HHS Public Access
Author manuscript
J Prim Prev. Author manuscript; available in PMC 2018 April 01.

Published in final edited form as:
J Prim Prev. 2017 April ; 38(1-2): 121–135. doi:10.1007/s10935-016-0458-z.

American Indian and Alaska Native Cancer Patients' Perceptions of a Culturally Specific Patient Navigator Program

Carol Grimes, MPH,
Project Specialist, Northwest Portland Area Indian Health Board, 130 NE Ainsworth St., Portland, OR 97211

Jenine Dankovchik, BSc,
Biostatistician, IDEA-NW Project, Northwest Portland Area Indian Health Board, 2121 SW Broadway, Suite 300, Portland, OR 97201, Phone: 503-416-3265, Fax: 503-228-8182, jdankovchik@npaihb.org

Megan Cahn, MPH, and
Doctoral Candidate, Oregon State University, College of Public Health & Human Sciences, 6430 SE Ogden St, Portland, OR 97206

Victoria Warren-Mears, PhD, RD, LD
Director, Northwest Tribal Epidemiology Center, 2121 SW Broadway, Suite 300, Portland, OR 97201

Abstract

Lack of access to care, funding limitations, cultural, and social barriers are challenges specific to tribal communities that have led to adverse cancer outcomes among American Indians/Alaska Natives (AI/AN). While the cancer navigator model has been shown to be effective in other underserved communities, it has not been widely implemented in Indian Country. We conducted in-depth interviews with 40 AI/AN patients at tribal clinics in Idaho and Oregon. We developed the survey instrument in partnership with community members to ensure a culturally appropriate semi-structured questionnaire. Questions explored barriers to accessing care, perceptions of the navigator program, satisfaction, and recommendations. AI/AN cancer patients reported physical, emotional, financial, and transportation barriers to care, but most did not feel there were any cultural barriers to receiving care. Navigator services most commonly used included decision making, referrals, transportation, scheduling appointments, and communication. Satisfaction with the program was high. Our study provides a template to develop a culturally appropriate survey instrument for use with an AI/AN population, which could be adapted for use with other indigenous patient populations. Although our sample was small, our qualitative analysis facilitated a deeper understanding of the barriers faced by this population and how a navigator program may best address them. The results reveal the strengths and weakness of this program, and provide baseline patient satisfaction numbers which will allow future patient navigator programs to better create evaluation benchmarks.

Correspondence to: Jenine Dankovchik.

Conflict of Interest: The authors declare that they have no conflict of interest.

Author Manuscript
Author Manuscript
Author Manuscript
Author Manuscript

Author Manuscript

Keywords

Qualitative; Survey; Satisfaction; Indigenous; Tribal

BACKGROUND

Cancer is a leading cause of mortality among American Indians and Alaska Natives (AI/AN) in the Pacific Northwest. Compared to the non-Hispanic White (NHW) population, AI/AN in the Northwest have similar incidence rates for all cancer sites combined, but higher cancer mortality rates and lower 5-year survival rates (Hoopes et al., 2011). AI/AN are more likely than NHW to be diagnosed at late stage for prostate, cervical, breast, lung and colorectal cancer (Jemal, Siegel, Xu, & Ward, 2010; Ward et al., 2004; Watson et al., 2014). While recent trends have shown decreases in cancer mortality among NHW, high rates for AI/AN have persisted (Espey et al., 2007; Hoffman, Li, Henderson, Ajani, & Wiggins, 2014; Stewart, King, Thompson, Friedman, & Wingo, 2004). Many financial, social, and cultural barriers contribute to these disparities (Petereit et al., 2008). Late stage diagnosis is a primary factor, and is linked to low screening rates and inadequate follow up of abnormal screening tests. Screening rates in the Northwest remain lower among AI/AN than NHW (Steele, Cardinez, Richardson, Tom-Orme, & Shaw, 2008), and mammography and Pap test screening rates are lower among AI/AN in the region than AI/AN nationally (Indian Health Service, 2010).

One intervention that has been suggested for this population is a patient navigator. A patient navigator acts as a constant support throughout patients' cancer journeys, coordinating their care between multiple providers and agencies. Patient navigators educate, support, and facilitate access to care and resources. This model has improved cancer outcomes in a variety of settings. Harold Freeman's groundbreaking program established in the 1990s positively affected the 5-year survival rates of minority women treated for breast cancer (Freeman, 2004). Since that time, a small number of patient navigator programs specifically adapted to serve AI/AN and Native Hawaiian cancer patients have been established and are beginning to report promising results (Braun, Allison, & Tsark, 2008; Gilbert, LaMarca, & Krebs, 2001; Petereit et al., 2008). Despite these promising findings, there have been few comprehensive examinations of AI/AN cancer patients' experiences, perceptions, and satisfaction with patient navigator programs.

We conducted a survey of participants enrolled in the Northwest Tribal Cancer Navigator Program. The objective of this study was to explore whether working with a navigator can improve the quality of life and subjective well-being of AI/AN cancer patients, determine the primary barriers to timely cancer care for this population, identify the most effective navigation strategies, and examine participant perceptions of and satisfaction with the program.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

METHODS

Study Setting

The Northwest Tribal Epidemiology Center implemented the Northwest Tribal Cancer Navigator Program (NTCNP) between 2006 and 2010 as one site of the national Patient Navigator Research Program (PNRP). One patient navigator was placed at each of four tribal clinics in Idaho and Oregon. Interviewers recruited patients from three of these clinics for this study. Due to administrative issues, we were unable to complete any interviews at the fourth community involved in the study.

