Navigation as an Intervention to Eliminate Disparities in American Indian Communities

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Abstract

Objective—To identify the role of patient navigation in decreasing healthcare disparities through an exemplar of a successful patient navigation program for American Indian populations living in the Northern and Southern Plains of the US.

Data Sources—Published literature and data from the Native Navigators and the Cancer Continuum study.

Conclusion—Native Patient Navigators successfully collaborated with local American Indian organizations to provide cancer education through a series of 24-hour workshops. These workshops increased community knowledge about cancer, influenced cancer screening behaviors and increased the visibility and availability of the navigators to provide navigation services.

Implications for nursing practice—Reaching those with healthcare disparities requires multiple strategies. Collaborating with patient navigators who are embedded within and trusted by

their communities helps to bridge the gap between patients and providers, increases adherence to care recommendations and improves quality of life and survival.

Keywords

American Indians; Community-based Participatory Research; Patient Navigation; Health care Disparities/Inequities

"Health disparities are differences, or inequities, in health outcomes and their determinants within and across counties and communities, as defined by social, demographic, environmental, and geographic attributes."[1] Inequities affect various segments of our society including racial and ethnic minorities, women, the elderly, the disabled and those living in rural and frontier areas or on reservations. In addition, multiple factors influence health disparities including education level, socioeconomic status, sexual orientation, language and literacy, unemployment, environmental contaminants, behavioral choices, comorbid medical conditions and unequal access to timely, quality healthcare services. These inequities lead to increased chronic disease incidence and prevalence, more advanced disease at diagnosis, fewer treatment options, the potential for increased or poorly managed treatment side effects, and decreased quality of life and premature death, particularly in the most vulnerable populations.[2]

Health Inequities in American Indians/Alaska Natives

American Indians/Alaska Natives (AIANs) have long experienced lower health status when compared with other Americans. AIANs born in 2011 have a life expectancy of 5.2 years less than US all race populations (72.6 years to 77.8 years, respectively; 2003-2005 rates), while AIAN infants die at a rate of 8.0 per 1,000 live births, as compared to 6.8 per 1,000 for US all race populations (2004-2006 rates).[3] AIANs have a poverty level nearly twice that of the overall US population and only half as many have health insurance. AIAN adults also are more likely to be obese, have high blood pressure, and are more likely to use commercial tobacco than white adults. Additionally, AIANs are disproportionally more likely to work in unsafe and unhealthful conditions without health benefits, retirement, proper training and protections or notification of risks.[2] Unhealthy living conditions may also extend to the home where approximately 12% of AIAN homes lack safe, adequate water supplies and waste disposal facilities as compared to 1% of the homes for the general US population.[4,5]

Health literacy barriers can delay or inhibit access to health services. Barriers may include limited or no information about available services, difficulties communicating with healthcare providers, and inability to use local healthcare systems efficiently. Additionally, patients may not be aware of their right to an interpreter or understand health information that is not culturally or linguistically relevant.[5] These challenges may lead to decreased treatment adherence, inadequate follow-up care and delays in seeking care for treatment and disease-related side effects.

AIAN populations are more likely to have a lower socioeconomic status and live in poverty when compared to Non-Hispanic Whites (NHWs), all indicators of less access to cancer prevention and control services.[6] Lower socioeconomic status is associated with financial,

structural and personal barriers to health care including inadequate health insurance and reduced access to recommended preventive care and treatment services.[7] The Indian Health Service (IHS) noted in 2009 that screening rates were significantly lower than for the US population as a whole with only 59% of AIAN women receiving Pap smears, 45% of eligible AIAN women receiving mammograms and only 33% of eligible AIAN men and women receiving colorectal cancer screening.[8]

The cancer burden continues to escalate among AIANs,[6,9] affecting both patient and family alike. This burden includes the multiple ways cancer impacts the whole family such as loss of income from losing a job, relocation of family members to serve as patient caregivers, increased demands of time and money for transportation, child care costs, alterations in relationships, and a myriad of other burdens that affect everyday life for the patient and family.[6,9]

Cancer incidence rates vary among AIAN populations and often differ from rates among NHWs living in the same geographic regions.[10,11] (See Table 1) Between 1997 and 2006, short-term trends in death rates for all cancers combined decreased for all genders and racial/ethnic groups except for American Indian (AI) women.[11] According to the 2008 IHS data,[12] there are regional differences for most cancer sites with AIs in the Northern and Southern Plains having elevated incidence and mortality in comparison to AIs living elsewhere in the 48 contiguous states. AIs continue to have the poorest five-year relative survival in comparison to all other ethnic and minority groups in the US.[13]

