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Shared and Unshared Barriers to Cancer Symptom Management Among Urban and Rural American Indians

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Abstract

Purpose—Before the end of the 20th century, American Indians (AIs) primarily resided in non-metropolitan areas. Shifting demographic trends have led to a majority of AIs now living in urban areas, leading to new health care barriers for AIs. AIs experience the poorest survival from all cancers combined compared to all other racial groups. Identifying and classifying barriers to cancer care may facilitate supportive interventions and programs to improve access and treatment.

Methods—A 5-year cancer symptom management project targeted AIs in the Southwest. The first phase of the randomized clinical trial consisted of 13 focus groups (N=126) of cancer patients/survivors and their caregivers. Discussions explored existing and perceived barriers and facilitators to cancer symptom management and cancer treatment.

Findings—Significant barriers to cancer-related care were found among urban AIs, as compared to their rural counterparts. Barriers were classified within 4 sub-groups: a) structural, b) physical, c) supportive, or d) cultural. Urban AIs reported barriers that are both structural and physical (inadequate access to care and public transportation) and supportive (lack of support, resources and technology, and less access to traditional healing). Rural participants reported communication and culture barriers (language differences, illness beliefs and low levels of cancer care knowledge), as well as unique structural, physical and supportive barriers.

Conclusion—It is important to identify and understand culturally and geographically influenced barriers to cancer treatment and symptom management. We provide recommendations for strategies to reduce health disparities for AIs that are appropriate to their region of residence and barrier type.

Keywords

access to care; cancer; geography; health disparities; social determinants of health

PURPOSE

The United States' population and geographic distribution have been rapidly changing for decades. From 2000 to 2010 alone, the urban population has increased by 12.1%, more rapidly than the nation's overall growth rate.[1] As the US population as a whole grows increasingly "urban" each decade, a phenomenon, termed "metropolitanization,"[2] of the American Indian/Alaska Native (AI/AN) population follows suit. The US Census Bureau classifies "urban" areas as having a population density of at least 1,000 people per square mile; a classification of "rural" consists of all territories, populations, and housing units located outside of urban areas.[3] The population of AI/ANs residing in urban locations is

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steadily growing, and it is currently at 60%.[4,5] During the 20th century and previously, AI/ANs primarily resided in isolated rural areas. The population shift for AIs to urban centers was expedited during the mid 20th century for several reasons that included a government policy of assimilation which emphasized the termination of and relocation of AIs from reservations to major cities, economic migration, and an influx of World War II veterans who did not return to the reservations, but instead remained in urban centers.[6,7] From 1970 to 2000, AI/ANs were least likely to live in metropolitan areas, compared to all other races. Only 20 years ago, at the time of the 1990 census, did a majority (51%) live in metropolitan areas for the first time (Hobbs & Stoops, 2002).[2] According to the US Census, only 22% of AI/ANs now reside in tribal areas (ie, federal reservations, off-reservation trust land, state reservations, etc.) with 5 of the 10 most populated reservations being located in Arizona.[8]

Unlike rural reservation populations, urban AI/AN populations tend to be more diverse, encompassing multiple tribal groups who have diverse ethnic, cultural, and social characteristics. The extent of acculturation into urban and mainstream culture can vary greatly, and many traditional beliefs and practices from rural reservation living are transplanted with individuals and families into urban areas, often over several generations. In addition, movement around urban areas (transiency) is common, and it has been postulated to be a result of feelings of social and cultural isolation associated with living away from reservations.[9,10]

While rural populations typically fare worse on many dimensions of health compared with populations at other levels of urbanization, urban Indian populations are less likely to live within designated Indian Health Service (IHS) service areas where health care services are provided by federal (IHS) and tribal health programs,[10,11] raising new health care access concerns. To provide health care for the increasingly urban Indian population, the IHS currently funds 33 urban Indian health programs.[5,10] Unfortunately, assessing health status and even the level of health care access of the AI/AN population by area of residence is difficult to study due to racial misclassification in state and national health databases.[12] Even statistical reports generated by the IHS do not stratify health status by rural/urban location of residence, and AI/ANs not residing in defined IHS service areas are not included in aggregate statistical reports.[12]

