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A Community-Specific Approach to Cancer Research in Indian Country

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This research was supported by Spirit of EAGLES. Submitted 12 January 2009, Revised 3 April 2009, Accepted 9 April 2009.

Abstract

Background: Health care leaders in a small, rural, American Indian community and university partners used the community-based participatory research (CBPR) method to survey cancer survivors.

Objectives: We sought to provide support for the use of CBPR to generate ideas for how to improve the detection and treatment of cancer in American Indian communities.

Methods: Partners worked together to develop a mail-out survey and send it to the Indian health clinic's patients who had cancer in the past 5 years. The survey sought information on their experiences with cancer screenings, cancer diagnoses, and accessing and receiving cancer treatment.

Results: Community leaders identified three priority areas for intervention: (1) high incidence of breast cancer; (2) lack of culturally appropriate cancer education; and (3) need for a more in-depth assessment.

Conclusions: CBPR's partnership principle allowed for results to be viewed within the community's context, availability of community resources, and relevant cultural beliefs and traditions.

Key Words

American Indians, cancer, health care disparities, community-based participatory research, health care access

Disparities in cancer incidence and mortality rates among American Indian populations have been well documented both between regions and states of residence, and between tribes and bands within a given state or region.¹⁻⁷ Such variability suggests the need for understanding community-specific experiences regarding the detection and treatment of cancer. Community-based projects that gather local data may be crucial to addressing cancer disparities among American Indians in that they allow not only for an assessment of community-specific needs and resources, but also the collection of data necessary to develop and implement community-specific interventions.⁸ Despite potentially small sample sizes, data collected at the local level may prove more beneficial to tribal communities than state, regional, or national data.⁴ Indeed, such local-level data may be particularly relevant to the management of community programs, the

allocation of community resources, and/or the improvement of the quality of prevention and treatment experienced by community members.

When conducting community-level research, however, two potential problems often arise: (1) underserved communities report feeling over-surveyed with no resulting benefits, and (2) community members perceive researchers as working in—as opposed to with—their communities.⁹⁻¹² Many tribes' experiences involve research conducted without any meaningful partnership, perceived benefit to the community or capacity building.¹⁰ Although exceptions do exist¹³⁻¹⁵ and groundbreaking progress has been made in this area,^{16,17} many studies on cancer health disparities with minority communities still do not feature substantial community input.¹⁸⁻²⁰ In this article, we consider the potential benefits of researching the cancer experiences of American Indian populations using

a research methodology that focuses on a partnership between the community and outside researchers, namely, community-based participatory research (CBPR).

CBPR acknowledges the importance of local, community-specific data and community-researcher partnerships.²¹⁻²³ This methodology takes the form of a collaborative research process that involves community members and researchers at each stage, and has emerged as a potent new force in the fight against health disparities.^{21,24-27} It concentrates on building strengths and assets within a community and aims at creating long-term, sustainable relationships to improve communities through empowerment of their members.²⁸⁻³⁰ CBPR is preferred by many American Indian communities, particularly those who have had negative experiences with nonparticipatory research practices that lack community input and a true partnership.¹¹

The purpose of this paper is to provide support for the use of CBPR to generate ideas for how to improve the detection and treatment of cancer in American Indian communities. Using this approach, the health care leaders of a small, rural, American Indian population partnered with our university research team to gather information on community cancer survivors' experiences. Our experience suggests that the use of localized community assessments—even if the sample sizes are small—conducted in partnership with the community provides an optimal method for effectively understanding a community's needs with regard to its own experience of cancer.

METHODS

Partnership

Our research team was already working with the community's health care leaders on a cancer project such that a foundation of trust had been established. The leaders were working with their tribal-run, community-based health care clinic either as employed administrators, physicians, nurses, or community outreach workers, or as community volunteers. Our research team was composed of a social work researcher, three research scientists, and an American Indian outreach specialist, all of whom were affiliated with, or members of, the University of Wisconsin Carbone Comprehensive Cancer Center.

The community leaders expressed interest in surveying community cancer survivors concerning their experiences

in accessing and receiving cancer care. The community chose to use the National Cancer Institute's definition of a cancer survivor, that is, "a person is considered to be a survivor from the time of diagnosis until the end of life."³¹ They felt the first step would be to conduct a mail survey that would allow these survivors to feel safe in answering questions on this sensitive subject. Project approval was sought and received from the Tribal Health Board, and the Institutional Review Boards of the National Indian Health Service (IHS) and the University of Wisconsin Health Sciences.

