Trailblazing Health Equity: Mapping Cancer Care Challenges for American Indian and Alaskan Native Peoples

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Pledge: I pledge, on my honor, that I have neither given nor received unauthorized aid on this assignment.

Cover Letter

After reviewing the comments and feedback on the first draft of this modified systematic literature review, I made strides by removing unnecessary information, and improving the clarity of my buckets in the qualitative synthesis components of the results section. I also made efforts to strengthen the overall flow of this paper, working specifically on the organization in the discussion section. Statements that appeared awkward or out of place were moved or removed, and incorrect subject-verb agreements were corrected.

Additionally, strengths and limitations of my paper were revised to exclude the limitations of the studies referenced in the results section. Lastly, I strengthened my justifications for grouping the studies as they appeared in the results section, and drafting a conclusion that is more consistent with the findings illustrated in the results section, and the topics developed in the discussion section. The ending to this paper is stronger and more conclusive than in the initial draft.

Acknowledgments

Firstly, I would like to thank Dr. Paige Hornsby for her consistent and steady advice and guidance during the construction of this paper. Additionally, I would like to thank Andrea Denton for her assistance in providing the resources necessary to compile the sources and data needed for this paper. I would also like to thank the University of Virginia's Global Public Health and Global Studies Department for their leadership and efforts to ensure I was provided all the resources needed to conduct and perform this investigation and complete my Capstone project. I would also like to cite the use of ChatGPT (Version:3.5, Manufacturer: OpenAI, Date of use: February 28, 2024) for its help in brainstorming my topic in the initial phases of the paper. I take full responsibility for the integrity of the content generated. Lastly, I would like to thank my peers in the Global Public Health major, who offered constant feedback and assistance on how to complete this paper, providing reassurance every step of the way. This feat could not have been accomplished without any of the aforementioned individuals.

Abstract

Objective: This study analyzed how the operation and services of the IHS have affected cancer incidence and mortality for the AI/AN population in the US with respect to screenable cancers of female breast, colorectal, lung, and uterine cervix. The justification for this study is that identifying barriers to cancer prevention and care should facilitate policy development to address the resulting health care disparity in cancer for the AI/AN population.

Method: A modified systematic literature review was conducted. Peer-reviewed original literature from well-respected databases was gathered and synthesized to understand the context of cancer incidence, mortality, prevention and screening in the AI/AN population and to identify the challenges faced by AI/AN population in accessing cancer prevention and screening through the IHS.

Results: The qualitative synthesis of the literature revealed that the IHS has met challenges in reaching the needs of the AI/AN community with respect to cancer prevention and screening for female breast, colorectal, lung and uterine cervix cancers. The themes, or barriers, include IHS underfunding, lack of access to medical specialists and diagnostic testing, inadequate referral by IHS providers for cancer screening, discrimination, prejudice, and lack of culturally competent healthcare and education. These barriers all contribute to low cancer screening prevalence in the AI/AN community and the resulting health disparities in cancer.

Conclusions: These findings highlight the need for multilevel approaches to improve cancer screening through culturally competent education of AI/AN community on cancer risk and prevention at the individual level, promotion of positive health behaviors at the community level, and increased funding at the IHS level to improve access to culturally competent care, diagnostic testing, and medical specialists.

Introduction

According to the 2020 United States Census, there are an estimated 9.7 million individuals who identify as American Indian or Alaskan Native (AI/AN), which represents about 3% of the United States (US) population.(1) There are 574 federally recognized tribes plus more than 200 unrecognized tribes that currently reside in the US.(1)The majority of AI/AN individuals live either on tribal reservations, or the surrounding counties referred to as Purchased/Referred Care Delivery Areas (PRCDA), in six primary regions: Alaska, East, Northern Plains, Pacific Coast, Southern Plains and Southwest.(1) It is estimated that there are over one million AI/AN individuals that live on tribal reservations.(2) As of 2022, there are 326 reservations spanning 33 states.(2)

The Indian Health Services (IHS), established in 1955, is the federal agency within the U.S Department of Health and Human Services that is responsible for providing healthcare services to approximately 2.6 million AI/AN individuals.(1,3) IHS provides services directly through IHS-operated facilities or provides budgets for the tribes to operate their own tribally operated health programs.(3) The IHS directly operates 28 acute care hospitals in eight states, many of which are in remote locations.(3) IHS contracts with tribes to operate an additional 18 hospitals.(3) IHS also provides services through Purchased/Referred Care (PRC) which are non-IHS facilities and outside providers through contracts with the IHS.(2)

Despite the purpose and mission of the IHS to provide a comprehensive healthcare delivery system for the AI/AN population to achieve the highest possible health status, their efforts up to date have been disappointing.(3) The disparities in health for the AI/AN population have been well established in medical literature. Previous research has found that AI/AN individuals have significantly higher prevalence of obesity, diabetes, hypertension, physical inactivity, and lower health status and leisure-time.(4)

Previous studies have consistently found that the AI/AN population suffers a higher burden of cancer than any other ethnicity group in the US.(1,5) Based on data from 2014 to 2018, the overall incidence of cancer rate among AI/AN individuals was 2% higher than white individuals.(1) Another study identified the leading cancers with an elevated incidence rate among AI/AN men to be liver, stomach, kidney, colorectal, myeloma, and lung cancer.(5) The leading cancers with an elevated incidence among AI/AN women included the ones above, in addition to uterine cervical cancer.(5) The incidence rate for colorectal or cervical cancers is about 50% higher in the AI/AN population compared to the white population.(1,5) The incidence rate of lung cancer is as high as 80% higher in certain AI/AN regions compared to the white population.(1) Although AI/AN women may have a lower incidence of female breast cancer compared to white women, the breast cancer mortality rate is incongruently higher in AI/AN women, with an increasing mortality rate, contrary to the decreasing trend in other groups.(2)

The excess burden of female breast, colorectal, lung, cervical cancer in the AI/AN population is troubling as these are all screenable cancers, in other words, cancers which can be detected early through screening technologies before onset of symptoms to improve treatment and prognosis.

