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Providing Community Education: Lessons Learned from Native Patient Navigators

Linda Burhansstipanov,

Native American Cancer Research Corporation (NACR), 3022 South Nova Road, Pine, CO 80470, USA

Linda U. Krebs,

College of Nursing, University of Colorado, Anschutz Medical Campus, ED2N Room 4209, 13120 East 19th Avenue, Box C288, Aurora, CO 80045, USA Linda.krebs@ucdenver.edu

Lisa Harjo,

Native American Cancer Research Corporation (NACR), 3110 South Wadsworth Blvd., Suite 103, Denver, CO 80227, USA LisaH@NatAmCancer.org

Shinobu Watanabe-Galloway,

Epidemiology Department, College of Public Health, University of Nebraska Medical Center (UNMC), 984395 Nebraska Medical Center, Omaha, NE 68198-4395, USA swatanabe@unmc.edu

Noel Pingatore,

Inter-Tribal Council of Michigan, Inc., 2956 Ashmun Street, Sault Ste. Marie, MI 49783, USA noelp@itcmti.org

Debra Isham,

Oklahoma City Area, 701 Market Drive, Oklahoma City, OK 73114, USA Debrai99-mail@yahoo.com

Florence Tinka Duran,

Great Plains Tribal Chairmen's Health Board, Northern Plains Tribal Epidemiology Center, 1770 Rand Road, Rapid City, SD 57702, USA tinka.duran@gptchb.org

Loretta Denny,

429 W 150th St., Glenpool, OK 74033, USA memabear52@yahoo.com

Denise Lindstrom, and

Native American Cancer Research Corporation (NACR), 3110 South Wadsworth Blvd., Suite 103, Denver, CO 80227, USA

Kim Crawford

John T. Vucurevich Regional Cancer Care Institute, 353 Fairmont Boulevard, Rapid City, SD 57701, USA KCrawford@regionalhealth.com

Abstract

Native Navigators and the Cancer Continuum (NNACC) was a community-based participatory research study among five American Indian organizations. The intervention required lay Native Patient Navigators (NPNs) to implement and evaluate community education workshops in their local settings. Community education was a new role for the NPNs and resulted in many lessons learned. NPNs met quarterly from 2008 through 2013 and shared lessons learned with one another and with the administrative team. In July 2012, the NPNs prioritized lessons learned throughout the study that were specific to implementing the education intervention. These were shared to help other navigators who may be including community education within their scope of work. The NPNs identified eight lessons learned that can be divided into three categories: NPN education and training, workshop content and presentation, and workshop logistics and problem-solving. A ninth overarching lesson for the entire NNACC study identified meeting community needs as an avenue for success. This project was successful due to the diligence of the NPNs in understanding their communities' needs and striving to meet them through education workshops. Nine lessons were identified by the NPNs who provided community education through the NNACC project. Most are relevant to all patient navigators, regardless of patient population, who are incorporating public education into navigation services. Due to their intervention and budget implications, many of these lessons also are relevant to those who are developing navigation research.

Introduction

Northern and Southern Plains American Indians (AIs) experience higher rates of cancer and other chronic conditions compared to non-Hispanic whites living in the same region and AIs living in other regions within the 48 contiguous states [1, 2]. American Indian and Alaska Native (AI/AN) people in general continue to be at higher risk for cancer than whites [3]. The *American Journal of Public Health* released the AI/AN all-cause mortality supplement on April 22, 2014, and confirmed that Contract Health Service Delivery Areas (CHSDA) provided less racial misclassification and was more accurate when describing AI/AN cancer incidence and mortality; thus, only CHSDA data are reported here. Common themes among these data include the following:

1. The substantial progress in reducing cancer death rates experienced by whites over the two decades was not shared by AI/ANs [4]; cancer mortality rates remained the same or more commonly were increased from previous data [5–9].
2. There are significant geographic regional differences for AI/AN cancer incidence and mortality, whereas white rates remain fairly homogeneous nationwide. Thus, aggregated national AI/AN data are misleading and inaccurate. There are substantial cancer disparities between AI/AN and white populations in regional analyses (particularly for breast, cervix, colon, and prostate cancers) [10–16].
3. AI/ANs from Alaska and the Northern and Southern plains have significantly elevated cancer incidence and/or mortality rates while AIs from the Southwest have significantly lower rates.

4. AI/ANs are more likely to be diagnosed with cancer at a younger age and at more advanced stages in comparison to whites who typically are diagnosed with early-stage disease and over 60.

In both the Northern and Southern plains, death rates for AI/AN men were elevated compared with white men for cancers of the lung, colon, rectum, prostate, and larynx. AI/AN women in these two regions also had significantly higher rates of lung, colorectal, and cervical cancers [17]. For lung, CRC, and breast cancers, significant declines in death rates occurred in whites, whereas the corresponding death rates for AI/ANs remained unchanged or increased [18]. Most AIs are diagnosed with advanced stages of cancer [19].