Patient Navigation to Reduce Health Inequities

Patient navigation, which focuses on overcoming barriers and increasing access to health care, has the potential to mitigate or prevent health inequities, increase access to quality, timely care, and subsequently improve healthcare outcomes.[14] This is particularly true for managing cancer care where navigation has a unique role in improving the overall health of the patient, family and community at large through efforts in cancer prevention and early detection, cancer care access and coordination, insurance coverage and continuity, identification and referral to cancer resources and support services, and palliative and end-of-life care. Patient navigators, particularly those from the same community or with the same or similar cultural background, can reduce fear and anxiety, build trust, decrease literacy barriers, facilitate patient-provider communication, provide psychoemotional support and manage logistical obstacles to cancer care.[1,15-19]

Patient navigators who are not directly involved in the patient's day-to-day medical care are particularly important, as they are able to "be there" for the patient and family in a manner not possible for members of the patient's immediate healthcare team. Patients frequently see the navigator as an insider to the healthcare system, but not a direct part of the system. The navigator is able to understand the needs of the patient as well as the requirements of the healthcare system/team and facilitate coordination between the two while keeping the survivor at the forefront and providing both personalized emotional support and comprehensive access to care and resources. Thus, the navigator serves as a bridge between

the patient and the healthcare system and can help both to identify strategies that support survival and quality of life. (personal communications – NNACC navigators)

Multiple authors[15-19] have identified the roles and responsibilities of patient navigators when working with cancer patients, their families/caregivers, and their communities. Whether lay patient navigators embedded in their own communities or healthcare providers navigating within and across healthcare systems, the roles and responsibilities of the cancer patient navigator take into account the individuality of the patient, the healthcare environment and the cultural beliefs and mores of the patient, family and community. Tasks vary by patient, disease factors, cultural beliefs and identity, healthcare systems, and the characteristics of the individual navigator. Table 2 identifies the various roles and responsibilities of cancer patient navigators.

Braun and colleagues[15] identified the tasks of the cancer patient navigator through evaluation of five National Cancer Institute-funded Community Network Programs that currently provide cancer patient navigation. These navigation programs included Native American Cancer Research Corporation (NACR), Hands of Hope, PATH for Women, Redes En Acción National Patient Navigator Intervention Study and Kukui Ahi. The authors used two frameworks: the phases of the cancer care continuum and the "5 A's of quality care" (to which they added a sixth attribute, understandable) to identify common tasks of cancer patient navigators. The cancer care continuum includes the six possible phases (education and outreach, screening, diagnosis and staging, treatment, survivorship and end of life) during which a patient may encounter and experience a cancer diagnosis, treatment and follow-up care. These phases are not unique, but rather overlap and may repeat themselves throughout the individual's life. Tasks across the continuum meet the support and resource needs of patients during each specific phase and will vary based on specific patient, family and community characteristics. In order to obtain quality healthcare, the five attributes of care (accessible, affordable, available, appropriate and accountable) must be attainable. The authors added understandable to these attributes, since information and care not understood generally do not lead to quality care. During each phase, the six attributes are assessed and strategies identified.[15] Using both frameworks, patient navigators can greatly improve access to care, information, support services and education, especially for those experiencing healthcare disparities who have limited access to prevention, treatment and supportive care services and resources.

Evidence-Based Native Patient Navigation

The Native American Cancer Research (NACR) navigator program evolved over time. It had its roots in the Native American Women's Wellness through Awareness (NAWWA) program supported by the Robert Wood Johnson Foundation in 1994[20,21] and progressed through multiple phases to the current program. Since 2005, NACR's Native Patient Navigation Program has been affiliated with Spirit of Eagles, the Community Network Program based at the Mayo Clinic in Rochester, Minnesota. Currently, NACR employs three grant-funded Native Patient Navigators (NPNs) in Colorado (originally called Native Sisters), and works with additional navigators throughout the US and most recently in Michigan, South Dakota, Nebraska, Florida and Oklahoma. Each of the NPNs has

completed a minimum of 125 hours of initial cancer specific education and training, followed by refreshers and supplemental trainings provided in person or via webinar. Since 1996, the NPNs have provided outreach services and education programs to numerous AIAN communities and assisted more than 1000 AIAN men and women to access cancer care including screening, diagnostic, treatment, and end of life services.

"Native Navigators and the Cancer Continuum" (NNACC)

Native Navigators and the Cancer Continuum (NNACC) is a community-based participatory research (CBPR) study. NNACC originally was a partnership among three sites: NACR, Colorado; Inter Tribal Council of Michigan, Michigan; and Rapid City Regional Hospital's "Walking Forward" Program in collaboration with the Great Plains Tribal Chairmen's Health Board, South Dakota. A fourth site, the Muscogee (Creek) Nation of Oklahoma was added in 2010. Each organization has a strong presence and credibility within its respective community.

