

Determinants of Lung Cancer Screening in a Minnesota Urban Indigenous Community: A Community-Based, Participatory, Action-Oriented Study

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ABSTRACT

Although lung cancer screening (LCS) with annual low-dose chest CT has been shown to reduce lung cancer deaths, it remains underutilized. Northern Plains American Indian and Alaska Native (AI/AN) communities experience extreme lung cancer disparities, and little is known about the acceptance and adoption of LCS in these groups. We conducted interviews with healthcare professionals and focus groups with patients in an urban Minnesota community clinic serving AI/AN. Data collection took place during winter 2019–2020. Indigenous researchers collected and analyzed the data for emergent themes using simultaneous collaborative consensus with a LCS researcher. Participants reported some similar barriers to LCS as previous studies reported but also shared some new insights into traditional ways of knowing and recommendations for effectively implementing this evidence-based preventive care

service. Lung screening is largely acceptable to patients and healthcare personnel in an AI/AN-serving community clinic. We identified barriers as previously reported in other populations but also identified some unique barriers and motivators. For example, the concept of the seven generations may provide motivation to maintain one's health for future generations while providing additional support during screening for persons traumatized by the Western medicine health system may facilitate increased screening uptake.

Prevention Relevance: Secondary prevention of lung cancer through screening is potentially lifesaving considering that overall survival of lung cancer is 20% at 5 years but curable if detected at an early stage. This work provides insight into culturally tailored approaches to implementing the service in individuals at high risk of the disease.

Introduction

Lung cancer is the deadliest cancer (1), killing more people than prostate, colon, breast, and cervical cancer combined. Moreover, American Indian and Alaska Natives (AI/AN) in the Northern Plains die of lung cancer at nearly twice (2) the rate of non-Hispanic Whites. This disparity is likely explained by the high prevalence of commercial tobacco smoking in AI/AN in the Northern Plains (ref. 3; 59%) compared with the general population (16%). A new and effective screening test for lung cancer promises to reduce lung cancer deaths. Since 2013, the US Preventive Services Task Force recommends lung cancer screening (LCS) with

low-dose CT for older individuals who have smoked regularly for many years. LCS was recommended (4) for 55 to 80 years old who have smoked at least 30 “pack-years” (the equivalent of a package of cigarettes per day for 30 years) at the time of this study. Recent estimates are that around 5% of eligible persons nationally (5) have been screened, and this was before updated LCS guidelines in 2021 expanded eligibility (individuals over 50 years old with 20 pack-years of smoking history). Implementation of LCS in the US has been slow, but very little is known about LCS among AI/AN. A recent study (6) showed that only a quarter of tribes recognized by federal and state governments had access to an accredited lung screening center within 200 miles.

Since widespread recommendation for LCS, numerous studies have revealed patient-, provider-, and system-level barriers (knowledge of eligibility criteria and insurance coverage, time constraints; ref. 7–10) and attitudes [skepticism, fatalism (11), perceived stigma (12)]. While previous studies have demonstrated lower knowledge, acceptance, and implementation of screening for other cancers in AI/AN compared with Whites (13), there are no published reports of LCS knowledge, attitudes, and barriers for AI/AN. LCS is an opportunity to reduce AI/AN lung cancer deaths, but key information is needed to effectively implement LCS in this unique population. Cigarette smoking is the strongest risk factor for lung cancer,

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but the sacred and traditional role of tobacco in some tribes (14) may have implications for LCS implementation. Similarly, cultural beliefs about cancer detection and treatment may impact health behaviors. Understanding these beliefs is vital to equitable promotion of and access to LCS for AI/AN.

The objective of this study is to assess knowledge about and attitudes toward LCS among patients and healthcare personnel (HCP) in an urban AI/AN-serving clinic. We report the exploratory qualitative data from a staged mixed methods study. The results of this study provide recommendations and guidance for this and other community clinics to best implement a referral program for LCS.

