Establishing a Patient Navigator Program to Reduce Cancer Disparities in the American Indian Communities of Western South Dakota: Initial Observations and Results

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Background: American Indians (AIs) in the Northern Plains region suffer disproportionately high cancer mortality rates compared with the general US population and with AIs from other regions in the United States.

Methods: The National Cancer Institute developed the Cancer Disparity Research Partnership to address these inequities. This initiative in Rapid City, South Dakota, attempts to lower cancer mortality rates for AIs by access to innovative clinical trials, behavioral research, and a genetic study. Patient navigation is a critical part of the program. Two navigation strategies are described: navigators at the cancer center and navigators on each reservation. A retrospective analysis was performed to determine if navigated patients (n = 42) undergoing potentially curative radiotherapy had fewer treatment interruptions compared with nonnavigated patients (n = 74).

Results: A total of 213 AIs with cancer have undergone patient navigation. For those undergoing cancer treatment, the median number of patient navigation interactions was 15 (range 1 to 95), whereas for those seen in follow-up after their cancer treatment, the median number of contacts was 4 (range 1 to 26). AIs who received navigation services during curative radiation treatment had on average 3 fewer days of treatment interruptions compared to AIs who did not receive navigation services during curative radiation treatment (P = .002, N = 116).

Conclusions: Early findings suggest that patient navigation is a critical component in addressing cancer disparities in this population. The program has established trust with individual cancer patients, with the tribal councils, and with the general population on each of the three reservations of western South Dakota.

Introduction
Factors contributing to health care disparities are complex and include various financial and nonfinancial barriers. In 1989, the American Cancer Society conducted a series of hearings with underserved cancer patients to begin elucidating some of these barriers. This report documented significant barriers that prevent these populations from seeking cancer treatment at an earlier stage of disease. As a result, these patients suffer higher death rates, thus reinforcing a fatalistic attitude about cancer.

American Indians (AIs) in the Northern Plains suffer cancer mortality rates approximately 40% higher than the over-
all US population.6 As part of the Trans-Health and Human Services Committee goal to eliminate cancer health disparities by 2010, the National Cancer Institute (NCI) developed the Cancer Disparities Research Partnership. This program pairs a community cancer treatment center, located in an area with an underserved population, with an NCI-designated Comprehensive Cancer Center. The Cancer Care Institute in Rapid City, South Dakota, has partnered with the University of Wisconsin-Madison Comprehensive Cancer Center to begin addressing disparities in this population. The details of this disparity program have been previously published.6,8

Patient navigation (PN) in cancer care is an emerging strategy that has been successful in assisting health care consumers (patients, survivors, families, and caregivers) in overcoming barriers to quality care. Navigators in the PN program help their patients move through the complexities of the health care system.

The first successful PN program was conceived and implemented in 1990 by Freeman et al in Harlem, New York. Through an extensive PN program, the 5-year survival rate for patients with breast cancer increased from 39% to 70%. This decrease in cancer mortality was achieved through free and low-cost screening mammography and improved outreach and public education that led to patients presenting with earlier stages of breast cancer.2,3 Steinberg et al10 recently described the lay PN program implemented at Centinela/Freeman Regional Medical Center to address disparities in the urban Latino-African American population of South Central and South-west Los Angeles County.

Similar to the African American population in Harlem, the Lakota, or Western Sioux-population of western South Dakota, suffer significant cancer-related health disparities. The age-adjusted cancer mortality for Northern Plains AIs is 232 per 100,000 compared with 166 for the general population.11

Barriers to timely and effective cancer diagnosis and treatment for AIs include the following: lack of knowledge about cancer screening and treatment; logistical problems in accessing cancer-related health care (ie, transportation, finances, family care, communications); lack of trust, hope, and/or emotional support concerning cancer treatment and recovery; difficulty understanding options; referral and payment issues among multiple health care entities; and fragmentation of cancer-related health care services and payment. Taken together, these data and barriers indicate serious problems and significant disparities in cancer outcomes among AIs.

To underserved cancer patients, navigators can make the difference between suffering a cancer death or becoming a cancer survivor. If navigators are involved soon after a cancer diagnosis, they can direct patients and their families to appropriate care and treatment in a timely fashion that may ultimately lead to higher cure rates.

