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Findings from the Native Navigators and the Cancer Continuum (NNACC) Study

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Abstract

Native Navigators and the Cancer Continuum (NNACC) was a community based participatory research 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 Chairman's' Health Board, SD; and Muscogee (Creek) Nation, OK. The project goal was to collaborate, refine, expand and adapt navigator/community education programs to address American Indian communities' and patients' needs across the continuum of cancer care (prevention through end-of-life). The intervention consisted of 4 to 6 site-specific education workshop series at all 5 sites. Each series encompassed 24 hours of community education. The Social Ecology Theory guided intervention development; community members from each site helped refine education materials. Following extensive education, Native Patient Navigators (NPNs) implemented the workshops, referred participants to cancer screenings, helped participants access local programs and resources and assisted those with cancer to access quality cancer care in a timely manner.

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The intervention was highly successful; 1,964 community participants took part. Participants were primarily American Indians (83%), female (70%) and between 18 and 95 years of age. The education programs increased community knowledge by 28%, facilitated referral to local services, and, through site-specific navigation services, improved access to care for 77 participants diagnosed with cancer during the intervention. Approximately 90% of participants evaluated workshop content as useful and 92.3% said they would recommend the workshop to others. The intervention successfully increased community members' knowledge and raised the visibility of the NPNs in all 5 sites.

Keywords

American Indian; community based participatory research; CBPR; patient navigation; cancer education

Introduction / Background

American Indians (AIs) continue to have the poorest five-year relative survival from cancer in comparison to all other ethnic and minority groups in the US (66.7% for Non-Hispanic Whites (NHWs) vs. 59.0% for AIs).¹² Cancer incidence rates vary among AI populations and frequently differ from rates seen in NHWs living in the same geographic region.³⁴⁵⁶ Data show that AI cancer incidence rates have increased⁷⁸⁹ and that the burden of cancer continues to escalate in this population.¹⁰ Cancer incidence and mortality are consistently higher in AIs from the Northern and Southern Plains (within the 48 contiguous states), with higher rates for breast, lung, colorectal and cervix cancers than NHWs living in the same region.¹¹ In most cases, increased mortality is due to diagnostic delays, resulting in advanced stage of disease at diagnosis and an increased risk of dying from cancer.¹² Patient Navigation programs can help to address such disparities.

Overview of NNACC

Native Navigators and the Cancer Continuum (NNACC) was implemented to help address this growing cancer health disparity among Northern and Southern Plains AIs. NNACC was funded by the National Institutes of Minority Health and Health Disparities from 2008 to 2014. It was a community based participatory research study among 5 Partners: Native American Cancer Research Corporation, CO (NACR); Inter-Tribal Council of Michigan, MI (ITCMI); Rapid City Regional Hospital's Walking Forward, SD (RCRH); Great Plains Tribal Chairman's' Health Board, SD (GPTCHB) and Muscogee (Creek) Nation, OK (MCN) with statistical analysis through Southeastern Program Evaluation, KY. The goal was for the Partners to collaborate, refine, expand and adapt navigator/community education programs to address the AI communities' and patients' needs throughout the continuum of cancer care (prevention through end-of-life). 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 implemented and evaluated 3-6 series of 24-hours of community education workshops at each site. Content addressed topics within the full continuum of cancer care. Native Patient Navigators (NPNs) implemented and evaluated the workshops using an

audience response system to collect demographics, pre- and post-workshop knowledge, attitudes and behaviors and workshop evaluation and satisfaction. Each Partner had an independent online evaluation program for uploading workshop data and summaries as well as to document NPN interactions with workshop participants related to obtaining cancer screening or receiving supportive navigation care. Workshop content was designed to increase participants' abilities to make informed decisions about personal health behaviors, encourage healthy practices such as taking part in cancer screening or being supportive of those diagnosed with cancer, and to help family and friends improve their behaviors. The workshops also were designed to increase the visibility of NPNs within their respective communities. NPNs created 2 Memoranda of Agreement per year with a local organization that served AIs. Each organization coordinated and implemented the workshop series as well as 2 Family Fun Events (one for baseline and "kick off" of the project and the other, 3 months following the completion of the workshops series to function as delayed evaluation and dissemination of local NNACC findings).

Methods

Social Ecology Theory

The Research Team used the Social Ecology Theory to guide development of the intervention. This theory begins with the individual (workshop content encouraged healthy behaviors, increased the participants' knowledge, and addressed barriers to screening or healthy behaviors) and facilitates identifying cues to action to meet goals or overcome barriers. Self-efficacy was integrated into Workshop content and included interpersonal concepts by including family and friends as well as referring participants to local resources to reinforce and support healthier behaviors. Organizational concepts were addressed through the annual Memoranda of Agreements with local AI organizations. The Theory "cycles" among the concepts to reinforce behaviors or, if new barriers emerge, to help the individual identify new cues to action to overcome barriers and to interact with more or other community organizations and so on.