With only limited information available characterizing the health status of AI/ANs living in rural and urban areas, there is a dearth of research examining cancer, cancer-related symptoms and related barriers to care in this population. AI/ANs experience the poorest survival rate from all cancers combined compared to all other racial groups.[13] Contributing factors may include late or inadequate access to treatment, lack of access to culturally sensitive education, language barriers, poverty, unreliable or nonexistent transportation, and cultural beliefs surrounding cancer,[14,15] all of which may be influenced by region/location of residence. Reservation clinic clients may obtain initial screenings from providers and referrals to IHS contract care specialists. However, because IHS clinics have limited numbers of specialists and screening equipment, referrals to specialists at larger metropolitan hospitals or clinics are not always approved for funding.[16] Urban Indian residents, on the other hand, may have more ready access to specialists, provided they have sufficient insurance coverage, either through Medicaid/Medicare, private or work-related insurance. Urban residents may also have the option of returning to their tribe's reservation or IHS clinic for primary care; however, they may or may not be eligible for contract health care services and referrals by the IHS clinic due to their urban residence.[16] Thus patients in both geographic settings may experience delays in treatment and disjointed care.

Studies have demonstrated how health care disparities result from a complex interplay of economic, social, and cultural factors.[17,18] For colorectal, female breast, cervical, and

prostate cancer the proportion of cases diagnosed at a localized stage is lower and the proportion diagnosed at a distant stage is higher in high-poverty compared with low-poverty census tracts.[19] For breast cancer, the proportion of women diagnosed with regional- and distant-stage disease is higher among African Americans, Hispanics/Latinos, and AI/ANs than among whites and Asian Americans/Pacific Islanders. In a study of rural-urban differences in cancer stage at diagnosis, rural residents were twice as likely to have unstaged cancers compared to urban residents, and tended to have more advanced disease than urban patients.[10,20] Results suggested that differences in access to or utilization of early detection methods at urban sites may contribute to the rural-urban differential in the extent of disease at diagnosis.[10,20]

This paper describes the results of the first phase of a large randomized intervention study designed to reduce/overcome barriers to cancer-related symptom management among AIs residing in the Southwest United States. The goal of the project was to identify and categorize illness beliefs and barriers to symptom management faced by AI cancer patients/survivors and family members, and to better understand how these constructs impact the cancer experience. Structural barriers, such as extent of health insurance and financial support; physical barriers, including geographical distance to health care facilities and limited access to transportation; cultural barriers, such as illness beliefs and practices, and distrust of the health care system; as well supportive barriers, were examined in this study.

METHODS

Adult male and female AI cancer patients/survivors, along with caregivers/family members (n=126), participated in 13 focus group discussions on cancer symptom management. Participants were recruited for focus groups through the use of flyers posted at community/health sites and word of mouth. Inclusion criteria were: (1) self-identify as AI, (2) age 18 years or older, (3) experience as a cancer patient (with active disease, before, during or after treatment) or survivor (not currently experiencing active disease), or experience as a family member (immediate or extended family) or caregiver (typically relatives, also including close friends or home health care workers) of an AI patient/survivor. Focus groups were held in conference rooms at 2 urban AI clinics and one community center at a reservation site in eastern Arizona. Rural sites were classified as such if the population density was less than 1,000 persons per square mile.[3] Each participant was consented prior to enrolling by trained project facilitators with experience working with AIs. The sessions, 1 to 2 hours in length, were audio-recorded with permission from the group members who were asked to use pseudonyms or numbers instead of names during discussion for confidentiality purposes. Thirty-five-dollar gift cards were offered as incentives for participation. Focus group discussions centered on the following areas: cultural constructs and personal experiences with cancer, barriers to self-management of cancer symptoms, and cancer beliefs, myths and fears. The study received Institutional Review Board approval from the University of California, Los Angeles and the Phoenix Area Indian Health Service.

At the beginning of each focus group session, following consenting and enrollment, the facilitators explained ground rules for focus group discussions, emphasizing speaking in turn and respectful listening. Focus group topics included the identification of cancer etiology, barriers, treatment and experience with cancer-related symptoms and their management. Facilitators followed a focus group protocol with prompts to guide open-ended discussion. The facilitators audiotaped the sessions, but participants were allowed to request the audiotape to be turned off at any time, during which case the facilitators would take notes. All participants were given the opportunity to speak, but all were not required to do so.

