally-appropriate, understandable information written at an appropriate health literacy level. Second, the materials need to involve an oral component. Third, the materials should incorporate outreach to different parts of the community, e.g., specific tribes, urban areas, etc.

Providers explained further that oral presentations and open discussions can be one of the most effective ways to communicate with the elderly due to oral tradition and low literacy levels. There was a consensus that awareness is key to solving the problem of low colorectal cancer screening among their patients and, therefore, campaigns must be launched to improve awareness and knowledge among the appropriate segment of the population. There was much discussion of the “Indian grapevine” and its importance in getting the word out about anything, including health topics. Most providers believed that if certain individuals in the community became vocal about colorectal cancer screening, others would follow and get screened.

4. Ancillary Support Services.

Patients need ancillary support services, including patient navigators, childcare, transportation services, among others. Providers are well aware of their patients’ needs for support services, but interviewees focused on patient navigation as a service that would make a large difference in screening rates. They described an ideal patient navigator as a Native person who is up-to-date on colorectal cancer screening and is a leader in the community, someone who can start the “Indian grapevine.” Therefore, this informed person can promote screening and help others to understand how to access available services.

> “I think also if you use – start with the elders, because they’re normally the heads of households and also deemed with high respect as far as wisdom goes, I think that if you focus on elder sites, focus groups, like that and for them to disseminate the word to their families, I think that would be effective… I also think that if somebody has the same belief systems then they will also be more apt to pattern with the new ideas than if it were an outsider speaking about Western science ideologies.”

In some parts of the country, this need has been met through the hiring of community health representatives (CHRs). Sometimes this is done through IHS facilities, other times it is through individual tribes. In our area, CHRs are available on some of the reservations, but not through the IHS.

5. Screening Compliance.

According to providers, endoscopy is perceived by patients as an invasion of personal space, painful, and something to be feared; FOBT is perceived as unpleasant or embarrassing. It is therefore difficult to get patients to follow through with either screening. Providers understand patient reticence to complete both endoscopy and FOBT. However, they believe that if the importance of the tests is emphasized and education is done correctly by the appropriate community advocates, these barriers can be overcome.

6. Scheduling and Follow-Up.

Scheduling and follow-up logistics are problematic. Associated problems with scheduling and follow-up include contacting patients, no-show rates, long waiting periods, and issues surrounding contract health. Staff members who schedule appointments explain that much patient contact information is poorly updated, leaving it difficult to schedule any appointments. In addition, there are high no-show rates among patients; many appointments for which patients did not show are then not rescheduled due to problems contacting the patients. When a patient does show up for an appointment, there is often a long wait before the patient is seen (up to several hours).

In addition to long waiting periods in the clinic, when a patient schedules a procedure, such as a colonoscopy, there can be waiting periods of several months before an appointment is available. These long waits allow patients to re-think having the procedure done, become busy with other things, or forget about the appointment entirely. Periods of long waiting are particularly common when using contract health for colonoscopies.

Providers and patients struggle with the process surrounding contract health. Confusion and frustration mounts for both groups because of problems such as scheduling appointments, waiting for scheduled appointments, and poor tracking and reporting of test results. Many providers noted that they had not received previously ordered test results. Though sometimes patients failed to show up for the appointment, sometimes the report was never sent to the ordering physician. These problems make it less likely for patients to follow through with any appointments using contract health.

7. Barriers in Relation to Patient Age and Gender.

Barriers often relate to patient age, with elders tending to be more traditional and have more problems with accessing services. Providers believed that colorectal cancer screening can be particularly problematic due to the age group involved. Elders tend to be more traditional, speak less English, and are less likely to use Western medicine. They are also more likely to have a problem with a provider of different gender, particularly women. A final complication is that elderly patients are more likely to have problems navigating the system, paying for services, getting transportation, and understanding educational materials.

DISCUSSION

Our data from both community leaders and providers present barriers to care among Native people in our area. Many of the barriers identified by community leaders and providers in both the free lists and the open-ended questions reflect the struggles of promoting colorectal cancer screening across diverse population groups: low awareness, costly tests, and unpleasant screenings. The perception characterizes many patients and community members who do not regard colorectal cancer as a relevant health issue.

Access to preventive care is a barrier for many underserved populations, especially those who are underinsured or uninsured. Approximately 36% of American Indians have private health insurance (US Census Bureau, 2006). Some of the remaining 64% can access care through the IHS, which possesses limited resources, and where acute care needs detract from preventive care resources. However, the intricacies of the IHS present additional difficulties in promoting screening. For example, while many of our community leaders perceived colonoscopy as the primary and optimal screening test, the test is unavailable at many clinics. In some cases, patients must travel several hours to reach an IHS center that offers colonoscopy. In some cases, colonoscopy may be provided locally through contract health services, but there are restrictions on the use of contract health (e.g., living in the immediate county where the contract center is located). Thus, for many Native people who do not have health insurance, there is no single procedure or path that will result in a screening colonoscopy. This situation creates confusion, lack of trust in the system, and opportunities for delayed or missed care.

Community leaders asked for culturally tailored information and educational strategies.
The strong oral tradition in many Native cultures suggests that print materials need to be supplemented with person-to-person intervention strategies. Native elders are an important influence in traditional communities, and could be powerful collaborators in educational efforts.

Increasing the pool of Native physicians and healthcare providers would assuage some of the obstacles concerning screening rates and health literacy. In turn, providers supported the call for culturally targeted education, and also emphasized health literacy promotion.

Both community members and providers advocated for ancillary support systems to help patients navigate the complicated systems of accessing care. The value of oral rather than written communication supports the use of a "navigator" or "lay-advisor" approach. Therefore, patients can be better informed as to "what to expect" throughout the process. The use of CHRs may be an effective way to combat some of these barriers. Some locations around the country have CHRs available; in our areas, there are some CHRs, but all have more work than they can handle. This is likely true in other parts of the country; additional resources are needed to provide more services. We are currently beginning training for lay audiences to become CHRs or patient navigators.

The major limitation to our study is that the data are not yet saturated. To alleviate this, we have conducted a series of 22 focus groups, which we are now analyzing to augment our initial data. Tied to this limitation is a lack of ability to transfer the data to another community, and a limited pool of potential respondents. Since our heterogeneous population comes from many different parts of the country, we believe at the end of our larger study, we will be able to shed light on barriers to colorectal cancer screening through Native communities in the United States.

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