AIs access care from different and often fragmented health care systems. A closer look discloses that there are differences within and between various regions of the USA in the health care systems that are available and accessed by AIs. If living on or near a federal reservation, most AIs access health care through the Indian Health Service (IHS); a few receive health care at public institutions. Those who have health insurance receive care in sites determined by their health care plans. IHS offers basic clinic services until there is a cancer diagnosis; then, patients are referred through Contract Health Services (CHS) out of the IHS system to private health providers. When there are not enough CHS funds available in a contract year, patients cannot be referred until the next year begins. Those without health insurance and not living near an IHS clinic access health care the same as others in poverty, often not receiving health care until the situation is an emergency. Due to fragmentation of services, many AIs fall through the cracks and do not access or take part in recommended cancer screenings.

Native Navigators and the Cancer Continuum (NNACC) was implemented partially to address this elevated and growing cancer problem. NNACC was funded by the National Institutes of Minority Health and Health Disparities of the National Institutes of Health. It was a community-based participatory research (CBPR) study among Native American Cancer Research Corporation, CO; Inter-Tribal Council of Michigan, MI; Rapid City Regional Hospital's Walking Forward, SD; Great Plains Tribal Chairmen's Health Board, SD; Muscogee (Creek) Nation, OK; and with statistical analysis through Southeastern Program Evaluation, KY. The goal was for the partners to collaborate, refine, expand, and adapt various navigator/community education programs to address Native American communities' and patients' needs throughout the continuum of cancer care (prevention through end-of-life) (Fig. 1). The research question was, "Can a Native specific comprehensive Navigator-implemented community cancer education intervention improve health behaviors among Native American community members?"

The study intervention was designed for eight Native Patient Navigators (NPNs) to implement and evaluate up to six series of 24 h of community education workshops from January 2009 through September 2013. The NPNs originally were to deliver the education intervention to 738 unduplicated American Indians; however, due to popular demand (see Fig. 2), the study reached 1,964 unduplicated participants (after receiving approval from the Western Institutional Review Board (IRB) to increase the study size).

The workshops were designed to increase participants' knowledge and to help increase the visibility of NPNs within their respective communities. Detailed findings are available in this issue in the article "Findings from the Native Navigators and the Cancer Continuum (NNACC) Study."

As identified by Dr. Harold Freeman, the initiator of the concept of patient navigation in the latter 1980s, navigators are individuals who work directly with individuals to facilitate timely access to health care by eliminating or navigating any barriers that may impede care [20]. They primarily work in medical settings but also can work in the community where they inform people about the need for recommended examinations and provide timely access to such examinations. In cancer care, a critical function is to eliminate barriers to timely diagnoses and treatment in patients who have abnormal or suspicious findings. Navigators may be lay (from the community) or clinical (health care professionals). All of the eight NNACC navigators are "lay navigators" who rely on the patient's health care provider to provide personal medical information and guidance. They are from diverse education backgrounds (high school graduates to nurses to masters' degree completion). Most were females (one male passed during the study, and another male was recruited to a new position). Only one Navigator was a new hire once the intervention began; thus, NPN retention was 90 % throughout the study.

Method: Education Intervention by NNACC NPNs

NPNs met in person ten times with administrative staff from December 2008 through January 31, 2013 (note: the grant received a 1-year cost extension through to 2014 but was prohibited by NIH to use any monies for face-to-face meetings) and quarterly webinars. All face-to-face or webinar meetings included NPNs sharing lessons they were learning with one another as well as with the administration team. NPNs responded to prompts such as, "What do we need to change to make the intervention or processes better? What is working well? What do we need to do for subsequent NNACC grants that we are unable to do now (due to limited grant monies)?" All meetings had note takers to record the NPNs' comments and suggestions. There were also debriefing sessions held with members of the administrative team and their respective NPNs. The administrative team member and respective NPN would share their discussion during the following call and webinar, and again, these were captured in notes. During July 2012, the NPNs met to review issues throughout the grant and how they were addressed or strategies to make future NNACC education interventions more effective. They had access to previous notes prior to the in-person gathering. Their July summary was quite lengthy (30+ pages, single spaced) and proactive. The summary outline was re-organized and edited four times, and then text was drafted and revised by all of the contributing authors of this paper. The NPNs also felt it was essential to include actual quotes from participants and one another to help clarify issues within the paper. Inclusion and priorities as summarized in this paper were determined by the NPNs; thus, early lessons were unanimously agreed as priority lessons, whereas later lessons were important but not universal issues for all of their sites.

