

Patient Navigation & Cultural Competency in Cancer Care



IN BRIEF

Culturally and linguistically appropriate cancer care paired with patient navigation improves access and participation of patients, and promotes the provision of more patient-friendly care by specialists and primary care providers. Between June of 2003 and 2007, 213 American Indian patients have been recruited to the *Walking Forward* Native American Patient Navigator Program in Rapid City, S.D. Developing a framework incorporating the social and cultural views of American Indian participants has been critical to the program's recruitment success, as well as helping these individuals feel they have healthcare allies and advocates in what they may otherwise believe is a hostile healthcare environment. Specific program strategies have fostered trust and increased the ability of patients and families to actively participate in cancer treatment.

The goal of the *Walking Forward* program is to increase cancer survival rates among American Indians in western South Dakota and the Northern Plains. The multi-part, five-year cancer disparities grant project aims both to identify barriers to care and to develop scientifically sound methods to overcome these barriers. *Walking Forward* is funded by a grant to Rapid City Regional Hospital by the National Cancer Institute (NCI) and is part of NCI's

Patient Navigator Kevin Molloy, RN, (left) meets with a patient.

Cancer Disparities Research Partnership, a federal program to reduce cancer mortality among minorities. Grant components include clinical trials, patient navigation, a genetic study, community outreach and education, and administration of a 1,000-participant community survey. (For more information, visit the CDRP website at: www3.cancer.gov/rrp/CDRP/index.html.) The Principal Investigator is Daniel Peterreit, MD, a radiation oncologist.

The patient navigator program promotes understanding and effective use of the healthcare system through community outreach and patient/family education. The patient navigator's primary function is guiding Native American cancer patients through the healthcare system. Assistance includes—but is not limited to: 1) addressing access to care issues; 2) developing relationships and collaborating with providers; 3) tracking interventions and outcomes; 4) advocating for pain control, treatment needs, side-effect management; 5) end-of-life issues; and 6) durable medical equipment.

The navigators also provide crisis management throughout the continuum of care. The *Walking Forward* Patient Navigator Program employs 1.5 FTE registered nurses. Day-to-day activities combine clinical nursing services; case management services; location of resources; and communication with patients and families, providers, and other service agencies. Patients are recruited into

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the navigator program through self or provider referral. Any patients that identify themselves as Native American and have received a diagnosis of cancer or need follow-up and further testing for a suspicious screening test are eligible for the navigator program. Participants do sign an informed consent to allow the program to collect data on barriers to care.

Currently, *Walking Forward* serves the American Indian communities on three reservations in western South Dakota (Pine Ridge, Rosebud, and Cheyenne River) in addition to the urban population of Rapid City. The John T. Vucurevich Cancer Care Institute at the Rapid City Regional Hospital has a service population of between 60,000 and 100,000 patients from the American Indian community.¹

Historical Background and Social Environment

Culturally meaningful interventions require awareness and validation of the significant historical trauma that American Indians have endured. Recognizing the history and incorporating the implications of that history into interactions with patients and families is critical to gaining trust and establishing a shared view of life on the Plains. The 1890 Wounded Knee Massacre took place 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 on Native American women at IHS facilities nationwide with marginally understood consents.² These examples and other historical occurrences are still a part of the American Indian community's conversations and underlie many trust issues between patients, families, and healthcare and other professional providers. Today, American Indian patients jokingly ask for assurance that the assistance provided by the *Walking Forward* program will not be deducted from their Black Hills claim.³ (The Black Hills were never ceded by the Sioux Nation in the Fort Laramie Treaty of 1876. The Sioux Nation won a lawsuit in 1980 for payment of the purchase of the Black Hills; however, payment was refused by the Sioux Nation because "the Black Hills have never been for sale.")

Cultural Competency Strategies

Early in the development of the *Walking Forward* program, staff recognized the importance of developing informative, factual, and culturally appropriate communications with American Indian patients. In collaboration with community partners, the program's name was altered from "Enhancing Native American Participation in Radiation Therapy Trials" to "*Walking Forward*." The Lakota translation, "*To'katakia zanniyan omani pi ye or yo*," means "walking forward in good health."

Some Lakota language and cultural norms have been incorporated into the patient navigation program as well.