Tribal clinics recruited navigators from a variety of medical backgrounds, including registered nurses and community health representatives. NTCNP provided navigators with standardized training, national training from the PNRP, and appropriate continuing education. We did not provide cultural training specific to their community, but navigators attended trainings conducted by staff from other AI/AN patient navigator programs, and we encouraged those who were not members of the community to educate themselves about the history and culture of that particular Tribe.

The NTCNP model evolved as the project was implemented. Originally, navigators only recruited patients who had received a cancer diagnosis or abnormal finding on a breast, cervical, prostate or colorectal cancer screening test. The navigator then followed the patients through their diagnostic workup and into treatment should they be diagnosed with cancer. Navigation ended when the patients received a non-cancer diagnosis, completed active treatment, or passed away. During implementation it became apparent that this design was problematic for our communities. Through review of pilot study findings and feedback from navigators, clinic staff, and tribal leaders, we determined that limiting eligibility to certain points in the cancer continuum and particular types of cancer was inappropriate within small tribal communities. To address this, we expanded the navigator’s role to include involvement in community screening events, to enroll patients with any cancer type, and to follow patients into survivorship and to support families of patients who passed away (Figure 1). Navigators worked with any patient eligible to be seen at their clinic who was 18 years or older, and who had either an abnormal finding suspicious for cancer or a cancer diagnosis.

Study Participants

The Portland Area Indian Health Service Institutional Review Board approved the study. We defined the study population as all patients who had worked with a navigator for at least three weeks, and had at least three encounters, either in person or by phone. Interviewers contacted all 112 eligible patients. In total, patients completed 40 interviews. We calculated response rates using the Council of American Research Organization (CASRO) method, with slight adjustments, yielding a response rate of 40%. We compared the demographics of non-respondents and respondents and found no statistically significant differences in age, sex, marital status, number of encounters, duration of navigation, or cancer site.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Survey Instrument

Current recommendations for adapting survey instruments to a specific culture focus on the importance of a cultural review and an iterative design process (Fisher & Ball, 2005; Macedo, Reano, Weber, & Easton, 2004). Including open-ended questions is advised to allow for a story-telling approach to interviewing, which aligns with the communication style of Native communities (Fisher & Ball, 2005; Macedo et al., 2004; Strickland, 1999). Some authors specify a face-to-face semi-structured interview as the mode of choice for AI/AN populations (Blinson, Dignan, Michielutte, & Wells, 1996; Macedo et al., 2004; Pearson, Cheadle, Wagner, Tonsberg, & Psaty, 1994). Each tribe has its own distinct communication style, language and culture; however, the literature review identified cross-tribal commonalities which, when combined with reviews by those familiar with the customs of the tribes involved in this project, generated the foundation for the design of the survey.

The survey instrument for this study was a semi-structured questionnaire developed by NTCNP research staff, in conjunction with navigators and community members. Navigators and community members reviewed the questionnaire to assess ease of understanding, relevance, and cultural appropriateness. Two respondents then pretested it and provided additional comments. We incorporated feedback from these three sources into the final questionnaire. Interview duration averaged 30 min and interviewers provided respondents with a $30 gift card upon completion.

Patient Interviews

Interviewers contacted patients to schedule the interview at the patient’s convenience. They contacted patients up to three times, and then classified the case as a refusal. The interview began with an explanation of informed consent, including a request to record the interview.

Interviews were primarily conducted in person (85%), the preferred method for surveying in AI/AN communities (Blinson et al., 1996). Interviewers gave respondents the choice to complete the interview over the phone or in person. Given the small number of interviews completed by phone, we had limited ability to compare the modes. However, we did not identify any major differences between the two groups.

Data Analysis

Interviewers recorded all interviews, and certified professional transcriptionists created verbatim transcripts from the audio files, purging identifying details. We used ATLAS.ti version 5.2 (ATLAS.ti., 2006) to code and analyze the transcripts. We grouped the transcripts by community and analyzed them using an inductive approach consisting of open, axial, and selective coding. Three research staff members created, reviewed, and refined a list of codes to create a final open coding guide. The lead researcher then coded all transcripts and transferred these open codes with corresponding quotes into a word document. Following the interpretive process of axial and selective coding, the study team examined similarities and differences between transcripts to extract broader themes illustrating the participants’ primary barriers to care and perceptions of the navigator program.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

RESULTS

The mean age of survey participants was 54.4 (*SD* = 2.9), and 65% were female. Most (44%) were enrolled in the program before they received a diagnosis. Not all went were subsequently diagnosed with cancer. We excluded two high-need participants who had more encounters than was typical, resulting in a mean of 20.7 (3 –74) encounters with the navigator. The duration of navigation services ranged from a few weeks to over three years for some who continued working with the navigator into survivorship. Interviewers asked about participants' experiences throughout their cancer journey, comparing their impressions before and after enrolling in the navigator program.

Primary Barriers to Timely Cancer Care

Participants described a range of challenges to accessing care (see Table 1 and Table 2). The most common were physical/emotional (*n*=26), financial (*n*=17), and transportation related (*n*=23).