Contrary to common perceptions of skills of minimally (HS; some college, but no degree) and well-educated (e.g., LPN, RNs, BS) navigators, all of the NPNs, regardless of academic

education, required extensive cancer information and intervention implementation practice during their training. There were also common issues expressed by NPNs regardless of their academic backgrounds. However, the sites did have some differences (e.g., Inter-Tribal Council of Michigan, Inc. (ITCMI) administrator and the ITCMI NPNs worked very close together for evaluation data uploads, and other (NACR and MCN) NPNs worked independently to upload evaluation data to their respective online programs). Some NPNs (RCRH-WF, ITCMI, MCN) had streamlined access to local clinical services, and others (GPTCHB, NACR) did not.

Among the goals of NNACC was to increase the visibility of the NPNs by having them conduct community education workshops for local AI community members. As part of the study, NPNs implemented the education interventions in collaboration with local AI community-based organizations such as Tribal Elder Meal Programs, Oglala Sioux College, Tribal Schools and Parent committees, and Denver Indian Family Resource Center. These collaborations ensured that services reached the broader AI community in each partner's local area.

Community education is *not* a common role for patient navigators. However, one of the NNACC partners has provided navigation services since 1994, yet repeatedly, AI cancer survivors in her area expressed surprise that such support and services were available. Through conducting the workshops in their respective settings, the NPNs and their navigation services became apparent and broadly known to community members. Throughout the study and particularly during debriefing meetings during the latter portion of the study, the NPNs shared their perspectives about integrating education workshops within their existing navigation roles. Their ideas and recommendations are organized as lessons and are relevant to patient navigators who also are implementing education workshops with any population.

Findings: Education-Specific Lessons from NPN's Perspectives

The NPNs wanted to provide lessons learned to navigators working in other group cancer education programs. National patient navigation leaders, such as Harold Freeman, M.D., adamantly states during public speaking engagements that navigators' roles need to be specific and limited and should not be expanded to include skills such as community public education. However, providing these workshops successfully increased the NPNs' visibility in all study sites of NNACC. Additionally, these workshops increased community members' knowledge about cancer and encouraged many to take part in cancer screening and other healthy behaviors. NPNs identified the following lessons as being crucial to providing successful education to community groups. These lessons can be divided into three categories with a final, overarching lesson for the study and for those providing navigation programs. Category 1 is about NPN education, category 2 is on content and presentations, and category 3 is on logistics. The final lesson (9) is an overarching issue.

Category 1: NPN Education

Lesson 1: Preparing and Role Playing/Practicing Before Implementing Education Workshops with Community Members Is Essential—Essential

components for presenting high-quality, comprehensive education workshops include feeling comfortable with one's personal presentation skills, being extremely familiar with the education content, having the cultural knowledge to present content effectively and in an acceptable manner, and understanding location logistics and possible barriers to successful presentations. This involved preparation and practice/ role play prior to workshop implementation.

In-Service Training for Presentation Skills—The NNACC project allocated time for detailed, in-depth, and in-breadth in-service training, particularly to develop group presentation skills and gain cancer knowledge. Trainings generally were tailored to the NPN's needs based on education and prior experience with making presentations and on knowledge of cancer and cancer care. Initial training included 120 h of content ranging from basic grant information to general cancer care to in-depth review of each proposed education topic. The training hours gradually increased over the duration of the study to more than 200 h. In year 01, the NPNs had three face-to-face in-service sessions; this was reduced to two face-to-face in-services and a 2.5-day semi-annual update meeting for years 02–04, with one in-service in year 05. During this time, NPNs also took part in eight education webinars for follow-up and/or new topics based on community requests. While providing necessary, basic education, the NPNs felt that the time allocated was insufficient to address the knowledge and skills they needed to implement the workshops effectively and efficiently. There was no difference in the need for more time to practice based on NPNs' academic backgrounds. They adamantly wanted more face-to-face sessions to practice, yet insufficient funding for such activities prohibited this. Thus, others using a similar navigator-implemented community education program need to allocate sufficient face-to-face in-service training that allows the navigators to practice teaching modules together.

Presentation Skills—The NNACC protocol required that the NPNs become skilled at presenting cancer education information to AIs and other community members. Several NPNs had never conducted a group presentation prior to this grant, and others had variable or limited presentation skills. When feasible or requested, members of the administrative team who were all experienced presenters would present a workshop topic and have less-experienced NPNs assist (see Fig. 3). Debriefings between NPNs and their respective regional administrative team member included presentation issues and strategies for improving such skills. The NPNs received information on how to present effectively and then practiced presenting the workshop topics to one another during face-to-face meetings and over webinars. Because all workshops included interactivity, NPNs also had to learn how to incorporate games, case studies, and other activities to enhance learning. These also needed to be practiced so that activities could be incorporated smoothly into the presentations.