Native Patient Navigators and Navigator Training

Dr. Harold Freeman initiated the concept of patient navigation and described navigators as those who work directly with individuals to facilitate timely access to healthcare by eliminating or navigating barriers that may impede care¹³. They primarily work in medical settings but also can work in the community to inform about and provide timely access to recommended examinations. In cancer care, a critical function is to eliminate barriers to timely diagnosis and treatment in those who have abnormal or suspicious findings. Navigators may be lay (from the community) or clinical (healthcare professionals). The navigators used in this project were called Native Patient Navigators (NPNs). All were "lay navigators" who relied on the patient's healthcare provider for medical information and guidance when navigating the patient.

In preparation for teaching the education workshop series and assisting patients and families with accessing cancer care services and resources, the NPNs received more than 200 hours of intensive education and training during the 1st year of the project. Topics covered the

cancer continuum (prevention/early detection to end of life) and ranged from protection of human subjects, confidentiality and HIPAA to basic cancer concepts and treatment and management of specific cancers. Trainings also included learning how to collect knowledge, attitude and behavior data before and following the workshop sessions and incorporated practice exercises to reinforce the new behavior or skill set. Each topic required 90-120 minutes for content and practice. Quarterly updates and new topics were presented in subsequent years. These topics were suggested by the NPNs to address issues they were facing or were requested by NNACC supervisors based on identified gaps in NPNs skills and varied by the needs, experiences and prior education of the NPNs.

In addition to face-to-face sessions, follow-up education included having the NPNs practice teaching a module to others through webinars or with their local NNACC Administrator or through role-playing with each other. Many complex topics, such as cancer treatments or clinical trials, needed 3 repetitions before the NPNs felt they truly understood the topic and could present it to others. Almost all face-to-face in-service trainings were videotaped and the raw footage provided on DVD for review as refreshers and to augment training of newly hired NPNs. Additional trainings varied by site. Training was reinforced through debriefings with the NPNs and their local supervisors.

Community Partnerships

Twice each year each NPN identified an organization that provided services to local AIs and approached the organization to determine its interest in partnering to implement the intervention. For those that agreed, a Memorandum of Agreement was created between the local AI organization and the NNACC Partner. Each local organization had several responsibilities: Promote the AI community education workshop series to organization members or frequent users of the organization.

- Recruit at least 35 unduplicated AI community members to attend the workshops.
- Coordinate logistics and host the workshops and Family Fun Events
- Assign a specific Audience Response System keypad to each participant and ensure that repeat participants receive the assigned keypad at both workshops and Family Fun Events
- Retain and update lists of all participants and their specific keypad numbers and distribute keypads at each session
- Disseminate the \$10 incentives to participants after workshop completion
- Assist the NPNs to prepare and share easy-to-understand findings with those who took part in the workshops as well as to the organization's community-at-large.

The local organizations generally were different for each Workshop series, however, some organizations coordinated more than one workshop series over the duration of the intervention. Benefits of having the local organization carry out the logistics, recruitment and hosting were two-fold: 1) partnering allowed the NPNs to focus on comprehensively teaching the workshops and 2) the organization was able to integrate the NNACC

workshops with other outreach services without having the pressure of learning or teaching new content.

NNACC Intervention

The NNACC intervention was composed of two parts: a series of education workshops and 2 Family Fun Events. The education intervention included 3-6 series of NPN-Implemented education workshops. Each workshop series consisted of 24 hours of content that addressed the full continuum of cancer care (prevention, early detection, survivorship and palliative care / end-of-life). The purposes of these workshops were to (1) increase cancer knowledge and (2) increase the visibility and accessibility of the NPNs who were available to (a) schedule screening appointments, (b) carry out follow-up recommendations, and (c) provide support and education for those diagnosed with cancer. All workshops lasted from 1 to 2 hours and included Audience Response System data collection of demographics, pre- and post-knowledge, attitudes and/or behaviors and workshop satisfaction/ evaluation. Sessions included participant learning objectives, education content on a specific cancer topic, discussions, question and answer periods and participant interactive activities designed to help the participant practice or recall information shared during the workshop.