Survey Design

Using input from the leaders, university partners designed a quantitative survey that sought to gather information on community members' demographic characteristics, and on their experiences with cancer screenings, receiving a cancer diagnosis, accessing cancer treatment, and interactions with medical personnel. Community leaders and university partners met to review the survey for accuracy, completeness, and cultural appropriateness. The leaders felt revisions were necessary concerning insurance questions, and culturally appropriate wordings and cancer treatment barriers. For example, the leaders asked that the list of insurances include IHS, because many community members referred to IHS as a health insurance. The leaders also requested that the term "cancer experience" be replaced with "cancer journey" and the list of potential treatment barriers include more culturally specific barriers, such as speaking a different language and providing for the health needs of another family member. Revisions were made and approved by the community leaders and the Tribal Board of Directors.

Sample

The community leaders proposed that participants be recruited from those served by the Indian Health Clinic who had been diagnosed with cancer in the past 5 years. The leaders chose the 5-year limit because they felt certain that in regard to the availability of screening and treatment services in the county, little had changed during that time period. They also felt that they wanted to start with clinic patients and then broaden the sample should the results show a need to do so. Using the community's on-site Indian Health Clinic Resource Patient Management System database, the names

of all the clinic's patients who were age 18 or older, enrolled tribal members and had cancer in the past five years were obtained, for a total of 37 names. These patients' medical charts were reviewed by clinic nurses to confirm the cancer diagnoses. Community leaders felt confident that all clinic patients meeting the study's criteria had been located.

A clinic nurse mailed survey packets to the 37 potential participants. The packets included a cover letter, the survey, a postage-paid return envelope, and a \$10 gas voucher as a token of appreciation. The cover letter explained the survey's purpose and confidential nature, and that it had been approved by the Tribal Board of Directors. The letter informed the recipients that their participation was voluntary, anonymous, and that they would not be penalized should they choose not to do so. If they chose to participate, they were asked to return the completed survey in 3 weeks. Twenty-six (70%) of the 37 surveys were completed and returned, three of which were deemed unusable: one participant reported not having had cancer, another self-identified as non-native, and the third did not fully complete the survey. Therefore, the final response rate was 66% based on 26 completed and returned surveys out of 35 eligible participants.

Measures

The mail survey was designed to gather information about each participant's cancer journey beginning with his or her cancer diagnosis and ending with his or her treatment experience. Participants were instructed at the beginning of the four-part survey to focus on their most recent cancer diagnosis when responding to questions, because they may have had more than one cancer diagnosis in the past. The first section of the survey gathered information regarding participants' gender, age, education, and health insurance status. The second section asked questions about their cancer diagnosis, age at diagnosis, and whether they had cancer screening tests before being diagnosed. In addition, they were asked if they experienced symptoms before diagnosis and, if so, how long they delayed before seeing their primary doctor. In the third section, participants were asked if their primary doctor referred them to a specialist, whether they received treatment, and how much time lapsed between receiving the diagnosis and starting treatment. For those who received treatment, questions were asked regarding the types of treatment, and side effects experienced

and treated. All participants were asked about barriers they may have encountered when attempting to access treatment. The last section focused on participants' interactions with the doctor who told them they had cancer and the medical personnel who treated their cancer. Descriptive statistics were performed; the small sample size resulted in cell counts that prevented the use of inferential statistics.

RESULTS

At the request of the community leaders, the university partners analyzed the collected data and drafted a report summarizing the results. This report was reviewed in a meeting of the community leaders and the university partners whereupon leaders prioritized the issues they felt should be addressed and proposed interventions for doing so. The following sections provide a brief summary of the actual results and a detailed description of the community leaders' interpretation of the results, their determination of priority issues, and their approaches to addressing these issues.

Brief Summary of Data Results

The results on participants' demographics, cancer screening, diagnosis and treatment, as well as patient-physician interactions, are reported in Table 1. As can be seen, the majority of participants (83%) were female, and the mean age of the group was 61 ranging in age from 35 to 84 years. No participant reported earning less than a 9th-grade education and 48% ($n = 11$) reported some technical training or college. In regard to insurance coverage, 22% ($n = 5$) had no insurance and, of the 18 who did, 89% ($n = 16$) reported receiving health care covered by IHS. Over one third ($n = 9$) of the participants reported not having had a screening test and another participant was unsure. Before being diagnosed with cancer, over one fifth ($n = 5$) of the participants reported not experiencing symptoms and of the 18 participants who did do so, about one third waited a year or more before seeing a doctor. Asked to report on their most recent cancer diagnosis, a surprising 68% of the female participants reported being diagnosed with breast cancer.