Cancer Knowledge—In addition to presentation skills, the workshop topics included cancer information that was new to the NPNs. In-depth education on each topic provided both basic and more advanced information. Activities to increase the NPNs' learning were incorporated in the content, and questions and discussion about each topic were encouraged. Some topics, such as cancer treatment information and technology changes, were much

more effective via face-to-face meetings than through webinars. Of note, regardless of education background (HS vs. RN academic background), all the NPNs needed cancer education in-service trainings, and the more educated were not better prepared to address cancer knowledge than the lesser educated. Thus, the nurses needed as much cancer content knowledge as did the high school-educated NPN.

Cultural Knowledge—The administrative team member for each partner was responsible for working with the NPNs to gain local AI cultural knowledge. All of the NPNs had some cultural background, but each site included tribal members from nations other than their own (see Fig. 3). Workshop participants asked the NPNs many cultural questions that required the NPN to understand the concept sufficiently to translate or interpret the issue for the participants. The need for such cultural knowledge varied for each NPN and by topic (e.g., ceremonial use of tobacco or the inclusion of traditional Indian medicine with Western medicine for cancer treatments). NPNs from the AI community were familiar with local cultural perspectives and language and used this knowledge to make the education content understandable and relevant.

Understanding Logistics—The NPNs needed to learn how to assess logistics specific to their upcoming workshops. These included room size, lighting (so that the slides could be shown), available equipment (screens, projectors), and potential barriers to learning (lack of child care, noise in adjoining spaces, etc.). Equipment and materials then could be pre-planned and brought to the location with the NPN (Table 1).

Before conducting a workshop, the logistics for the presentation need to be fully explored. This includes not only looking at the size of the room and available equipment for the presentation but also a number of other factors such as the number and placement of electrical outlets, whether a screen or a blank wall is available for the slide presentation (if the wall is dark, bringing a white sheet and masking tape to use the wall serve as a screen), and the ability to darken the room so that the presentation can be seen (i.e., some rooms had windows with no blinds). Additionally, seating arrangements, barriers to viewing slides, and identifying any additional equipment and materials needed are essential. When doing a number of educational sessions over time, it is helpful to develop a guide to help with the setup each time. This can be a list of items needed for every presentation or a bag packed and ready with the commonly needed equipment. The list grows out of practice and experience and can change when necessary. If a bag is packed at the completion of each educational event, it will be ready for the next time (note: this lesson is relevant to PNs of any race who are implementing education sessions or interventions).

Lesson 2: Ongoing Education and Support Assures Navigators Remain Current and Materials Are Up-to-Date

Through collaboration with the NNACC partners, the navigator in-service training evolved from 120 into 200 h for the initial overall training with additional training through semi-annual updates. These updates frequently were on topics previously presented, primarily because the NPNs had variable levels of readiness to learn and the opportunity to apply new content and new skills. For many complex topics, such as cancer treatments, in-service

training required three repetitions before NPNs responded with comments such as “now I get it” or “oh, I thought I understood, but now I see it has more steps in the process for us to help the patients.”

There was a very steep learning curve for all the NPNs and repetition facilitated learning. All NPNs practiced saying, “I don't know, but I will try to find out” during face-to-face and webinar sessions (see Fig. 4). By practicing such a phrase, the NPNs said it was easier to say in real life with workshop participants. Additionally, new content was added frequently, and questions raised by participants needed to be discussed and answered to ensure that the all NPNs' knowledge was upto-date. The NPNs needed to feel comfortable telling the participants when they did not know correct answers to their questions. Additionally, they needed to know how to follow up and provide the answers once they had obtained assistance to correctly respond to the question.

Ongoing support was available via email or phone to answer questions the NPNs could not readily answer or to clarify education content. The ongoing in-service trainings and support were keys to allowing the NPNs to stay current with new research and discuss changes in screening policies and recommendations among one another and with workshop participants. Materials (slides, handouts, etc.) were updated as new information became available.

Lesson 3: Face-to-Face Education Facilitated Learning in Ways that Other Methods of Education Could Not

Trainings for NPNs included both face-to-face and webinar formats throughout the grant period. Initial education was conducted face-to-face, allowing the NPNs to discuss, ask questions, and take part in interactive learning and role playing the processes of delivering content and answering questions. The administration team provided feedback to enhance both knowledge and skills. Almost all of the face-to-face sessions were videotaped and allowed NPNs to review raw video content for refreshers as needed. Over the course of the grant, face-to-face meetings decreased due to budget limitations while webinars for training increased. These webinars did not allow for viewing body language, seeing a raised hand or noticing a puzzled look that might indicate questions about content or the need to discuss a concept more in-depth (see Fig. 5). Role playing was not possible unless NPNs were together. Length of webinars was limited (generally 1 to 1.5 h) due to the inability for most to stay focused when unable to see or directly interact with each other. Thus, although the webinars were helpful, all felt these could not replace face-to-face trainings for cancer information that was new to them or for additional, supplemental training.