To add to this, previous research has also demonstrated that cancer mortality plays a large role in the life expectancy of the AI/AN population. In a study published by the CDC in 2021, analyzing data from both US census and IHS, the mortality rate of AI/AN people was 40% higher than the mortality rate of white people, 17% higher than that of black people, and 98%

higher than that of Hispanics, leaving AI/AN people with the highest mortality rate of any race or ethnicity in the US.(6) With an average life expectancy of 71.8 years, AI/AN people have a life expectancy that is 7 years less than white people, 3 years less than black people, and 10 years less than Hispanic people.(6) Cancer is the second leading cause of death in the AI/AN population.(6) From 2015 through 2019, overall cancer mortality in AI/AN people was 18% higher than white people, with higher mortality rates in the screenable cancers: female breast, colorectal, lung and uterine cervix.(1)

Although prior studies have established a higher cancer burden among AI/AN people, none of the studies have addressed how the IHS has contributed to the disparities in screenable cancers. The purpose of this study is to analyze the IHS as a mechanism for these disparities, by examining how the shortcomings of IHS services and operations have either created or not adequately addressed physical and cultural barriers to cancer prevention and screening.
This study will focus on cancers which can be prevented or detected early through screening tests: female breast, colorectal, lung and uterine cervical cancers.

In other words, my research question will analyze how the (IHS) has led to health disparities in screenable cancers in the AI/AN population?

This review aims to provide information to develop health policy initiatives that may be implemented through the IHS to promote cancer prevention education and screening interventions in the AI/AN community.

Methods

Study Design

The study conducted was a modified systematic literature review concerning how the IHS has allowed for, or contributed to the screenable cancer health disparities in the AI/AN population. This research question was framed upon looking through the lens of the IHS services and operations, as the main mechanism for determining the health outcomes of the AI/AN population in the US.

Search Strategy

Primary and secondary original literature were explored in PubMed,Web of Science (WoS) and Virgo, which serve as University of Virginia's online library catalog. The majority of the sources that were compiled for this study were found using an array of search terms. To gain a comprehensive understanding on the healthcare outcomes of the AI/AN population in the US, I began my search focusing on the "healthcare disparities" component of my research question. Boolean operators, such as the use of "AND" or "OR" in my search terms were incorporated into my initial searches. ('Native Americans' AND 'Health Disparities') ('Mortality AND 'Native American'). The search terms then became tailored to my specific research question, as I wanted to focus specifically on the association between the IHS and the aforementioned healthcare disparities for cancer in the AI/AN population. ('Indian Health Services' AND 'health disparities' AND 'cancer'). I used specific search terms to pull literature on specific cancers which can be screened ('American Indian' OR 'Alaskan Native' AND 'breast cancer' OR 'lung cancer' OR 'uterine cervix cancer' OR 'cervical cancer' OR 'colorectal cancer' OR 'colon cancer'). I utilized a blend of key terms identified in previously explored sources with synonymous terms ('American Indian' OR 'Alaskan Native' OR 'Native American') to further investigate the major problems that underlie these healthcare disparities. ('American Indian' OR 'Alaskan Native' OR 'Native American' AND 'access to healthcare'), ('American Indian' OR 'Alaskan Native' OR 'Native American' AND Vaccines'), ('American Indian' OR 'Alaskan Native' OR 'Native American' AND Vaccine hesitancy') , ('American Indian' OR 'Alaskan

Native' OR 'Native America' AND Distrust'), ('Indian Health Services' AND 'Distrust'), ('American Indian' OR 'Alaskan Native' OR 'Native America' AND 'Indian Health Services' AND 'Distrust') ('Indian Health Services' AND 'Policy' AND 'Health Disparities') ('Indian Health Services' AND 'Policy' AND 'Cancer') ('Indian Health Services' AND 'Policy' AND 'Cancer Screening') ('Alaskan Native' OR 'Native American' AND 'Discrimination'). In addition to this strategy, I employed hand searching when I encountered tertiary literature, where I plucked primary and secondary research studies that were cited in tertiary sources, to discuss in my own review. The above literature was accessed through the University of Virginia between February 5, 2024, and April 3, 2024. No filters were applied in any of these search strategies.

Eligibility Criteria

Since the primary focus of this investigation concerns the effects of the IHS on screenable cancer health disparities of the AI/AN population, in order to be included, any primary or secondary literature had to acknowledge or address the IHS as a characteristic of their study in their investigation. There is one exception that is noted in the results section. For purposes of this investigation, only studies that focused on screenable cancers were included in the synthesis of the literature. Additionally, any study regarding the AI/AN population must have taken place in the US, involving inhabitants of the US. In order to fully address my research question, I needed to include literature that discussed the policies and/or implementation of the IHS in order to accurately synthesize and deduce the findings in this paper. There were no restrictions placed on the age group of the target population.

Any studies that were not performed within the structure of the IHS in their analysis of health disparities for AI/AN individuals and the healthcare in the US were deemed irrelevant for this study. Since my research question was concerned with exploring health disparities regarding screenable cancer, studies that investigated non-cancerous health outcomes for the AI/AN population were excluded from the qualitative synthesis. Additionally, in order to ensure that the healthcare disparities and health status of the AI/AN population were applicable up to modern day, any publications before the year 2010 were excluded for this paper.

Data Extraction

All the literature discussed in this paper was compiled into the bibliographic software Zotero, an open-source and free management software. This allowed for easy access to review and analyze multiple studies at once. The variables that were most critical for this study were the factors that came out of each investigation that addressed a certain IHS healthcare trend, such as limited access to healthcare services, transportation, low cancer screening rates, as well as behavioral trends such as smoking incidence and vaccination hesitancy. The analysis of these factors were extracted for my investigation.

Quality Assessment

To ensure high quality and credible resources selected for this study, the impact factor of the journal in which each article was published was assessed. Additionally, only peer-reviewed literature was used for this study.

Results

Search Results

A total of 15 primary and secondary original studies were deemed eligible to be included in the synthesis of the paper. These original sources for this systematic literature review originated from three databases: PubMed, Web of Science, and University of Virginia's Virgo Library. Later, a full-text screening of the studies was conducted to determine the final sources to be included in this paper. The final set of studies that were deemed eligible for this study have been included in Table 1.