Materials and Methods

Terminology

Throughout this article we use terms that are similar or interchangeable: “American Indian/Alaska Native” and “Indigenous.” Preference and use of these terms varies by and within individual communities. Additional terms may also be used to refer to groups based on region or specific tribal nations and communities such as Anishinaabe (Ojibwe) and Dakota as appropriate.

Setting

In partnership with the American Indian Cancer Foundation (AICAF), we engaged clinic leadership at the Native American Community Clinic (NACC) who sought to increase use of clinical LCS services for their patients. NACC is an urban clinic serving AI/AN in Minneapolis, MN. The core component of LCS is the low-dose CT exam, which is not available at this and most community clinics. The clinic typically refers patients to one of three nearby health systems for imaging procedures (each less than 2 miles away and accessible via public transportation).

Procedures

Focus groups and key informant interviews were conducted between December 2019 and June 2020. The discussion guides were semi-structured and developed using selected constructs from the Consolidated Framework for Implementation Research to explore each component of lung screening. All focus groups (patient participants) were conducted in person in the clinic with food and drink for participants and took place prior to public health restrictions associated with COVID-19 pandemic. Earlier interviews (HCP participants) were on site at the clinic in comfortable private rooms while the later interviews took place over web conference (Zoom, San Jose, CA). Focus groups and interviews were facilitated by Indigenous staff from the AICAF. The facilitators did not have personal relationships with the participants but were connected through a partnership between their organizations. Transcripts were not returned to participants for review. All study procedures were reviewed and approved by Advarra institutional review board (IRB) and the community clinic

leadership. Written informed consent was obtained from all participants. The data generated in this study are not publicly available due to details which could compromise patient privacy or consent but are available upon reasonable request from the corresponding author.

Ethical oversight

The study was conducted in accordance with ethical principles underlying the involvement of human subjects in research including those outlined in the Belmont Report. Ethical oversight was provided by Advarra integrated IRB.

Participants - patients

Patient participants were recruited to focus groups through flyers posted in community buildings and by research staff seated at a table in the clinic waiting area (convenience sampling). Focus groups inclusion criteria identified patients who may become eligible for LCS: (i) age 45 to 79 years, and (ii) current or former commercial cigarette smoking history of 20 years or more. Anyone unable to speak and understand spoken English was excluded.

Patient participants were provided with snacks and a \$20 gift card in appreciation for their time. The semi-structured interview guide (Supplementary Materials 1 “Patient Participant Focus Group Questions”) explored general approach to healthcare, awareness of lung cancer and screening, and barriers to accessing screening. In addition, some practical considerations were included such as which local referral health system they favored and communication preferences for each phase of the LCS process to offer guidance for clinic practices and workflow.

Participants - HCP

All clinical employees (including nurses, physicians, advanced practice providers) were invited via email to participate in key informant interviews. HCP participants were provided with a \$20 gift card. The semi-structured interview guide (Supplementary Materials 2 “Healthcare Personnel Interview Questions”) included perceptions of lung cancer and body imaging in the AI/AN community, perceived LCS barriers and beliefs that might promote or deter screening. Demographic information was not obtained from HCP.

Data analysis

Focus groups and key informant interviews were audio-recorded and transcribed. The authors reviewed all transcripts and identified themes derived from the data. The authors coded all transcripts, analyzing the interviews and focus groups together. The coding was done with an iterative process of simultaneous collaborative consensus, i.e., reviewed all transcripts in real time together to assign codes and then later organized them into themes. Coding agreement was reached through discussion and individual contributions of expertise to interpreting the data (for example, integrating investigators’ personal cultural background with medical knowledge and

experience). Data saturation was not assessed because recruitment was terminated early due to the COVID-19 pandemic precluding further focus groups. Dedoose software was used for analysis (Los Angeles, CA: SocioCultural Research Consultants, LLC).

Data availability

Data may be available upon reasonable request with permission of the stewards of the data (the Native American Community Clinic).