An overwhelming majority (83%, $n = 19$) of the participants reported being referred to a cancer specialist and receiving treatment. Two of the four nonreferred participants received treatment from their primary care physician, and the

Table 1. Demographic Characteristics of the American Indian Participants ($N = 23$)

Variable	N/X	% Range	Variable	N/X	% Range
Gender			Diagnosed		
Female	19	83%	<1 year ago	2	9%
Age ^a	61	35–84	1–5 years	21	91%
Education			Symptoms experienced before diagnosis		
9th–11th	7	30%	None	5	22%
High School/GED	5	22%	≤1 week	4	17%
Some technical training or college	8	35%	>1 week, <1 month	3	13%
College degree or higher	3	13%	1 month, <4	4	17%
Types of health insurance ^b			4 months, <12	1	4%
Indian Health Services	16	70%	≥1 year	6	26%
Medicare, Part A	12	52%	Referred to cancer specialist ($n = 23$)		
Medicare Part B	8	35%	Yes	19	83%
Medicaid	5	22%	Physician–patient communication ($n = 23$) ^c		
Private insurance	4	17%	Physician made sure patient understood condition	22	96%
Other	1	4%	Physician made sure patient knew what to do next	21	91%
Number of insurance types per participant			Physician listened seriously to health concerns	21	91%
None	5	22%	Patient felt comfortable talking to physician	22	96%
1	10	44%	Physician treated them with dignity	22	96%
2	4	17%	Participants receiving treatment ($n = 21$) ^d		
3	4	17%	No barriers reported	14	67%
Screening tests received			Lacked insurance	2	10%
No screening test	9	39%	Treatment not covered by insurance	1	5%
Mammogram	8	35%	Health needs of another family member	1	5%
Mammogram and Pap smear	2	9%	No one at clinic available to answer questions	5	24%
Mammogram, Pap smear, and colonoscopy	1	4%	Drove >8 hours roundtrip for treatment	5	24%
Pap smear and colonoscopy	1	4%	Treatment not available locally	1	5%
Colonoscopy and PSA	1	4%	Cancer treatments received ($n = 21$) ^d		
Did not know if received screening test	1	4%	Alternative therapies	2	10%
Cancer diagnoses			Bone marrow transplant	1	5%
Bone	1	4%	Chemotherapy	12	57%
Breast	13	57%	Hormone therapy	3	14%
Colon or rectal	2	9%	Radiation	8	38%
Esophageal	1	4%	Surgery	18	86%
Lung	1	4%	Traditional American Indian medicine	3	14%
Kidney	1	4%			
Ovarian	1	4%			
Prostate	1	4%			
Thyroid	1	4%			
Uterine	1	4%			

^a Mean and range are reported for this variable.

^b The percentages for this variable do not total 100%, because some participants specified more than one type of insurance.

^c Each of the statements listed in this subsection are separate variables.

^d The percentages for this variable do not total 100%, because some participants specified more than one barrier or type of treatment.

remaining two reported not receiving treatment. Overall, the vast majority of participants felt their specialist made sure they understood their condition and what to do next concerning treatment, seriously listened to their health concerns, treated them with dignity and respect, and made it comfortable to talk about any cancer-related health problems. Barriers to accessing treatment were experienced by one of the two participants who did not receive treatment and by one third (33%, $n = 7$) of those who did. Barriers cited included lack of health insurance coverage, long travel distances, lack of access to medical personnel who could provide information about a new diagnosis, and personal issues.

A high percentage (76%, $n = 16$) of the 21 participants who received treatment reported experiencing side effects, and all but one participant contacted their physician or nurse for assistance (Table 2). The three most problematic side effects reported were pain ($n = 13$), nausea/vomiting ($n = 10$), and fatigue ($n = 9$). Of those who contacted a health care professional, more than half (54%) experienced only some, little, or no relief.

Community Partners' Interpretation of Results

Community leaders provided the university partners with a context in which to view the results, an understanding of the community's resources available to tackle issues, and the relevant cultural beliefs and traditions associated with cancer and health care. After reading through and discussing the survey findings, the leaders prioritized the issues they wanted to address, and provided insight and guidance regarding appropriate interventions.