Physical barriers resulted from the disease itself as well as side-effects of treatment. The most common physical challenges reported were pain (*n*=7), weakness (*n*=6), and limited mobility (*n*=5). Others mentioned included weight loss, hair loss, dermatological issues, and numbness. In some cases these delayed or prevented the participant from completing treatment. These issues also affected participants' emotional well-being as they contributed to feelings of insecurity, frustration and isolation. One patient mentioned the cultural aspect of his concern about hair loss during chemotherapy, saying, "We had a lot of pow-wows and Indian meals and I had one traditional dance, and I kind of let it grow long for that, for a little respect of the Tribe here." Physical issues also created financial consequences for a small number of participants who were unable to work due to pain, exhaustion or limited mobility.

Half of participants indicated some kind of emotional challenge. The most common included initial shock, confusion and anxiety resulting from the diagnosis or an abnormal finding (*n*=8), fear of treatment (*n*=7), and anxiety about financial consequences (*n*=7). Some participants were reluctant to pursue or continue treatment due to these fears. Another theme which emerged for some (*n*=9) was difficulty in obtaining appropriate care coupled with a belief that providers had mistreated or misdiagnosed them. One middle aged male reported,

> I had to get in a big fight and argument with [the clinic staff] to get me over [to the local hospital] to find out what was wrong with me…we had to wait until I was bleeding severely and I still had to argue with them to get to go.

Nearly half of participants experienced financial hardship (*n*=17). They reported anxiety about the consequences for their personal finances and their frustration due to the lack of coordination between agencies (*n*=5). These concerns impacted participants' ability to follow treatment recommendations. One participant noted, "The insurance company would call up and say, 'Well, we paid our share, why hasn't [Tribe] paid their share?'" Another explained that the Tribal clinic's delay in paying for referred care made him hesitant to return to the hospital for follow-up treatment: "I knew [the bill] hadn't been paid… I felt a

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

little bit nervous about going down there for another follow-up treatment, knowing that [the outstanding bill] was still out there."

The majority of those surveyed struggled with a lack of transportation (*n*=23). Most lived far from the nearest cancer center and public transportation was unavailable or too expensive.

Most Effective Navigation Strategies

Participants most commonly relied on the navigator's services to overcome logistic barriers (Table 1, Table 2, Table 3). These included obtaining referrals (*n*=28), transportation (*n* =23), and scheduling appointments (*n*=23). One participant recalled, "He would work very diligently on my schedule…he would check in with me, is this going to work if you have a CT scan and a doctor's appointment and chemo? So he was outstanding in that area."

More than half of participants reported that the navigator supported them with communication (*n*=22), and a majority found working with the navigator facilitated decision making (*n*=31). Navigators assisted participants in communicating with their providers by accompanying them to appointments, suggesting questions they may wish to ask, providing tools to track symptoms and supporting their decision to seek a second opinion. Many valued the navigator's ability to clarify the information given by health care providers. As one female participant stated, "The navigator was able to explain it in common terms instead of professional terms, because you know how doctor's words are. He could…make you feel a lot more at ease. You wouldn't be as afraid."

Most participants stressed the importance of referrals to support groups and counseling services (*n*=22), as well as direct emotional support provided by the navigator (*n*=19). They described navigators as easy to talk to, offering a shoulder to cry on, and providing a sense of security. Common sentiments echoed this female participant's comment, "I could see him and he'd just know…just being in his presence settled me down a little bit. I was not alone." Those who had a strong family and friend support network were less likely to report obtaining emotional support from the navigator.

Participants who obtained the navigator's assistance in completing paperwork (*n*=14) and finding housing while away from home for care (*n*=6), considered these services highly effective. Among these participants, 13 of 14 and 5 of 6, respectively, indicated that the process was "much easier" with the navigator's assistance.

Cultural Support

We expected navigator services around accommodating cultural practices within the health care system to be important to AI/AN patients in Northwest tribal communities. However, our data show that few participants surveyed experienced cultural barriers. Some did describe cultural traditions and ceremonies as a vital part of their healing journey. For example, one female elder recalled,

> They sang…songs and he did a ceremony…and then after that he had me say how I felt about the cancer and pray…It did help me. I did take the pill and I'm still taking it, but I do the white man's way and the Indian way.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

However, when interviewers asked patients directly about discrimination and lack of cultural competence, most indicated that today's health care systems were accepting of their cultural practices, in contrast to their experiences in the past. One female participant noted, "Growing up, being Indian was taboo…our little ways of doing things were always looked down on…It's more open nowadays. We can be who we want to be." Only one participant experienced overt discrimination, reporting,

> Well, the doctor was really insulting…he didn't believe in it; he called it "voodooism." He only believed in the medical, the pills and stuff. But your navigator, he had a different view. He was willing to say, "Yeah, go ahead, I'm just here to help you along in any way I can, whether that be what your doctor is going to recommend…and if you want to go through your Indian way, that is your option." That's what the navigator told me.

