



THE IHS PRIMARY CARE PROVIDER



A journal for health professionals working with American Indians and Alaska Natives

January 2017

Volume 42 Number 1

Use of Family History for Colorectal Cancer Outreach in the Alaska Tribal Health System

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Abstract

Colorectal cancer (CRC) is the second-leading cause of cancer incidence and mortality among Alaska Native people. First-degree relatives (FDRs) of persons diagnosed with CRC have twice the risk as the average U.S. population. We assessed CRC screening outreach to FDRs at Alaska tribal health organizations (THOs), use of family history information, barriers to CRC screening, and potential tools to improve CRC screening throughout the Alaska Tribal Health System (ATHS). Semi-structured, key informant interviews were conducted by telephone with regional THOs from October to December, 2012.

Types of CRC screening outreach included brochures/patient educational handouts (79%), mailed/phone patient reminders (71%), and provider reminders (50%). Other types of outreach included health fairs, Alaska Native-specific CRC prevention videos, radio and TV public service announcements, patient birthday cards, and advertisements in local newspapers and tribal newsletters. Only half (50%) said their facility provided

outreach to increase FDR screening. CRC screening outreach is common in the ATHS, but significant barriers still exist. Potential strategies include more Alaska Native-specific educational materials, development of integrated data systems, and provider training on screening guidelines and risk-appropriate referrals. These findings provide insight for health facilities seeking to increase systematic screening, especially among family members of CRC patients.

Background

Cancer is the leading cause of death among Alaska Native people.^{1,2} Colorectal cancer (CRC) is the leading cause of new cases of cancer and the second leading cause of cancer mortality among Alaska Native people.^{3,4} For the period 2009 to 2013, the CRC incidence rate in Alaska Native people was over two times the rate for U.S. Whites (91 vs. 41/100,000), and death rates were also twice that of U.S. Whites.^{3,5} Most CRCs begin as polyps which generally progress slowly over 10-15 years into cancer.⁶ This long lead-time presents a window of opportunity for screening and intervention. Screening tests, including colonoscopy, flexible sigmoidoscopy, and high-sensitivity fecal occult blood tests, can be used to detect CRC, prevent it through removal of precancerous polyps, or treat it if detected early in the disease progression.^{7,8} It has been estimated that consistent implementation of recommended screening could prevent about 60% of deaths due to CRC.⁹ This has profound personal and social consequences for patients and their

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families, as well as financial implications for healthcare systems.^{10,11}

The concern of Alaska Native people about the increasing burden of cancer has led to a focus on cancer prevention within regional tribal health organizations (THOs) statewide, collectively called the Alaska Tribal Health System (ATHS). The ATHS provides cradle-to-grave comprehensive care for approximately 143,000 tribal members. The ATHS is a hub and spoke network of small village-based clinics, sub-regional clinics, regional hospitals, with one tertiary care hospital located in Anchorage, Alaska. The tribal village clinics are staffed by Community Health Aides/Practitioners (CHA/Ps), who are laypeople trained as first responders for emergencies and provide basic primary and preventive village-based healthcare under supervision of licensed clinicians within the ATHS. Sub-regional clinics are generally staffed by CHA/Ps and midlevel providers. Regional hospitals provide inpatient, outpatient, and emergency services and are staffed by midlevel providers and physicians.¹² In many parts of Alaska, the regional THO is the only healthcare provider available for both Native and non-Native residents.

Because of the disproportionate burden of CRC among Alaska Native people, it is important to identify those at high risk and to provide easy access and encouragement to receive appropriate screening.¹³ First-degree relatives (FDRs; parents, siblings, children) of patients with CRC have twice the risk of experiencing CRC as the general population, especially if their family member was affected before age 45.¹⁴⁻¹⁶ American Society of Colon and Rectal Surgeons guidelines recommend that people with a family history of CRC begin cancer screening at age 40, or 10 years before the youngest age at diagnosis of their FDR, whichever is earlier.¹⁷ Although the fields of molecular epidemiology and genomics are rapidly expanding the potential for identifying persons at risk of CRC,¹⁸⁻²⁰ family history is a valuable tool for predicting increased CRC risk.²¹