Study Characteristics

Table 1 highlights the study characteristics for the final list of sources that were included in the qualitative synthesis. Since the focus of my paper is on the AI/AN population, all of the research was performed in a region of the US. Most settings for the research took place in regions of high AI/AN population density in the North-, South- and Midwestern regions, to the West Coast. The earliest publication date was 2011,(7) the most recent was 2024.(8) The data collection process for the studies varied, taking anywhere between 1-10 years. One study analyzed data from a span of eight years.(3) The oldest data was gathered over a time period from 2005-2013,(3) while the newest data collected originated in 2021.(8) Study designs used included surveys, interviews, or focus groups to conduct a retrospective cross-sectional or cohort analysis to answer the research question and measure certain outcomes. (3,7–15) Another study design consisted of a retrospective analysis of patient data that was used to answer the research questions and measure certain outcomes.(16,17) The number of participants of each study varied significantly from 43-490,305. The age ranges of the participants in the studies ranged significantly from studies that did not use age as a criterion, to studies that focused only on adult or elderly populations. In terms of factor(s), the studies focused on major traits that have dramatically affected healthcare for the AI/AN population. Such factors include underfunding, the lack of access to quality care, transportation barriers, inadequate referrals, a knowledge-and education-gap regarding medical standards and protocols, lack of cultural competency, and general mistrust and hesitancy of AI/AN individuals to participate in the US healthcare system.

Table 1: Characteristics of Included Studies

Reference	Setting	Time of data collection	Study Design	Sample Size	Factor(s)	Journal Impact Factor
Levinson 2016 (3)	Midwest, Southwest, Northwest and the South U.S.	2005-2013	Retrospective Cohort	N = 28 IHS - Hospitals	Underfunding of IHS contributes to lack of access to quality care due to geographic isolation, lack of technical equipment, lack of access to medical specialists, and facility understaffing.	N/A
Johnson-Jennings et al. 2014 (16)	U.S	2001-2010	Retrospective Cohort	N= BRFSS data (356,073)	The colorectal cancer screening prevalence in ages 50 and older was lowest among AI/AN (51%) compared to blacks (61%) and whites (60%).	Q1
Ndikum-Moffor et al. 2013 (9)	Midwestern U.S.	2010-2011	Retrospective Cohort	N = 15 rural AI/AN women N = 38 urban AI/AN women	Barriers to breast cancer screening include negative attitude and prejudice experienced by AI/AN women in outside mammography facilities and long distance to mammography facilities.	Q1
Gutnik et al. 2022 (10)	U.S	2016	Retrospective Cohort	N= 2016 BRFSS survey, 480,509 participants (7,238 AI/AN)	AI/AN population has lower colonoscopy screening rates which is attributed to inadequate gastroenterology density.	Q1
Sequist et al. 2011 (7)	Federally operated IHS - sites In the U.S	2002-2006	Retrospective Cohort	N = Adult Patients cared for within IHS N = 740 Federally employed physicians within IHS	Breast cancer screening rates in AI/AN women were higher at sites where physicians reported having routine access to mammography. Only 32% of physicians reported adequate access to screening for AI/AN women.	Q1
Liddell et al. 2018 (11)	South Dakota, U.S.	2014-2015	Retrospective Cohort	N = 43 AI/AN women	AI/AN women identified a lack of mammography equipment at IHS facilities and discomfort with disrobing as barriers to cancer screening.	Q1
Welch et al.	Nevada	2021	Cross-sectio	N = 58, tribal Elders,	AI/AN focus groups revealed lung cancer screening barriers included limited	Q1

2024 (8)			nal analysis	tribal leaders, and non-Native volunteers who worked in tribal communities	community awareness and limited provider referral for lung cancer screening, limited access to diagnostic testing, and limited discussions with healthcare providers about cancer risk.	
Sommerfield et al. 2021 (12)	Two states in U.S Southwest	2017	Concept-Mapping	N = 65 American Indian Elders (AIEs) N = 50 Professional Stakeholders	AI/AN individuals cited long distance and transportation as reasons to avoid medical care. Transportation barrier was calculated to have a large impact on AI/AN health.	Q1
Peña et al. 2023 (18)	U.S	2021	Cross-sectional analysis	N = Databases from US Department of Interior, ACR, and FDA	The mean distance between reservations and screening centers was 53 miles, with distances up to 200 miles, which creates a “cancer screening desert”.	Q1
Roubidoux et al. 2021 (17)	Nebraska, Iowa, North Dakota, South Dakota	2013-2017	Retrospective Cohort	N=1615 patients	Even with mobile mammography units, screening rates among AI/AN women was still lower at 38.6% than the average prevalence.	Q1
Bowen et al. 2014 (13)	U.S	2009-2010	Retrospective Cohort	N = 50 Adult Native American female caregivers of Native American girls aged 9 to 18 years old	Focus groups conveyed a lack of understanding of Pap smear and HPV vaccination and concerns about vaccine safety due to mistrust as reasons why Pap smear and HPV vaccination are underutilized in AI/AN population.	Q1
Findling et al. 2019 (14)	U.S	January to April 2017	Telephone Survey	N= 342 AI/AN N= 902 White adults	23% of AI/ANs surveyed reported discrimination in healthcare compared to 5% of whites. 15% of AI/ANs surveyed reported avoiding medical care because of fear of poor treatment or discrimination compared to 3% of whites.	Q1

Analytic Results

Underfunding of IHS

Levinson(2016) explored the consequences that underfunding of the IHS has on the infrastructure and operation of IHS hospitals and facilities through interviews of IHS leadership and staff.(3) Due to non-competitive pay, the IHS staff interviewed reported difficulty recruiting and retaining essential staff.(3) Many staff reported that the number of outpatients often exceeds the staff available to care for these patients, all resulting in long wait times for patients.(3) Administrators from all hospitals interviewed reported challenges because of the lack of access to medical specialists.(3) The IHS facilities primarily offer primary and emergency care services and do not have medical specialists in the facilities.(3) The patients have to be referred to non-IHS outside medical specialists.(3) Although IHS is responsible for paying outside medical specialists, the IHS does not have sufficient funds to pay for all the necessary care through outside medical specialists.(3) In the year 2013, 146,928 referrals to outside medical specialists were denied by the IHS due to inadequate funding.(3) The limited funding also prevents the installation of technologically advanced equipment in IHS facilities and the average length of time for renovating an IHS facility is 37 years which is nearly four times the average age of comparable hospitals nationwide.(3)