Historical Background of Relevance
In the Plains of South Dakota there are the Seven Council Fires (Oceti Sakowin) of the Teton Lakota Nation, which include three subdivisions and three distinct language groups: Lakota, Dakota, and Nakota, residing on three reservations of western South Dakota: Pine Ridge, Rosebud, and Cheyenne River tribes, in addition to the urban population of Rapid City. The Rapid City cancer center serves an AI population of between 60,000 and 100,000.

Researchers must be aware of the significant historical trauma that AIs have endured in order to develop interventions that are culturally sensitive. The 1890 Wounded Knee Massacre occurred on the Pine Ridge reservation. In 1973, the Wounded Knee Occupation took place a short distance from the original battlefield. Between 1973 and 1976 there were 3,400 sterilizations performed at Indian Health Service (IHS) facilities with marginally understood consents.12 These historic events are still part of the community conversations today. Understanding the history and incorporating that information in interactions with the patients are important parts of gaining trust and sharing a common view of life on the Plains. An example of local humor common in the communities is that many patients joke that they want assurance that the assistance we provide will not be deducted from their Black Hills claim.13

This paper describes the PN program, which led to the successful implementation of the disparity grant. This NCI initiative attempts to lower cancer mortality rates for AIs through access to innovative clinical trials, behavioral research, and a genetic study (ataxia telangiectasia mutated gene). An accompanying article in this issue provides further details (Peteireit and Burhansstipanov).

Methods
The PN program is a research protocol requiring informed consent that allows data collection to begin investigating cancer barriers. Two PN programs are discussed: one at the community level and one embedded within the cancer center. Only AIs are eligible for the PN protocols. All AIs with cancer who are seen at the cancer center in Rapid City are eligible for PN services.

Just as the PN program serves as the foundation for the entire disparity project, cultural competency is the foundation for a potentially successful patient navigation intervention. The above historical background provides key insights into establishing trust and cultural competence.

Cultural Competence
Cultural competence is a concept that has been developing over the last several years. Medical care that is both culturally and linguistically appropriate correlates with the concept of PN and with the development of more patient-friendly care provided by specialists and
primary care providers. Several steps need to be taken in order to deliver higher quality care and a more satisfying and less threatening health care experience. These include developing an understanding of the cultural and linguistic environment of the populations being served and offering culturally sensitive care and education with either interpreters or staff who speak the languages of the differing populations. These strategies may foster trust and increase adherence to proposed cancer care regimens by patients and their families.

Early in the process of developing this program, it was necessary to establish informative, factual, and culturally responsive communication. To better address this need, the grant staff, with community input, changed the name of the program from the NCI grant titled “Enhancing Native American Participation on RT Trials” to “Walking Forward.” In Lakota, the translation is To’katakiya zaníčtan ománi pi ye/yo — walking forward in good health.

In the Walking Forward program, the concept of cultural competence has evolved into active program components. For example, some staff members are fluent Lakota speakers, while others have a rudimentary ability to speak some conversational Lakota. Much of the educational material has been translated into Lakota in order to increase the patient comfort level and trust. The ability to discuss cancer treatment options and concerns with patients and families, with an accurate perspective of the Lakota way of life, has been an important component of developing trust in the PN program.

Cultural Competency Strategies
Creating a Friendly Environment Within the Cancer Center

Developing a framework that incorporates the social/cultural views of the clients involved in the PN program is an important part in helping AIs believe they have an ally and an advocate in what they might otherwise view as a hostile health care environment. The issue of trust cannot be overestimated. The Walking Forward program offers a warm handshake and welcome to patients and families as they arrive to ensure a friendly environment. The staff collaborate with physicians and nurses to assist with educating patients about treatment options and management of side effects. This strategy also builds trust that increases the probability that patients will successfully complete their cancer treatment regimen.