Results

Five primary themes were identified from participants: approach to healthcare, fear, trust, optimism, and determinants of lung screening. Themes and subthemes are listed in **Table 1**. Other than determinants (barriers and facilitators to screening), all themes were expressed on behalf of patients (i.e., HCP participants described the fear they perceived patients to have while patient participants described their own fear). **Table 2** shows which barriers were endorsed by which participant groups, as pertinent to each component of the screening process. In **Table 3**, we summarize recommendations for other community clinics to consider when implementing a LCS referral program.

Participants

We conducted four focus groups with a total of 15 patient participants and 9 key informant interviews with HCP. We did not administer demographic surveys of participants to protect privacy and perception of safety in this marginalized population. All patient participants were aged 45 to 79 years and included men and women who currently smoke commercial tobacco or formerly did so. Although we intended to segregate groups by sex and smoking status, some participants arrived at groups discordant with their sex or smoking status and were permitted entry. HCP participants did not report personal information like age or tobacco use.

Approach to health care

Analysis of patient participants' focus groups revealed two subthemes related to approach to health care: proactive versus reactive, and traditional ways of knowing.

Table 1. Emergent themes and subthemes.

Approach to healthcare
<i>Proactive vs. Reactive</i>
<i>Traditional knowledge</i>
Fear/Ambivalence
Trust
Optimism/Openness to screening
Determinants of LCS
<i>Knowledge</i>
<i>Resources</i>

Table 2. Barriers identified by participant type and domain.

Domain	<i>Insufficient knowledge</i>	<i>Resources</i>
Any cancer screening	Both	Both
Lung screening eligibility	Both	Both
Lung screening access	Both	Patients
Low-dose CT exam	Patients	Patients
Low-dose CT results	Patients	Patients
Lung cancer diagnosis and treatment	Patients	Not identified

Approach to health care – proactive versus reactive

While some patient participants reported a reactive approach to their own health care, others preferred a proactive approach to improving and maintaining health. Those who endorsed a proactive approach, and preventive services like screening, often cited family and relationships as a powerful motivator. The patient participants who expressed a more reactive approach were less likely to seek preventive services if they were not having concerning symptoms.

“If somebody that I trust or has a good relationship with me says, ‘Hey, did you – you should think about doing this because da, da, da, da, da,’ then I’ll – then it sometimes has more weight with me. I know the doc . . . that finally convinced me to do the colonoscopy had worked on me a couple of times. ‘Hey, you’re 53 now and you’re supposed to do this when you’re 50 years old. You’re three years in.’ And then, he said to me, ‘Wouldn’t you want to know that you have this? We want to catch that early. It’s really highly curable.’ And then, he said the magic words: ‘You have small children.’ I was like, ‘Oh, Lord. All right.’” (Male Patient, Former Smoker)

“You read the literature and people will be, like, you know, in our community there’s fatalism and all this other stuff. Like, I

Table 3. Recommendations from urban AI clinic that may be applicable to other communities.

<i>HCP participant-generated recommendations</i>
Culturally tailored and appealing multimedia education materials
Community-based screening events
Incentives to motivate and help defray burden of accessing screening
Patient support advocate (or caregiver) to accompany patient to screening exam
Easy-to-use tools to determine eligibility
Provide choice for referral site
Normalize LCS so it’s included in routine visits with conversation about other cancer screenings
Informal in-person interaction like booth, open house to get more information, e.g., “tabling”
Integrated holistic care so spiritual/behavioral health can reinforce medical recommendations
<i>Researcher-generated recommendations</i>
Connection to culture/worldview - understand values and use those to motivate health promoting behavior
Schedule referral/ tests while patient is present in clinic to obviate difficulty contacting patient later
Understand the unique barriers facing the community
Innovative ways to consolidate cancer screenings that value patients’ time

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don't think of some of that as fatalism. Like, there's an understanding and an agreement among Native people that we are – our approaches and our perspectives to health are different, as are our approaches and perspectives about getting sick and dying. But those are very, very different than the way that Western people think about those things. And that doesn't make us fatalistic. It makes us realistic." (HCP participant)

Approach to healthcare - traditional ways of knowing and indigenous perspectives

Some patient and HCP participants expressed understanding of traditional healing practices and how traditional health practices diverge from but may complement what is standard practice in Western medicine. Some patient and HCP participants reported using both traditional and Western medical practices/practitioners. For some participants, wellbeing of the individual is seen as responsibility to future generations, and this motivated their health behaviors, like cancer screening. Though colonization was not explicitly cited, acculturation to the societal changes brought forth from colonization such as diet and medicinal practices were mentioned.

