

Challenges in Community-Based Participatory Research Implementation: Experiences in Cancer Prevention With Pacific Northwest American Indian Tribes



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Background: Much has been written about community-based participatory research (CBPR) history and principles, but few have addressed challenges in implementation in transcultural situations. The goal of this discussion is to address CBPR implementation issues in cancer prevention research with American Indian tribal communities in the Pacific Northwest.

Method: Information in this discussion is drawn from qualitative research conducted over a 10-year period in which CBPR was employed in cancer prevention research with Pacific Northwest Indian tribes. CBPR principles provide the framework for the discussion: establishing trusting relationships, assuring participation, sharing power, and communicating.

Results: In this work, we found that CBPR is appropriate for use in Pacific Northwest Indian tribal communities and is compatible with cultural values. We also found that there are many challenges. Recommendations are provided on needed institutional and structural changes.

Conclusions: CBPR is an important research approach in addressing cancer prevention health disparities among American Indian tribal communities. Continued effort needs to be directed toward creating systems and structures to support researchers in utilizing this method. Findings are of value to researchers aiming to implement CBPR in Indian communities and to practitioners, policy makers, and administrators who make decisions about CBPR funding and support structures.

Introduction

Community-based participatory research (CBPR) has received considerable attention in the past decade; it is becoming a recognized and important approach in addressing health disparities in cancer prevention. It draws on several intellectual traditions such as critical theory¹ and social theory,² and its roots lie in both Parsonian (cooperation) and Marxist (conflict) theory in

sociology.³ It emphasizes the importance of knowledge and action that are directly useful to the population studied⁴ and aims to link knowledge gained from research with implementation.⁵ The community is engaged in all phases of the research process including the identification of the need for an investigation, the design of the study, implementation, analyses, and dissemination.^{3,6,8}

While the need to strengthen the relationship between researchers and the community has been recognized,^{9,10} discussions on challenges in CBPR implementation^{7,10-12} have only begun to be noted. Some reports have been published on CBPR efforts in American Indian communities,¹³⁻¹⁶ but we are still in the formative stages of identifying the conditions that are important in achieving the CBPR partnership in transcultural research and the structural supports needed to assure researcher success. The purpose of this paper is to share experiences from over 10 years of conducting CBPR research in cancer prevention among American Indian tribal communities in the state of Washington to illustrate challenges and strategies needed for successful CBPR implementation. Findings are expected to be helpful for researchers aiming to engage in CBPR in American Indian communities, for administrators making structural and funding decisions, and for American

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Abbreviations used in this paper: CBPR = Community-based participatory research.

Indian tribal communities aiming to form partnerships with researchers.

Review of Related Literature

CBPR evolved from community organization models and the intellectual traditions of critical and social theory.^{1,2} Roots lie in the early work of Parsonian cooperation and Marxist conflict theory.³ It emphasizes the importance of the advancement of knowledge that can be directly moved into action to serve the needs of communities,⁴ thus knowledge gained in research is directly linked to implementation.⁵ In tracing the historical roots of CBPR, Wallerstein and Duran¹⁷ note that work in the 1940s by Lewin¹⁸ provided the foundation for CBPR by recognizing the importance of linking action with research in the research problem-solving process.

Israel et al⁷ note that CBPR is “a partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process.” They outline key principles of CBPR as follows: (1) it recognizes the community as the unit of identity, (2) it facilitates collaborative, equitable partnerships in all phases of the research, (3) it promotes co-learning and capacity building among partners, (4) it emphasizes local relevance of public health problems and attends to multiple determinants of health, (5) it involves a systems development through a cyclical and iterative process, (6) information is disseminated to all partners and all partners participate in disseminations, and (7) it involves a long-term process and commitment.

CBPR builds on the principles of community organization but differs in that greater emphasis is placed on community involvement in all stages of the research and greater community power.^{3,6,7} CBPR aims to shift the leadership from the researcher control to greater community control by placing community members in positions such as the principal investigator, the facilitator of planning teams, and the authors and coauthors of related publications.