Participant Perceptions and Satisfaction

Overall satisfaction with the navigator program was high (Table 4). The majority (n=34) rated the navigator program as 'good' or 'excellent.' Most would recommend the program to a friend or family member (n=35). On an individual level, participants described navigators as "invaluable" and reported many instances of navigators going beyond their job description to help. They made home visits, picked up prescriptions, and identified resources to resolve other family issues that prevented the participants from following treatment recommendations. Several participants expressed profound gratitude to their navigators, as in this statement from a middle-aged female participant: "I'm not one to make speeches, but I got up in front of everybody and told them they had a great program and that I felt the navigator had actually saved my life."

Navigators were also highly regarded within the community due to their commitment to their patients and their patients' families, and because they showed understanding and respect for the Tribe's unique culture. Several comments highlighted how important it is for navigators to participate in community events in addition to direct patient encounters. For example, one elder commented, "I think I went to a couple of funerals that I'd seen him at too, which showed he cared out of respect for the families."

When we assessed satisfaction with specific aspects of the navigator, participants gave their highest ratings to navigator's respect for their values and choices, ability to answer questions, and responsiveness. These were also the aspects they considered most important in a navigator.

Criticism and Recommendations

There were a few participants who were critical of the program. They tended to be those who only had a few encounters with the navigator or had entered the program late in their cancer journey. These participants reported feeling that they hadn't received enough information, had little contact with the navigator, or were confused about what kind of services the program offered. One male elder stated, "I'm not sure what the program's even about, to tell you the truth. I guess [the navigator] hasn't explained to me that much about it that I can remember."

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Recommendations to improve the program included increased financial resources, more home visits and referrals to counseling services, increased collaboration with outside health care providers, and raising awareness of the program through advertising. Despite reporting few cultural barriers, several participants also recommended the navigator program increase its focus on cultural support.

LIMITATIONS

Study data are limited to self-reported opinions and we did not validate the instrument due to the small sample size and few published AI/AN cancer patient surveys. Instead, we drafted a questionnaire based on the literature review of AI/AN survey best practices and guidance from the community.

The results presented here are based on a very small number of responses from three Northwest tribal clinics, and should not be considered representative of the entire Northwest AI/AN population. Despite these considerations, the results provide novel observations about a population for which published data are limited and can be used to gain insight and provide context during planning of future AI/AN navigator program models.

DISCUSSION

The primary barriers to timely cancer care faced by this population included physical, emotional, financial, and transportation challenges. We also identified lack of insurance, financial instability, poor coordination between agencies and providers, and difficulty scheduling appointments as barriers.

In assessing the most effective navigation services, we determined that assistance in overcoming logistic barriers such as housing, transportation, appointment scheduling and completing paperwork had the greatest impact on participants' lives. However, in describing their experiences with the program, the predominant recurring theme was the depth of emotional support the navigator provided, in particular for those who did not have strong personal support systems in place. Other studies have identified similar categories of navigator tasks as valued by patients, although participants of this study were less likely to mention financial assistance, help with insurance benefits, and child/elder care (Braun et al., 2012; Burhansstipanov et al., 1998; Carroll et al., 2010; Domingo, Davis, Allison, & Braun, 2011; Gabitova & Burke, 2014; Krebs et al., 2013; Petereit et al., 2008).

Results from PNRP navigator programs have shown navigation can significantly decrease delays in obtaining diagnostic resolution of screening abnormalities (Battaglia et al., 2012; Fiscella et al., 2012; H. Freeman, 2003; Markossian, Darnell, & Calhoun, 2012; Paskett et al., 2012; Raich et al., 2012). Through a quantitative analysis of the NTCNP model conducted earlier, we demonstrated that patients who worked with a navigator were 3.6 times more likely to obtain a definitive diagnosis within one year than control patients. (Warren-Mears, Dankovchik, Patil, & Fu, 2013). NTCNP navigators attempted to identify and enrol patients as soon as they received an abnormal finding, but this was challenging. Being the sole navigator for a community was also difficult for the navigators. The responses

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

of survey participants highlight the role additional staff and better promotion of the program could play in addressing these issues and increasing the program's impact.

Several authors have identified the ability of navigators to address cultural barriers as a particularly important component of AI/AN and Native Hawaiian navigator programs (Eschiti, Burhansstipanov, & Watanabe-Galloway, 2012; H. P. Freeman, 2004; Guadagnolo, Cina, Koop, Brunette, & Petereit, 2011; Matsunaga et al., 1996; Petereit et al., 2008). We anticipated that accommodating cultural needs would also be an important aspect of the NTCNP; however, only one of the participants reported needing assistance in this area. Several noted that, while traditional Indian medicine and cultural practices were 'taboo' in the past, they now felt the medical community was open to these practices. It should be noted that participants nonetheless expect navigators to participate in important cultural events in the community and to be culturally competent.

Participants made several suggestions to improve the NTCNP, including the expansion of financial support, referrals to emotional support services, more frequent home visits, better collaboration with health care providers, greater emphasis on cultural resources, expanded staffing, and better promotion of the program. Other patient navigator programs also reported uncertainty about the navigator's role within the health care team as a weakness (Gabitova & Burke, 2014), a finding that was congruent with our results. However, as cancer patient navigation moves towards professional certification, researchers are making progress toward defining the navigator's role and developing core competencies, including those programs specifically aimed at serving indigenous populations (Braun et al., 2012; Burhansstipanov et al., 1998; Carroll et al., 2010; Domingo et al., 2011; Gabitova & Burke, 2014; Krebs et al., 2013; Petereit et al., 2008).