"I want to go up to my maker, you know, with all my parts in me, even if it's cancerous. Don't cut nothing out of me. But that's my traditional thoughts, okay? . . . I was born with all my parts, I'm gonna leave with all my parts. Don't cut nothing out of me even if it's cancerous. . . . You start cutting things out of me and there's nothing left, you know, for the maker to recognize me with." (Male Patient, Smoking Status Unknown)

"I think if I got diagnosed with cancer, I would seek out traditional healing. I wouldn't do it as an alternative to Western healing" (Male Patient, Former Smoker)

"But you look at us 60 to 70 years ago, our Native culture didn't have all the diseases that they have now neither. We had our own medicines. That has a lot to do with our health" (Female Patient, Smoking Status Unknown)

"Native people see themselves and their health and wellbeing in relationship to family, community, and nation differently than white people do" (HCP participant)

Fear or ambivalence

Our patient and HCP participants perceived fear or ambivalence impacting patients' approach to care and ultimately, screening behavior. They acknowledged that some people do not want to find out if they have cancer. It was not always clear if this ambivalence is rooted in fear or some other belief. Some patient participants expressed fear of the process—undergoing the low-dose CT exam—as well as the outcome, a potential diagnosis of cancer. This fear also manifested in communication preferences, as many patients sited fear of bad news as a motivator for their preferred communication method.

"Um, I think that some people are afraid to find out. I've noticed that some people don't want to know if they have cancer" (HCP participant)

"I've heard patients say to me, 'I just don't want to know' " (HCP participant)

"What if I found out I had cancer? That would probably be so devastating, I would maybe stop taking care of myself" (Male Patient, Current Smoker)

Trust

Trust, or lack thereof, impacted how many patient participants thought about making health decisions in general as well as attitudes about LCS. Mistrust of healthcare (in general) as well as previous negative experiences with specific local healthcare systems was evident. Encouragingly, patients expressed trust in their community clinic and the providers there. This trusting relationship seemed to be a powerful facilitator for accepting health service recommendations, including LCS. Both patients and HCP participants volunteered mistrust as a major barrier. Notably, trust was not explicitly probed in the structured facilitation guides, but emerged independently by many participants.

"I laid in there and I just – I thought they were just checking me out really good, you know?" (Male Patient, Current Smoker)

"That fatalistic approach and not trusting the healthcare system, sometimes thinking that they're just going to find whatever, not thinking that they have their true and highest benefit in their minds, some of the professionals." (HCP Participant)

"My doctor is my primary care and she cares about me. She's my health provider and part of my heart and my life." (Male Patient, Current Smoker)

Optimism or openness to screening

Most participants expressed optimism or at least openness to screening. Some patients expressed interest in receiving the service after first learning about LCS during the focus groups.

"Well, now that I know, I'm gonna start looking into it and get a screening on my lungs." (Male, Current Smoker)

"Check yourself for cancer. I think that's a really good idea because, you know, that's one thing I want to do now is get checked, you know?" (Male Patient, Current Smoker)

"They, like most patients that I've met, are okay with imaging. Imaging is a good diagnostic tool. So, it's easy to get people on board with that to say this is what it'll look for. This is what it'll tell us. People are pretty open to that. I don't get a lot of resistance with imaging." (HCP participant)

Insufficient knowledge about lung screening

Although HCP participants uniformly agreed lung cancer is an important problem for AI/AN, patient participants did not uniformly recognize it as a problem. We did not explore whether this was because they perceived other health issues to be higher priority or because they were unaware of the burden of lung cancer.