CBPR also emphasizes community capacity building and involvement of the community in all phases of the research including the assessment of need.¹⁹ Much like the contributions of Kretzmann and McKnight,²⁰ it includes a focus on the positive attributes of the community as well as needs in the assessment. Israel et al¹⁹ provide guidelines for conducting CBPR including details on topics such as partnership formation and community assessment. Key to CBPR is the concept of community, partnership, and shared power.^{21,22} It is believed to be important to quality in research in that it evolves from the people and reflects their voices; it is believed to be particularly useful to improve quality in transcultural research.^{7,22}

A number of researchers have begun to report on implementation challenges in conducting CBPR and have noted the need for changes in systems and institutional structures. Nyden¹⁰ recognized the obstacles that traditional universities need to overcome to support CBPR such as changing institutional practices that are not supportive; institutionalizing CBPR was viewed as important. Among specific strategies noted were fostering team approaches in research, mentoring of faculty and students, linking to national networks, modifying tenure and promotion guidelines, working with Institutional Review Boards, and creating CBPR centers.¹⁰⁻¹² Minkler et al¹² noted funding issues and Lantz et al²³ outlined challenges that the researcher might encounter in implementation such as organizational constraints, time, and organizational interests. Stoecker²⁴ recognized a number of different roles that a researcher may play in implementing CBPR such as initiator, consultant, or collaborator and suggested that the role may be dependent on the needs, wants, and ability of the community to take on the role of research. None have specifically considered issues that may be relevant for transcultural research or for cancer prevention researchers working in National Cancer Institute networks outside the university setting such as Comprehensive Cancer Centers, the Southwest Oncology Group, and Community Clinical Oncology Programs.

Less attention has been devoted to challenges that transcultural CBPR research may pose. Researchers have only just begun to share experiences from work in American Indian communities. While many are involved in research with American Indian communities and have reported on activities to involve the community at various levels, in this discussion, we will focus primarily on those contributions that have specifically addressed CBPR. Chrisman et al¹⁴ and Burhansstipanov et al¹³ outline steps in conducting CBPR in Indian communities and lessons learned. Davis and Reid,¹⁵ Burhansstipanov et al,¹³ and Dickson²⁵ focus on its value in fostering trust, in designing more culturally appropriate interventions, and in building on cultural values.

Many speak to the matter of the complexities of implementation in sovereign nations and the importance of building trust and assuring effective communication channels.^{13,16} Boerner²⁶ reported on a conference in which tribes from the Pacific Northwest participated; participants noted differences in cultural traditions and patterns of communication and suggested that tribal members reacted favorably when traditions and cultural values were respected in communications in CBPR work.

Others have recognized some of the challenges such as maintaining sustainable funding, adhering to time lines, and interpreting data with the tribe.^{13,27,28} Burhansstipanov et al¹³ reported on the use of CBPR in

projects they implemented through the Komen Foundation and the National Cancer Institute funding and suggested that CBPR is appropriate for use in American Indian communities. In focusing on lessons learned, they outline the importance of investing time to create the partnership, distributing funding resources equitably across the partnership, and creating partnerships with leaders; they clearly illustrate the importance of the CBPR principles.

Some have begun to report on cancer control efforts in Indian communities. Dignan et al²⁹ and Burhansstipanov et al³⁰ provide examples of clinical trials development and approaches of program implementation in American Indian communities. While the emphasis is not on CBPR, they illustrate the importance of involving the community through the use of focus groups and community navigators. Although working in African American communities, Fouad et al³¹ also illustrate the importance of coalition building in women's health screening and recognize the importance of intervening at the individual, provider, and structural levels.

CBPR has been recognized as an important tool in transcultural research. It is expected to contribute to higher-quality research and the design of interventions that may be expected to be useful for the community that is also congruent with community values. It is an approach that researchers believe may be viewed with more trust by disenfranchised populations. While only a few contributions have been reported on CBPR in American Indian communities, researchers are beginning to suggest that it is consistent with cultural values; however, they also recognize the costs, the communication issues, and the complexities of working within the structures and policies of sovereign nations. While CBPR holds promise for transcultural research, greater understanding of researcher challenges in implementing CBPR in American Indian communities and structural supports needed to assure success is needed. Such is the intent of this contribution.

Methodology

This discussion focuses on the salient components of CBPR that were employed in two cancer prevention studies with two Pacific Northwest Indian tribes conducted over a 10-year period. CBPR can be used as a research method or a philosophical orientation and includes the involvement of the community in all stages of the research from the identification of the research question to the analysis and dissemination of findings.^{4,5,8} Research results and methodologies utilized in each of these studies have been noted elsewhere³² and in a University of Washington School of Nursing intramural grant proposal (unpublished data, 2006, CJS).