Patient navigation incorporates traditional Lakota/Dakota/Nakota values through advocacy on behalf of providers and patients alike. Strategies to ensure patient readiness and understanding of the cancer care continuum require collaboration with physicians, patients, and families.⁴ Prior to patient consults, navigators often collaborate with physicians to determine which treatment options may be available. They meet with patients and families to begin a dialogue regarding treatment options. A meeting may then be held between physicians, navigators, and patients to discuss these options. Finally, navigators will meet with patients and families to discuss options and assist with decision making by educating patients and families about the implications of different treatment options.

Community members serving as *Iyeska* (translators) and *Eyapaha* (advocates) historically are respected and recognized as having a valued role in Lakota/Dakota/Nakota culture. The Lakota terminologies (see Table 1 on page 40) are recognized observable behaviors exhibited in communities by individuals fulfilling valued cultural roles. These roles have been respected historically and are still used today. Incorporation of these important cultural characteristics into the navigation program has been an integral aspect in developing trust and continuity with patients and families.

Components of Cultural Competency

Jirwe and colleagues describe a theoretical framework for culturally competent programs that includes:

- An awareness of diversity among human beings
- An ability to care for individuals
- A non-judgmental openness for all individuals
- The enhancing of cultural competence as a long-term continuous process.⁵

Each of these is discussed in more detail below. However, the *Walking Forward* program experience recognizes linguistic competence as another building block to establishing successful and culturally competent programming. Additionally, understanding the local community history and social environment are important factors in a patient navigation program. Adapting the provision of care and patient/family healthcare education with either interpreters or staff who speak the languages of the differing populations are important steps to delivering higher quality care and a more satisfying, less threatening healthcare experience.⁶

Awareness of diversity. Personal autonomy is one of the more important components of Lakota culture. *Walking Forward* staff have learned that not every American Indian patient wishes to be treated with the most aggressive regimen available. The medical and/or radiation oncologist(s) discuss all treatment options. The navigators and physicians work closely together. Each patient's situation and

Table 1. Translation of Lakota Words

Lakota Word	Contemporary Translation	Traditional Translation
Lakota	Friend; ally	Ally
Wo'lakota	Lakota way of life	To be surrounded by friends as well as representing the Lakota way of life
Iyeska'	Bringing two voices into one voice	Translator
Eyapaha'	Voice that speaks for others	Voice/announcer
Wo'añhuala	The quality of behaving in a gentle, non-confrontational manner	Humility
Wo'uñšila	The quality of behaving in a compassionate manner	Compassionate
Wo'wicáke'	The quality of simple, sincere, honesty	Truth teller
Wo'okiye'	The quality of kind generosity; meaning generous with time and encouragement, as well as resources like money, housing, etc.	Generous
Wo'ableza	Developing understanding	Enlightened understanding
Wo'ohitika	The quality of dignity and courage in public without bravado	Bravery

understanding of the treatment process options is assessed and reinforced in culturally appropriate and respectful terms. This strategy of using culturally appropriate terminology and conversational etiquette is also used in discussions regarding participation in clinical treatment trials to ensure that there is no coercion of patients. The choices of the patient are respected and followed. The consent process for undergoing cancer treatment was recently detailed by Peterreit and Burhansstipanov.⁷

Allowing quiet pauses in conversation for deliberation is another very important cultural component of the patient navigator program. Individuals unfamiliar with this trait might interpret breaks in conversation as signaling inattentiveness, misunderstanding, and/or mistrust. On the contrary, such pauses very often indicate careful consideration of the issues being discussed.

Importantly, Lakota community members do not necessarily recognize authority in and of itself to be a reason to follow the recommendations of a medical professional. Many American Indian patients prefer to visit with a native healer and participate in a traditional ceremony as part of assessing the potential efficacy of a proposed treatment regimen before agreeing to participate in it. This means that recruitment for clinical trials can require a longer timeline. Also, the concept of leadership in Lakota culture is based on the consensus of the community. Leadership is usually temporary and situational, defined by ability and competence. In comparison, the U.S. healthcare system authority is traditionally based on legal and institutional mandates.