Patients expressed general lack of awareness of LCS as a health service while HCP participants had variable knowledge of specifics about the screening process, and whether it is

covered by health insurance. **Table 2** demonstrates which participants expressed insufficient knowledge about each component of the LCS process. Patient participants expressed a poor understanding of what the low-dose CT exam entails and what happens after the exam, such as how a cancer diagnosis is made, what treatment options are available, and lung cancer prognosis. Recommendations for reducing barriers were offered by HCP participants (**Table 3**), including use of culturally tailored education materials, systematic changes like incorporating lung screening into other routine cancer screening identification processes, and community events that provided a comfortable casual way to learn more.

"Is it gonna hurt? And what are you gonna chop out as far as a biopsy? Are you gonna hack into my lung or what? Are you gonna do a biopsy or just gonna get a quick screen?" (Male Patient, Smoking Status Unknown)

"That prevents us from sometimes seeking out that kind of care. It's like, oh, we don't know the advances of technology. We don't know the different things that are available." (Female Patient, Former Smoker)

Resources/capacity

Both patient and HCP participants cited insufficient resources and/or capacity as barriers to screening. Time, transportation, insurance coverage, and childcare were cited as resources whose scarcity were patient-level barriers to LCS. The HCP participants also cited insufficient time as a barrier to conducting screening. HCP suggested that putting system resources in place to identify eligible patients would facilitate referring more patients for screening. Providers desired more educational and promotional materials about lung screening, like those available for other screening services. While HCP participants described inadequate resources for ordering/referring for screening, patient participants described inadequate resources for completing most steps in the process.

"In the midst of everything else, what the patient's priorities are in any given day, if there's a lot of other things going on then it can be hard to – it maybe doesn't come up in a visit or doesn't happen." (HCP participant)

Communication preferences

We specifically elicited communication preferences from patient participants about eligibility notification and results notification to guide a planned implementation in the clinic. The most commonly expressed preference was written notification (postal or electronic mail) for both LCS eligibility and low-dose CT results. Learning about eligibility during a routine office visit from the primary care provider was also acceptable. Most patients reported they would not be offended to be singled out for screening (with a letter) based on smoking history, although some thought this would be off-putting.

Recommendations for LCS uptake in community settings

Participants made recommendations for practical adaptations that could be used in many community settings to

improve adoption of LCS (**Table 3**). For clinicians, engaging the community and trusted health sources within it is paramount to understand and appreciate differences in worldview and connection to culture, and how those impact health behaviors. Culturally tailored education materials (both in design as well as content) and community events with informal exchange of information to provide comfortable ways to learn more about LCS, which can be frightening for many patients. Offer easy to understand educational materials, such as the LCS brochure developed by AICAF (Supplementary Materials 3: Lung Cancer Brochure developed from this work). One example of a low-stakes, informal exchange for patients is "tabling", where an information table with a knowledgeable and approachable person can answer questions. Whenever possible, referral center choice should be offered to patients to accommodate transportation barriers and personal preferences, including avoiding health centers where they have had negative experiences. More concrete support like transportation assistance, scheduling assistance, and even small monetary incentives were also endorsed as methods to facilitate LCS participation. In addition, systematic mechanisms that efficiently identify eligible persons and initiate referral for LCS may relieve some of the burden of competing priorities to improve the patients' health, which HCP may face during a time-limited visit.

Discussion

In this qualitative study of an urban Minnesota AI/AN community, we have explored knowledge, attitudes, barriers, and facilitators to LCS. In addition, we solicited specific preferences and recommendations for implementing screening in this AI/AN-serving urban clinic. As such, these results have both instrumental and conceptual utility (15). Although LCS is a recommended service for older individuals with a heavy smoking history, and many Northern Plains AI/AN individuals are expected to be eligible, very little is known about LCS among the AI/AN community in MN.

In many Indigenous traditions, "tobacco is a sacred gift used for spiritual, cultural, and ceremonial practices," however even among these, beliefs about and uses of tobacco vary widely (14). Traditional tobacco is one of four sacred medicines and can be used as an offering or gift to the Creator or another person, it might be burned, but typically the smoke is not inhaled. Some traditions believe the smoke rising to the sky creates a direct link to the Creator (16). Until the Indian Religious Freedoms Act of 1978, numerous laws prohibited traditional practices, thus AI/AN were forced to substitute harmful (but legal) commercial tobacco for traditional tobacco.