Lack of Access to Cancer Screening Through Medical Specialists and Diagnostic Testing

Six studies analyzed a lack of access to cancer screening through the IHS as a major problem for the AI/AN people stemming from the IHS underfunding. Two studies demonstrated that AI/AN people have the lowest rate of colorectal cancer and breast cancer screening compared to any other race or ethnicity.(9,16) A study examining the prevalence of colorectal cancer screening, through either fecal occult blood or colonoscopy, from 2001 to 2010 in a sample of 356,073 respondents aged over 50, found that AI/ANs had the lowest colorectal cancer screening rates compared to blacks and whites.(16) The AI/ANs had a colorectal cancer mixed screening prevalence rate of 51% compared to 60% in whites and 61% in blacks.(16) As of 2022, the incidence of colorectal cancer was quantified as significantly higher in AI/AN people (50.7/100,000) compared to white people (36.6/100,000).(10)

Exploring this point further, a study by Gutnik et al. (2022) identified multiple reasons for lower colorectal cancer screening in the AI/AN population, such as education and low income, but it specifically examined the relationship between gastroenterologist density to colorectal cancer screening rates in the AI/AN population.(10) The study found that a higher gastrointestinal density, 3.98 gastroenterologists per 100,000 people, had a positive effect with increased colorectal cancer screening rates.(10)

With respect to breast cancer screening, AI/AN women had a lower breast cancer screening rate compared to other races.(9) In that sample, 64% of participants had obtained annual mammograms, which was lower than the average 67% among all women over the age of 40.(9) A longitudinal study of the patients from 2002 to 2006, and a physician survey in 2007, examined the correlation between physician reports of access to mammography and clinical performance of breast cancer screening in AI/AN women.(7) Only 29% of responding physicians reported adequate access to high quality specialists; and only 32% of physicians reported adequate access to high quality imaging services for AI/AN women.(7) That same study found that breast cancer screening rates were higher at sites with higher rates of physicians reporting routine access to mammography compared to sites with lower rates of physicians reporting such access (46% vs. 35%).(7)

Unfortunately, not all the IHS hospitals or clinics have fixed cancer screening services available. In a study which surveyed AI/AN women on their experiences with cancer treatment, 45% of them reported some form of healthcare infrastructure barrier to accessing cancer care, such as "At Indian Health Services…and their mammogram machine was broken down" or "[o]ur hospital is so bad and such poor healthcare, they [the hospital] didn't have a doctor to do my Pap smear".(11) With respect to CT scan technology for lung cancer screening, AI/AN participants reported "lack of tools to diagnose or screen at our local Indian Health Service facility". (8)

Five studies drew conclusions that transportation presented a major barrier to getting medical care. The participants of the Ndikum-Moffor et al. study identified the lack of mammogram equipment at the IHS and the costs associated with traveling to mammogram facilities and facilities as a barrier to care.(9) These participants cited that the cost of gas and the time to travel makes it difficult for their community which depends on shared transportation and rides.(9) In another study which engaged concept mapping to rank nine factors which impair access to healthcare from the viewpoint of 65 AI/AN members, the AI/AN participants cited the high cost of transportation, the need to travel long distances, and not having reliable transportation as barriers to care.(12) Using a ranking system, the study calculated transportation barriers to have a large impact on AI/AN health.(12)

Peña et al. (2023) evaluated the geographic accessibility for mammographic screening, lung cancer screening, and colorectal cancer screening centers for AI/AN tribes on reservations.(18) It was determined that 77.8% of the tribes were located within 200 miles of a cancer screening center, with a mean distance of 53 miles, and with 20% of tribes having to travel over 200 miles away for cancer screening.(18) These findings documented a significant distance to screening centers creating a “cancer screening desert”.(18) Peña et al. (2023) concluded that lack of nearby screening centers and limited transportation were associated with reduced use of breast, lung and colorectal cancer screening, which have played a negative role on cancer outcomes.(18)

One attempt at eliminating the transportation barrier was placement of a mobile mammography unit at 24 IHS clinics in the Great Plains region from 2013 to 2017.(17) The study found that adherence to mammogram screening, defined as having another screening mammogram within 9-27 months, remained low among AI/AN women at 38.6% compared to 59% reported in the National Mammography Database.(17) The prevalence of a greater than 27 month gap between mammograms was three times higher among women who used the mobile units compared to the National Mammography Database.(17) Notwithstanding the adherence issue, the study showed the mobile mammography was effective at drawing in first time breast cancer screeners with 34.5% reporting that they had never had a mammogram.(17)

Inadequate Referral for Screening Services From IHS Provider

Three studies provided key insight on another issue in the function of IHS - a lack of referral by IHS providers for necessary medical screening. Bowen et al. (2013) evaluated the underutilization of Pap smear and HPV in AI/AN women. Although uterine cervical cancer is preventable with Pap smear screening and HPV vaccination, AI/AN women are more likely to die from cervical cancer compared with white women and the five year cancer survival rate is lower for AI/AN women (81%) compared to white women (84%).(13) A sample of 50 adult AI/AN women were split up into five focus groups.(13) Most women were confused about what HPV was, what an HPV test was, and what the HPV vaccine was meant to do, and many were concerned about vaccination safety, signaling a gap in the IHS provider’s role in explaining and referring for HPV vaccination.(13) The women expressed that they relied on the IHS provider to provide them with information to make an informed choice.(13)

With respect to mammogram referrals, in a focus group of 53 AI/AN women, several AI/AN women indicated that their IHS provider did not counsel them about breast cancer or the importance of getting screening mammograms.(9)

There is currently no data available regarding lung cancer screening rates for AI/AN people.(8) A study interviewed 58 AI/AN participants about lung cancer screening. One dominant theme that emerged from the participants was the limited discussions with healthcare providers about lung cancer screening, with 57% of the participants being unaware of lung cancer screening.(8) After learning about the availability of lung cancer screening through that study, many participants characterized their conversations with physicians as inadequate, pointing to limited discussions by IHS providers about screening referral.(8)

Discrimination and Prejudice

There are three studies which demonstrate that the IHS has not adequately addressed the cultural barriers faced by AI/AN, namely discrimination and prejudice and lack of cultural understanding, that have prevented AI/AN from seeking cancer screening.