Category 2: Workshop Content and Presentations

Lesson 4: Workshop Content Needs to Be Culturally and Geographically Appropriate to the Local AI Communities—All partners collaborated on modifying the content of the community education and tailored the content to their local settings. The most commonly presented topics are shown in Table 2. Local data replaced national or regional data summaries when such data were available. Local graphics also replaced the global Native-specific graphics within the slides whenever possible.

Each partner made great efforts to “listen to the community” (e.g., community advisory committee, focus groups, community members). Based on local community guidance, ITCMI's staff focused their education workshop on elders. GPTCHB and RCRH focused theirs on young adults. The other two partners selected different MOAs, and the MOAs' population group was the focus (e.g., homeless adults). Although the partners targeted their audiences slightly differently, all adults were welcomed to take part, and most sites included other racial groups in addition to AIs.

Each partner modified curricula templates to tailor the content to their respective geographic area and to integrate respect for local cultural issues. Thus, reserving tobacco for spiritual or ceremonial uses (vs. habitual/addictive use of tobacco) was addressed slightly differently by each partner based on how tobacco was used spiritually by their local communities. In a few workshop series, traditional Indian healers spoke about traditional ways to show respect for tobacco as a sacrament. Exposure to environmental contaminants included many slides that identified all potential contaminants in each partners' location. However, each partner removed the slides describing contaminants of little or no relevance to their location. The Cancer 102 Treatments module was also adapted because access to standard care or state-of-the-art care was not accessible in all partners' locations. Clinical trials are included within that module, but again, the examples had to be modified for what was accessible in the partners' respective regions. As all partners agreed that it was important to create strong, collaborative working relationships with key local community organizations, partnerships were made and these groups helped to tailor the content as well (see the article on NNACC Partnerships available in this JCE issue). The partners also varied the length of workshops from 90 to 120 min. RCRH, GPTCHB, and ITCMI provided 1– 1.5-h duration workshops, while NACR and MCN provided 2 h. All partners included pre- and post-tests, discussions of the topics, and participant interactive learning opportunities within the workshop sessions regardless of length. For all partners, tailoring the workshop content resulted in the community feeling comfortable with the very effective and culturally appropriate information for their respective AI communities.

Lesson 5: Additional Discussions, Education, and Materials Facilitate Being Able to Address Technical and Clinical Questions from Participants—When feasible, the NPNs initially observed and then team-taught with members of the administrative team prior to conducting workshops on their own. Also, when practical, the NPNs from the same partner organization teamed up to copresent the workshops (see Fig. 6).

Such exposure or shadowing experiences helped the NPNs identify potential questions, hear possible responses, and observe how more experienced presenters interacted with the audience. Webinars included examples of frequently asked questions so that the NPNs could practice. In most sites, the local administrative team member provided a debriefing to review the workshop implementation and provided guidance on how to improve performance and respond to questions.

Although the debriefings and webinars discussed examples of common questions to expect from community members, the NPNs requested a handout of these questions and their

answers to help prepare them to present workshops on their own. This was not feasible for the NNACC and would have been of great benefit to the NPNs. The NPNs recommended that such a resource be included in future NNACC grants. Additionally, the NPNs shared questions they received during the workshops and related how they responded to them as peer education with one another. As needed, additional readings and resources were provided to increase the NPNs' knowledge base. These materials, discussions, and additional education increased the NPNs' comfort level with providing information and answering questions during the workshops.

Lesson 6: Local Expertise Should Be Sought to Present Workshop Topics Requiring Special Knowledge or Skills (e.g., Final Wills and Advanced Directives, Management of Cancer Treatment Side Effects)

NPNs invited experts to present topics that required special knowledge or information not readily available or common for the navigator. NPNs shared information about the type of expert they invited to their respective workshops with one another during the face-to-face and quarterly webinars. Such expertise was not available in all sites but provided ideas of other organizations or resources that may provide such expertise. The most common topic for including experts was for the "Final Wills and Advanced Directives" workshop. All invited experts to speak about these topics. Tribal laws related to final wills are complex. Finding local legal guidance was always recommended as legal mandates varied across sites and specifics for each tribal nation needed to be clarified. Participants had multiple questions (see Fig. 7) that could not be answered by the NPN and required the expertise of a local lawyer or judge knowledgeable about tribal law. For example, both the Northern Plains Legal Services and Muscogee (Creek) Nation Tribal Legal Services professionals came to help answer the questions so that the NPNs were not providing legal advice. The NPNs collaborated with these legal services to help set up appointments for workshop participants interested in developing legal documents.

"Wills and Advanced Directives" was only one of the workshop topics for which NPNs invited local experts. For example, ITCMI invited local nutritionists to speak on healthy eating and local educational resources in their community, tribal environmentalists spoke on environmental contaminants, and tribal fitness center directors presented on physical activity for the "energy balance" workshop. Bringing in local tribal experts not only ensure accurate information was provided, but it also increased visibility of these programs and resources for the participants.