Research staff transcribed the audio-recordings of focus groups verbatim. The transcriptions were analyzed by 3 members of the research team and coded following constructivist Grounded Theory techniques[21] to identify major codes and categories in the data. Transcripts were read in their entirety by one investigator, and then excerpt-by-excerpt coding was conducted to capture the meaning expressed in each excerpt. Codes were reviewed and grouped by importance, similar concepts, and frequency in order to identify major themes emerging from the data. A second investigator independently reviewed the categorized codes and key themes. Community representatives reviewed excerpts from transcripts and evaluated the developing framework to assess accuracy of interpretation and provided validation of the codes and themes. Code description and categorization were discussed and modified until agreement among the entire research team was achieved. A matrix listing final codes and excerpts was created to synthesize data. Results from this study were shared with participating tribes and urban sites, and a review of findings was completed by the Phoenix Area Indian Health Service prior to publication.

FINDINGS

The study sample included 81 urban (64.3%) and 45 rural participants (35.7%). Additionally, 20.6% were urban and 9.5% were rural cancer patients/survivors. The majority of participants were female (89 females, 37 males). Further details of sample characteristics have been reported elsewhere.[22] Through the application of qualitative analysis numerous common—and several significantly different—barriers to cancer symptom management were identified among urban and rural Southwest AIs. Both groups reported experiencing physical barriers, such as transportation difficulties and lack of cancer care services. Within major categories of common (shared) barriers and differing (unshared) barriers, factors were further categorized within sub-groups of structural, physical, supportive, and cultural barriers.

Common (shared) barriers to cancer symptom management

Study participants reported common barriers in their cancer symptom management experience, which although distinguishable by varying geographic, lifestyle or cultural constructs, are still fundamentally similar. (See Tables 1 and 2 for qualitative data on barriers identified for rural and urban Southwest American Indians.)

1) Structural Barriers—Structural barriers include those factors beyond one's personal control and involve the system's organization and provision of care. Both the urban and rural groups described lengthy time between appointments and among service providers (appointments for a nutritionist, oncologist, etc., were often scheduled on different days). Native language translational services, largely available for rural groups—were non-existent for urban groups. The availability of and access to advanced technical cancer screening and treatment modalities and equipment was reported to be sparse in the rural areas, as compared to urban sites, often leading to reported inadequate treatment/misdiagnosis or late diagnosis among rural AI patients/survivors.

2) Physical Barriers—Physical barriers, described as distance to cancer care services and transportation difficulties, were experienced by both groups; however, the limitations that define these barriers are due to 2 major defining experiences. For the urban Indian group, living in a city presented difficulties in transportation— not because of distance factors—but due to traffic congestion and the expense and time burden of using the public transportation system. While reservation or rural-based Indians did not report experiencing such difficulties in transportation, they did note a lack of transportation options (such as not having a vehicle, no public transportation, or needing to rely upon relatives to provide rides

to appointments). In addition, rural groups described dealing with complications of coordinating transportation with others in light of the extremely long distance from isolated rural-reservation sites to medical care services. Long distances, coupled with numerous appointments, often necessitated overnight stays (added expense) and increased reliance on others for help with rides, childcare, etc., while away obtaining care, which introduced other significant issues described below.

3) Supportive Barriers—A third common barrier described was the lack of supportive services and care for cancer patients/survivors and their families. Both urban and rural Indian residents reported a general lack of access to appropriate information about cancer care and treatment. In addition, they noted that they often did not receive the attention of cancer advocates. This lack of support has been explained as the limited number of patient advocates or "navigators" employed on or near reservations or in urban settings. When available, advocates were not typically perceived as culturally competent or knowledgeable about the cancer patients'/survivors' support needs. Many urban and rural participants noted that they have access to Community Health Representatives (CHRs) who can help with such tasks as transportation, picking up prescriptions and other health-related services. Unfortunately, not all sites have CHRs, and those that do may experience limited availability of CHRs who are overwhelmed tending to the needs of AI residents who have type 2 diabetes, heart disease, or other chronic diseases.

A lack of social or emotional support of family and friends was noted by both groups. The practice of "not bringing one's troubles home" appeared to lead to increased social isolation and low support for cancer patients/survivors. AI cancer patients/survivors alike discussed the inability to "bring home" information about their cancer diagnosis, treatment, and survivorship experience. "We don't talk about it," was a common view voiced by participants regardless of geographic region of residence, as to do so would bring even more stress, problems, and grief to an overburdened family. The inability to turn to family and friends and share the cancer experience served to isolate the cancer patients/survivors in many instances.

Differing (unshared) barriers to cancer symptom management

While level of acculturation may vary among AIs of different tribal affiliations regardless of geographic setting, a number of barriers identified in this study typified cultural differences between urban participants holding more acculturated view points, and more traditionally minded rural AI participants. These differing or unshared barriers were more evident among the rural/reservation group than the urban group. (See Tables 1 and 2 for qualitative data on barriers identified for rural and urban Southwest American Indians.)

