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Rationale for “Cultural” Native Patient Navigators in Indian Country

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Introduction/Background of NNACC

“Native Navigators and the Cancer Continuum” (NNACC) was a community-based participatory research study awarded by the National Institute of Minority Health and Health Disparities (2008–2014). The partners for the research project were five organizations that have a long history of successful engagement in the American Indian community or are federally recognized tribes. They are Native American Cancer Research Corporation, CO (NACR), Intertribal Council of Michigan, Incorporated, MI (ITCMI), Rapid City Regional Hospital, SD (RCRH), Great Plains Tribal Chairmen's Health Board, SD (GPTCHB), and Muscogee (Creek) Nation, OK (MCN) (referred to as the “Partners” in this CPBR study). The NNACC study utilized native patient navigators (NPNs) who are lay patient navigators (i.e., none work directly for a clinical setting) from each community setting. The lay NPNs were very successful in implementing education sessions, referring participants to screening and navigating the process when necessary through diagnosis and treatment.

Many people question why there is a need for a navigator from the local community who is familiar with local culture and customs and health care systems accessed by American Indians (AIs) in their respective communities. Although there are many reasons, the five most common are [1] as follows:

Issues of Trust due to Prior History of Mistreatment and Its Impact on Health Care Access

AI populations have valid reasons for distrust of researchers and health care systems. [2] Historical trauma is cumulative and collective. The impact of this type of trauma manifests

itself, emotionally and psychologically, in members of different cultural groups [3]. As a collective phenomenon, those who never even experienced the traumatic stressor, such as children and descendants, can still exhibit signs and symptoms of trauma. Historical trauma is described as a multigenerational trauma experienced by a specific cultural group [4]. A conceptual model of historical trauma offers an explanation of the relationship between historical trauma and how American Indians access health care and public health [5]. This relationship has resulted in a barrier to care that NPNs in each community can address due to a personal knowledge of the history and the resulting trauma in the local area. Historical trauma has resulted in a fear of the health care system and a feeling of futility on the part of the native patient. As a result, many American Indians do not access health care until there is an emergency. The NPNs reduce the feelings of fear through education and navigation. In addition, Christopher et al. documented multiple examples of natives' distrust of researchers based on numerous historical events [6]. Unethical research or care protocols have historical relevance to government policies designed to annihilate AIs in the nineteenth and the first half of the twentieth centuries; others are more recent and include sterilization of AI women without informed consents in the 1970s [2]. In 2010, the Havasupai won their lawsuit against Arizona State University (ASU) researchers for misusing blood samples taken from nearly every tribal member. Such behavior creates mistrust throughout "Indian Country" and makes the ability to develop successful community-academic partnerships for the purpose of research even more difficult to establish. Appreciating and understanding the multiple reasons for this lack of trust is critical in order for PNs to be successful and for researchers to pursue areas of investigation in this population [7].

Communication Unique to Culturally Specific Tribal Populations (e.g., Muscogee (Creek) Nation Versus Dakota Nation)

Communication includes verbal (words), vocal (tone, volume), and non-verbal (body language) ways of interacting. NNACC participants from Muscogee Creek Nation (MCN) and the Dakota Nation most often speak English; however, their English is limited English speaking as they also use native words and phrases they know as well as hand and body gestures. Non-natives sometimes stereotype AIs as being stoic and lacking expressions, but such non-verbal patterns are unique to each tribal culture. Local subtleties may include avoiding direct eye contact and sentences with word order and/or patterns that are different than English. In addition, the translation of many native words can instill fear and mistrust. An example of this is the Navajo word for "cancer" which is translated as "the sore that never heals." This translation informs the patient that they will never be cured and the cancer cells will never heal. NPNs bridge the gap between the translation, the fear and mistrust, and the patient in order to support treatment completion. Several tribal nations refrain from pointing with one's fingers, but rather will use lips or head tilt. Others have cultural issues with touch. For example, in some tribal cultures, it is disrespectful to touch the hair of native men; in others, one would avoid touching a person (such as a comforting touch to the native's forearm) unless the patient initiates such touch, and in many, the non-Native may receive a very timid or limp handshake because this type of touch is not intrinsic within the local Indigenous culture. Such subtleties are subconscious and natural to NPNs who work in their local communities.