Both studies were qualitative and aimed at either designing/developing or implementing behavioral science interventions to influence Indian women's cancer screening preventive behaviors. In one, the primary research method was grounded theory and CBPR was employed as the philosophical underpinning; interviews and focus groups were utilized in that study. The aim was to generate hypotheses and build a theoretical model related to Indian women's health screening. In the other study, CBPR was the methodology and focus groups were employed. The goal was to adapt a research protocol conducted through the Southwest Oncology Group (SWOG) for influencing women to conduct breast self-examination (BSE) that was found to have a positive and significant impact on women's BSE screening practices³³ and to expand to include a women's health emphasis including cervical screening.

The SWOG intervention being adapted was based on adoption theory and included three intervention components: (1) a physician statement that BSE is important, (2) a physician message plus a 45-minute education class, and (3) an intervention that included the physician message, the education program, and follow-up telephone calls and card reminders to do BSE. Through the use of focus groups and the CBPR planning team, a protocol was developed to link the Indian women to the tribal clinic for the physician message and identified culturally appropriate education materials and approaches. For example, instead of a written contract to assure commitment to do BSE in the original SWOG protocol, the tribal community felt that a verbal commitment to the family and community would be more appropriate. Rather than telephone calls, it was suggested that follow-up letters would be more appropriate for the follow-up reminders.

With both studies, we worked with a health planning team. The tribal communities identified the need for the research and supported the investigator in obtaining tribal council approval. Each tribe selected the Institutional Review Board where the study would be reviewed. With both studies, the University of Washington was selected as the Institutional Review Board. The steps in CBPR were implemented: a health planning team was engaged in all phases of the research from identification of the need, recruitment, data collection, data analysis, data validation, and dissemination. Tribal members recruited study participants and participated in all phases of the research efforts, from data collection to analysis to dissemination. They were also trained to conduct interviews in the descriptive and grounded theory studies and supported focus group work. The health planning team and/or tribal research assistants were engaged in the data analyses and in validating findings. Finally, study participants were engaged in dissemination by participating in national presentations and/or related publications.

Results

A brief description of the tribes and the partnership relationships provides an introduction to the discussion. The eastern Washington tribal people are high plateau hunters and gatherers, and the coastal people are ocean and inland river people. Their ceremonies, art, and cultural practices are different. The eastern Washington tribe is large, with a population of about 14,000 people. The western Washington tribe is small, with an enrollment of approximately 1,000 people.

In the study involving the eastern Washington tribe, the co-principal investigator (co-PI), as an outreach coordinator with the Pacific Northwest Cancer Information Service (PNWCIS) and adjunct faculty with the University of Washington School of Nursing, initially worked with the tribe to assess needs and sought University of Washington School of Nursing intramural research funding and academic support. Later in the research, the co-PI transitioned to a faculty position with the University of Washington School of Nursing and was the PI on the work with the western Washington tribe. The CBPR planning team for the eastern Washington tribal research consisted of a three-way partnership among the University of Washington, the PNWCIS, and the tribal community. Likewise, in much of the work with the western Washington tribe, the partnership involved the PNWCIS, the University of Washington, and the tribe.

The discussion of findings in this work is organized by CBPR key principles: establishing trust, assuring participation, sharing power, and communicating. This is followed by a consideration of major challenges and strategies that were used to address them.

Establishing Trust

Key to establishment of the trusting relationship in both these research efforts was openness in the communication, follow-through on commitments, and an understanding of the community expectations about the PI involvement in community activities. The PI invested effort in telephone calls to be sure that staff received payment for services and that promises were kept. The PI also participated in community events and attended Long House services. Visits were made to the hospital when children were born, and funeral services were attended when there were deaths. The work was adjusted to incorporate the values of involvement of the community. In some cases, lodging was arranged for family members who needed a place to stay when relatives came into the hospital in Seattle. While many researchers might not be able to support community members at this level, this example is provided to offer greater understanding of community expectations. Thus, the establishment of trust requires funding for travel, telephone contacts, personal commitment, and an

understanding of cultural values. Establishing a three-way partnership to share the responsibility was crucial.

Assuring Participation

Assuring participation in this work was dependent upon understanding the life flow of the community, and cultural values. An important strategy in assuring participation is establishing partnerships in which all parties have a vested interest and funding to assure grassroots participation. In the initial work with the eastern Washington tribe, the tribe allocated funding for an individual to manage the research effort. Grant funding paid for meetings and for staff to gather data. In the western Washington tribal community, grant funding paid for a part-time research assistant to oversee the project, arrange the CBPR planning meetings, and assure the implementation of all phases of the research. The PI also invested time in understanding the cultural values and expectations of the community. For example, it was recognized that many steps in our work could not happen during the winter ceremonial season and during the spring and summer hunting and gathering seasons. Understanding the ebb and flow of tribal life was crucial to assuring participation. Investing time in the community and working with tribal experts to guide the planning were crucial. Understanding cultural values also contributed to assuring participation in CBPR planning teams in these communities. By scheduling meetings at the most convenient times and providing food, raffles, and crafts, the PI was able to assure high levels of planning team participation in meetings.