We sought to explore how working with a navigator affected AI/AN cancer patients' quality of life and well-being throughout the cancer journey. The themes identified through these interviews demonstrate that navigators provided participants with emotional and logistical support that improved their quality of life when compared with their prior health care experiences. Participants described feeling misunderstood and treated poorly by providers, and feeling overwhelmed and disempowered before working with a navigator. After enrolling in the program, most reported a sense of relief, reassurance, and confidence in understanding their diagnosis and in communicating their needs and decisions to their providers. The study also assessed participant satisfaction with the program, which we found was high.

Patient navigation is a good fit for native communities, and a variety of models have shown promise toward decreasing cancer disparities for AI/AN populations. The results of this study reveal the strengths and weaknesses of the navigation model as implemented by the NTCNP. As more tribal health facilities explore navigator programs, these findings assist in program design by identifying common barriers, and guiding the effective implementation of policies and procedures for patient navigators. Replication of the survey questions will serve to deepen our understanding of the primary issues faced by AI/AN patients receiving navigation services and to suggest further programmatic enhancements.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Acknowledgments

We would like to acknowledge the patients and their families for sharing their stories and the navigators for their commitment to the project. This study was funded by the National Cancer Institute's Center to Reduce Cancer Health Disparities, Grant Number U01 CA116925-01.

REFERENCES

ATLAS.ti., M. T. ATLAS.ti Scientific Software Development GmbH. 5. 2nd. Berlin: 2006.

Battaglia TA, Bak SM, Heeren T, Chen CA, Kalish R, Tringale S, Freund KM. Boston Patient Navigation Research Program: The impact of navigation on time to diagnostic resolution after abnormal cancer screening. Cancer Epidemiology, Biomarkers & Prevention. 2012; 21(10):1645–1654.

Blinson K, Dignan M, Michielutte R, Wells HB. The cost of conducting face-to-face household interviews in a rural, Native American population. The North Carolina Native American Cervical Cancer Prevention Project. Cancer. 1996; 78(7 Suppl):1587–1591. [PubMed: 8839576]

Braun KL, Allison A, Tsark JU. Using community-based research methods to design cancer patient navigation training. Progress in Community Health Partnerships: Research, Education, and Action. 2008; 2(4):329–340.

Braun KL, Kagawa-Singer M, Holden AE, Burhansstipanov L, Tran JH, Seals BF, Ramirez AG. Cancer patient navigator tasks across the cancer care continuum. Journal of Health Care for the Poor and Underserved. 2012; 23(1):398–413. [PubMed: 22423178]

Burhansstipanov L, Gilbert A, LaMarca K, Krebs LU. An innovative path to improving cancer care in Indian country. Public Health Reports. 2001; 116(5):424–433. [PubMed: 12042607]

Burhansstipanov L, Wound DB, Capelouto N, Goldfarb F, Harjo L, Hatathlie L, White M. Culturally relevant "Navigator" patient support. The Native sisters. Cancer Practice. 1998; 6(3):191–194. [PubMed: 9652252]

Carroll JK, Humiston SG, Meldrum SC, Salamone CM, Jean-Pierre P, Epstein RM, Fiscella K. Patients' experiences with navigation for cancer care. Patient Education and Counseling. 2010; 80(2):241–247. [PubMed: 20006459]

Domingo JB, Davis EL, Allison AL, Braun KL. Cancer patient navigation case studies in Hawai'i: The complimentary role of clinical and community navigators. Hawai'i Medical Journal. 2011; 70(12): 257–261. [PubMed: 22187512]

Eschiti V, Burhansstipanov L, Watanabe-Galloway S. Native cancer navigation: The state of the science. Clinical Journal of Oncology Nursing. 2012; 16(1):73–82. 89. [PubMed: 22297010]

Espey DK, Wu XC, Swan J, Wiggins C, Jim MA, Ward E, Edwards BK. Annual report to the nation on the status of cancer, 1975–2004, featuring cancer in American Indians and Alaska Natives. Cancer. 2007; 110(10):2119–2152. [PubMed: 17939129]

Fiscella K, Whitley E, Hendren S, Raich P, Humiston S, Winters P, Epstein R. Patient navigation for breast and colorectal cancer treatment: A randomized trial. Cancer Epidemiology, Biomarkers & Prevention. 2012; 21(10):1673–1681.

Fisher PA, Ball TJ. Balancing empiricism and local cultural knowledge in the design of prevention research. Journal of Urban Health. 2005; 82(2 Suppl 3):iii44–iii55. [PubMed: 15933330]

Freeman H. Commentary on the meaning of race in science and society. Cancer Epidemology, Biomarkers & Prevention. 2003; 12(Supplement):232s–236s.

Freeman HP. A model patient navigation program. Oncology Issues, Sep/Oct. 2004:44–46.