Cultural Perceptions Common to a Specific Tribal Nation, Band, or Clan

The most common example, and certainly not unique to American Indian and Alaska Native (AIAN) cultures, is avoidance of the word ‘cancer’. Each NPN encountered participants who were uncomfortable using and hearing words such as cancer. Many tribal nations feel that using such words invites the disease to the one speaking or to the speaker's family or neighbors. During one of the first workshop series (2009), a participant asked the presenter about using cancer and alternative words. After a brief discussion, the participant said “but don't you know that you are inviting cancer to affect you or someone else from NACR.” The presenter said, “well, we have 8 staff and cancers like breast occur in about 1 out of every 8 women. We are all women. Yes, it is likely that one of us will be diagnosed with breast cancer whether or not we use the word ‘cancer’. We are aware of the concern. How would you suggest we handle it? We do want people to know there are AIs diagnosed with cancer who do survive, so we use the word.” The participant thought a few minutes and then said okay. She talked with her traditional AI healer and came back to the next workshop. She said the healer said it was okay to use the word ‘cancer’.

Several beliefs surround “disease words” and differ greatly among tribal nations. Although Navajo is not a tribal nation that took part in NNACC, the Navajo Cancer Glossary is an important example of a native tribe's efforts to provide translation that Navajo people can use to help them understand the disease that they have and how it can be treated. It explains how important words are, both in how they are used and the intent behind the use of potentially powerful words and concepts (see Fig. 1) [8].

Another example of the need for NPNs and their cultural knowledge is tobacco. Tobacco is used as a sacrament for ceremonial purposes by many tribal nations in the 48 contiguous states (i.e., this is not a common practice among Alaska Natives). When NPNs are working with community members who smoke, they make effort to distinguish between use of commercial/manufactured tobacco and use of tobacco for ceremonial or traditional practices. The actual sacred practices that use tobacco can be unique between two tribal nations living adjacent to one another. Thus, the local, culturally astute NPN understands the unique practices and ways to ask or not ask questions about tobacco in their local settings.

Spirituality (Traditional Indian Medicine Versus Modern Western Medicine and/or Complementary Medicines Unique to Specific Tribal Nations or Geographic Regions)

Details are not shared about actual religious or spiritual ceremonies because this would be disrespectful. Many non-natives have heard about ceremonies or spiritual practices such as sweat lodges, vision quests, Sun Dance, or Green Corn ceremonies, primarily because they are referred to in movies and books. As such, there are many misinterpretations of how ceremonies renew one's spirits and bring balance within body, mind, emotions, and spirits. NPNs are aware of the intricacies and protocols for how traditional Indian medicines are used in their respective areas or who to go to for traditional guidance. Descriptions are published elsewhere [9] and are available on <http://www.natamcancer.org/page87.html>.

Most cancer patients, regardless of culture or ethnicity, are very spiritual during and following the cancer experience [10]. Traditional Indian Medicine and spirituality may be

practiced in conjunction with organized religions or it may be totally independent. NPNs have helped Western health care providers communicate with the traditional Indian healer. Some of the preparations by the traditional Indian healer may interfere with the absorption or metabolism of chemotherapy or other medications. The Western health care provider needs to know what types of products the traditional Indian healer is using.

Traditional Indian Medicine and spiritual practices differ greatly across tribes. NPNs active in their communities know who and where to find the respected local traditional Indian healers. NPNs establish a relationship with the patient and are aware of their needs, particularly when they are far from home and their usual traditional healer is not accessible. The NPNs provide a bridge between these patients and the local traditional Indian healers. They work with the cancer patient and the traditional Indian healer so that the patient receives the healing products/ceremonies needed/desired, while not receiving anything that could negatively interact with the Western cancer treatments the AI patient is receiving. Additionally, the NPN can help the patient with certain beliefs they have such as bringing a medicine bag into surgery by hanging it on the fluids pole, talking to the doctor about the beliefs of the patient so that the doctor understands their importance, or asking the nurses to remove the empty chairs from a patient's room so that spirits would not be there when they returned from surgery.