Sharing Power

Research in federally recognized tribes requires an understanding of the power structure and decision-making process. The researcher needs to know not only when tribal elections are being held, but also the effects of changes in positions following an election. It is important to establish working relationships across family groups and maintain a neutral positive working relationship. Tribes have rules and regulations regarding meetings, approvals of grants, and dissemination.

With both of the tribes in this discussion, relationships were established with the health policy and planning administration to assure compliance with regulations. Members of the tribal administration were always responsible for taking decisions about grants and the work in progress to the appropriate decision-making bodies within the tribes. Guidelines for dissemination and protection of tribal rights were established through the IRB consent process and also the tribal protocols. It was always recognized that the tribe had major veto power and control.

Of concern to both tribes was the use of data and dissemination. The tribes developed a review process,

and in most cases funding was allocated within the grant and/or from other sources for a tribal member to participate in dissemination efforts. Wording was included in consent forms to protect tribal as well as individual rights, particularly as it related to secondary analysis of data. Researchers working with state- and/or federally recognized tribes need to understand the power issues in working within sovereign nations; for those who are not aware, linking to tribal community experts is crucial.

Communication

As noted in CBPR literature, communication is a crucial part of the process of CBPR work. In working transculturally, it is critical. Developing an understanding of the cultural values, the formal and informal family networks, the formal and informal patterns of communication, and communication in groups is part of the process and takes time. For this reason, it is helpful for the researcher to be American Indian; If not, the researcher must recognize that it will take more time to build this understanding and will require the involvement of tribal experts and payment for tribal members. The researcher must plan on investing time in establishing working relationships and reading culturally related information and historical documents. Observation and participant observation were crucial approaches used in this work to learn about patterns of communication. Forming partnerships, as recommended in CBPR, provides the linkage to tribal experts that is needed to support the growth process. Even so, developing a humble position of letting the community be the teacher was important in this work.

A 1999 publication³⁴ on assuring culturally appropriate focus groups in American Indian research provides an example of what is meant by addressing cultural patterns of communication in a group. This work noted that focus group meetings should take about 45 minutes to an hour, that the room should be arranged in a U shape, that participants should not be related, and that all participants should be encouraged to speak. Based on a number of years of conducting focus groups in American Indian communities in the Pacific Northwest, the author noted that focus groups usually take 3 to 4 hours, that the room is usually arranged in a circle, that it is seldom possible to include participants who are not related since most people in the community are related, and that respected elders can be expected to speak last, if at all, in the first meeting; it would be culturally inappropriate to expect otherwise. In assuring communication, it is most important to consider the time investment needed to observe and prepare, the importance of community experts, and the systems and structures needed to support the work.

Challenges and Systems/Structures Needed to Support CBPR

Implementing CBPR in any community, and particularly in American Indian communities, is costly. It requires an investment of time and resources in development and maintenance that is seldom fully funded. The researcher must be committed, obtain intramural grant support or other more flexible funding, and be prepared to make personal financial contributions. With the research in this work, we invested at least 1 year or more in establishing the planning committee before funding was sought. Subsequent intramural grants and tribal investment supported the efforts. Major researcher challenges included managing time, obtaining funding for travel, communicating and disseminating, providing community training to participate in CBPR planning and research, and assuring confidentiality in data analysis. In addition, it was recognized that institutional rewards systems and support structures are also crucial to successful CBPR work.

Intramural funding seldom supports faculty travel to remote communities or provides funding for incentives that are important for work in American Indian communities. However, CBPR planning team activities must be maintained even when funding is not available. For faculty researchers, managing the load of teaching and faculty responsibilities along with research requires creativity. Researchers working outside academic setting (eg, the Community Clinical Oncology Program) may be expected to face similar issues. Partnerships with Comprehensive Cancer Centers and outreach staff in Cancer Information Services might be expected to provide an important linkage to the implementation of CBPR. Creatively combining job responsibilities such as teaching, research, and practice was found to be useful for faculty. Involvement of students was crucial in these research efforts. Students were involved through independent study in the implementation of portions of these studies, they served on planning teams, and they helped in focus group implementation. In addition, small community grants and intramural funding were helpful in assuring maintenance of the planning teams.