Assisting With Insurance Issues

Each reservation has an IHS service unit and its own local set of interpretations of policies. This can lead to misunderstandings and confusion on the part of patients/families and cancer care staff. IHS direct services and contract health services (CHS, which are delivered by a non-IHS provider through contracts with the IHS) are different components of health care for AIs that are often poorly understood by the cancer care staff and by patients and families. It has been helpful to develop a liaison component to our program in order to negotiate these potential pitfalls. Working directly with IHS CHS personnel has been both challenging and rewarding. Patients have been refused CHS funds because of the funding priority policy. Delays in cancer treatment and the metastatic potential of cancer have taxed the IHS CHS policy of determining “life or limb” eligibility for scarce funds. However, we have successfully appealed on the behalf of patients to secure treatment funding. The PNs also review patient accounts in the cancer care center to identify potential recipients of Medicaid and Medicare benefits. The program staff also follows up with potential beneficiaries with referrals to social services and determines eligibility in a timely fashion.

Obtaining Medications

Pharmacy services have also been an intermittent source of frustration for the AI population. Initially, a policy at one reservation stated that narcotics prescriptions were limited to a 3-day supply. Some AI patients could not fill their prescriptions in Rapid City even though they were receiving 6 weeks of daily radiation therapy and lived an average of 140 miles from the cancer center. Driving 280 miles every 3 days to receive adequate pain control while also receiving daily radiation for 6 weeks proved to be too great a burden for some patients and their families and made it difficult for patients to adhere to their cancer treatment regimen. Consequently, successful negotiations took place with IHS providers to permit a 30-day supply of pain medications. Oncology physicians are obtaining hospital privileges at the IHS units to further alleviate this bottleneck. As a result of these actions, patients can now receive a monthly supply of pain medications in a timely fashion. This process of active advocating, negotiating, and “the give and take” between IHS and our oncology physicians has also raised the trust level and confidence among reservation community members. This has led to patients successfully completing cancer treatments with adequate pain control.

Navigating Patients Through Cancer Therapy

The PN routinely visits patients and families at their hotel rooms when they are experiencing treatment side effects. For example, a recent AI with throat cancer refused several times to undergo his treatments due to adverse treatment effects. It is well documented that patients who undergo potentially curative concurrent chemoradiotherapy for head and neck cancers experience significant short-term side effects. These effects can lead to treatment interruptions that might compromise ultimate cure rates. The PN went to his hotel room on each occasion, assessed his toxicities, and
drove him to the treatment center. As a result, the patient completed his treatment in a timely fashion with adequate pain control. In the “prenavigation” era, this patient might have experienced treatment delays or might not have completed his treatment.

The PN can identify options to reduce logistical barriers to obtaining and completing treatment. As mentioned above, the average distance from a patient’s residence to the cancer center is 140 miles. For patients requiring daily treatments, travel time and expenses are daunting prospects. Some patients do not own a car and must pool resources with others who have access to a vehicle in order to arrange transportation to their medical appointments. Even though a van travels from some reservations to the cancer center, this service is available only on selected days of the week, and some transport vans are not handicapped accessible.

The PN program provides a cash stipend for transportation expenses. This stipend is not equivalent to the standard mileage rate but does reduce the travel costs of treatment. For patients requiring treatment on sequential days, the program also provides accommodations and money for meals during the cancer treatment.

PNs interact with patients during cancer treatment and in subsequent follow-up. During cancer therapy, PNs assist in scheduling medical and radiation appointments. Once treatments are complete, they assist in scheduling diagnostic tests and follow-up appointments with several physicians on the same day, saving time and trips for the patient. The PNs also assist with medication consolidation so prescriptions can be filled to ensure effective pain control and management of treatment-related side effects.

Navigation Programs

Hospital-Based PNs

The embedded nurse PN provides patient support and management services to AI patients receiving treatment at the cancer center as discussed above.

Community Navigation by Community Research Representatives

Lay health care providers on the reservation are known as community health representatives (CHRs). A similar model was adapted on each reservation where the community navigators are known as community research representatives (CRRs). CRRs are trained by staff from the Native American Cancer Research and Education Program and have been described elsewhere.7 The responsibilities of the CRRs who live and work on the reservation and in urban AI communities include providing cancer education, networking with local health resources, collecting community survey data, and developing liaisons between the Walking Forward program and the IHS, the tribal government, and health and wellness groups active in the communities. The CRRs also provide a resource for the cancer patients who return to their reservation communities following cancer treatment. The CRRs are community members who live on the reservation they serve.