Logistical Issues Unique to Indian Health Service Contract Health Services

American Indians share issues that differ from other culturally specific populations in the USA. This is due to their unique legal status as members/citizens of their tribal nations as well as US citizens. Resulting from the treaties signed with the US government, the US established the Indian Health Service (IHS) to provide health care to the AIs on reservations. The IHS is a very complex system and is sorely under-funded. It provides very limited services to those AIs living on the reservation and even more limited services in urban areas. Individual AIs receiving IHS health care are funded at a rate that per individual that is less than the amount per individual allocated for prisoners. IHS clinics on reservations have limited staff, services, and equipment. Therefore, AIs are referred out of the IHS system when they are diagnosed with cancer or other serious disease and illness. This is known as "Contract Health Services" (CHS). Many isolated and rural tribal clinics only provide ambulatory care service and rely on local hospitals for routine screenings, such as mammograms, colonoscopies, and other cancer-related tests. Once diagnosed, the patient is then referred to a treatment center or facility from a few miles to hundreds of miles away through CHS. The IHS has no oncologists or similar types of cancer specialists on staff (note: Alaska Native Medical Center provides the only oncologist within the IHS system).

The U.S. Congress determines how much money is allocated to the IHS CHS budget and IHS policies are restricted by the availability of those monies. This creates an incredibly frustrating situation for both providers and patients. As monies are available, the AIAN patients are provided travel and accommodations only for themselves to the specified health care setting that has a contract with IHS to provide the recommended tests and procedures. The frustration from this system is that many American Indian cancer patients wait on "priority" lists for months at a time until their priority is raised to a level that allows them to

access appropriate follow-up cancer care. Finally, in urban areas, health care providers are misinformed and believe that their AIAN patients can get funding for their cancer care in the urban area through the IHS. NPNs must explain this over and over, and then they work to find and develop funding for their patients utilizing resources for all Americans, rather than through the IHS (Fig. 2).

The “Native American Cancer Education for Survivors” program is the largest native cancer survivorship support program in the USA. Almost 900 native patients completed surveys and only 12.5 % successfully obtained help and referral to treatment through IHS CHS. The NPN who is familiar with the challenges of accessing cancer care through IHS CHS can assist the patient to actively seek alternative resources for cancer care (Medicaid, VA, indigent care services) while the patient is on the CHS waiting list, rather than “assume” the IHS CHS will successfully provide the necessary referrals in a timely manner. Thus, NPN services are essential to help the patient access quality cancer care in a timely manner.

Figures 3 and 4 [11] provide examples that illustrate some of the nuances and complexities that NPNs need to be aware of to enable them to work proactively on behalf of AIs diagnosed with cancer. Navigators who have never personally used the IHS CHS system or worked within it lack efficiency. Working within IHS CHS is a key reason why there is the need for cultural NPNs for AI community settings.

Conclusion

American Indians and Alaska Natives experience great disparities in accessing and benefitting from health care services for cancer care as demonstrated by data from tribes throughout the nation. In the field of cancer care, there is a growing acknowledgement of the value of patient navigators in improving patient outcomes. There is also a slow but growing number of funders that are willing to support patient navigation. Yet, there still exists a tremendous gap for AIAN in accessing and receiving cancer care. NPNs can bridge the unique and complex cultural issues, practices and barriers that AIANs face when diagnosed with cancer. As discussed above, serious and identifiable barriers exist and NPNs are successful in leveling the field and improving outcomes for AIAN patients.

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Navajo Cancer Glossary

Excerpt from the Navajo Cancer Glossary

[ed. The translations of medical terminology are] to be used with understanding and respect for the Navajo language. The Navajo language, as are all languages, is powerful. In the Navajo tradition, the spoken word is powerful and becomes a reality and therefore they say be mindful and careful of what you say. It is our responsibility to use these terminologies carefully.

Our elders teach us that we should never joke or tease each other about diseases and abnormal conditions that affect the body, mind, and spirit. Disease, diagnosis, treatment and medicines are to be handled with great care. These traditions and belief are the background to translation and interpretation in all cases.