Two Family Fun Events were held in conjunction with each workshop series. The first occurred prior to the initiation of the workshop series to promote the workshops and collect baseline data (demographics and knowledge items). The second occurred at least 3 months following completion of the workshop series and was used to collect demographics, assess knowledge retention and disseminate workshop findings. All workshop participants, their families and the local organization's community-at-large were invited. These events lasted 2-3 hours and included food and family activities such as Bingo, dance competitions and health fairs. Easy-to-understand summaries of the findings were described orally and provided to all participants.

Online evaluation

An online evaluation program was created by NACR in 2006,¹⁴ and refined by the Partners for the NNACC project. Each Partner had its own online evaluation program, with the PI having access to all. The NPNs uploaded demographic, pre- and post-test summaries and workshop evaluation/ satisfaction data following each workshop. The online programs allowed the PI timely access to each Partners' accomplishments and data to generate summaries and reports.¹⁵ Similarly, each Partner was able to generate reports for its own uses (e.g., applying for other grants) and provide summaries to Tribal Councils and Health Boards and the community through local newsletters.

The Online Evaluation Program included tabs on components such as partnerships, products, dissemination, navigation (included cancer screening and survivor navigation and referral to clinical trials), and NNACC workshop summaries (document unduplicated workshop participants and workshops series logistics of dates, locations). The navigation tab documented how many minutes the NPN spent with each patient per visit and what tasks were complete. Reports could be generated by each Partner from its independent online evaluation database and allowed the NPN to generate summary reports specific to a

particular workshop series. This information was used in the workshop series summaries disseminated during the second Family Fun Event.

Findings

Study Aim #1: “Expand and enhance (a) Navigator/ community education in-service trainings and (b) modify the Native American Community Education Workshops to include the full continuum of cancer care.”

Navigator education for previous projects consisted of 80-hours of in-service training sessions. However, NNACC was a much more extensive project, thus the NNACC Administrative Team collaborated to expand the training to 200+ hours, most of which was completed during the 1st year of the study. After Year 01, quarterly updates, provided face-to-face, through webinars or by role-playing, were presented to ensure the NPNs remained up to date with the workshop content, their teaching skills and knowledge about local cancer-related resources and services.

The Administrative Team modified or developed almost all the possible workshop topics during Year 01 of the study (some topics, such as “clinical trials” within the cancer 102 “treatments” workshop and cancer 103 “side effects”, were updated throughout the education intervention). To assist with this process, each Partner identified community leaders to serve on a local Community Advisory Committee. This committee provided guidance for what should be included for local cultural and geographic relevance for each topic. The draft versions of the workshops were reviewed by local focus groups and through pilot tests. At least 4 Workshop topics were included in the cancer continuum categories of “prevention”, “early detection”, “survivorship” and “palliative care”.

Study Aim #2: “Implement and evaluate 24 hours of Native American Community Education Workshops to at least 738 unduplicated Native Americans.”

In conjunction with each Partners’ community organization, the topics for inclusion in the 24-hour workshop series were selected. The original aim was to reach 600 unduplicated participants (200 per site for NACR, RCRH/GPTCHB and ITCMI and 138 for MCN which was not added as a supplement site until 2011). However, the Administrative Team greatly under-estimated the AI community response to the education intervention and only estimated average workshop sizes of 15-20. However, as word spread throughout the communities about the the workshops, the number of participants in each group increased, with some groups growing to 40-60 participants early in the initial workshop series (For example, GPTCHB had 40+ participants per workshop by the end of the 3rd series and MCN had 40+ participants at its initial workshop sessions and averaged more than 60 participants for each workshop session). This enthusiasm led Administrative Team to submit an amendment to the Western IRB during Fall 2010 to increase the number of participants. As is evident from Table 1, the Partners reached 1,964 unduplicated participants, far surpassing the initial 738 proposed number of participants in the original application.

Although the intervention was tailored for AI cultures, people of different racial and ethnic groups took part. The education intervention reached people of all ages, regardless of how

individual Partners initially targeted specific age groups (e.g., GPTCHB initially targeted young adults and ITCMI targeted people from 50-64 who are at greatest needs for screening, but people of all ages took part at both sites). Table 1 displays the demographics of the unduplicated participants for which there are data (ITCMI lost data due to computer theft and hard drive reformatting prior to data upload to the online evaluation program).

Study Aim #3: “During years 02 through 04, the Native American Community Education Workshops will increase the knowledge and intended behaviors among the Native American participants by at least 20%.”

