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Disparities in Radiation Oncology

The pervasive crisis of diminishing radiation therapy access for vulnerable populations in the United States, part 2: American Indian patients

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Abstract

Introduction: American Indian/Alaska Native (AI/AN) patients with cancer disproportionally present with more advanced stages of disease and have the worst cancer-specific survival rates of any racial/ethnic group in the United States. The presence of disparities in radiation therapy (RT) access for AI/AN patients has rarely been examined.

Methods and materials: National Cancer Institute (NCI) initiatives toward addressing AI/AN disparities were examined. Additionally, an extensive PubMed literature search for studies investigating RT access disparities in AI/AN patients was performed.

Results: Literature describing RT access disparities for the AI/AN patient population is sparse, revealing only 3 studies, each of which described initiatives from the Walking Forward program, the NCI Cancer Disparity Research Partnership initiative to address barriers to cancer screening among AI populations in the Northern Plains region (eg, geographic remoteness and mistrust of health care providers). This program has used patient navigation, community education, and access to clinical trials for more than 4000 AI/AN patients to combat high cancer mortality rates. Over the course of its 15-year existence, the program has resulted in patients presenting with earlier stages of disease and experiencing higher cure rates. Lung cancer, the most common cause of cancer-related mortality in AI/AN patients, is the most recent and ongoing focus of the program.

Conclusion: The amount of information regarding RT access in AI/AN patients is limited, with nearly all peer-reviewed published progress in this area being associated with the Walking Forward program. Further initiatives from this program will hopefully inspire similar initiatives throughout the country to reduce the barriers to optimized cancer care that these patients face. Given the

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similarities with cancer disparities of populations worldwide, the AI/AN experience should be included within the broad issue of a global shortage of cancer care among underserved populations.

Introduction

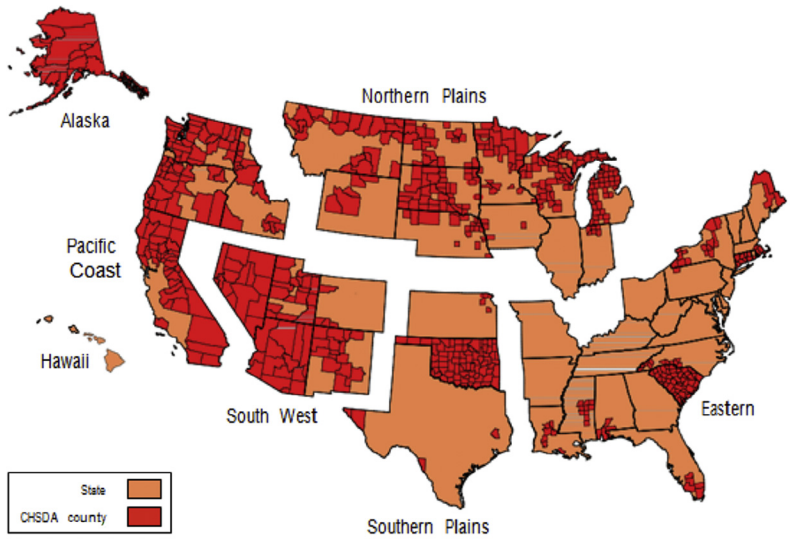
Populations that historically have faced displacement, marginalization, and structural disadvantages in the United States also face the painful and often life-threatening reality of disparities in modern health care access. Part 1 of the current series investigated the disparities in radiation therapy (RT) access faced by African-American patients.[1,2] In this review, we examine a population that has suffered arguably more structural violence and disadvantage than any other population in U.S. history, American Indian/Alaska Natives (AI/ANs), and the barriers they face in receiving optimal cancer care.