Improving outreach to persons at increased CRC risk due to family history is important to efforts to reduce CRC morbidity and mortality.²² Healthcare professionals in the United States have long used family history information collected from individuals as a risk assessment tool.²³ However, family histories are rarely used to identify and provide systematic outreach to those at increased risk for disease, especially for CRC.^{24,25} Studies have shown that documentation of family cancer history is lacking in over half of primary care patient health records.^{26,27}

Purpose

A few studies have examined collection of family history for cancer outreach,^{28,29} but none have been conducted previously on use of family histories for increasing CRC screening among Alaska Native people. The primary objective of the current study was to assess the use of CRC screening outreach based on family history in the ATHS, as

well as determine how family history information was collected and used for outreach. Lastly, regional tribal health providers were asked about barriers to CRC screening and potential tools and activities that could improve family member outreach and screening more systematically throughout the ATHS.

Methods

The study population was all ATHS tribal health organizations (THOs) that either provide CRC screening or refer patients to other facilities for screening (N=17). Regional THO representatives who were knowledgeable about CRC outreach at their tribal health facilities were invited to participate in key informant interviews held October to December 2012. The regional THOs interviewed serve an estimated 139,118 Alaska Native people, representing 97% of the total Alaska Native population living in Alaska. An initial email describing the project was sent to ATHS regional contacts requesting that they participate in the interview or identify another individual who would be better able to respond. If participants did not respond to the initial or follow-up emails, a follow-up phone call was made. Interviews were conducted by telephone and recorded on data collection sheets prior to entry into a database (SPSS 16.0; IBM, Chicago, Illinois). The key informant moderator's guide developed for this study was based on previous ATHS surveys, and pilot tested with three members of the priority population. Interview administration time ranged from 15-25 minutes. The interview design was semi-structured and included a mix of closed-ended (yes/no/don't know) and open-ended questions to allow participants the opportunity to provide more in-depth responses. Responses to closed-ended questions were tallied to produce frequencies. Responses to open-ended questions were recorded in a spreadsheet and common themes were summarized for this report.

The interview instrument asked whether specific CRC screening outreach methods were used at the THO, including patient wellness handouts, provider reminders, mailed or telephone patient reminders. Respondents were then asked if there were any other tools used for CRC screening outreach, followed by whether the THO provided CRC screening outreach specifically to family members of patients with CRC, what types of outreach were used for those family members, and whether there was outreach provided specifically to relatives of CRC patients. The interviewer also queried how family members of CRC patients were identified, including electronic health records, patient charts, asking CRC patients directly for family member names, or taking family histories when patients came to the tribal health facility. Respondents were then asked about other methods used to collect family history information. For each method, the informant was asked to specify who collects the family history information, where information is stored, and how (or if) information is used for outreach. THOs that reported not offering CRC screening outreach to patients were asked about their perceived

barriers. All respondents were asked what would help their THO expand CRC screening outreach to patients. Lastly, informants provided feedback on the types of CRC screening materials and continuing education most helpful for their THO and which staff would use the information, especially for outreach to patients at increased risk of CRC due to family history. The Alaska Area Institutional Review Board (IRB), the University of Alaska Fairbanks IRB and the Alaska Native Tribal Health Consortium and Southcentral Foundation research and ethics committees reviewed and approved the study protocol.

Results

Participants

Fourteen out of seventeen THOs (82%) provided interview data. Of the regional respondents, two elected to provide a written response to the interview instead of by telephone. At least one staff member was interviewed from each organization; two THOs had two staff participate in the interview. The 16 interviewees included seven medical/clinic directors or case managers, four patient navigators, three program coordinators, and two health education staff. Of the THOs surveyed, 8 (57%) provide CRC screening at their regional facility, while the remaining THOs refer patients to Anchorage for CRC screening.