Each workshop included 3-4 IRB-approved knowledge items; the same items were used for both the pre- and post-tests. All items were multiple choice (4 responses and a 5th for “don’t know / not sure”). The content for all items was included in the workshop discussion and/or reinforced during the participant interactive activities. The percentage of increased knowledge (20%) for the study aim was set based upon the Administrative Team’s successful experience with previous education interventions of 15%. However, this goal was surpassed with an overall increase for all Partners averaging a 28.4% increase (see highlighted row 3 of table 2). The NPNs also administered multiple choice items to evaluate the successfulness of and satisfaction with the workshops. Table 2 also summarizes these scores. The AI community members rated the workshops very favorably. Of note are the very high scores for Muscogee (Creek) Nation that confirm the great need and acceptance of education as that provided through the NNACC education intervention. RCRH scores were low due to NPN staff turn-over at the end of year 01. Once the new NPN had been trained through the NNACC in-service videos and peer education, her RCRH evaluations for the last 18 months of the intervention were comparable with the other Partners.

As shown above, 1,964 unduplicated individuals participated in the NNACC educational workshop sessions during the project period. However, when combining the unduplicated participants with those who attended more than 1 workshop session, the total number of participants at all sessions was more than 4000. Attendance varied by session type. The Tobacco/Lung Cancer sessions had the highest percentage of overall attendees (duplicated and unduplicated) (12.4%) and the Palliative Care sessions had the lowest percentage of overall attendees (3.6%).

Post-session knowledge scores increased from pre-session knowledge scores for all session types. The largest increase in participant knowledge was for the Prostate Cancer workshops, which showed a 35 percentage point increase in mean pre to post-test scores. The workshop with the smallest increase was the Tobacco/Lung Cancer workshop sessions, which only showed a 15 percentage point increase in mean pre to post-test scores.

Mean knowledge scores increased across demographic characteristics when comparing pre- and post-session data from all sites and sessions (See Table 3). Looking at specific demographic categories, mean knowledge score increased throughout the intervention. Mean pre to post score percentage point increases were 23 percentage points. However, some groups showed increases in mean pre to post knowledge scores that were at least 3 percentage points more than the overall increases. These groups included Pacific Islanders;

Asians; Non-Hispanic Whites; Hispanic/Latino/Chicanos and those with some college education, but no degree. In contrast, other groups showed increases in mean pre to post knowledge scores that were at least 3 percentage points less than the overall increase. These groups included those aged 65-80 and those with less than high school education.

Study Aim #4: “During years 02 through 05, Navigators will provide one-on-one support for Native American cancer patients and families identified in the course of the education intervention.” Throughout the intervention period, the NPNs provided navigation services for a total of 77 AI cancer patients (NACR = 18, ICTMI = 12, RCRH/GPTCHB = 22, and MCN = 25). In addition, NPNs assisted numerous workshop participants to find resources for other medical conditions such as cardiovascular problems, arthritis, weight management and diabetes. The NPNs documented the evaluation and support they provided to and for cancer patients and their family members using the online evaluation database. All NPNs obtained appropriate HIPPA approvals prior to accessing any patient information or accompanying patients to healthcare visits.

The NPNs successfully assisted 77 cancer patients to access quality and timely state-of-the-art care. Most patients began receiving care within 1 month of a positive cancer biopsy. This time frame is a significantly shorter interval from diagnosis to initiation of treatment reported elsewhere for AI cancer patients.¹⁶¹⁷¹⁸

Each partner provided support differently. For example, the NPNs in South Dakota directly assisted patients and had a pipeline directly into Rapid City Regional Hospital where the hospital Navigators continued to provide support services. In Michigan, the ICTMI NPNs assisted survivors to get into local clinical services and continued to help them for cancer treatment issues addressed at the local clinic. However, the patients were referred to Contracted Health Services for surgery, radiation, chemotherapy and adjuvant therapy. In Oklahoma, the Muscogee (Creek) Nation NPNs continued to work with family members face-to-face and over the phone. They also helped coordinate applications with Contract Health Services to refer patients for cancer treatment and care. Most are referred to clinical facilities in Tulsa, but others are sent further away to access the care needed. While the patient and/or family members took part in cancer care outside of the area, the NPN was available via phone to help the patients remotely. In Colorado, the NACR NPNs have strong relationships with local hospitals. They obtained HIPAA permissions for each patient and accompanied the patients and/or family members for many of their appointments at the hospitals. All the NACR NPNs continued to interact with the cancer survivors identified during the intervention. For the those who passed during the study, the NACR NPNs assisted with obtaining palliative care (about 7 included hospice care). Thus, the NPNs from all sites provided navigation services throughout the full continuum of cancer care.