The sense of discrimination and prejudice against AI/ANs acts as a barrier to care. Findling et al. (2014) conducted a telephone survey of 342 AI/AN adults and 902 white adults from January to April 2017 to calculate the percent of AI/ANs reporting discrimination in different domains compared to white people.(14) Based on the surveys, 23% of AI/ANs reported discrimination because of their ethnicity in healthcare, compared to 5% of white people.(14) The health risk associated with discrimination was that 15% of AI/ANs reported that they have avoided healthcare for themselves or their family because of concerns they would be discriminated against or treated poorly, whereas only 3% of white people felt that way.(14) However, it is important to note that these surveys did not specify whether AI/ANs felt discrimination in the IHS facilities or at external medical providers.(14)

Following a similar tone, another study revealed a sense of discrimination and prejudice where 53 AI/AN women over the age of 40 were interviewed with respect to their mammography experiences at outside mammography facilities.(9) The AI/AN women complained of prejudice and negative attitudes from the mammogram technologists which was identified as another factor for avoiding mammogram screening.(9)

On another note, an interesting finding in two studies was that the AI/ANs expressed a high level of trust in their IHS providers.(9,13) The AI/AN members expressed that they preferred IHS or tribal clinic services over outside providers.(9) Although 64% of the women had private health insurance, more than half these women still used the IHS or tribal clinics as their primary care indicating that they were more comfortable with IHS providers.(9) Further, in another study about HPV vaccination, the AI/AN women reported positive relationships with the IHS or tribal clinic provider and that they trusted their IHS providers as a source of information concerning the vaccine.(13)

Cultural Differences

Ndikum-Moffor et al. (2013) observed that AI/AN women identified cultural reasons for not openly discussing breast cancer and/or mammograms with each other. In a culture that values and is taught the importance of modesty, the topic of breast cancer and screening is considered an embarrassing topic.(9) Similarly, in a focus group study of 50 AI/AN women on their perception of Pap smears, the women expressed that getting a Pap smear was intrusive and embarrassing.(13) In another focus group study, AI/AN women reported feeling uncomfortable disrobing and being examined by a male doctor.(11)

Discussion

Summary of Findings

This systematic literature review of 15 original studies explored how the IHS, or more appropriately, the shortcomings of the IHS, have led to health disparities in screenable cancers in the AI/AN population. These health disparities have stemmed from the increased incidence, the delayed diagnosis, and higher mortality rate from cancer in the AI/AN population when compared to other groups. After an exploration of primary and secondary studies that examined these health disparities, the barriers to cancer prevention and screening for the AI/AN population include lack of access care, inadequate referrals by IHS providers, and lack of cultural competence in care and education to the AI/AN community.

Interpretation of Results

It is a widely accepted medical principle that early detection of cancer is critical to survival from the disease.(1,2,8,16,17,21) There are some cancers, namely colorectal and cervical, that can altogether be prevented through screening. (1,13,21) With respect to female breast and lung cancers, the most important intervention to reduce mortality is diagnostic screening through mammogram and chest CT scan, respectively.(2,8,17) Notwithstanding, AI/AN people have the lowest screening prevalence for female breast, colorectal, and uterine cervical cancers compared to any other group in the US.(1,2,16,21) The screening prevalence for lung cancer has not yet been evaluated.(8)

The results demonstrate a positive correlation between access to diagnostic testing and medical specialists and increased cancer screening.(7,10) However, the underfunding of the IHS creates an inadequate healthcare structure that is unable to meet the needs of the AI/AN community as the resources do not facilitate adequate diagnostic testing or medical specialties within the IHS facilities themselves. A survey of four governmental health programs from 2013 through 2019 demonstrated that the per-capita (per-person) healthcare spending levels of the IHS each year was lower than the spending levels of Medicaid, Veterans Health Administration, and Medicare.(22) In 2019, the IHS per capita expense of $4,078 was significantly lower than the per capita spending levels of Medicaid ($8,109), the Veterans Health Administration ($10,692), and Medicare ($13,185).(22)

The IHS facilities offer only primary and emergency care services, and medical specialist services are often contracted out to private facilities in the PRCDA. As such, the IHS facilities cannot not consistently offer gastroenterologists for colorectal cancer screenings or gynecologists for cervical cancer screening. Further, not all IHS facilities have mammogram or CT equipment available.(2,8,9) As a result, many IHS facilities are unable to offer cancer screening to its patients.

This requires AI/AN people to travel a long distance off reservation to outside providers to get screening, sometimes up to 200 miles or even more.(18) Having to travel long distances is particularly burdensome in the AI/AN community which traditionally relies on shared transportation. Indeed, two survey studies confirmed that distance to seek medical services was a reason not to get necessary care.(9,12)

One study, which examined the various legislative policies behind the IHS which led to its significant underfunding, determined that the IHS budget would require an additional $3 billion per year to reach a level similar to other health benefit plans.(23) While this may sound like a large sum of money, it represents only a few tenths of the $800 billion budget.(23)

Although mobile mammogram units placed at IHS facilities, which eliminated the transportation barrier, did not significantly improve adherence to mammograms in the Great Plains region, it still showed promise as it drew in 34.5% first time mammogram screeners.(17) As such, mobile mammography is important as an outreach strategy to improve access, and combined with improved IHS provider referral and education on cancer screening, mobile mammography should improve adherence as well.