Gabitova G, Burke NJ. Improving healthcare empowerment through breast cancer patient navigation: A mixed methods evaluation in a safety-net setting. BMC Health Services Research. 2014; 14:407. [PubMed: 25234963]

Guadagnolo BA, Cina K, Koop D, Brunette D, Petereit DG. A pre-post survey analysis of satisfaction with health care and medical mistrust after patient navigation for American Indian cancer patients. Journal of Health Care for the Poor and Underserved. 2011; 22(4):1331–1343. [PubMed: 22080713]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Hoffman RM, Li J, Henderson JA, Ajani UA, Wiggins C. Prostate cancer deaths and incident cases among American Indian/Alaska Native men, 1999–2009. American Journal of Public Health. 2014; 104(Suppl 3):S439–S445. [PubMed: 24754659]

Hoopes, MJ., Dankovchik, J., Kakuska, E., Canniff, B., Vinson, E., Lopez, K. Cancer Among Northwest American Indians and Alaska Natives. N. T. E. Center, Trans. , translator. Portland, OR: Northwest Portland Area Indian Health Board; 2011.

Indian Health Service. 2010 GPRA Area Summary Report. 2010. Retrieved from http://www.ihs.gov/crs/documents/gpra/201012AreaReport.pdf

Jemal A, Siegel R, Xu J, Ward E. Cancer statistics, 2010. CA: A Cancer Journal for Clinicians. 2010; 60(5):277–300. [PubMed: 20610543]

Krebs LU, Burhansstipanov L, Watanabe-Galloway S, Pingatore NL, Petereit DG, Isham D. Navigation as an intervention to eliminate disparities in American Indian communities. Seminars in Oncology Nursing. 2013; 29(2):118–127. [PubMed: 23651681]

Macedo, J., Reano, L., Weber, J., Easton, A. Strategies for Surveying American Indian and Alaska Native Communities. Paper presented at the Statistics Canada Symposium; 2004.

Markossian TW, Darnell JS, Calhoun EA. Follow-up and timeliness after an abnormal cancer screening among underserved, urban women in a patient navigation program. Cancer Epidemiology, Biomarkers & Prevention. 2012; 21(10):1691–1700.

Matsunaga DS, Enos R, Gotay CC, Banner RO, DeCambra H, Hammond OW, Tsark JA. Participatory research in a Native Hawaiian community. The Wai'anae Cancer Research Project. Cancer. 1996; 78(7 Suppl):1582–1586. [PubMed: 8839575]

Paskett ED, Katz ML, Post DM, Pennell ML, Young GS, Seiber EE. Ohio Patient Navigation Research, P. The Ohio Patient Navigation Research Program: Does the American Cancer Society patient navigation model improve time to resolution in patients with abnormal screening tests? Cancer Epidemiology, Biomarkers & Prevention. 2012; 21(10):1620–1628.

Pearson D, Cheadle A, Wagner E, Tonsberg R, Psaty BM. Differences in sociodemographic, health status, and lifestyle characteristics among American Indians by telephone coverage. Preventive Medicine. 1994; 23(4):461–464. [PubMed: 7971873]

Petereit DG, Molloy K, Reiner ML, Helbig P, Cina K, Miner R, Roberts CR. 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]

Raich PC, Whitley EM, Thorland W, Valverde P, Fairclough D. Denver Patient Navigation Research, P. Patient navigation improves cancer diagnostic resolution: An individually randomized clinical trial in an underserved population. Cancer Epidemiology, Biomarkers & Prevention. 2012; 21(10): 1629–1638.

Steele CB, Cardinez CJ, Richardson LC, Tom-Orme L, Shaw KM. Surveillance for health behaviors of American Indians and Alaska Natives-findings from the behavioral risk factor surveillance system, 2000–2006. Cancer. 2008; 113(5 Suppl):1131–1141. [PubMed: 18720374]

Stewart, SL., King, JB., Thompson, TD., Friedman, C., Wingo, PA. Morbidity and Mortality Weekly Report (MMWR). Vol. 53. CDC; 2004. Cancer Mortality Surveillance --- United States, 1990–2000; p. 1-108.

Strickland CJ. Conducting focus groups cross-culturally: Experiences with Pacific northwest Indian people. Public Health Nursing. 1999; 16(3):190–197. [PubMed: 10388336]

Ward E, Jemal A, Cokkinides V, Singh GK, Cardinez C, Ghafoor A, Thun M. Cancer disparities by race/ethnicity and socioeconomic status. CA: A Cancer Journal for Clinicians. 2004; 54(2):78–93. [PubMed: 15061598]

Warren-Mears V, Dankovchik J, Patil M, Fu R. Impact of patient navigation on cancer diagnostic resolution among Northwest Tribal communities. Journal of Cancer Education. 2013; 28(1):109–118. [PubMed: 23242563]

Watson M, Benard V, Thomas C, Brayboy A, Paisano R, Becker T. Cervical cancer incidence and mortality among American Indian and Alaska Native women, 1999–2009. American Journal of Public Health. 2014; 104(Suppl 3):S415–S422. [PubMed: 24754650]

Imi Hale Native Hawaiian Cancer Network. Ho'okele i ke Ola: Overview. 2015 [Retrieved 5/5/2015] from http://www.imihale.org/patient.htm.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