Caring for individuals and families. The importance of establishing authenticity and trust with American Indian patients and their families cannot be underestimated. The *Walking Forward* program offers a warm handshake and welcome to patients and family members as they arrive at Rapid City Regional Hospital to ensure a friendly environment. Pairing patient navigation services with healthcare providers builds trust across the healthcare team, increasing the probability that patients will successfully participate in and complete their cancer treatment regimen.

Non-judgmental openness for all individuals. The patient navigator role incorporates individual and family

belief systems into discussions about treatment options. Specifically, discussions include the diversity of beliefs in traditional medicine as well as other religious practices.⁸ Many American Indian patients and families combine traditional American Indian medicinal practices and ceremonial activities along with their chemotherapy and radiation therapy. Some patients and families incorporate complementary medicine as well. The patient navigator includes such topics in discussion with patients, families, and with treating physicians in order to minimize misunderstandings and avoid interruptions in the treatment schedule.

Continuity in cultural competence. Lay healthcare providers in the *Walking Forward* program provide the necessary bridge for patients between the cancer treatment center and community. Similar to the Indian Health Service's Community Health Representatives, *Walking Forward* community navigators are known as Community Research Representatives. Living on the reservation they serve, Community Research Representatives provide cancer education, network with local health resources, administer community surveys, and serve as links between the *Walking Forward* program and the Indian Health Service, tribal government, and health and wellness groups active in the communities. The Community Research Representatives serve as important educational resources for the cancer patients and families who return to their reservation communities following cancer treatment.

Culturally appropriate cancer education modules provide basic information about the disease, the cancer screening process, treatment options, and the option to participate in clinical trials. In addition, the Community Research Representatives provide information about the patient navigator program at Rapid City Regional Hospital. *Walking Forward* Community Research Representatives are recognized and respected as community authorities on cancer prevention, screening, and treatment resources.

Making a Difference

A well-described phenomenon for patients undergoing potentially curative radiotherapy is the adverse impact of treatment prolongation.⁹ For some tumor types, such as

Table 2. Impact of Patient Navigation on Treatment Interruptions

Treatment Delays in Days	N	Mean	95% Confidence Interval		Significance
			Lower	Upper	
Control Group (curative radiation/ not navigated during treatment)	74	4.45	1.132	4.855	0.002
Experimental Group (curative radiation/ navigated during treatment)	42	1.45			

cervical or head and neck cancer, treatment interruptions of 7 to 10 days can reduce cure rates by as much as 10 percent.⁹ Therefore, it is critical that patients complete their course of radiotherapy in a timely fashion. Initial statistical analysis of data from a group of patients that received radiation treatment with curative intent indicates that navigated American Indians have significantly fewer treatment delays than non-navigated patients. Navigated American Indians have on average 1.5 days delay versus 4.5 days (the equivalent of one treatment week) for non-navigated patients (see Table 2). This improvement translates into a potentially higher curative intervention rate for American Indian cancer patients who have been navigated since there are fewer treatment interruptions.

Patient navigation intensifies during cancer treatment. The median number of patient navigator contacts is 15 (range 1-95) during treatment; whereas, for those seen in follow-up, the median number is 4 (range 1-26). Although the Indian Health Service covers most of the costs associated with cancer treatment, a shortfall exists in providing basic support critical to the success of treatment completion. The *Walking Forward* program helps bridge this financial gap. The average distance traveled by patients in the *Walking Forward* program is 140 miles one way. One of the hypotheses of the *Walking Forward* program is that distance and lack of personal resources have been barriers to early and successful access to cancer treatment. Patient assistance is designed to address those issues. Patients undergoing treatment and follow-up have received nearly \$210,000 in assistance for food, transportation, and lodging. This translates into approximately \$1,000 per patient. This has also generated good will and is seen as very helpful among the reservation communities. It is not uncommon for our staff to hear: “*Walking Forward* is the first program that actually does something about cancer.”

Cultural competence in patient navigation enhances patient care and plays an integral role in adherence to cancer treatment regimens. Patient navigation improves the delivery of cancer care; from screening to diagnosis as well as through treatment and follow-up. Navigation has also been helpful with palliative care and end-of-life issues. The *Walking Forward* Native American Patient Navigator Program's success lies in its ability to interweave cultural competence with patient navigation. ■

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