

5-2013

Needs Assessment Using Community-Based Collaborative Action Research in an American Indian Community

Jane Peterson
St. Catherine University

Follow this and additional works at: http://sophia.stkate.edu/dnp_projects

Recommended Citation

Peterson, Jane, "Needs Assessment Using Community-Based Collaborative Action Research in an American Indian Community" (2013). *Doctor of Nursing Practice Systems Change Projects*. Paper 47.

This Systems Change Project is brought to you for free and open access by the Nursing at SOPHIA. It has been accepted for inclusion in Doctor of Nursing Practice Systems Change Projects by an authorized administrator of SOPHIA. For more information, please contact ejasch@stkate.edu.

Needs Assessment Using Community-Based Collaborative Action Research in an American
Indian Community

Systems Change Project,
Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Nursing Practice

St Catherine University
St Paul, Minnesota

Jane Peterson
May, 2013

ST. CATHERINE UNIVERSITY
ST. PAUL, MINNESOTA

This is to certify that I have examined this
Doctor of Nursing Practice systems change project
written by

Jane Peterson

and have found it is complete and satisfactory in all respects,
and that any and all revision required by
the final examining committee have been made.

Rozina Bhimori, PhD, DNP, RN, CNP

Faculty Project Advisor

5/31/13

Date

DEPARTMENT OF NURSING

Copyright Jane Peterson, 2013

All Rights Reserved

Dedication

This project is dedicated to Chairman Stanley R. Crooks and the Shakopee Mdewakanton Sioux Community. I would like to acknowledge and thank my advisor, Dr. Rozina Bhimani for her support throughout my doctoral program my reader, Dr. Carol Geisler, and my site mentor Dr. Nancy Hawkins. Special thanks to my husband Allan and my beautiful daughters Amanda and Nicole for their support and love during the past two years while pursuing the degree of doctor of nursing practice.

Abstract

Community-Based Collaborative Action Research (CBCAR) holds promise when conducting nursing research in Native American communities. This article identifies through review of the literature common issues inherent in conducting traditional research in Native American Communities. The purpose of this article is to share first steps in implementing community-based collaborative action research in a Native American community. It addresses not only issues identified by the community but also provides insight into the future use of CBCAR in other Native American communities.

MeSH Terms: Community-based participatory action research, Indians, North American health care disparities and needs assessment.

The United States has well documented inequities in health amongst its diverse ethnic populations. Numerous factors play a role in the inequities of health among disadvantaged groups here in the United States. Lack of equitable education, healthcare and socioeconomics are all factors influencing health inequities. American Indians (AI) in the United States have long been known to represent a significant group affected by inequities in health, social and economic disparities compared to the general American population (Indian Health Service). Community-Based Collaborative Action Research (CBCAR) is defined as a collaborative and equitable relationship between a community and research organization that utilizes joint processes, which engages the community in identifying issues of concern, data collection, data analysis and finally the formation of a community wide plan (Wallerstein & Duran, 2006). Community-based research continues to emerge in the literature as a transformative research paradigm which can be used to develop, implement and sustain effective community centered strategies to eliminate marginalized population health status among AI (Wallerstein & Duran, 2006, 2010). The purpose of this article is to share first steps in implementing community-based collaborative action research in a Native American community.

Review of the Literature

Multiple models of research are available in publication. Review of the literature has increasingly demonstrated the slow but steady acceptance of CBCAR as a valuable framework to guide research with communities. CBCAR is defined as an equitable collaboration between researchers and community members which recognizes that all participants are valued members of the research team and that all participants possess unique and valuable knowledge as well as

skills that are vital to research (Jerinigan, 2010; Pavlish & Pharis 2012; Richmond, Peterson & Betts, 2008; Teufel-Shone, Syuja, Watanhomigie & Irwin, 2006). This type of partnering between researchers and AI communities allows for the community to take ownership and the lead in identifying and responding to their communities needs (Thomas, Rosa, Forcehimes & Donovan, 2011). The hope is that as more researchers embrace CBPR as a viable and valuable research framework, the historical mistrust between researchers and AI communities will be healed allowing for better solutions and partnering in addressing health disparities and improving overall health and wellness in AI communities.