First Prioritized Issue: Incidence of Breast Cancer. The issue that leaders raised as the top priority manifested itself

in the cancer diagnoses reported by participants and their age at diagnosis. As previously reported, the results showed that 68% of the 19 female participants had been diagnosed with breast cancer, many at young ages. Community leaders expressed surprise and deep concern at this finding noting that they provide care to numerous patients each day and had not been aware of this trend. They also noted that patients are often referred for diagnostic cancer tests to health facilities off the reservation, which do not always send results back to the clinic.

The community leaders raised two issues in need of targeted intervention. First, the leaders expressed concern that the high percentage of participants diagnosed with breast cancer in such a small community, combined with their young age at diagnosis, begged the question as to whether there might be a familial link. They decided that clinic staff would review the patient records to determine whether participants were related and, if so, request they come into the clinic for targeted screening education and possible testing for the breast cancer gene. Second, leaders planned to establish a protocol for following up on patients referred to other health facilities for diagnostic testing, which would involve examining the Indian Health Clinic's current follow-up practice and which referral facilities were less vigilant in their reporting. Community leaders felt that, because of the need to honor clinic patients' right to confidentiality, these two projects would be handled by clinic staff.

Second Prioritized Issue: Education and Screening. The second issue raised by leaders was the potential for detecting cancer in the later stages owing to low screening rates, the lack of symptoms experienced by participants signaling the need for medical attention, and the delay of a year or more in

Table 2. Treatment Symptoms/Side Effects Experienced ($n = 21$)

	Pain	Nausea/ Vomiting	Fatigue	Shortness of Breath	Bad Cough
Experienced Side Effect	13	10	9	4	2
Told Physician or Nurse	13	10	7	3	1
Received Medication	11	7	3	2	1
Experienced Relief	7	2	2	1	1

seeking care by those experiencing symptoms. Leaders noted that some community members delay care to avoid burdening the tribe's health funding, a practice that they noted was particularly true for elders who felt that limited IHS funds should be spent on the younger generation. The leaders pointed out that it is well known in the community that the IHS funds appropriated by Congress have remained insufficient to meet the health care needs of American Indian tribes.³²

In response, leaders proposed an outreach program focused on early detection. Elders would be educated on how detecting cancer sooner could actually result in fewer health care costs over time. In addition, all community members would be educated on the importance of screening, the signs and symptoms of cancer, and the need to go to their physician when experiencing them. Leaders noted that although educational cancer materials were available at the clinic, they would have greater reach if distributed at well-attended community events such as the annual pow-wow. The cultural tradition of storytelling was also suggested as a means to spreading information. Furthermore, the current printed materials were not culturally appropriate and their literacy level was too high. The university partners agreed to research the availability of literacy level-appropriate and culturally relevant materials.

Third Prioritized Issue: Additional Assessment. The CBPR methodology involves a long-term commitment to communities,²¹ a commitment evident in the third priority noted by leaders: the need for a more thorough assessment conducted with a wider range of community members. Leaders reported concerns over two survey results for which they felt a need for additional information to determine the appropriate intervention. First, they were concerned about participants' reports of not experiencing relief from their pain, breathing difficulties, nausea and vomiting, and fatigue. Leaders wanted to know whether these participants contacted the clinic or treatment facility for assistance. In addition, they sought understanding as to why some participants chose not to contact medical personnel, why some who made contact did not receive medication, and why some who did receive medication experienced little or no relief. Leaders felt that a plausible explanation was that these participants may have had a previous experience sharing their symptom concerns with a medical provider and had their issues superficially addressed such that little, if any, relief was experienced. Leaders noted that pain assessments conducted

by medical providers often do not take into account, or may underestimate, the stoic nature of American Indians toward pain and other symptoms. The leaders felt it was important to determine whether consideration should be given to developing more accurate and culturally specific symptom assessment practices and tools for use with American Indians.

Second, leaders expressed concern over participants' reports of having difficulty accessing a physician or nurse to answer questions about their newly received cancer diagnosis. Leaders wanted to know whether participants had these experiences at the clinic or at another facility and, if not at the clinic, whether they had attempted to contact the clinic.