Using the CBPR model, the partners have equal decision-making roles through all aspects of the project as well as an equal budget to conduct the intervention. The partnership equitably involves community members, organization representatives, and professionals in all aspects of the planning, implementation and evaluation processes of the study.[22] This type of collaborative process recognizes the unique strengths of each partner and creates a forum for information sharing and decision-making. Through CBPR, the partnership has the potential to effectively tailor interventions for diverse communities, collect assessment and evaluation data to inform decision-making and study implementation, provide a level playing field among the different partners, enhance trust in government initiatives and decrease the community stigma towards cancer.[23-32]

The overall goal of NNACC is to refine, expand and adapt various navigator/community education programs to address AI communities' and their members' needs throughout the continuum of cancer care (prevention, early detection, diagnosis, treatment, survivorship, palliation and end-of-life). The research question is, "Can a Native specific comprehensive Navigator-initiated community cancer education intervention improve health behaviors among Native American community members?" The study, which began in May 2008, has 3 phases: Planning (Phase I, Year 01); Implementation Phase II, Years 02-04) and Evaluation (Phase III, Years 01-05). The study population originally was projected for a total of 200 unduplicated AIs from each of the three original sites (CO, MI, SD) and 138 from Muscogee (Creek) Nation for a total 738 participants; however, extreme interest among community members in the education intervention resulted in Western IRB approval to increase the sample size to 2200.

Each site has two Native Patient Navigators (NPNs) and collaborates with a local AI community organization to coordinate and implement a 24-hour, tailored, community education program focused on cancer. The NPN may be a lay health worker or a healthcare professional (LPN or RN) depending on the position specifications of each partner. The education programs address the full continuum of cancer care and occur in multiple 1.5 to 2 hour presentations over days to weeks as decided upon by the NPN and community

organization. The rationale for the education programs is to increase cancer knowledge among community participants and also to increase the visibility of the local NPN who is available to help participants and others to schedule screening appointments, carry out follow-up recommendations, and provide support and education for those diagnosed with cancer.

Recruiting Native Patient Navigators

Each site recruited and hired its own NPNs, but characteristics of a successful NPN across sites were quite similar. Based upon lessons learned from earlier Native patient navigation studies conducted by NACR, the most important characteristic for an effective Navigator is passion and dedication to the local community. Additional characteristics include being respected by local AI leaders and community members, having worked successfully within the local AI community and being seen as having cultural sensitivity and respect for community beliefs. Education level and prior experience with cancer/cancer care, while of value, are less important to predicting success of the NPN in providing education and working with the community. The majority of the NPNs live within their local communities, are respected members of these communities and are trusted to assist with facilitating decision-making, accessing resources and providing cancer-related health information. The NPNs were of both genders, which was particularly helpful when education content and navigations needs related to topics such as prostate cancer, impotence, and incontinence.

More recently, in addition to the above noted characteristics, real life situations and case studies were sent to the Native individual applying for an NPN position prior to the interview appointment. This allowed the applicant to view potential, real-life situations the NPN might encounter within the community and to prepare responses of how he/she would handle each specific situation. Additionally, the administrative staff conducted telephone interviews with known and respected AI leaders from the local community to assess their opinions about the candidates' ability to address certain situations or settings. The interview, case study responses and AI leader evaluation, along with the necessary characteristics, were all components considered in the decision to hire the applicant.

Training Native Patient Navigators

A "training session" includes collecting knowledge, attitudes and behavior data before and following an education session and incorporates practical exercises to facilitate learning and enhance acquisition of new skills and behaviors learned during the education session. NNACC NPN training required changes in the NACR standard in-service education format and significant expansion of content to meet the specific requirements for educating the NPNs to provide community education and patient navigation. Training sessions varied by the needs, experiences and prior education of the NPNs and included an initial overall training of 125 hours plus approximately 35 hours of additional education through national seminars and site-specific education and 40 hours of planned semi-annual updates (See Table 3). Trainings included didactic, interactive, and practice components and occurred in classrooms, seminars and through individual study and online formats over a six-month

period. Refresher sessions and new content were added during the semi-annual updates and as needed.

For many complex topics, such as cancer treatments or clinical trials, review of in-service training materials occurred up to three times to ensure that NPNs felt comfortable enough with the content to begin the community education programs. The need for training and the time needed to grasp content varied by NPN and was not based on prior level of education or whether the NPN was a lay health worker or healthcare professional. All required similar levels of education and practice to master the content and associated skills consistently.