Recent estimates are that nearly a quarter of AI/AN over 50 are eligible for LCS, which is a greater proportion than any other racial group (17). Estimating eligibility for screening is difficult in all groups due to use of a quantitative smoking history threshold. But it is likely that many AI/AN aged 50 to 80 who smoke commercial tobacco will be eligible. A recent study

showed the majority of AI/AN who used tobacco had done so for at least ten years and smoked more than ten cigarettes per day (18). Another study of commercial tobacco smoking (19) showed that AI/AN reported on average 15 cigarettes per day (3/4 package) and this was confirmed in a small regional sample in MN (20).

Regionally, there is substantial variation in AI/AN lung cancer rates, being significantly higher than Whites in Alaska and the Plains and significantly lower than Whites in the East and Southwest US (21). Regional variation of lung cancer rates in AI/AN may be related to commercial tobacco use but regional environmental and policy factors may also contribute. Screening uptake in Northern Plains Indian health settings is thought to be very low even compared with low overall uptake in the United States. Culturally tailored approaches must encompass the unique perspectives from members within the community rather than assuming all Indigenous peoples are the same. As poignantly described by one participant, it is not enough for “interventions or things that were developed for Western individuals or non-Native people, they . . . slap some feathers on it maybe, you know, a beaded border or something like that, and . . . send it out to Indian people, not recognizing that we – that Native people see themselves and their health and wellbeing in relationship to family, community and nation differently than White people do.”

In some respects, these participants report similar barriers to LCS as others have previously reported, including mistrust (12), knowledge avoidance (22), perceived low value and practical barriers. In addition, other clinical settings have low prevalence of lung screening patient-provider discussions (23) and providers found screening reimbursement (24) challenging to understand. Unlike other studies (12), we did not identify any evidence of stigma towards lung cancer or individuals with lung cancer. This may be due to the uniquely prevalent use of commercial tobacco and association of tobacco with traditional healing practices in this community.

This study is limited by its size, as planned recruitment was impacted by the COVID-19 pandemic. In addition, we intended to segregate the focus groups by sex and smoking status, but some participants arrived to focus groups where they did not match the sex or smoking status and were permitted to participate in acknowledgement for their efforts and to avoid alienating community members or damaging trust. Importantly, the views of these participants do not reflect a homogenous tribal identity or experience. We do not have details of tribal affiliation for the participants. Presumably, most have some connection to Ojibwe or Dakota traditions, which are the most represented tribal identities in Minnesota. Nonetheless, the study is strengthened by its strong community engagement. This study was embedded in a community clinic serving AI/AN and the clinic was both engaged in the effort and prepared to implement the recommendations we elicited. The data were also collected and analyzed by researchers who are AI/AN. Thus, this work is community-based, participatory, and action-oriented (25). The investigator team discussed all themes and

codes together and has rich experience with Indigenous tradition, culture, and public health expertise as well as LCS expertise. We used a simultaneous collaborative consensus analysis approach, which added depth and richness to our analysis as we repeatedly were able to provide complementary explanations/perspectives.

Findings from this study will provide tangible recommendations from patients and HCP on how to improve LCS in an urban AI/AN clinic and may be applicable to other community clinics serving marginalized populations. Furthermore, we provide some insight into Indigenous ways of knowing and how these perspectives might impact cancer screening behaviors in Indigenous people.

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Disclaimer

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Authors' Contributions

M.D. Anderson: Formal analysis, investigation, writing–review and editing, indigenous ways of knowing and interpretation. **W.J. Pickner:** Data curation, formal analysis, investigation, methodology, writing–original draft, writing–review and editing, indigenous ways of knowing and interpretation. **A. Begnaud:** Conceptualization, resources, formal analysis, writing–original draft, project administration, writing–review and editing.

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