Approximately 5.2 million AI/ANs live in the United States, belonging to 566 federally recognized tribes that comprise 6 geographic regions as defined by the Indian Health Service (Fig 1).[3] Over a recent 20-year period (1990-2009), overall cancer death rates for AIs linearly increased while simultaneously linearly decreasing for Caucasians.[4] Cancer is the leading cause of death among AI/ANs nationwide,[5] and AI/Ans disproportionately present with more advanced stages of disease.[6,7]

Indian Health Service geographic regions demonstrate distinct patterns in cancer incidence rates. In the East, Northern Plains, Southern Plains, and Pacific Coast, the most common cancer diagnoses for women were breast, lung, and colorectal cancer; for men, they were prostate, lung, and colorectal cancer.[4] In the Southwest, the most common cancer diagnoses for women were breast, colorectal, and uterine cancer; for men, they were prostate, colorectal, and kidney cancer. In Alaska, the most common cancer diagnoses for women were breast, colorectal, and lung cancer; for men, they were lung, colorectal, and prostate cancer.[4]

Low- or no-income status, historical trauma with its resulting mistrust from events such as Wounded Knee and the 1880 Indian Wars, lack of adequate government health care funding, low rates of cancer screening and physical activity, geographic isolation, and high-risk health behaviors have all contributed to the reality that AI/AN populations have the worst cancer-specific survival rates of any racial/ethnic group in the United States[8,9]; this is especially true for AIs.[5,10] Furthermore, the northern plains AI population has some of the highest poverty rates in the United States, approaching 90% in some areas, particularly on the reservations in western South Dakota.[5,11]

In 2002, the National Cancer Institute (NCI) created the Cancer Disparity Research Partnership (CDRP) program for community cancer centers that worked with these vulnerable populations.[12] Patient navigation was part of the CDRP program as a potential strategy to mitigate the



States and Contract Health Service Delivery Area (CHSDA) Counties by Indian Health Service Region, 1999-2009. American Journal of Public Health, 2014. Published online ahead of print April 22, 2014

Figure 1 Six Indian Health Service geographic regions in the United States.

aforementioned disparities. Walking Forward was the only CDRP site of the original 6 that was created to address AIs.

Literature regarding disparities in RT access for AI patients is relatively sparse compared with that for African-American patients. A comprehensive PubMed database search for articles published up to and including April 20, 2017 using the search terms "Native American or American Indians," "radiotherapy," and "disparities" revealed articles describing the Walking Forward Program in South Dakota.[6,13,14] More recently, Guadagnolo described the consequences of decades of policies that were designed to fracture AI communities, including increased rates of unhealthy lifestyles and high-risk behaviors, low rates of physical activity, and lower cancer-screening rates, even after adjustments for income, state of residence, and education.[15] Barriers to cancer screening for the AI population include geographic remoteness (especially among reservation-based communities) and cultural barriers that manifest as a mistrust of health care providers, which contribute to disparate cancer outcomes.[16,17]

Although African-American patients have the highest overall cancer death rate and the shortest survival time of any racial/ethnic group in the United States, the AI population has the worst cancer-specific survival rates of any racial/ethnic group because they present with advanced-stage cancer and often have significant comorbidities.[18-20] A Surveillance, Epidemiology and End Result Medicare analysis revealed that AI patients are less likely to receive adjuvant chemotherapy or RT and are overall less likely to receive guideline-concordant care compared with Caucasian patients with cancer.[20] The Walking Forward Program has been a successful model for combating RT access disparities for AI patients with cancer.

Walking Forward program

The Walking Forward program was created in 2002 to address the ominously high cancer mortality rates observed within the AI population living in western South Dakota.[6] The original program addressed these disparities through patient navigation, assessment of barriers to cancer detection for screen-detectable cancers, community education, and access to clinical trials.[6] To date, more than 4000 AI patients have participated in Walking Forward research studies.[21]

From 2009 to 2012, Walking Forward initiated a comprehensive navigation program for cancer-screening education and care and has reached more than 1900 AI patients and survivors. Program findings have been published extensively,[6,14,21-28] with critical outcomes including establishment of trust within tribal communities, identification of barriers to cancer screening, creation of research infrastructure, higher treatment completion rates and patient satisfaction for patients undergoing cancer treatment, enrollment of patients in phase 2 trials with excellent clinical outcomes, and the establishment of new research partners. Recent Walking Forward data analysis suggests that AI patients with screen-detectable cancer now present with earlier stages of disease and higher cure rates.[21,28] The significance of these findings shows that actual results rather than proximal mediators can be attributed to the Walking Forward interventions.