The inadequate referral by IHS providers for cancer prevention and screening came out as a dominant theme in the survey studies. It is not enough to rely on government issued recommendations to secure cancer screening adherence in the AI/AN community. When the CDC or the US Preventive Services Task Force, as a branch of the US government, recommends routine cancer screening or vaccination, the AI/AN community may be hesitant to follow those recommendations due a history of violated trust. Two examples of this are the studies which showed that mistrust in the US government was a source of HPV and COVID 19 vaccine hesitancy in the AI/AN community.(13,24,25)

The backbone behind mistrust is the accumulation of historical trauma and oppression endured by the AI/AN community from the US government. This dates back to the Indian Removal Act of 1830 with forced displacement and relocation of the AI/AN population from stolen tribal lands to the Midwest rural lands.(1) It has also manifested at the hands of the US medical community. In the 1970s, the IHS was found responsible for performing 3406 involuntary sterilizations on AI/AN women aged 15 to 44 years old, either in violation of court orders prohibiting sterilization of women younger than 21 years old, or without adequate legal consent.(26) Then, from 1989 to 1994, the researchers of the Havasupai “diabetes project” collected blood, something that has spiritual value in the AI/AN community, from more than 200 tribal members upon a representation that it be used to study diabetes, but the researchers improperly used the blood samples to study the genetic causes of schizophrenia, which had not been authorized by the tribe.(26) These events have strained the AI/AN community's relationship with the US government and the medical community, and may also deter them from seeking medical screenings.(26) Notwithstanding the IHS' role in these past events, the IHS appears to have regained the AI/AN community's trust as the majority of those surveyed expressed trust in their IHS providers.(9,13,24) As such, the IHS provider appears to be in the best position to counsel the community on cancer risk, cancer prevention and screening availability, and to make a referral for such services. There is a need for IHS providers to close the gap of mistrust by providing the AI/AN people with accurate and complete information and with referrals for screening and vaccine cancer prevention.

The full extent to which prejudice and discrimination have damaged the cancer health of the AI/AN community has not been extensively researched. However, the findings here suggest that discrimination and prejudice experienced by AI/ANs in the healthcare setting presents as a reason to avoid necessary cancer screening. Although one survey study did not specify whether discrimination was felt in the IHS facilities or at outside medical providers,(14) one study identified discrimination in an outside mammogram facility.(9) This is consistent with AI/AN participants in another study who ranked outside providers to be the least helpful and trustworthy.(27) On the other hand, as stated above, the majority of AI/ANs expressed a high level of trust in their IHS providers and preferred their IHS providers over outside providers.(9,13,24)

The AI/AN community should experience increased cancer screening if the IHS infrastructure is broadened to bring screening services within the IHS facilities. By incorporating mammogram, lung CT, Pap smear, and colonoscopy screening into the IHS facilities, the AI/AN community will have easier access to them through an established and trusted relationship with their IHS providers. Bringing screening services into the IHS facilities should not only alleviate the transportation barriers, but it should reduce the sense of discrimination and prejudice felt at outside providers. An additional method to eliminating prejudice and discrimination in healthcare is by incorporating cultural competence into the system.

The role of cultural competence in healthcare has been growing as a way to promote efficient cross-cultural communication.(28) Cultural competence is the ability to understand and respect the beliefs, values, and histories of all cultural backgrounds.(28) The AI/AN community has different standards for what constitutes good health, measured not only in physical health, but in one's ability to contribute to the community, pass down knowledge and wisdom, and engage in self-health and efficacy.(28) The AI/AN community's distinct ideals for good health must be at the foundation of any possible medical interventions from foreign parties.(28) By understanding their culture of modesty and privacy, as well as the hardships they face in healthcare, this should build trust, instill comfort, and increase the chances that they will be more compliant with medical recommendations.

The concept of cultural competence has shown importance in contemporary legislation. In the 2023 National Indian Health Board Legislative and Political Agenda for Indian Health, one clause calls for establishing a standard for culturally educated healthcare workers. It also requires that any potential policy initiative that targets behavioral health must consider the culture, tradition, language, and the well-established tribal practices.(29) The IHS and tribal healthcare providers have requested investment from the government to create this culturally sensitive healthcare community, through education and recruitment efforts, that should lead to an influx of high-quality medical professions into IHS healthcare.(29) The inclusion of these initiatives in a government report yields promising potential towards effectively addressing AI/AN behavioral health inequities that have contributed to centuries-long poor outcomes.

With respect to behavioral health, the AI/AN community's lag in smoke cessation behind the rest of society means that the current nationwide tobacco control interventions which have included smoke free policies, cessation access, tobacco price increases, and mass media campaigns are not reaching the AI/AN community.(19) From 2011 to 2020, the overall adult smoking prevalence declined from 19% to 12.5%, with linear downward trends in all racial and ethnic groups except the AI/AN group.(19) As of 2020, there was a 27% prevalence of cigarette smoking in AI/AN people compared to 13.3% in white people, 19.4% in black people, and 8% in Hispanic people.(19) In another study, a 2019 survey revealed that smoking cessation - the percentage of smokers who quit smoking - was 61.7% among all adults, compared to 48.8% among AI/AN adults.(20) Tobacco control in tribal lands has been challenging as the tobacco industry directly targets the AI/AN community through use of cultural specific names.(1) Further, tobacco is less expensive because it is not subject to a state excise tax.(1) This calls for a need to educate the community with targeted interventions to increase smoking cessation, with a heavy emphasis on delivering education in a culturally competent manner in order to be conveyed effectively.

There may be a misunderstanding in the AI/AN community between commercial tobacco versus traditional tobacco. Traditional tobacco is commonly used as part of tribal culture and spirituality for medicinal or ceremonial purposes.(1) For education on smoking cessation to be effective, it should be delivered in a way which distinguishes undesirable commercial tobacco from acceptable traditional tobacco. This highlights the complexity of addressing health disparities for the AI/AN population, as promoting health interventions, such as smoking cessation initiatives, must be careful not to present as an acculturation effort to diminish their cultural beliefs through westernized practices. One pilot study showed promise with a culturally tailored smoking cessation program, portraying tobacco as a sacred plant, with twice as many participants reporting an intention to quit compared to the participants of the non-culturally tailored program.(15)

The AI/AN community may be more likely to heed to education and advice from tribal leaders. Studies have shown that shared identities between patients and physicians improve communication, trust, and compliance with recommendations.(2) Elders have symbolic and practical importance in many AI/AN communities as they have traditionally been leaders responsible for carrying down history and culture to the younger generations.(28) The use of Community Health Representatives (CHR), tribal members themselves, to educate the AI/AN community on COVID 19 vaccine use and safety was favorably received by 60% of the community and with improved vaccination rates.(24) Similarly, there was a general positive reaction among AI/AN women to have peer educators HPV vaccination.(13) The use of local tribal members to promote positive health behaviors and cancer preventative care through education may be an effective adjunctive approach to reaching the AI/AN community.