Outreach Methods

Of the THOs interviewed, 13 (93%) provided at least some CRC screening outreach to patients. A total of 11 (79%) used brochures and patient educational handouts, 10 (71%) used mailed patient reminders, 10 (71%) used phone patient reminders, and 7 (50%) used provider reminders. Of all the outreach tools used, phone patient reminders were considered the most useful for encouraging CRC screening (90%), followed by provider reminders (86%), mailed patient reminders (80%) and brochures (64%). Respondents were also asked if the methods were sufficient for encouraging screening and if health care providers at their facility used these methods with patients. No respondents (0%) said that brochures were sufficient, 2 respondents (14%) reported provider reminders as sufficient, and 3 (21%) reported mailed and phone reminders as sufficient to encourage screening, respectively. Only 1 (7%) respondent reported providers at their facility using brochures, 2 (14%) respondents reported providers at their facility using mailed/phone reminders, and 4 (29%) reported providers using provider reminders.

Respondents were asked to describe other types of CRC screening outreach used by their facility. All but one THO reported other types of outreach, including provision of CRC screening information at health fairs and community events, displaying 'Nolan the Giant Inflatable Colon',³⁰ Alaska Native-specific CRC prevention videos, radio and TV public service announcements, patient birthday cards, medical staff in-services, and advertisements in local newspapers and tribal newsletters. Additionally, many THOs reported use of

grant-funded small giveaway items, including calendars, water bottles, veggie bags, tee shirts, berry buckets, and coffee sleeves with CRC prevention messages.

Outreach to Family Members

Although general CRC screening outreach is conducted to varying degrees through the ATHS, only half (50%) of respondents said that they do any sort of outreach explicitly focused on encouraging family members of CRC patients to get screened. A total of 4 (29%) said that they ask CRC patients for a list of their FDRs. At 9 (64%) THOs, medical providers take family history if a patient comes in for a health concern. Family history information is entered into the electronic health record at 7 (50%) THOs. Six respondents (43%) also reported that their facility uses other types of outreach based on family history, such as using a database or log to keep track of FDRs in need of screening, sending an outreach letter to FDRs due for screening, distributing family tree worksheets to patients, and provider review of health records for relatives to determine their need for screening referral at an earlier age.

Barriers and Challenges

Over half (57%) of respondents described barriers and challenges to increasing CRC screening outreach at their facility to patients at average risk, and even more so for FDRs. The most commonly cited issue was lack of time and dedicated personnel. Respondents said that their tribal health facility generally provides care to patients who come in for a specific medical complaint and then a screening referral might be offered if the provider deemed it appropriate. For most facilities CRC screening outreach is not part of usual clinical duties, and if performed is carried out by just one or two individuals, who have other additional job responsibilities.

Respondents also pointed to the challenge that most Alaska Native people live in communities where endoscopic CRC screening is not available locally. Therefore, patients have to travel far distances by small airplane, which is costly, time-consuming and makes patients reluctant to complete the screening procedure. Further, data have indicated that guaiac-based fecal occult blood testing among Alaska Native people could lead to high false positive rates and so have not been widely promoted in the ATHS.³¹ Respondents also said that patients are often unaware of the benefits and importance of screening, and that it is difficult to convince some patients to complete CRC screening, especially those who are healthy or asymptomatic or who rarely access the medical system.

Some respondents also gave examples of systemic barriers to increasing outreach, including only having paper medical charts or electronic health records that lack functionality to create a list of patients who are due for screening or who have a family history of CRC. Two (14%) respondents reported trying to set up provider reminders in their EHR, but ceased due to lack of staff time to enter accurate data into

the system, as well as inconsistency in where screening information was located in the health record, which made it difficult to implement more systematic outreach for CRC screening.

Suggestions

Respondents were also asked what would help them increase screening outreach among the population they serve. Responses varied, from wanting information on how traditional wild foods might assist with cancer prevention, to more Alaska Native-specific educational materials, to needing templates for outreach letters, telephone scripts, and provider notations in the health records. One suggestion mentioned by all respondents was more training for ATHS healthcare providers on CRC screening recommendations and age-appropriate referrals. Respondents reiterated that the most beneficial way to increase screening would be dedicated staff time to talk with patients, attend community events and work with multiple departments within each THO to encourage CRC screening among their specific patient populations (diabetes, tobacco control, etc.). Respondents did not feel that this had to be a doctor per se, but other types of mid-level or allied healthcare professionals (patient navigators, case managers, etc.) could also effectively provide these types of outreach.