The majority of the education took place as part of face-to-face sessions that were videotaped to allow for individual refresher sessions and for immediate training of new NPNs as they were hired and integrated into the project. Originally, webinars were to be used for training, particularly on an as needed basis for new topics and refreshers; however, while very effective for meetings, most NPNs believed that training sessions were best accomplished and learning was at its highest with face-to-face meetings. A particularly important component of training was the ability to ensure that information and support were both comprehensive and timely to meet the individual NPN education needs before, during and following the community workshop series.

Training sessions were reinforced through debriefings with the NPNs and their supervisors. During debriefings, the NPNs discussed their comfort and confidence with the topics, concerns about their presentations, types of questions asked and responses provided during the presentation, additional information needed for follow-up and any navigation services provided. In the future, an anonymous Survey Monkey is planned to allow the NPNs to self-assess their level of comfort and confidence in order to document variability in readiness and training needs. Repetition each year will document status and progress.

American Indian Community Education

Workshop Series

The intervention component of the NNACC project included having each partner conduct six series of community education workshops (Muscogee Creek Nation joined the project midway through and conducted only 4 series). Each series included 24 hours of community education, divided into 12 topics each generally presented in a two-hour timeframe. Each series was conducted in collaboration with a local AI organization that, in many cases, changed with each workshop series. Content of the workshops was selected from four general categories: cancer prevention, early detection information and strategies, quality of life/survivorship and palliation/end of life (see Table 4; PDF versions of the workshop slides are available under the "handouts" tab in the upper right-hand side of the opening page at http://www.NatAmCancer.org).

Each workshop included data collection (demographics, pre- and post-workshop knowledge, and overall workshop evaluation) using an anonymous Audience Response System (ARS), education content and one or more interactive activities (games and group activities) to reinforce learning. The AI organization selected the workshop topics and identified the

timing and sequencing of each series in collaboration with the local NPN based on the needs and interests of the organization's membership. Some series occurred weekly over 12 weeks while others occurred twice or more weekly until all 12 selected topics were presented.

The NPNs implemented and evaluated the workshops, while the local AI organization coordinated logistics, hosted each event and kept track of participants' ARS keypad numbers so that a returning participant used the same ARS keypad through the workshop series. Participants who completed a workshop received a gift card of $5 or $10 (varies by Partners' sites) per session. Attendance at each workshop in the entire series was encouraged and in some sites, participants attended more than one series, bringing friends and family to subsequent workshops. What was particularly important to the success of these workshop series was the fact that participants were willing to travel long distances over rough Reservation roads to take part in multiple workshops. These participants expressed their need to learn more about cancer and particularly about strategies to decrease their cancer risks and were willing to brave the roads, weather and long distances to attend.

Family Fun Events

Family Fun Events are used to initiate the workshop series and to wrap-up and evaluate the series three months following their completion. Potential workshop series participants are invited to attend and bring family members. The initial Family Fun Event is the "Baseline" (Kick-off). The local AI organization invites local family and community members for a fun activity that includes healthy food and about 30 minutes of NPN-provided instruction. Instruction includes 15 minutes for project overview, explanation of the upcoming 24-hours of community education and dissemination of a project information sheet and an additional 15 minutes to collect demographic and pre-intervention knowledge and behavioral items using the ARS. These events may incorporate health fairs, bingo games, outdoor picnics or any other fun event that would be of interest to the community and the organization's membership.

The post-Family Event occurs three months following the completion of the 24-hour series of workshops. Again, the AI organization coordinates the logistics and documents distribution of keypads to designated users (participants use the same keypad for baseline Family Event, the each workshop and the 3-month delayed Family Event). Twenty to thirty minutes of the event is allocated for the NPN to share results from the 24 hours of community education (increases in knowledge, comments about the workshops and processes) and to collect demographics and delayed evaluation knowledge items.

Collaboration with Local AI Organizations

The partners and their respective NPN create relationships and memoranda of agreement with AI organizations from their respective areas. These organizations have strong relationships with their local AI communities and may or may differ for each Workshop series (some Partners used a different organization for each workshop series while others used a different organization or only two or three organizations). Each organization coordinates the Family Fun Events and the 24-hour workshop series, managing logistics, hosting the event, and providing healthy snacks. In addition, these organizations:

- Promote the NNACC community education workshop series to members or frequent users of the organization.

- Recruit at least 35 unduplicated AI community members to attend the 24 hours of community education workshops (the organization invites the same AI participants to each workshop, as well as inviting those who have not previously attended).

- Retain and update lists of all participants and the specific ARS keypad each used in the workshop and distribute keypads at each session (the participant uses the same keypad for each session and Family Fun Event attended; no one else uses that key pad even when a previous participant does not attend).