Category 3: Logistics

Lesson 7: There Needs to Be a Centrally Located and Easily Accessible Site for Obtaining the Most Up-to-Date Workshop Presentations—Each community had preferences for which workshop topics they wanted to include within each series. However, those topics needed to address the full continuum of cancer care (see Table 2). During the initial years of the grant, the current versions of the workshops were posted on a SharePoint website so that all could access the originals and post any modifications. However, the site was too small to include all of the tailored variations of each session, and it was difficult to find the most current, revised/updated version of a workshop.

Subsequently, all NNACC workshop presentations were moved to a password-protected location within NACR's website pages. Both administrative team members and NPNs shared changes they made in the workshop content with one another via discussion (in-person and webinars) and within slides posted on the NACR NNACC web page. This simplified the processes for finding the most recent version of the workshop slides.

Lesson 8: Data Collection Systems (Hardware and Software) Need to Be the Same Across All Sites, and NPN Presenters Need to Be Able to Troubleshoot Problems on the Spot—

Data for the NNACC workshops were collected using an audience response system (ARS). ARS is a computer-assisted tool consisting of handheld keypads linked wirelessly to a computer system and an audiovisual display. NPNs used ARS to collect workshop demographics, pre- and post-workshop knowledge, attitude and behavior items, and overall workshop satisfaction. NACR, GPTCHB, and ITCMI each had some experience working with ARS prior to NNACC. However, not all sites had the same hardware or software, resulting in the need for multiple versions of the Western IRB-approved ARS questions. The use of systems that differed from site to site and different layouts for questions resulted in some unnecessary confusion. Over the years, all partners migrated to the same software, and a lot of unnecessary confusion was avoided. Thus, using the same ARS hardware/software for all partners eliminated this issue.

Similarly, each partner has its own online evaluation web page. NPNs uploaded demographic and average knowledge correct summaries from pre- and post-tests following each workshop. The program was not intuitive and required individual passwords to access their respective web page. Most people needed one-on-one help to improve their skill level using their program's online evaluation program. Once uploaded, the program produced quick report summaries specific to each partner's NNACC program.

Multiple problems can occur when gathering evaluation data electronically. Among them are power failures, inactive polling features, and poor communication between the laptop and LCD projector. Particularly during the initial year of the education workshops (year 02 of the study), the NPNs had to troubleshoot ARS on site prior to the workshop, while trying to get the system started, and after the workshop, when trying to download files. Gradually, all of the NPNs became very competent and familiar with how to operate the software, download files, generate reports, and summarize/interpret results.

Some NPNs were particularly creative about how to use the system at NNACC events held in the open or when electrical power failed or was unavailable. For example, one NPN collected follow-up knowledge data at an event held at a local AI park where there was no power and no screen available. The staff distributed the ARS keypads and Ms. Harjo gave everyone a handout of the questions. She facilitated data collection by reading each question and the possible answers to the participants. The participants responded by clicking their answers on the keypads, and the NPN's laptop, running on battery, collected the data. This same strategy was successfully used in the South Dakota sites.

Overarching Lesson

Lesson 9: When a Project Meets the Needs of the Community, It Is Likely to Be Successful—All partners experienced a very pleasant but surprising phenomenon: The AI community members wanted to take part in the workshops. The study was supposed to educate 738 un-duplicated participants, and this estimate was based on previous education workshops implemented in each partner's location (i.e., average of 6–12 participants). However, 1,964 un-duplicated participants took part in the workshops (IRB approval for the increase in number of participants was received from the WIRB prior to enrollment). The workshops all started with small numbers of participants and rapidly expanded to 20–25 participants for most settings. The exceptions were MCN, the site that was added to the NNACC late in year 02 after the intervention had already been initiated in all other partners' locations (see Fig. 8). Also, adjacent communities asked each partner how they too could have NNACC introduced in their settings (five formal requests for such partnerships of which one was successfully initiated during NNACC through ARRA funding within Comanche Nation (PI: Eschiti)).

While exciting and rewarding, additional funds needed to be obtained to provide every participant with the US\$10 gift card given as an incentive at the end of each workshop and cover other unexpected workshop costs. Each partner used innovative and different approaches to obtain this additional funding. For example, GPTCHB received a small grant to support the additional incentive gift cards. One of the two ITCMI sites received donations for larger raffle items, and for each workshop attended, participants received one raffle ticket.

The NPNs and administrative team discussed why there was such a strong, positive response to the education workshops. All agreed that the AI community was hungry to learn more about how to prevent cancer as well as how to support family and friends diagnosed with cancer. One NPN commented that our AI ancestors took a strong personal responsibility for taking care of themselves. After colonialism, the Bureau of Indian Affairs, IHS, and other federal agencies addressed AIs' health conditions but not until *after* the problems occurred. People lost their sense of self-responsibility for promoting and protecting their own health and well-being. Members of the Denver community repeatedly stated that they needed to have control over their health and wanted to focus on prevention and pro-active behaviors as did their AI ancestors before the governmental agencies got involved with I/T/U health care.