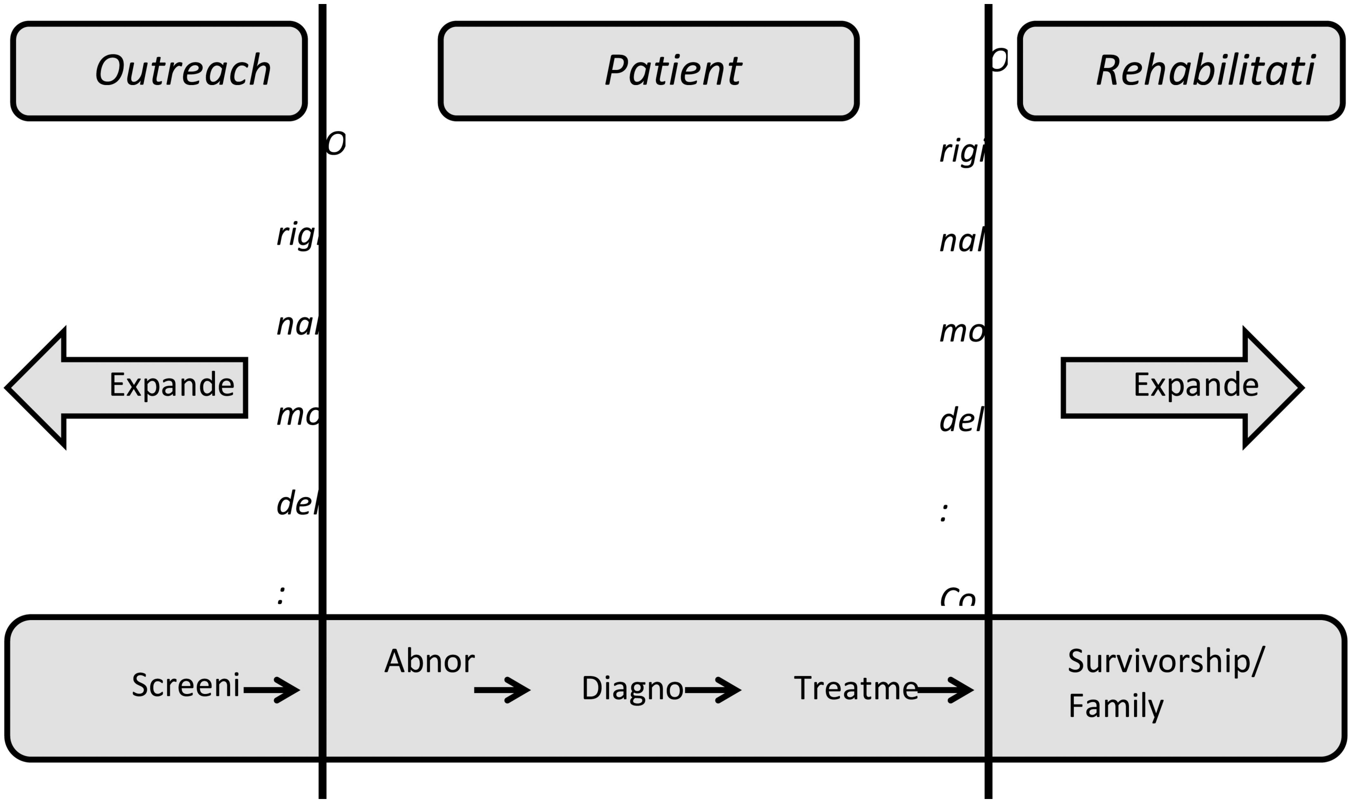

Figure 1.

Navigation Process. This figure shows the role of the navigator throughout the patient's cancer journey, and how it was changed to adapt the program to tribal communities.

Author Manuscript
Author Manuscript
Author Manuscript
Author Manuscript

Table 1

Summary of Barriers and Services

Physical barriers to care	***n***	**%**
Pain due to disease	7	18%
Weakness/exhaustion	6	15%
Limited mobility/independence	5	13%
Weight loss	3	8%
Hair loss	3	8%
Confusion	2	5%
Allergic reaction to treatment	1	3%
Numbness	1	3%
Total unique respondents who experienced physical barriers	**13**	**33%**
Emotional barriers to care		
Distrust of medical system	9	23%
Shock, confusion, anxiety, stress	8	20%
Fear (e.g., of treatment, prognosis)	7	18%
Anxiety about financial consequences	7	18%
Depression, frustration, hopelessness	4	10%
Afraid to leave the house	4	10%
Difficulty with decision making, feeling uninformed	4	10%
Loss of social support	1	3%
Intimidated by cancer center	1	3%
Total unique respondents who experienced emotional barriers	**20**	**50%**
Financial barriers to care		
Could not afford transportation	23	58%
Uninsured or underinsured	6	15%
Lack of coordination between facilities, insurers	5	13%
Credit rating threatened	5	13%
Could not afford housing away from home	2	5%
Could not afford living expenses	2	5%
Total unique respondents who experienced financial barriers	**23**	**58%**
Most useful navigator services		
Obtaining referrals	28	70%
Transportation help	23	58%
Scheduling appointments	23	58%
Communication	22	55%
Support group/counseling referrals	22	55%
Direct emotional support	19	48%
Completing paperwork	14	35%

Author Manuscript
Author Manuscript
Author Manuscript
Author Manuscript

Housing	6	15%

Note. Responses are out of a total $N = 40$.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Table 2