CRRs provide education at community events and meetings. These education sessions are based on the PowerPoint series “Cancer 101,” which was developed by the Spirit of Eagles Program for the Northwest Area IHS and was revised by the Northern Plains staff to be culturally appropriate for Northern Plains AIs. This education tool provides basic information about the disease of cancer, cancer screening, treatment options, and participation in clinical trials. In addition, the CRRs also provide information about our PN program and distribute other educational materials on cancer in their communities. Like the CHRs, the Walking Forward CRRs are considered community authorities on cancer prevention and screening.

CRRs fill the “distance gap” between the cancer center, the hospital navigator, and other staff of the Walking Forward program. They are crucial in the communication process with the tribes and community organizations. They convey information and assist managers in the Walking Forward program in accomplishing administrative tasks between the tribal leaders, IHS, and the research staff based in Rapid City. CRRs routinely attend Tribal Council and Tribal Health Board meetings, participate in educational events with CHRs, and provide an exchange of information about the activities of other research groups and organizations on the reservations.

The community navigation program in Rapid City differs from the navigation program on each reservation in a number of ways. Unlike the reservation, the urban community in Rapid City has no form of representative government. This urban-based AI population has presented unique challenges in forming trusting relationships. The AI population of Rapid City is widely distributed and resides in all areas of the city. Networking throughout the community by our CRR has led to the successful collection of survey data in Rapid City.

Research Surveys

Three surveys are currently being administered: the community survey, the cancer survey, and the PN survey.

The community survey was developed to identify and document the barriers to timely and effective cancer screening, diagnosis, and treatment. The goal is to identify barriers that could lead to a successful intervention. Focus groups were held on each reservation and in Rapid City to formulate and test these questions. It was requested to delete questions related to socioeconomic status. The anticipated number of survey participants is 1,000.

The cancer survey is being administered to 200 cancer patients: half AI and half non-AI. This survey
investigates whether there is a correlation between attitudes and beliefs and cancer stage at presentation. It is hypothesized that patients presenting with earlier-stage cancer have a positive perception toward cancer screening and treatments, whereas patients with advanced or metastatic disease may have a pessimistic perception.

The PN survey is given to navigated patients once their cancer treatment is complete. This survey assesses several variables and the potential impact of navigation.

**Obtaining Tribal Health Approvals and Institutional Review Board Approvals**

In order to receive resolutions and letters of support from tribal councils and tribal health boards, presentations were required, in person, for all survey tools, protocols, and any modifications. The IHS Institutional Review Boards (IRBs) would not review any Walking Forward protocols until these letters of support were obtained. This process involved the Aberdeen Area IHS IRB, the National IHS IRB, the Rapid City Regional Hospital IRB, and the IRBs of our partner institutions: the University of Wisconsin-Madison and Mayo Clinic. The CRRs were critical in obtaining these letters of support. They often waited at the tribal health building for hours before they were allowed to present. This persistence, diligence, and continued presence over the years further fostered a trusting relationship between the hospital and tribal board on each reservation. To date, these councils have collectively written nearly 100 resolutions and letters of support for our various research protocols. As requested by the tribal health boards, the CRRs have provided quarterly progress reports on each of the three reservations.

**Results**

Since the PN protocol opened, 213 patients have been navigated. For patients undergoing cancer treatment, the median number of PN interactions is 15 (range 1 to 95) whereas for patients seen in follow-up after cancer treatment, the median number of contacts is 4 (range 1 to 26). A PN contact/interaction is defined as a person-to-person contact (majority of contacts) and a telephone call. Patients undergoing cancer treatment have received nearly $218,000 in assistance for food, transportation, and lodging, translating into about $1,000 per patient.

A retrospective analysis was performed to determine if navigated patients (n = 42) undergoing potentially curative radiotherapy had better completion rates compared with non-navigated patients (n = 74). AIs who did not undergo navigation missed an average of 3 days of treatment compared with navigated patients (P = .002). A match-paired analysis is also underway to determine if navigated patients experienced improved quality of life.