Conclusion/Summary

Providing cancer education to local community groups is beyond the normal purview of patient navigators. However, such an undertaking was the key education intervention for the NNACC study. NPNs from Northern and Southern plains' AI settings dedicated themselves to learning totally new content and presentation skills to implement this intervention. They experienced steep learning curves and needed more face-to-face training sessions for optimum developing of such skills. Regardless, each overcame workshop education challenges to deliver dynamic, interactive, and highly effective education workshops to their respective communities. The NPN-implemented workshops resulted in significant

knowledge increases by community members as well as successfully greatly increased the visibility of NPNs and their services within their respective communities. Key lessons from the NPN's perspectives were summarized within the paper.

The NNACC NPNs and administrative team plan to integrate these lessons in future CBPR patient navigation projects. These are also appropriate for navigators from other tribal settings and for non-native navigators that plan to expand lay navigators' roles to community education.

Budget issues of needing to expand the training to 200 h and repeat some topics (e.g., cancer treatments) three times need to be included in future NNACC grants were not planned for but were essential. Thus, each administrative partner adjusted their organization's budget to accommodate additional training needs of the NPNs. Several other related issues occurred, such as each of the partners received requests for patient navigation services that were beyond the scope of the NNACC. When feasible, participants were referred to other comparable services, but majority of the time, there were no such comparable services available. Also of interest was the number of community members who wanted to know how they could learn and be trained to be a lay native patient navigator. The NNACC partners plan to prepare a dissemination grant that can address such requests in a very limited manner.

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Abbreviations

AI	American Indian
ARS	Audience response system
CHS	Contract Health Services
GPTCHB	Great Plains Tribal Chairmen's Health Board
IHS	Indian Health Service
ITCMI	Inter-tribal Council of Michigan, Inc.
MCN	Muscogee (Creek) Nation
MoAs	Memorandum of Agreement with local AI organizations
NACR	Native American Cancer Research Corporation
NNACC	Native Navigators and the Cancer Continuum
NPNs	Native Patient Navigators
Partners	NACR, ITCMI, RCRH, GPTCHB, and MCN
RCRH	Rapid City Regional Hospital

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Fig. 1.
Location of NNACC CBPR partners

Unsolicited comments from community members included:

- "I never thought cancer screening was really important for ME to do. But because of [NPN], now I understand why it is important and I have scheduled my appointment with her help!"
- "This is the 1st time I have EVER attended a community workshop that didn't sound like it was designed for white people. [NPN] talked with us and knew and understood our community and what resources we are not able to get. I am recommending the workshops to all of my family and friends... and I'm picking them up and bringing them with me (laughs)."
- "I never would have gotten Western Medicine care until I learned more about cancer screening from [NPNs]."
- "We want to learn how to be more responsible for our own health again"
- "We want more knowledge about our bodies and prevent problems."
- "I'm from _____ tribe. How can we get these classes for our tribe?" (she was from another tribal Nation based in OK and participated in a MCN workshop with a friend)

Fig. 2.
Unsolicited comments from community members

“Administrative Member Mentoring NPNs”

Lisa Harjo, MS (Choctaw) is the Navigator Coordinator for NNACC and has a long experience conducting local AI community education workshops. Audrey Marshall, Denise Lindstrom (2011 breast cancer survivor), Rose Lee and Linda Lucero were local NPNs and at least 1 would attend each workshop conducted by Lisa. After each workshop, Lisa would debrief what had happened during the workshop with the NPNs and respond to their questions about what, how or why things happened as they did. They also practiced how they would have responded to challenging questions that arose during the workshop. For example, in the living wills and advanced directives session, participants asked questions about how to deal with parents who come from different tribes, one recognizing female lineage and the other paternal lineage for descendants. Lisa and a local AI lawyer discussed the legal tribal implications on inheritance with the NPNs.

Fig. 3.
Administrative member mentoring NPNs

“It’s okay to say, ‘I don’t know, but let me check and get back to you’”

Noel Pingatore is the Administrative Team member for ITCMI. When Amanda Leonard, the Sault Saint Marie NPN, had questions for which she was uncertain how to answer, she would write the question down, tell the participant she would ask and find an answer and then get back to the participant. Such questions during the 1st year of the education intervention included, “who should I talk with at the clinic about my screening test results?” Amanda met with Noel and then went to the local clinic and introduced herself to the receptionist and to others who worked with cancer screening. She created proactive, dynamic and collaborative working relationships.

Fig. 4.