It cannot be expected that communities will readily be able to undertake program planning as a part of the CBPR model or be able to take on research responsibilities; training through education and role modeling was used in these studies. Over time, each phase of the research process was introduced into the planning teams, and community participants were hired and trained to conduct interviews, participate in planning, analyze data, and participate in presentations and publications. While some participated because of interest as a part of their normal jobs, the majority of the work was done by tribal members who were paid specifically to do the work through tribal funds or the research grants.

Assuring confidentiality in a CBPR model is also a challenge. Care was taken in work with the data to prevent identification of study participants so that planning team participants could deal with either extracted codes or only small portions of the actual data. This allowed for community input without violating confidentiality.

Dissemination is an important part of any research effort. In CBPR it is a crucial element. In this work, members of the planning teams were involved in local and national presentations and included as coauthors in related publications. Unfortunately, grants seldom provide funds for dissemination after the grant funding period and that is when much of the dissemination is likely to occur. Thus, the researcher needs to plan in advance in the grant proposal to assure adequate support for dissemination.

Finally, a major issue in the implementation of CBPR is the institution reward and evaluation structure. For example, an institution that places high value on single authorship in publications is problematic for CBPR. An institution that does not allow or have funding to support faculty practice time in maintaining relationships with communities between grants is problematic. Faculty assignments that do not support involvement of students in the CBPR effort are problematic. In this work, the University of Washington School of Nursing Psychosocial Department administration and faculty, and the Appointment, Promotion, and Tenure committee valued CBPR and supported coauthorships, presentations, involvement of students in CBPR research, and community involvement in all phases of the research.

To assure successful CBPR research, the individual researcher must create a long-range plan and carefully consider the major challenges posed by CBPR. Systems and structures of evaluation must be created within institutions to support researcher efforts, and funding agencies must address funding issues. In these two research efforts, we found that it is possible to conduct CBPR studies in tribal communities and that CBPR holds promise in addressing health disparities and in meeting both research agendas and community needs. Even so, it takes time, funding, and commitment to undertake and maintain these relationships. Attention must be devoted to all elements of the CBPR principles. While there is much interest in supporting CBPR work, it is important to understand the challenges in implementation. Additional effort needs to be directed toward continuing to identify, better understand, and address these concerns.

Discussion

In this discussion of CBPR cancer prevention research among American Indian tribes in the Pacific Northwest, the CBPR framework was used to highlight the chal-

lenges and strategies for success. In all, it has been suggested that (1) it is possible to conduct CBPR in tribal communities with institutional and intramural grant support, (2) CBPR is compatible with cultural values in the Pacific Northwest American Indian communities, (3) partnerships are important in balancing the costs and responsibilities, and (4) factors that are important to success include funding community leadership, having well-qualified researchers, creatively managing researcher time, and involving students in the CBPR. Funding is needed in the developmental stages of CBPR research to establish trust; funding is also needed to maintain relationships between grants. As noted by Burhansstipanov et al,¹³ funding agencies need to revise grant announcements to better support CBPR efforts. Academic and other research institutions also need to examine the reward structures to assure better support for CBPR. National Cancer Institute (NCI)-supported cancer research networks, comprehensive cancer centers, and the NCI Cancer Information Service need to further explore ways to work collaboratively to ensure the translation of efficacious research into communities that shoulder heavy health disparities burdens.

These findings further support the work of those who have noted the challenges in conducting CBPR such as time, funding, tenure guidelines and institutional structural supports, and the readiness of communities to undertake research.^{10-13,23,27,28} This work adds to the understanding of these issues by providing additional examples from work in American Indian communities and offers additional specific strategies for success. This discussion is similar to the contributions of those who have reported on CBPR in American Indian communities in that it further recognizes the complexities in working with tribal governments noted by Smith¹⁶ and Chrisman et al¹⁴; it illustrates the steps needed for implementation as outlined by Chrisman et al,¹⁴ Garwick and Auger,²⁷ and Israel et al.¹⁹ It also builds on the contributions of Dickson,²⁵ the Northwest Area Indian Health Board,²⁶ and Burhansstipanov et al¹³ in which it is recognized that communication and an understanding of cultural values are crucial to CBPR work.

Our poor and underserved communities shoulder the heaviest burdens in cancer health disparities. CBPR holds great promise for producing more useful and culturally appropriate cancer prevention interventions and for providing a model to empower communities to become partners in the elimination of cancer health disparities. By addressing the needs for structural and institutional change and challenges in implementation, greater understanding of strategies to assure CBPR success can be achieved.

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