Conclusions

Community participants primarily were American Indians (83%) ranging in age from 18 to 95. The majority (70%) were females. Their interest and willingness to take part in the education intervention was much greater than anticipated. Rather than the intended 738 participants, the final sample included 1,964 unduplicated individuals. The workshop

intervention was effective regardless of the community members' gender, age, race, and education level. The site-specific (tailored), Native Patient Navigator-implemented cancer education programs addressed the full continuum of cancer care and:

- a. Increased workshop participants' knowledge by 23%, surpassing the 20% estimated in the grant proposal,
- b. Increased the visibility and availability of the NPNs to help local community members find healthcare assistance and resources and obtain cancer screening services, and
- c. Improved access to quality cancer care, with 77 cancer patients assisted by the NPNs to obtain cancer care services in a timely manner,

Thus, the NNACC education intervention successfully increased community members' knowledge and the visibility of the NPNs in all 5 sites.

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Table 1

Demographics

	NACR	ITCMI [*]	RCRH	GPTCHB	MCN	Total
GENDER (unduplicated)						
Females	356	159	285	219	356	1375
Males	135	23	202	130	99	589
RACE / ETHNICITY (unduplicated)						
AIANs	348	121	467	293	407	1636
African American	7	3	3	3	8	24
Pacific Islander	3	2	3	10	1	19
Asian	3	1	1	1	2	7
Non-Hispanic White	44	51	6	20	29	150
Hispanic	80	4	3	13	2	103
Other	7	1	4	8	6	26
AGES (unduplicated)						
18-21 (<21)	20	8	37	26	20	112
22-30	70	8	95	50	43	267
31-40	76	15	104	56	48	300
41-50	84	17	118	32	53	304
51-60	143	45	98	45	131	462
61-70	80	40	31	23	137	311
71-80	17	34	1	112	2	166
Over 80	2	15	3	4	20	44
Total unduplicated participants	491	182	487	349	455	1,964

• NACR – Native American Cancer Research, Inc.

• ITCMI – Intertribal Council of Michigan

• RCRH – Rapid City Regional Hospital's Walking Forward Program

• GPTCHB – Great Plains Tribal Chairman's Health Board

• MCN – Muskogee (Creek) Nation

* Undercounted due to data loss

Table 2

Increased Knowledge and Overall Workshop Evaluation

	NACR	ITCMI	RCRH	GPTCHB	MCN	Total
Average % of participants that answered pre-session knowledge items correctly	37.5%	44.6%	33.0%	42.5%	43.7%	40.3%
Average % of participants that answered post-session knowledge items correctly	66.9%	61.5%	65.7%	65.7%	67.2%	65.4%
Difference between the average percentage correct for the pre- and post-session knowledge	29.7%	25.3%	32.7%	29.8%	24.6%	28.4%
Average % of participants that rated the workshop content as "understandable"	95.2%	86.2%	78.1%	88.3%	97.4%	89.0%
Average % of participants that responded "I agree" about the workshop providing useful information	95.6%	92.9%	76.5%	95.5%	98.1%	91.7%
Average % of participants that answered "yes" they would recommend the workshop to others	95.7%	93.4%	82.1%	95.2%	95.1%	92.3%

Table 3

All Sites and Sessions by Demographic Characteristic: Mean Pre and Post Scores*

	Pre			Post			Difference
	Missing	Number	Mean % Correct	Missing	Number	Mean % Correct	
Gender							
Male	13	1098	35%	44	1067	58%	23
Female	38	2606	38%	111	2533	62%	24
Missing=562							
Age							
81 +	2	177	33%	10	169	56%	23
65-80	5	685	40%	25	665	60%	20
50-64	6	1039	39%	41	1004	63%	24
41-49	8	562	36%	22	548	60%	24
31-40	10	555	37%	24	541	60%	23
18-30	16	783	34%	35	764	59%	25
Missing=469							
Race/Ethnicity							
American Indian / Alaska Native	36	3145	37%	112	3069	60%	23
Pacific Islander	0	53	34%	2	51	66%	32
Asian	0	44	37%	0	44	63%	26
African-American	2	55	36%	5	52	61%	25
Non-Hispanic white (Caucasian)	4	254	41%	11	247	67%	26
Hispanic / Latino / Chicano	4	238	35%	30	212	63%	28
Missing=482							
Education							
Less than High School	12	1030	33%	38	1004	53%	20
High school graduate / GED	6	887	35%	33	860	59%	24
Technical school/apprentice training	3	376	42%	17	362	64%	22
Some college (no degree)	11	912	39%	37	886	65%	26
College (AA, BA, BS, Masters or Doctorate degree)	10	609	44%	33	586	67%	23
Missing=461							

This table includes unduplicated (single workshop) and duplicated (attended multiple workshops) participants