- Assist the NPNs to prepare and share easy-to-understand findings from the workshops with community members participated.

These organizations create stronger community partnerships for the NNACC sites and NPNs. They allow the NPN to focus on teaching the workshop content while the organization promotes and coordinates the workshops and Family Fun Events. Similarly, the organizations are able to integrate the NNACC program within their other outreach services without having the pressure of learning or teaching new content.

Evaluation Processes

Workshop Evaluation

The Western Institutional Review Board (IRB) approved all community education slides and ARS evaluation items prior to workshop implementation. The NPNs collected ARS data (demographics, pre- and post-workshop knowledge, embedded opinion items and workshop evaluation) during each of the community education workshops and at both Family Fun Events. Following each session/Family Event, the NPNs uploaded their workshop evaluation data to the online evaluation program.[33] During and following each workshop series, the NPNs met with their local supervisors for debriefing to evaluate their personal performances, discuss workshop processes and outcomes and identify additional personal learning needs.

Online Evaluation

Between 2006 and 2008, NACR staff created a comprehensive, confidential, HIPAA-compliant Online Evaluation Program to compile evaluation data for staff activities and all grants and projects. The major components, identified as tabs, include Staff, Mentoring, Committees, Partnerships, Grants/Studies, Products, Dissemination, Cancer Screening and Survivor Navigation. Individual participant data are entered using a site-specific, individually coded identifier to maintain participant confidentiality, and data reports across participants and projects can be generated without compromising participant privacy.

To improve timely access to each partners' accomplishments and data, NACR modified the Online Evaluation Program and data fields so that each site had its own database and access to its own NNACC evaluation data and project activities. In 2010, the Survivor Navigation tab was modified further to more clearly document the amount of time, in minutes, that the NPN spends with each patient. Likewise, the Dissemination tab was modified to document

the demographics and pre- and post-knowledge of AI community participants attending each community education workshop and the Family Fun Events.

Each site is able to generate reports that meet the site's specific data needs. Within minutes, NNACC data can be summarized for the workshops conducted by each NPN, for a particular time span and for other variables as needed. This allows each partner to generate summaries for inclusion in other grant applications or reports to their respective Tribal Councils, Health Boards, and regulatory bodies.

Additionally, the NPNs can generate reports of findings specific to each local AI organization that coordinated the community education workshops. This information is integrated into an easy to understand Project Summary that is disseminated during the post-intervention Family Fun Event. The summary is a respectful way for preliminary findings to be shared with the community and provides the community with timely access to results in a manner that addresses the common complaint that AI communities rarely or never receive study findings. Providing timely feedback to the community is key to successful program implementation and for continued local community support for the project and future projects.

Outcomes

The NNACC project has achieved several outcomes. The first is the development of site-specific (tailored), AI navigator-implemented cancer education workshops that address the full continuum of cancer care. The communities have been eager to take part in the education programs, they asked good questions of the speakers and many asked to have the same workshop(s) repeated. Participants frequently commented on the use of ARS, noting it was useful for learning and that they liked seeing the correct answers, particularly when their answers were correct. The participants viewed the workshops as fun, productive, interactive and effective with overall learning, as measured by pre- to post-workshop knowledge evaluations, is 28.4% across all settings.[34]

Anecdotal reports indicated that participants have shared information with a friend or family member, made changes in their own lifestyles, and urged others to get cancer screening or other health related services. Participants have encouraged family and friends to attend future workshops, have frequently attended more than one series and have lobbied to have additional workshops and other presentations in their local settings. Requests for workshops continue even though the project will conclude in early 2013.

Participation exceeded original expectations and available ARS keypads and gift cards. The Western IRB was approached to increase the number of total unduplicated participants taking part in the study and agreed to an increased sample size of approximately 2200, almost triple the original sample size. Keypads were shared among sites to meet the demands while additional funding was obtained to purchase the needed gift cards.

Because of these workshops, the NPNs' visibility and skills were greatly increased. The NPNs have been able to provide help to more than 80 community members to facilitate the scheduling and completion of cancer screening and diagnostic appointments. This resulted

in patients with cancer receiving improvements in the timeliness, level and quality of the healthcare, and particularly the cancer care, obtained.

An additional, and unexpected, outcome of NNACC has been the overall impact of the partnership created to undertake this project. The partners have collaborated to create a program for cancer care that exceeded everyone's expectations. The collaboration is unique in that each member of the project team, regardless of role (Research Team, NPN, project staff), shares in the outcomes of the project, is valued by all team members and has a voice in the processes and progress of the study.