Discussion

This study examined the prevalence of CRC screening outreach in the ATHS, especially to FDRs of CRC patients. One of the key findings of this study was that dedicated staff time was rated by all respondents as important to increasing screening outreach, especially to FDRs, but also a current challenge. Overall respondents reported that most screening outreach job duties are incorporated into other positions, which results in a varying ability to conduct outreach, especially to family members of CRC patients.

These activities are even more crucial in light of respondent comments that much of the screening done is opportunistic care, that is, healthcare facilities in the ATHS do not have systems in place to facilitate CRC screening. Only if a patient comes in for another reason and it is somehow recognized that the patient is due, then that patient will be scheduled for screening. Family history information was also opportunistically updated in the health record if a patient came in for care, but most facilities did not provide outreach to FDRs based on that information. This is in contrast to an organized approach, where a healthcare facility has a system in place to notify providers whether average risk and increased risk patients are due for CRC screening along with a method to notify patients that they are due at the age-appropriate interval.³² This is known collectively as provider reminder systems, and is listed as one of the five recommended evidence-based interventions for increasing CRC screening by *The Guide to Community Preventive Services*.^{33,34}

Alaska faces challenges in addressing increasing healthcare costs and improving access to and quality of medical care.³⁵ Timely access to essential medical information by providers at the point of care is critical to good outcomes for patients and to improving quality and coordination of patient care. Each THO maintains health records for users of their system. The majority of these health record systems, although not all, are electronic, which has the potential for increasing provider ability to note family history in the health record and use it for outreach to family members. Previously, the main health record used by all Alaska THOs was the Resource and Patient Management System (RPMS). However, many regional THOs have now moved to using other electronic health records (EHR) systems, which do not interface with one another and which are not consistent in where family history and previous cancer screening information is placed within the EHR. Some respondents reported trying to set up provider reminders in their EHR, but lack of staff time to enter accurate data into the system, as well as inconsistency in where information was located in the health record, limited usability. As a result, inability to use family history and previous cancer screening information for systematic outreach to patients due for screening is widespread within the ATHS.

Provider reminder is one of the strongest predictors of CRC screening completion among patients.³⁶⁻³⁸ Respondents noted that it would be helpful to expand training opportunities for ATHS healthcare providers at all levels of care. This would address knowledge gaps on CRC screening guidelines and age-appropriate referrals,³⁹ especially for FDRs and other increased risk groups, to help improve screening rates among the Alaska Native population.

Limitations of this study include a study design in which only one or two respondents per regional THO completed the key informant interview. This individual might not have been the best person to answer interview questions on behalf of the THO. However, potential respondents were selected on the basis of prior knowledge of their THO responsibilities, including CRC screening management. Also, respondents were asked at the beginning of each interview if they felt they were the best person to answer the questions, and to provide another individual's name if they felt another would be a better candidate for the interview. Only one respondent gave another name, but it was solely to provide additional information on sub-regional outreach efforts. Another potential study limitation is that these results might be subject to social desirability response bias in that respondents may have said that their organization was doing more to promote CRC screening than they actually were. Data from the present study are based on perceptions of the interviewees rather than data from actual practice. ATHS CRC screening rates might be used to further assess the veracity of self-reported screening outreach efforts. Lastly, although a census was used to identify organizations for participation, the final sample size was small, and limits the generalizability of the findings beyond Alaska THOs.

This study was conducted to better understand how CRC outreach occurs across the ATHS, and whether family history information is being collected and used for outreach to FDRs of CRC patients. Although reported CRC screening outreach was common in the ATHS, significant barriers to increasing screening were reported, most notably a lack of dedicated staff. These study findings provide insight for Indian Health Service, tribal, or urban Indian facilities seeking to increase screening, especially among family members of CRC patients, and may also have relevance to improving CRC screening for increased risk patients in other healthcare delivery systems nationwide.

Acknowledgements

Funding for this study was provided by the Centers for Disease Control and Prevention, Division of Cancer Prevention and Control. We acknowledge the contributions and support of the Indian Health Service and the Alaska Native Tribal Health Consortium Board of Directors. The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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