Samples of Barriers to Care

Gender	Age	Representative Quotes
M	60s	I just had this thing about not wanting to go out in public, because I had probably lost about close to 40 pounds and I just didn't have any energy, no desire to get up and even move and go out anywhere to leave the house.
F	20s	I wasn’t contacted for any type of follow-up examinations and was kind of just left on my own. That’s where my whole life just crumbled apart where I was; my mom had to move into the house because I was so scared to go to sleep by myself, because I was afraid I wouldn’t wake up. I started having panic attacks. Anytime I felt any type of pain or stress in my chest, it just sent me into a panic attack. I lost a lot of sleep. I actually failed out of school because it was so much on my mind.
M	Age missing	I just worry about my credit…I had an appointment in April and…they sent me a letter telling me they hadn’t been paid and that they were going to turn me over to collections. I felt a little bit nervous about going down there for another follow-up treatment.
F	50s	I think one of the tests I went to get the mammogram…it was never paid for. The thing I didn’t like about it is…you’d have to write some kind of paper to some people to get the help, financial help. If you’re sick and you have cancer, I don’t know if you would feel like writing a report.
M	50s	I call it in Indian language “money scent.” They want that money. The cut me open and bill me with $8000…I told [the navigator] I didn’t want [the doctor] around, because…they are just there to get that money. They don’t care about the patient, they wait till the patient is ready to die and then they want to be there just to get that overtime. That’s what I hate about these doctors over here.
M	50s	I just blew up because prior to getting cancer I had to get mad at the doctor over there because I wanted a PSA test. He wanted to give me a blood test, a urine test, to find out if I was smoking marijuana…I said I didn’t want that, I wanted a PSA test, a blood test to find out what my count was. He didn’t want to give me one.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Table 3

Samples of Most Useful Navigator Services

Gender	Age	Representative Quotes
M	60s	He was always there, [the navigator], did so much for so many people and he seemed to know when I had an appointment because he was always there to talk to me after…he got copies of papers for me that I needed, he just did everything.
F	50s	My Navigator, she's very involved in the treatment. She is always in touch with you, seeing if you need anything or how your doctor appointments are going. She helps set up the appointments, make sure you have your medicines and she visits your house…asks how you are feeling, if you are eating. She is very on top of everything. She brings a notebook. She keeps track of all of that. If you have any problems, you can talk to her about them. I am having problems with a doctor that I had before when I had the breast cancer, and she checked into it and found me another doctor to go to for a second opinion.
M	70s	[The navigator] gave out information, things you didn't know about yourself and your body and everything…so it made it easier to make decisions.
F	70s	[The navigator] did make several phone calls for me because at the time I was looking for help to come to the house…he called state agencies and things to see if he could find help for me, and he did find help for me.
F	70s	[The navigator] gave me a journal to keep track of what I had in my health care and my doctor visits and who went with me and what I found hard or what I found fairly easy to refer to when [the doctor] talked to me. I would know, I'd have my little notes that would tell him what I needed to work on.
F	50s	When I was supposed to be first starting chemo, [the navigator] showed up. He was going to go with me because it was that doctor who treated me really bad. We ended up filing complaints…and [the navigator] took those and said, "I'll make sure they are turned in where they are supposed to go." He just totally supported us on our decision for that and that's when I got transferred up to [local hospital].
M	80s	It made it much easier to have a navigator with me because the navigator knew what was going on, where the doctors usually are dropped right in the middle of the little thing and don't quite see the whole story. So [the navigator] can fill them in.
F	50s	It seemed like everybody wanted insurance and money up front and I had none of the above because I had run out. But with [the navigator's] help I was able to get medical assistance from the state, Medicaid.
F	40s	The tribe said they were not able to pay for my travel every week. But the travel check I got once a month, and then the scholarship funding [obtained by the navigator]…it did help as far as me being able to pay for motel rooms and stuff like that when I had to stay up there.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 4

Samples of Satisfaction and Recommendations

Gender	Age	Representative Quotes
F	70s	I think the attention that each and every one of us received…if you have a very caring person, like we did, he would do anything and everything for you, all you had to do was give him a call…I think that makes all the difference in the world.
F	50s	I think it's an outstanding program, I really do. Unless you have had cancer and been through it…the littlest assistance goes a really long ways. Whether it's making sure your meds are there or calling us up to see how treatment went. I mean, those types of things are invaluable. Truly.
M	Age unknown	[The navigator] made me feel like a person and that I was important. When I left here, I left with some really good thoughts about myself and the program. I was really glad that they had the program and the assistance available.
F	60s	The attentiveness to detail on – I'll just call it day-to-day operations – on appointments, scheduling appointments, making sure pre-meds were there, making sure confirmation on appointments and test. The navigator just followed through on all of it in a very, very timely fashion which just took all of that off. I didn't have to worry about it.
F	70s	I would definitely recommend the navigator because in my situation I think the navigator was a lifesaver in helping me get my medical and my assistance and talk with others about my history and made me feel, I don't know, that because I had cancer didn't mean that I wouldn't be able to have a life.
F	50s	criticism [The navigator] made a few phone calls for me but…that was the limit of it, making a few phone calls and getting me pamphlets that had lists of resources for me.
F	40s	recommendation I think if you're going to be a navigator you really need to understand the cultural, traditional and maybe the spiritual side of the native people, and maybe integrate the program more towards that type…so I think maybe that side needs to be built upon a little more
M	50s	criticism/recommendation The fact is I didn't know that [the navigator] was available until I had this problem and I was in the hospital…I didn't realize the fact that they even had a navigator program and maybe…it needs to be advertised more or make people more aware of the fact that they are available.