Conclusion

NNACC has been a successful program with more than 2100 unduplicated AIs reached through navigator-implemented, community cancer education. Additionally, numerous AIs have sought and obtained individual assistance from the local NPNs, resulting in improved healthcare for cancer and other health-related problems. Communities are better able to evaluate their cancer education needs and available resources and NPNs have been able to advocate for additional resources within their communities. The NPNs' visibility has increased and many communities see the NPN as a trusted source of cancer information and support. Communities and their members view the NPN as someone who can bridge the gap between the community, the healthcare system and the cancer patient and family, with the result that all benefit from increased health, decreased problems with adherence to screening and treatment protocols and increased quality of life.

The NNACC study is one strategy to overcoming healthcare disparities in those most in need of coordinated, comprehensive, quality cancer care. Through NNACC, Native patient navigators were made visible to their communities, increasing access to health care resources and services throughout the cancer continuum. Patient navigation offers even the most vulnerable of the US population the opportunity to access cancer care, support services and community resources. Using patient navigators, both lay health workers and healthcare professionals, to facilitate cancer care has the potential to decrease the overall US cancer burden and increase long-term cancer survival and quality of life.

Acknowledgments

References

1. Natalie-Pereira A, Enard KR, Nevarez L, Jones LA. The role of patient navigators in eliminating health disparities. Cancer. 2011; 117(15 Suppl):3543–3552. [PubMed: 21780089]

2. Colorado Cancer Coalition. [Accessed November 9, 2012] Colorado Cancer Plan 2010-2015. http://www.coloradocancerplan.org/index.php/healthdisparities/overview

3. Department of Health and Human Services. Indian Health Service. [Accessed November 9, 2012] IHS Fact Sheets. http://www.ihs.gov/PublicAffairs/IHSBrochure/Disparities.asp

4. US Department of Health and Human Services. Indian Health Service. [Accessed November 9, 2012] Strategic Plan 2006-2011. http://www.ihs.gov/planningevaluation/documents/IHSStrategicPlan20062011.pdf

5. Burhansstipanov, L. Health disparity: The morbidity and mortality picture. In: Joe, JR.; Gachupin, FC., editors. Health and Social Issues of Native American Women. Santa Barbara, CA: Praeger; 2012. p. 79-100.

6. Espey DK, Wu X, Swan J, et al. Annual report to the nation on the status of cancer, 1975-2004, featuring cancer in American Indians and Alaska Natives. Cancer. 2007 Nov 15; 110(10):2119–52.10.1002/cncr.23044 [PubMed: 17939129]

7. American Cancer Society. Cancer Facts and Figures 2012. Atlanta, GA: American Cancer Society; 2012.

8. [Accessed November 9, 2012] Government Performance and Requirements Act. Indian Health Service: 2009 National Summary. ww.ihs.gov/california/assets/File/GPRA/2009_National_Summary_FINAL.pdf

9. Burhansstipanov L, Dignan M, Jones K, Krebs LU, Marcionada P, Kaur JS. A comparison of quality of life between Native and non-Native cancer survivors. J Cancer Educ. 2012; 27(Suppl 1):S106–113. [PubMed: 22302431]

10. Wiggins CL, Espey DK, Wingo PA, et al. Cancer among American Indians and Alaska Natives in the US, 1999-2001. Cancer. 2008; 113(5 Suppl):1142–52. [PubMed: 18720375]

11. Edwards BK, Ward E, Kohler BA, et al. Annual report to the nation on the status of cancer, 1975-2006, featuring colorectal cancer trends and impact of interventions to reduce future rates. Cancer. 2010 Feb 1; 116(3):544–73. [PubMed: 19998273]

12. Haverkamp, D.; Espey, D.; Paisano, R.; Cobb, N. Cancer mortality among American Indians and Alaska Natives: regional differences, 1999-2003. IHS; Rockville, MD: 2008. p. 31

13. National Cancer Institute. [Accessed November 9, 2012] Cancer trends progress report 2011-2012. http://progressreport.cancer.gov/print.asp

14. Battaglia TA, Burhansstipanov L, Murrell SS, Dwyer AJ, Caron SE. Assessing the impact of patient navigation. Cancer. 2011; 117(15 suppl):3553–3564. [PubMed: 21780090]

15. Braun KL, Kagawa-Singer M, Holden AEC, et al. Cancer patient navigator tasks across the cancer care continuum. J Health Care Poor Underserved. 2012; 23(1):398–413.10.1353/hpu.2012.0029 [PubMed: 22423178]

16. Madore, SL. Overcoming treatment barriers of underserved breast cancer patients. University of Colorado at Denver; 2012. UMI Number 1509634