“It’s okay to say, ‘I don’t know, but let me check and get back to you’”

The need for face-to-face in-service NPN trainings

Several of the NPNs commented that they learned a lot from the webinars when Dr. Linda Krebs presented specifics about cancer treatments. However, they all felt the sessions were more powerful and effective via face-to-face sessions. Dr. Krebs would tell stories via both venues (webinar and face-to-face), but the webinars lacked much of the non-verbal communication. Using video with webinars was better, but still lacked much of non-verbal communication. They all preferred face-to-face sessions even though they were more costly and required time away from home.

Fig. 5.

The need for face-to-face in-service NPN trainings

“Peer training was essential for NPNs who had no presentation experience ”
RCRH had staff turn-over shortly after the intervention (year 02) began. Ms. Kim Crawford was provided raw video taken during in-service trainings in years 01 and beginning of year 02. The videos were helpful, but she needed more one-on-one help in learning workshop topics, presentation skills, and appropriate and accurate ways to answer questions. Ms. Tinka Duran, GPTCHB coordinated as many sessions as was feasible for Kim to observe her teach and how she handled the community education sessions, and co-presented a few topics with her to help her improve her teaching performances. Such collaboration and peer education was essential and was reflected in the improved knowledge scores in Kim's classes over time.

Fig. 6.

“Peer training was essential for NPNs who had no presentation experience”

Muscogee (Creek) Nation (MCN): Success of the Project.

MCN was a supplemental site added early in year 03 of the NNACC study. Because they had a shorter period for the intervention, the goal was 135 unduplicated participants rather than 200 (as for each other partner, ITCMI, RCRH/GPTCHB, NACR). However, the MCN community responded with such enthusiasm that they surpassed their goal by the end of the 1st workshop series (each series includes 12 2-hour workshops). Loretta Denny was the lead NPN and conducted most of the workshops. Her initial Workshop series was held in conjunction with Pam Iron and Associates (the MOA), held in Okmulgee, OK and reached 203 unduplicated participants. By the end of the 4th workshop series, MCN had 455 unduplicated participants (NOTE: Western IRB approved the increased number of study participants in 2010).

Fig. 7.

Example of participant's question during “Final Will, Living Will, and Advanced Directives” workshop

Example of participant's question during "Final Will, Living Will and Advanced Directives" workshop.

This is a paraphrasing of a participant's question and story from NACR 2011: This is a blended family. The mother was married to 2 men from 2 different tribes. The father of the 1st set of children was from the southwest and the father of the 2nd set of children was from Northern Plains. Both fathers passed prior to the mother. When the mother passed, the Northern Plains children executed her will and tribal code included all of the children (i.e., including the southwestern children) as descendants of the 2nd father. The Northern Plains children wanted to know how to fight it. The NPN referred them to Indian legal aid (i.e., non-Native lawyer would not be familiar with the tribal codes and federal laws).

Fig. 8.

Muscogee (Creek) Nation (MCN): success of the project

Table 1

List of materials to bring to workshops

Materials	
Items for all workshops	Items for specific workshop topics (examples)
ARS receiver	Hand calculators (Energy Balance)
ARS keypads and replacement batteries	Food containers for label reading (Healthy Eating)
ARS sign-in sheet	Sage, cedar, sweet grass (Keep Tobacco Sacred)
Gift cards and sign-in receipts	Sage, cedar, sweet grass (Keep Tobacco Sacred), walnuts ("Get on the Path to Prostate Health")
Extension cords	Wills worksheets to list valuables (Living Wills)
Power strips	Handout of ARS questions (for backup if lose electricity)
LCD projector (back-up bulbs)	Fact sheet handouts
Computer (with charged battery in case there is no electricity or power losses)	Handout of ARS questions (for backup if lose electricity)
Computer power cord	
Electronic pointer	
Items as needed	
Tape recorder	Overhead project for supplemental light in dark rooms (electrical switches did not have option for partial lighting in room)
Audio speakers	
External DVD player	
Screen or sheet to function for screen (check out prior to workshop session)	Masking tape (for sheet)

Table 2

NNACC workshop topics to address the cancer continuum

Workshop topics	
Prevention	Early detection
Healthy Eating	“Get on the Path to Breast Health”
Energy Balance (physical activity and weight management)	“Get on the Path to Cervix Health”
Exposure to Environmental Contaminants	“Get on the Path to Colon Health”
Keep Tobacco Sacred	“Get on the Path to Lung Health”
Introduction to Cancer	“Get on the Path to Prostate Health”
Survivorship	Palliative care
“Native American Cancer Education for Survivors” (NACES)	Cancer 103 Cancer Treatment Side Effects
Cancer 101 Diagnosis and Staging of Cancer	Palliative Care
Cancer 102 Cancer Treatments	Caring for the Caregiver
Cancer Survivor Support Circles	Wills and Advanced Directives