Interpretations should be in the context of positive thinking, hope and compassion. Whenever possible, include the use of kinship terms. Using the Navajo language appropriately gives a person great joy, satisfaction, and sense of pride.

Fig. 1. Excerpt from the Navajo Cancer Glossary¹

¹Austin-Garrison, Martha A and Garrison, Edward R. Glossary for Basic Cancer Terminology in the Navajo Language. Kayenta Public Health Nursing Program, Navajo Nation Division of Health, Dine College, January 2010.

Close working relationship between NPN and CHS Staff.

Loretta Denny (Muscogee (Creek) Nation Tribal member) was the NPN for MCN. She was able to walk to the CHS office and work directly with CHS staff on the priority of community members who required referral for biopsy, cancer treatment, and/or quality of life care. Loretta learned that cancer was not a high priority for CHS referral. She helped the CHS staff understand more about treatment. Enrolled MCN citizens were usually approved pending available CHS funding. Non-tribal members (i.e., enrolled in a federally recognized tribe other than MCN) were usually denied. With Loretta's assistance, those denied were then submitted to their own tribe for assistance, which is how the system is supposed to work for those living outside their own tribal boundaries. However, she also needed to refer to Medicaid, Medicare and the Veterans Administration for both MCN=eligible patients and for patients from outside tribes (e.g., insufficient CHS funds, long waiting time for referral to service. According to Loretta, COMMUNICATION was essential for all to understand and help the patient!

Fig. 2. Close working relationship between NPN and CHS staff

Local IHS cancer referral clinic.

Tinka Duran, (Rosebud Sioux) is the NPN for Great Plains Tribal Chairmen's Health Board. While working with Northern Plains AI community members, she found that not being connected to a hospital or clinic made it difficult for her to coordinate screenings and follow-up with patients. Tinka was able to provide many resources that the community was not always aware of such as wigs from ACS, hotel discounts for families, tribal travel assistance, and information about a local Native Cancer Survivor Support group. When her patients needed access to clinical settings and when feasible (e.g., patient's federal tribe allowed CHS referral to RCRH), she would refer the patients to Kim Crawford and RCRH in South Dakota.

In comparison, Kim Crawford (Oglala Lakota Sioux tribe) is the NPN for Regional Health (RCRH) in Rapid City. Regional Health is a CHS-cancer-referral clinic. When Kim encountered AI community members who had received a cancer diagnosis and choose to have treatment at RCRH, she would contact a Patient Navigator at the RCRH to coordinate care with the patient. The Patient Navigator would work with the patient throughout treatment. One aim of the program was to help eliminate some financial burden of the patient by providing meal, hotel and transportation options to assist the patient in timely completion of treatment. Additionally, when a patient completed treatment, it became a joint effort to continue to follow the patient once back in the community. Working collaboratively, these processes were seamless and highly efficient.

Fig. 3. Local IHS cancer referral clinic

No local IHS cancer-related services

In contrast to example 2, NACR has no IHS or urban Indian clinical services that provide follow-up cancer care. Denver Indian Health and Family Services (DIHFS) is partially supported by IHS. DIHFS does provide diabetes, well-baby and several other types of programs, but not cancer care. Thus, NACR's NPNs were unable to refer any local community members to DIHFS for follow-up care for positive biopsies, cancer treatments, and so on. This is not unique to DIHFS. No urban Indian program in the 48 contiguous states provides direct cancer treatment.

Als living in urban areas and without private health insurance face challenging issues. Most must return to their home reservation to re-establish tribal residency to be eligible for referral to cancer care, a process that usually takes more than 6 months. Alternatively, they can apply for care through other public programs like Medicaid or Medicare. Not all Als have a home reservation, or even if they have a reservation, there is no guarantee that the tribe will admit them as a member. According to Ralph Forquera, MPH, Urban Indian Health Institute, some urban clinics have had a fair number of clients who have been denied reinstatement for residency (just to qualify for contract care). For those trying to access Medicare or Medicaid, the NPN and patient need to "negotiate" with public program staff about which agency is the "last payer of choice" and most Als have to apply 2-3 times and explain how IHS is unable to provide cancer care for them. This process averages 3 months.

Fig. 4. No local IHS cancer-related services