17. Petereit DG, Molloy K, Reiner ML, et al. Establishing a patient navigator program to reduce cancer disparities in the American Indian communities of Western South Dakota: initial observations and results. Cancer Control. 2008; 15(3):254–259. [PubMed: 18596678]

18. Wells KJ, Battaglia TA, Dudley DJ, et al. Patient navigation: state of the art or is it science? Cancer. 2008; 113(8):1999–2010.10.1002/cncr.23815 [PubMed: 18780320]

19. Wilcox B, Bruce SD. Patient navigation: A "win-win" for all involved. Oncol Nurs Forum. 2010; 37(1):21–25. [PubMed: 20044337]

20. Burhansstipanov L, Bad Wound D, Capelouto N, et al. Culturally relevant "navigator" patient support: the Native Sisters. Cancer Pract. 1998; 6(3):191–194. [PubMed: 9652252]

21. Burhansstipanov L, Dignan MB, Schumacher A, et al. Breast screening navigator programs within three settings that assist underserved women. J Cancer Educ. 2010; 25(2):247–252. [PubMed: 20300914]

22. Christopher, S.; Burhansstipanov, L.; Knows His Gun McCormick, A.; Simonds, VW. Using a CBPR to develop an interview training manual with members of the Assáalooke Nation. In: Israel, BA.; Eng, E.; Schulz, AJ.; Parker, EA., editors. Methods in Community-based Participatory Research for Health. 2. San Francisco, CA: Jossey-Bass, John Wiley and Sons; 2012. p. 225-248.

23. Strong LL, Israel BA, Schulz AJ, et al. Piloting interventions within a community-based participatory research framework: lessons learned from the Healthy Environments Partnership. Prog Community Health Partnersh. 2009; 3(4):327–334.10.1353/cpr.0.0094 [PubMed: 20097994]

24. Andrews JO, Tingen MS, Jarriel SJ, et al. Application of a CBPR framework to inform a multi-level tobacco cessation intervention in public housing neighborhoods. Am J Community Psychol. 2012; 50:129–140.10.1007/s10464-011-9482-6 [PubMed: 22124619]

25. Israel BA, Coombe CM, Cheezum RR, et al. Community-based participatory research: a capacity-building approach for policy advocacy aimed at eliminating health disparities. Am J Public Health. 2010; 100:2094–2102.10.2105/AJPH.2009.170506 [PubMed: 20864728]

26. Ramanadhan S, Salhi C, Achille E, et al. Addressing cancer disparities via community network mobilization and intersectoral partnerships: a social network analysis. PLoS ONE. 2012; 7(2):e32130.10.1371/journal.pone.0032130 [PubMed: 22384156]

27. Christopher S, Watts V, Knows His Gun McCormick A, Young S. Building and maintaining trust in a community-based participatory research partnership. Am J Public Health. 2008; 98(8):1398–1406.10.2105/AJPH.2007.125757 [PubMed: 18556605]

28. Christopher S, Saha R, Lachapelle P, et al. Applying indigenous community-based participatory research principles to partnership development in health disparities research. Fam Community Health. 2011 Jul-Sep;34(3):246–55. [PubMed: 21633218]

29. Peterson JC. CBPR in Indian country: tensions and implications for health communication. Health Commun. 2010 Jan; 25(1):50–60. [PubMed: 20390670]

30. Harrison MB, Graham ID. Roadmap for a participatory research-practice partnership to implement evidence. Worldviews Evidence-Based Nurs. 2012; 9(4):210–220.

31. Department of Health and Human Services. [Accessed November 9, 2012] Office of Behavioral and Social Sciences Research. Community-based participatory research. http://obssr.od.nih.gov/scientific_areas/methodology/community_based_participatory_research/index.aspx

32. PolicyLink. [Accessed November 9, 2012] Community-based participatory research: a strategy for building healthy communities and promoting health through policy change. http://www.policylink.org/atf/cf/%7B97C6D565-BB43-406D-A6D5-ECA3BBF35AF0%7D/CBPR.pdf

33. Burhansstipanov L, Clark RE, Watanabe-Galloway S, et al. Online evaluation programs: benefits and limitations. J Cancer Edu. 2012 Apr; 27(Suppl 1):S24–31.10.1007/s13187-012-0320-9

34. Burhansstipanov L, Krebs LU, Watanabe-Galloway S, Petereit DG, Pingatore NL, Eschiti V. Preliminary lessons learned from the "Native Navigators and the Cancer Continuum" "NNACC". J Cancer Educ. 2012 Apr; 27(Suppl 1):S57–65.10.1007/s13187-012-0316-5 [PubMed: 22410710]