To obtain these answers and others, community leaders felt a more in-depth assessment was necessary and proposed three approaches. First, current participants would be sent a letter from community leaders thanking them for sharing their wisdom and experiences. The letter would explain that a follow-up, face-to-face interview was being conducted to gather additional information; however, they should not feel obligated to participate. Second, the leaders felt it necessary to recruit community cancer survivors who had not used the clinic, and suggested posting flyers at community events as a recruitment technique. Third, leaders proposed that face-to-face interviews be conducted with the caregivers of community members who had died from cancer. The leaders noted that community members tended to die more quickly from certain types of cancer and interviewing their caregivers would allow information to be gathered on the deceased individuals' cancer journey. For example, leaders noted that it was not surprising that none of the 23 participants reported a lung cancer diagnosis because community members usually die quickly after receiving this diagnosis. Because of the high incidence of breast cancer rates, the community leaders also noted the need to gather data on family history and prior cancer diagnoses, something not done previously done. The university partners agreed to work with community leaders to create an in-depth mixed methods survey for face-to-face interviews with community members, as well as a version for caregivers. The issue of potential recall bias on the part of cancer survivors no longer receiving treatment and caregivers of deceased cancer survivors was discussed. Community leaders acknowledged the issue but felt that, because of the small size of their community, it could take a while to collect

enough information if the survey was limited only to those who were actively struggling with cancer. Leaders felt that completing the assessment in a reasonable amount of time outweighed the issue of recall bias. Finally, funding options for the proposed assessment were discussed.

DISCUSSION

The assessment conducted in a small, rural, American Indian community provided important information regarding the struggles experienced by 23 community members diagnosed with cancer. In keeping with CBPR's recognition of insiders' insight and knowledge regarding their community, university partners sat down with the leaders to discuss the results.

Findings revealed a mix of positive results and those that raised concerns. Questions asked of participants regarding screening practices, experiencing symptoms before diagnosis, time between experiencing symptoms and going to see a physician, and the type of cancer diagnosed raised some concerns. The high rates of breast cancer in this small community were noted as a priority issue, as was the need for education regarding screening and the signs and symptoms of cancer. Participants' reports of being referred to a specialist, receiving treatment, and the type of treatment received were, for the most part, positive, as were participants' interactions with the doctor who told them they had cancer and the medical personnel who treated their cancer. The results were not as positive, however, concerning the treatment side effects experienced by participants and the amount of relief they received from medical assistance. The leaders expressed concern over these findings, as well as some of the findings regarding the barriers to treatment that were reported by participants, and felt that a more in-depth assessment was needed. Although the number of participants was small, community leaders found the results compelling and used their knowledge of the community to prioritize issues and propose community-specific interventions.

CBPR Advantages

CBPR can prove challenging, particularly when attempting to gain a community's trust and ensuring that results lead to change²³; however, the advantages are numerous. First, CBPR increases the likelihood that the data collected will be germane and useful to the community, as well as valid.^{21,22} In

this study, working at the community level in partnership with community leaders enabled the university partners to contact all clinic patients diagnosed with cancer in the past 5 years. Furthermore, community leaders felt that the high response rate (66%) and low amount of missing data (only 8%) was due to the cover letter noting that the project had been approved by the Tribal Council and was being sponsored by the Tribal Health Clinic.

Another advantage of CBPR is the expertise the community brings to the partnership in regard to providing insight into the results.^{21,22} In the current study, knowledge of the geographic area, the availability and location of area health care facilities, as well as existing social service programs, was necessary for understanding the absence of some barriers to accessing treatment. The university partners had questions regarding transportation, lodging, and distance barriers that would normally be found in a rural community but were not reported by participants as problematic. Community leaders explained that financial assistance for transportation, gas, or lodging during cancer treatment was available from a local social service program.

Leaders also provided insight regarding the participants' satisfaction level with physician-patient interactions. Based on research conducted with white elders that indicates a lack of satisfaction with physician interactions,³³ the university partners was surprised that the participants were, for the most part, satisfied. Leaders were not surprised and noted that the satisfactory interactions may have been due to the clinic's standard practice of having a community health representative present at medical appointments to listen and act as the patient's advocate.

A third advantage of CBPR is the partners' ability to use the research findings to direct the development of community-specific interventions.^{21,22} Working at the community level, the assessment results provided information about community members' cancer journeys. Insight from leaders allowed for three priority areas to be chosen for intervention and follow-up assessment. These actions are in process, as the leaders and the university research team continue to work in partnership.

CONCLUSION

The study results underline the need for the use of community-specific research to generate ideas for improving the

detection and treatment of cancer in underserved American Indian communities, and to do so using the CPBR method. Using this approach, results can be interpreted by community and university partners within the context of the community's knowledge of cancer, available resources, and cultural values and beliefs. The community can use the results to set priorities

for subsequent development and implementation of interventions. This type of research may not only increase the likelihood of understanding the cancer experiences of underserved communities, but also empower and build communities' capacity for conducting research, and establish lasting partnerships between communities and outside researchers.

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