A total of 900 of 1,000 community surveys have been completed. Preliminary results based on 289 participants demonstrated that half of adult AIs who were eligible for screening reported having received cancer screening at least once. Factors associated with screening were greater knowledge of cancer and female sex. The results also suggested that an educational program on cancer and the importance of early detection and treatment, aimed at both men and women, could be effective in reducing cancer disparities in this population. A more detailed analysis is underway based on 600 participants.

The cancer survey has been completed by 27 AIs, and the post-PN survey has recently opened for accrual.

**Discussion**

PN programs have been successfully implemented at the cancer center in Rapid City and at each of the three reservations in western South Dakota. The ultimate goal of our PN program is to reduce cancer disparities through education, screening, and access to clinical trials. It is anticipated that stage migration (presentation of cancer at earlier stages) will occur over time as demonstrated in the breast cancer population of Harlem, New York. While AIs have access to some of the best radiation delivery systems, ie, brachytherapy and tomotherapy, the PN program “paves the pathway” for patients to access the cancer treatment center in Rapid City.

Establishment of trust with both the patients and the reservation communities has been critical to the implementation of the Walking Forward program. Individual patients have reported a more positive experience while undergoing cancer treatments in Rapid City compared with those who were treated in the prenavigated era (a formal analysis is underway). The positive effect of such word-of-mouth communication as patients return to their communities reinforces the trust relationship.

Navigated patients undergoing radiotherapy had fewer treatment breaks compared with nonnavigated patients. The latter patients required 3 additional days to complete potentially curative radiation (P = .002). The importance of minimizing treatment interruptions has been documented for both cervical and head and neck cancers. Therefore, actively navigated patients may experience higher cure rates for some tumor types as a result of this intervention.

Constant communication with various tribal entities on each reservation has also garnered increasing support from year to year during this grant. The nurse PN in Rapid City has participated in the Lakota culture for over 30 years (K.M.), and this has been instrumental in building relationships with the tribal government and administrative bodies. Our CRRs have a constant presence on each reservation, which negates an
impression that the AI communities have had toward previous research groups (ie, “helicopter research”), referring to groups that come to the reservation, abstract the data, leave, and publish the results without feedback or continuity. Tribal government and groups now initiate interaction with Walking Forward CRRs and the Principal Investigator (D.G.P.) to discuss future opportunities for collaboration and expansion of the Walking Forward program.

IHS ranks medical priorities to allocate the limited funds available for health care. Compared to the general US population, where Medicare expenditures per enrollee averaged $6,784 for 2005, IHS appropriations and collections per user averaged $2,130 for the same period.19 A former chief executive officer at the Cheyenne River IHS facility commented that the Walking Forward staff were instrumental in his desire to move cancer treatment on the priority referral list from No. 7 to No. 3. This significantly increased health care dollars available for cancer treatment.

Although 80 clinical trials are available to AI cancer patients, the majority are ineligible due to advanced stage of disease and/or significant medical comorbidities that preclude potentially curative, aggressive cancer interventions. To address this issue, efforts are underway to further promote screening and education. The next proposed grant will investigate the effectiveness of a cancer screening coordinator, embedded within the IHS clinic, who will work in conjunction with the PN. In addition, a men’s screening clinic for prostate and colorectal cancer was conducted in May of 2007 at the Cheyenne River reservation. A total of 27 AI men were screened and no cancers were detected.

The education provided by our CRR navigators and the advocacy provided by our embedded cancer nurse navigator are critical to the future outcome and quality of life of cancer patients from the western South Dakota Sioux tribes.

During the past 4 years, we have succeeded in establishing trust and accountability with the tribes and communities in which we work. The Principal Investigator and the Walking Forward program staff, working with tribal representatives, have developed an important model of community-based participatory research and accountability of researchers who seek to conduct research programs with the Sioux tribes of western South Dakota. This model has evolved cautiously over a period of 5 years and requires constant attention on the part of the research team and the Principal Investigator.

Significant reductions in cancer mortality rates for this population are expected, primarily through education and increased opportunities for screening. We believe the successful implementation of a PN program will facilitate this ultimate goal.

Disclosures

No significant relationship exists between the authors and the companies/organizations whose products or services may be referenced in this article.

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Disclaimer

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References