With tobacco-smoking rates in the Northern Plains AI communities reaching 50%, Walking Forward implemented a smoking-cessation project using mHealth technology (2012-2016) as part of a comprehensive effort to prevent smoking-induced cancers (R01 CA170336). This project enrolled 256 AI smokers who were randomized to interventions that consisted of nicotine replacement and motivational pre- and/or post-cessation counseling and/or text messaging. Of the participants who successfully completed the 6-month intervention, 69% were smoke-free, whereas 10.5% of all participants were smoke-free. Note that this number does not include individuals who quit smoking and chose not to continue with the study. Equally important results of this study are the lessons learned with regard to reaching remote and underserved target populations, the challenges of mobile-health technologies, and culturally tailoring materials to the target population, including the ceremonial use of tobacco (publication pending).

Lung cancer accounts for most cancer deaths both nationally and in South Dakota. Plescia et al reported that lung cancer mortality rates for Northern Plains AI patients were the highest in the nation: 94.0 AI patients compared with 55.3 Caucasian and 49.7 all AI/AN.[29] Tumor registry data collected in Rapid City between 2009 and 2015 confirm these trends. The use of low-dose computerized axial tomography (LDCT) is an effective way to diagnose lung cancer at earlier stages, resulting in lower mortality rates, as demonstrated by the National Lung Cancer Screening Trial for screen-eligible patients (55-77 years of age with a 30 pack-year or greater smoking history who had quit smoking within the last 15 years).[30,31] Nationwide surveys, including a review by Jemal[32] in 2015, reveal that only 2% to 4% of those who are eligible are currently receiving LDCT screening, in part due to a lack of screening knowledge. Multiple studies[32-35] have verified that primary care providers have a limited understanding of screening; Lewis[35] reported that 24% of providers surveyed did not know any of the screening guideline components.

Therefore, in an effort to reduce lung cancer mortality rates for all patients in western South Dakota, including non-AI patients, Walking Forward has completed a lung cancer screening pilot project that informed an R01 project application recently submitted to the NCI: Increasing Lung Cancer Screening For High Risk Smokers In A Frontier Population. The research question is "Will provider- and/or individual-level interventions increase LDCTs for lung cancer screening among high-risk smokers living in western SD?" The innovative individual intervention will include 100 community educational workshops and introduce the

online resource developed with the pilot project. This novel health care provider intervention will include 135 primary care providers and staff in 30 clinics and will introduce the online resource. The primary outcome metric will be an increase in the number of lung-cancer-screening LDCTs performed. Finally, with these results, the project will engage community members, state and tribal leaders, and primary care providers in a strategic policy symposium and health care forum using findings from this study to promote sustainable, evidence-based, and culturally and regionally appropriate recommendations.

Walking Forward is seeking its fourth cycle of NCI funding to address the high cancer mortality rates experienced by northern plains AI patients, which will extend the program for another 5 years. In its first 15 years, the Walking Forward program has succeeded in reaching a population that understandably has been very mistrustful of non-AI research groups. A variety of approaches have been used to this end, including community-level engagement, spending time/resources to understand community problems and concerns, and developing potential solutions to these problems. Employing AI community members who understand these issues personally has been a vital piece of the Walking Forward program. Overall, the absolute persistence of the Walking Forward team, particularly when barriers to addressing these complex socioeconomic issues appeared difficult or insurmountable, has led to the program's longevity and continued success.

Indigenous populations in resource-rich countries share similarities with underserved populations in low- and middle-income countries. This includes poor health care systems, geographic isolation, and poverty. The Union for International Cancer Care has held workshops on indigenous populations at previous meetings (2012 and 2014, personal communication, as of June 2017), involving Australia, New Zealand, Canada, and the United States (including Inuits). The International Cancer Expert Corps (www.icecancer.org), which is in the process of initiating programs and developing support for its mentorship model, will include a pilot program to determine whether the Walking Forward model could be duplicated in additional geographic regions within the United States. Bringing AI/AN populations together with other global health efforts will highlight similarities and allow for the sharing of ideas, experiences, and resources.

Conclusion

The amount of information regarding RT access in AI/AN patients is limited, with nearly all peer-reviewed work either published or in process in this area being associated with the Walking Forward program. Further initiatives from this program hopefully will inspire similar initiatives throughout the country to reduce the barriers to optimized cancer care that these patients face and to increase RT use for AI/AN patients. Given the similarities in cancer disparities among populations worldwide, the AI/AN experience should be included within the broad issue of a global shortage of cancer care among underserved populations.

In the words of Margaret Meade: "Never believe that a few caring people can't change the world. For, indeed, that's all who ever have."

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