1) Cultural Barriers—Culture played a significant role in the management of such cancer-related symptoms as pain, depression, fatigue, and loss of function among rural/reservation participants. Difficult patient-provider communication, language differences, illness beliefs, disagreement regarding/lack of access to Native healing practices and low levels of cancer care knowledge were reported as barriers to cancer symptom management more frequently among rural residents. Because rural focus group participants for the most part did not have access to patient advocates, there was frequent noting of the inability to understand and communicate with the doctor. Patients and survivors reported that it was not unusual for the doctor to complete the visit without responding to the patient's questions. Additionally, the rural participants felt that the providers did not understand the culture of American Indians, medical terms and discussions were not understandable, and language differences contributed to misunderstandings and poor communications. These challenges may have also contributed to the patients'/survivors' low level of knowledge regarding cancer

screening, diagnosis, treatment and survivor issues, as well as the management of cancer symptoms. Rural participants typically reported levels of cancer knowledge and awareness of the cancer diagnosis, treatment and potential outcomes on the lower end of the spectrum, compared to a decent command of the terminology, diagnosis and treatment options more commonly reported among the urban group.

The use of traditional healers among the rural group was evident in their discussion of treatment preferences and healing ceremonies. Knowledge of traditional healers and ceremonies were voiced, and the use of both Western and traditional medicine was explained as a way to "maintain balance." Urban groups discussed the use of Western medicine, sometimes in combination with traditional healing. Distance barriers appeared to place urban Indians farther away from traditional medicine resources, which although sometimes available in urban locations are more prevalent on reservations. Rural participants' experience with traditional healers often included family and community members in the healing process. Urban Indians reported it was more typical to visit Western doctors, who are more easily accessible in urban locations, on an individual basis; with privacy regulations and hospital rules, the inclusion of family members is more inhibited. Discussion indicated that urban Indian communities may struggle to balance a desire for traditional cultural practices with available medical services.

2) Structural Barriers—Rural/reservation participants reported greater financial stress, as well as unique structural, physical and supportive barriers. Because of the isolation of rural reservation sites, employment opportunities are scarce and the financial stress of cancer-related treatment and care can become unmanageable. Even with the availability of the IHS clinic and hospital services, participants voiced that they are often without the needed specialized care, and referrals to outside agencies or to specialized care become financially unobtainable. Not only are these services more apt to be located in larger cities, having little or no insurance other than the care provided by the IHS left some rural patients/survivors vulnerable for refusal due to the inability to pay. Those who did find a way to enter a "support group" or to find a patient advocate told of uncomfortable meetings, long wait times, and rapid discussions regarding illness, loss of function and even death—a taboo topic among many tribes.

Both rural and urban AIs demonstrated unique, yet significant, structural barriers. Distance and systems barriers were perceived as more understandable barriers—it was the lack of social and family support, coupled with the cultural-related barriers, which were noted as major problems.

CONCLUSION

Identification and classification of the significant barriers faced by urban and rural populations are critical to improving cancer care and quality of life for AI cancer patients/survivors. While some barriers are more easily ameliorated, such as improving communication pathways, others are intrinsically systemic and challenging, such as large geographic distances, financial stress and limited access to care. Unique barriers faced by rural AI cancer patients/survivors included lengthy travel to obtain care, language and cultural differences between providers and patients, Native illness beliefs and practices, a general lack of family/social support, resources and technology, as well as preferences for traditional healing in combination with Western health care regimens. Financial stress and competing priorities were also particularly emphasized in the rural group, as participants discussed fearing missing work despite doctor's orders for rest and ignoring troubling cancer symptoms for fear of defaulting on financial and family responsibilities. This group also

noted that the huge burden of medical treatment, medication, and travel costs placed on the patient further added to their stress.

In contrast, urban groups noted difficulty in accessing care, late/misdiagnosed cancer, inadequate treatment (ie, poor pain management), lack of appropriate information and reliance on public transportation to obtain care as significant barriers. Among the care issues faced by the urban group were lengthy waiting periods to see their health care providers and inadequate patient-provider communication, resulting in the dismissal of cancer symptom concerns and improper treatment of these symptoms.