Implications and Interventions

The findings of this literature review have important implications for the future healthcare of the AI/AN community. The results indicate that the AI/AN community experiences a variety of obstacles to healthcare, including lack of access, prejudice and discrimination, cultural barriers, and lack of education. It is observed that cancer is generally diagnosed at a later stage in the AI/AN population in female breast, colorectal, lung and uterine cervix.(1,2,8) It is also observed that cancer mortality was higher in AI/AN population for female breast, colorectal, uterine cervix, and lung cancers.(1,8) The late stage at diagnosis and lower survival in the AI/AN population are reflective of the barriers to care and education for early detection.

As cancer screening progresses through expanding knowledge of disease coupled with advancement of medical technology and developing treatments, there is a risk that the disparities in cancer in the AI/AN population will be exacerbated. As such, the pursuit of improving cancer screening status for AI/ANs should be a high priority in policy making.

Considering the difficulty many AI/ANs experience to get screened for cancer, screening programs are an essential need. The IHS should develop a culturally competent educational and screening program through multilevel interventions. A multilevel intervention is one that influences two or more levels - the patient, the community, and the healthcare provider. Prior studies have shown that multi-level approaches have been effective at addressing minority health disparities.(30)

The National Institutes of Health (NIH) created the Intervention Research to Improve Native American Health (IRINAH) program aimed to develop strategies to develop interventions that influenced the individual level and the community level. (Blue Bird Jernigan). Many of IRINAH's studies, namely the MICUNAY study, the THRIVE study, the TCU-BeWell study, the FRESH study, have been assessing the effectiveness of multilevel interventions on topics such as alcohol and drug use, good nutrition, and traditional healing. These studies focus on projects that promote true community involvement, which includes communication with tribal leadership and observing tribal members to determine the most culturally appropriate and sustainable strategies within the unique cultural AI/AN community. This formula for multilevel intervention strategies, which has focused on reaching the community through community involvement and culturally centered approaches, has so far yielded encouraging results towards fostering sustainable positive health behaviors that should reduce AI/AN health disparities. (31) This blueprint for engaging the tribal leaders and community members in the shared goal of promoting good health as a multilevel approach has promise.(31) Other studies have found similar results, asserting that it is critical for tribal communities themselves to play a critical role, where they take responsibility in improving their health.(32) Notwithstanding, most interventions currently implemented in the AI/AN communities are not multilevel which is attributed to a lack of knowledge of tribal policies and limited data on the sources of health disparities in this population.(31)

A multilevel approach would involve, at the individual level, educating the AI/AN people about cancer prevention behavior - smoking cessation - and about the importance of cancer screening and HPV vaccination. Based on the AI/AN community's deep connection to their tribe and its culture and traditions, and a strong sense of trust in fellow tribe members based on the shared culture, AI/ANs may be more likely to participate in education programs which are implemented through a tribal education model. As such, the IHS partnering up with tribal members, such as elders, peer health educators or community health representatives, to implement cancer education to AI/AN individuals may be effective at delivering health messages and in recruiting the AI/AN community to participate in vaccinations and screening. The elders, peer educators, or community health representatives may be particularly well suited to find common grounds between AI/AN's more holistic approach to health and the Western models of cancer screening and prevention. The IHS may also partner with local AI/AN tribes to develop culturally sensitive educational materials to be delivered through elders, peer educators, or community health representatives to the community which should alleviate long-standing mistrust, and foster a better understanding of cancer, cancer risk reducing behaviors, and cancer screening despite low health literacy. One attempt to improve communication was providing cancer educational material with culturally sensitive messaging to Navajo women by including a glossary of terms with descriptive phrases in the native Navajo language. Qualitative data revealed a higher reported satisfaction with the educational materials and a changed outlook on the importance of breast screening.(2)

To augment the effectiveness of education, additional interventions should be targeted at the community level such as media displays for cancer screening and vaccination, as well as smoke-free zones, while continuing to allow traditional tobacco for ceremonial and medicinal purposes.

Finally, the IHS should make significant changes at the healthcare provider level by improving access to care and eliminating barriers. The AI/AN community generally favors the IHS or tribal facility and has generally reported positive relationships with and trust in their individual IHS provider. Building on this concept, there is a need for increased funding to the IHS to build up the IHS infrastructure with staff and technology so that they can purchase updated screening technology and contract with medical specialists, namely gastroenterologists and gynecologists on site, to facilitate cancer screenings which should improve AI/AN participation. AI/AN individuals may be more likely to participate in screening programs that are run at the IHS or tribal facility.

Mobile mammograms that come to the reservation still show promise to fill the gap in mammogram screening. Although the Roubidoux et. al. (2021) study showed low mammogram adherence, mobile mammogram in conjunction with cancer screening education and improved referrals as suggested above, should improve adherence. The convenience of mobile services in providing screening closer to home should be appealing and the concept of mobile medicine may one day be expanded to include Pap smear, lung CT, and even colonoscopy screening.

Finally, because of the historical experiences by the AI/AN community of prejudice and discrimination and cultural conflict, all healthcare providers should undergo cultural competence training to better understand the AI/AN culture and the hardships they have endured. This type of training should improve an understanding on the potential impact cultural differences can have on healthcare, and improve cross-cultural communication to AI/ANs to improve cancer screening compliance.