Table 1

Cancer Incidence Data for Southern and Northern Plains American Indians[10]

	US[a]		Southern Plains[a]		Northern Plains[a]	
	AIAN	NHW	AIAN	NHW	AIAN	NHW
All	368.4	475.9	492.6[b]	461.2	538.1	464.8
Breast	85.3	134.4	115.7	129.6	115.9	130.3
Cervix	9.4	7.4	14.1	9.1	12.5	7.4
Colon	46.3	50.8	60.2	51.8	72.5	52.3
Kidney	17.9	11.8	21.3	12.4	23.7	12.1
Lung	48.5	58.6	87.1	82.2	104.3	65.5
Prostate	105.4	154.4	156.7	146.5	174.5	162.2

AIAN = American Indian/Alaska Native

NHW = Non-Hispanic White

[a]Rates are per 100,000 persons

[b]Increased incidence in AIs

Table 2

Roles and Responsibilities of Cancer Patient Navigators[15-18]

Educate about screening guidelines, signs and symptoms of cancer, treatment modalities, side effects, follow-up care

Maintain library of materials and access to online materials

Coordinate and serve as support for medical visits

Assist with transportation, child and elder care

Assist with accessing financial services including obtaining/managing health insurance or public assistance

Maintain a directory of services and advocate for needed and additional services

Connect patient to resources and support systems; refer to counselors

Assist with "understanding" of information during patient – provider communication

Remove structural and cultural barriers to services

Track procedures, interventions and outcomes

Collaborate with providers to provide culturally sensitive care based on knowledge of patient, community and culture

Facilitate local collaborations to expand and improve services and care

Assist in obtaining tribal and IRB approvals.

Collect community data as appropriate

Create a friendly healthcare environment

Serve as local resource when patients return home from distant treatment

Table 3
Navigation In-Service Training Topics

Topic	Approximate Time
Overview of the NNACC Study	3
NIH Protection of Human Subjects (online training)	3
Confidentiality/HIPAA	9
Overview of Navigation Programs	3
Audience Response System (ARS) Evaluation	3
Presentation Skills	3
Online Evaluation Program	6
Health Eating	6
Energy Balance	6
Reducing Exposure to Environmental Contamination	3
Cancer Basics Series -100 – Overview; 101 – Diagnosis and Staging; 102- Cancer Treatments; Cancer 103 – Side Effects	12
Get on the Path series: Breast Health, Cervix Health, Colon Health, Lung Health, Prostate Health (6 hours each)	30
"Native American Cancer Education for Survivors" (NACES)	3
Clinical Trials Education for Native Americans (CTENA)	3
Survivors Support Circles	3
Cancer Survivorship/Survivorship Care Plans	3
Palliative Care for the Native Cancer Patient	3
Supporting the family caregiver	3
Advanced directives, wills	3
Hospice Care (benefits, limitations, choices)	3
Navigating the Local Healthcare System	3
Safety Working out in the Community/Rural Settings	3
Assessing Community Resources/Creating Resource Binder	3
Communication skills	5
Required topics	125 hours
Additional trainings (national seminars, and workshops), topics requested by Navigators or Staff; refreshers;	75 hours
Total NPN education and training	**200 hours**

Table 4
Possible Topics for Community Education Workshops [33]

PREVENTION

1	Exposure to Environmental Contaminants
2	Energy Balance / Weight Management
3	Healthy Eating
4	Get on the Path to Lung Health (or excerptcalled "Keep Tobacco Sacred")

EARLY DETECTION

1	Cancer 100 – Overview
2	What is Cancer? (NPCCCP)
3	The Cancer Burden (NPCCCP)
4	Get on the Path to Breast Health
5	Get on the Path to Cervix Health
6	Get on the Path to Colon Health
7	Get on the Path to Prostate Health
8	HPV and Cervix Cancer (NPCCCP)

QUALITY OF LIFE / SURVIVORSHIP

1	"Native American Cancer Education for Survivors" (NACES) Program
2	Native American Cancer Survivors' Support Circles
3	Cancer 101 – Diagnosis and Staging
4	Cancer 102 – Treatments
5	Cancer 103 – Side Effects
6	Basics of Cancer Treatment (NPCCCP)
7	Cancer Diagnosis (NPCCCP)
8	Clinical Trials Education for NativeAmericans (CTENA)

PALLIATIVE CARE AND END-OF-LIFE

1	Native American Palliative Care
2	Wills and Advanced Directives
3	Palliative Care, Hospice and End-of-Life Care
4	Caring for the Caregiver
5	Support for People with Cancer and caregivers (NPCCCP)

NPCCCP – Northern Plains Comprehensive Cancer Control Program