For several decades, there has been increasing awareness of cancer disparities. Numerous federal programs, such as the Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program, focus on reducing cancer disparities, specifically in areas of screening. While improving cancer screening is critical for timely diagnosis and prevention, programs often do not focus on issues beyond medical treatment post-diagnosis, namely symptom management. Since symptom management is primarily left to the patients themselves, along with their family caregivers, attention must be given to equipping families to treat common symptoms at home. While long distances from health care services and a higher degree of poverty in rural areas may make it more difficult for rural AIs to obtain care, urban populations may or may not have better access to health services through private insurance, Medicaid, or Urban Indian Health Organizations (IHS allocations for these organizations represent only 1% of the total IHS budget)[11,21] Further complicating the issue of reducing health disparities is the lack of available data on urban-rural health status; studies that do look at place of residence often only look at differences between AIs and whites, and not within racial groups.

Differences in barriers across level of urbanization may reflect socioeconomic and demographic differences, since these can vary widely by region. Other factors, such as cultural and geographic differences in lifestyle, dietary preferences, ceremonial and spirituality practices, may also be involved. An improved understanding of these factors will assist in efforts to reduce health disparities.[22]

Recommended Strategies

The development of more effective programs to reduce health disparities for AIs must focus on reducing geographically influenced barriers. It is important to identify urban–rural patterns in modifiable risk factors that may contribute to the rural–urban disparities [23] for cancer and symptom management. Recommended strategies based on study findings for both urban and rural AI communities include:

- Developing a local resource directory (support groups, financial help, etc.)
- Incorporating a communication building component for patients, family and providers
- Training cancer care navigators/advocates to work with patients and family members
- Tailoring materials to the appropriate literacy level; providing AI translations

Strategies unique to urban communities may include providing bus passes/gas cards to patients and arranging carpooling between appointments. Recommendations for rural communities may include involving community members/health representatives to help provide support, communication, and transportation to cancer screenings, etc., as well as emphasizing cultural beliefs, values, practices and imagery in health programming.

Solutions to improve cancer-related symptom care must be tailored to address the barriers specific to a geographic area, as well as to the local AI population. Continued research into the health of AIs in urban and rural areas is needed to help reduce health disadvantages, as well as provide information to the government and policy makers to enable them to better target limited public health resources.[23] Further research is also needed to better understand the reach and impact of existing urban health services programs for AIs in both rural and urban areas, including programs funded through IHS, tribal health, private insurance, and other programs.[10] It is also recommended that partnerships between tribal, federal, state, and local public health institutions be pursued to successfully assess, address, and eliminate these disparities.[24]

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Table 1

Qualitative Data on Barriers Identified for Rural Southwest American Indians

Barrier Type:	
Language Differences	• "He was told that he had terminal cancer…I told him in (our language) what the doctors said…he lowered his head and said 'adalezy,' situation is helpless."
Lack of Support	• "(The doctor) asked 'are there places back home, any group, where I can talk [about] my problems?' I told him no, there is no one here." • "(My family) didn't deal with it and talk about it."
Illness Beliefs	• "…other people talk about, oh you must have been a bad person to get that sickness." • "My sister said not to get too close to grandpa… she thought cancer could spread like a cold."
Long Distances to Care	• "…too much pressure on them to travel the distance and take care of her." • "If I ever get sick and end up in Phoenix or Tucson...(want to make sure family) will have the money to go."
Financial Stress	• "I am thinking about my job, do I have enough energy, if I don't go to work today I won't meet my bills." • "That is why I keep working…the doctor said I should stop (working) because I have to pay bills, who will help?"

Table 2

Qualitative Data on Barriers Identified for Urban Southwest American Indians

Barrier Type:	
Lack of Access to Care	• "…wait for care due to lack of insurance or the process of referrals." • "Having to go to several places for care."
Late/Mis-Diagnosis	• "They found it too late…spread all over." • "It was not until I went to the ER…" • "Why was this not caught three years ago when she was complaining about pain?"
Inadequate Treatment	• "…kind of being put on a conveyer belt." • "(Nurse would) just dismiss these things that I was worried about." • "They did not give me medications and I had no one to talk to."
Lack of Appropriate Information	• "The doctors and the pamphlets that you get at the doctor's office is all the technical stuff…but there was really no other alternative." • "(I needed) someone to talk to, to explain symptoms" • "I could not read the information...I would need someone to explain to me."
Reliance on Public Transportation	• "I have no transportation." • "I have no money for gas or the bus." • "By bus it takes two hours…I have to transfer three times and take three different buses."
Lack of Communication	• "I don't know why I didn't ask if it was cancer. I never asked if it was cancerous. I don't know, I just left it at that." • "I had bruising and bleeding but our local doctor told my mom that American Indians don't get leukemia."