Research Gaps

One issue which has not been adequately explored is how the IHS has addressed the progressive shift and urbanization of the AI/AN population. When the IHS was first established in 1955, at least 70% of AI/ANs lived on the tribal lands. However, as of 2022, an estimated 70% of AI/ANs live in urban settings off tribal lands.(33) In modern day, more AI/AN people reside in New York city than North Dakota, which has historically been home to a large AI/AN community.(33) Currently, the IHS focuses on delivering healthcare to those who live on tribal lands either through IHS facilities or PRC contracts. There are 41 Urban Indian Organizations (UIOs) that work to provide healthcare to urban American Indians, but results have been inconsistent with the program.(33) This study proposed the creation of a Federal Indian Health Insurance Plan with funding from the federal government to work alongside the IHS to deliver healthcare to AI/ANs regardless of their geographic location.(33)

The solutions proposed here may not address the delivery of services to those living outside the tribal lands. There is little research on how the demographic shift of the AI/AN population has impacted the health or health disparities in cancer of AI/ANs living off tribal lands. There was no study included in this literature review which compared the incidence of cancer in AI/ANs on tribal lands to those off tribal lands. Further research is required exploring health disparities in cancer among AI/ANs living outside of tribal lands so that polices can be developed and aimed at allocating resources to ensure cancer screening services are available for the AI/AN community's demographic shifting population.

Another issue which has not been researched is the costs to the IHS due to late-stage cancer diagnosis in the AI/AN population. There is research that the mean and cumulative healthcare costs over four years for members of a private health insurer were higher for patients diagnosed at Stage III and IV compared to patients diagnosed at Stage I and II in certain cancers.(34) The extent to which earlier diagnosis of screenable cancers - female breast, colorectal, lung, and uterine cervical - may reduce the healthcare costs to the IHS is a worthy topic. A study which showed that the potentially preventable hospitalization rate for AI/ANs with diabetes and hypertension was 1.5 times higher than that of whites served as a basis for policy to improve access to outpatient services.(35) In this regard, research examining the costs of potentially preventable care caused by late stage diagnosis of cancer in the AI/AN population could serve to motivate policy to increase funding on the cancer screening side. If there is evidence that funding the screening side of cancer through education and cancer screening access could lead to an overall decrease in costs to IHS, this should yield more support to increase funding to the IHS facilities for testing and medical specialists. This type of research could show the double benefit of lowering healthcare costs for IHS while simultaneously improving the cancer outcomes in the AI/AN population.

Strengths and Limitations

The strength of this literature review is that it synthesized quantitative data with qualitative data from original peer-reviewed literature published in credible journals with medium-to-high impact factor. Using quantitative data with numerical properties was essential to establish some key concepts in this review, such as the underfunding of the IHS, excess cancer burden, low cancer screening prevalence in AI/ANs, and the distance to cancer screening facilities. The benefit of quantitative data is that it is reliable and relatively easy to analyze. However, it was the incorporation of qualitative data gathered through interviews, surveys, and focus groups, that complemented the quantitative data to better understand the complex issues. The qualitative data which analyzed words, language, and attitudes into predominant themes provided valuable insight into AI/AN perceptions of healthcare and into their responsive behaviors which shed light onto and made sense of the low cancer screening prevalence. Another strength was that there was congruence in the resources as each source fit into the broader topic of healthcare obstacles or poorer health outcomes in AI/ANs giving further validity to the research question. Finally, another strength is that this literature review drew from an array of databases to construct a well-balanced collection of sources.

There are some limitations in this literature review that should be identified. One limitation of this literature review is that it does not differentiate cancer disparities between different tribes or different geographical regions. The diversity of the tribes with different customs and different geographical locations may impact risk factors for cancer. Kratzer et. al. (2022) observed significant differences in incidence rates of certain cancers in AI/AN population dependent upon geographical location.(1,2) One important example is that Alaska Natives have the highest reported incidence and mortality rate from colorectal cancer than any other tribe.(1) Additionally, the different tribes have different experiences with the US government and the healthcare system which may affect the cultural barriers faced by each tribe. As such, the generalizability of this literature review to apply to the AI/AN population as a whole may be compromised. Another limitation of this literature review is that other factors which may contribute to health disparities in cancer, namely AI/ANs who are uninsured or do not meet IHS eligibility criteria, were not included in this systematic literature review.(11) Finally, some studies that were relied upon for analysis were based on relatively small sample sizes and were applied to general populations.(3,9)

Conclusion

The IHS has contributed to the cancer disparities in the AI/AN community by falling short in meeting the needs of this community by offering access to culturally competent care and education. Despite its shortcomings, one important observation is that the AI/AN community has generally expressed a high level of trust in their IHS healthcare providers. However, in its current operation, the IHS facilities do not have adequate medical specialists or diagnostic testing to meet the needs of their community with cancer screening. Up to date, the IHS does not have adequate programs to ensure that cancer education and screening referrals reach the AI/AN community.

Nonetheless, due to the trust established by IHS providers, it is pertinent that we don’t omit the IHS in future policy, but rather augment it to better provide healthcare for the AI/AN community. Future priorities by the IHS for the AI/AN population should include a multi-level approach with interventions at the individual, community, and IHS facility levels to better reach the AI/AN community. At an individual level, the AI/AN community has more trust in fellow tribe members who understand AI/AN tribal culture as well as the historical prejudices against the AI/AN community, having tribal peer educators may serve as a viable gateway to delivering health messages and recruiting participation in cancer prevention and screening. At a community level, these health messages should be carried into the tribal community with media displays and accessible written materials. At the IHS facility level, the lack of medical specialists and diagnostic testing on site, which forces AI/AN individuals to have to travel long distances for screening, appears to have the most dramatic impact on low cancer screening prevalence. The interventions at the IHS facility level should be directed at increasing funding for additional medical specialists and testing within the facilities themselves, or for the use of mobile medical services to fill the screening and vaccination gap caused by lack of access to care. Additionally, it is essential that culturally competent training of all healthcare providers who treat the AI/AN population should be integrated to ensure effective cross-cultural communication of health messages and referrals to better reach this population.

By augmenting the capabilities of the IHS and addressing these priorities, we can work towards eliminating cancer disparities and improving healthcare outcomes for the AI/AN community. It is not merely about acknowledging the shortcomings but actively working to enhance and strengthen the system to better serve those who rely on it most. Through concerted efforts, focused on a commitment to cultural sensitivity and accessibility, we can strive for a future where all members of the AI/AN community receive the quality healthcare they deserve.

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