The 2003 report by the Institute of Medicine, calls for CBCAR to be taught as a core competency in health teaching institutes has also added to the increasing interest in the CBCAR paradigm of research (Gebbie, Rosenstock & Hernandez, 2003). Community based collaborative action research uses a holistic perspective where community drive the research agenda, generate research questions, gather data and evaluate findings based on local context.

Conducting research in AI communities has a long history of challenges. Not only has traditional research been met with its challenges, but so has CBCAR. Although CBCAR is an appropriate research method for changing the negative history between researchers and AI communities, CBCAR research also has its share of challenges. CBCAR challenges include; research design and quantification of research effectiveness, expansion and acceptance of project constraints by the Institutional Review Board (IRB), implementation of the project in the context of researcher and community relationship building, community consent and protection as well as data propriety (Burhansstipanov, Christopher, & Schumacher, 2005; Johnson, Bartgis, Worley, Hellman, & Burkart, 2010; Makosky Dailey et al., 2010; Wallerstein & Duran, 2006).

Trust

Native American communities may demonstrate increasing interest in participating in CBCAR however this apparent enthusiasm for research has not always held true (Jernigan, 2010; Makisky Daley et al., 2010; Matloub et al., 2009). Addressing health disparities among AI populations has presented researchers as well as AI communities with challenging issues. Historically AI communities have suffered colonization, racism, land theft as well as research abuse and exploitation resulting in mistrust of research (Makosky Daley et al., 2010; Jernigan, 2010; Matloub et al., 2009; Richmond et al., 2008; Teufel-Shone et al., 2006; Thomas et al., 2011).

Community-based collaborative action research presents researchers and tribal communities with an alternative framework to traditional research. CBCAR requires that an equitable collaboration between researchers and community members exists where the researcher and the community recognizes that all participants are valued members of the research team and that all participants processes unique and valuable knowledge and skills that are vital to research outcome (Jerinigan, 2010; Pavlish & Pharis 2012; Richmond et al., 2008; Teufel-Shone et al., 2006). This type of partnering between researchers and AI communities allows for the community to develop a trusting relationship and allows the community to take ownership and lead in identifying and responding to their community's needs (Thomas et al., 2011).

Community Collaboration

Community and researcher collaboration requires equitable involvement of community members, tribal government and researchers at all stages of the project (Baezconde-Garbanati, Beebe, & Perez-Stable, 2007). Challenges between the community, researcher, university authorities, and research funders have risen as a result of researchers and funders setting the project agenda rather than the project direction coming directly from the community (Johnson et

al., 2010; Makosky Daley et al., 2010). For example, researchers may be met with significant resistance from their partnered community when, despite IRB approval of a study protocol, the funder dictates to the community that a rigorous quasi-experimental research design which heavily concentrates on outcomes needs rather than community identified issues to be investigated. Conflict may also arise when researchers attempt to design and administer research questionnaires without the input of the community (Johnson et al, 2010; Makosky Daley et al., 2010). Sometime researchers' knowledge and focus is different than that of the community. This is further complicated when the knowledge and focus of tribal government may differ than that of the community. These issues are important as in CBCAR all participants must have an active role in the negotiations of the research endeavor. Resolving these types of conflicts may cost the project several months of negotiations and lost time (Makosky Daley et al, 2012; Wallerstein & Duran, 2006, 2010).

Devoting time to building relationships is essential in the successful implementation of a CBCAR project. Spending face-to-face time with stakeholders as well as practicing patience and flexibility adds to the depth of building the relationship and in the long run eliminates potential conflicts between researchers and community stakeholders (Makosky Daley et al, 2010; Matloub et al, 2009).

Community Consent

The question of tribal community consent can be nebulous to researchers who are not familiar with Tribal Nations and sovereignty. Each tribal community may have its own unique process for if and how research is conducted. In order to conduct research, researchers need prior approval either as a written memorandum of understanding or a letter of support from the tribal leadership, or in some instances, the tribal council will provide a letter as a resolution or tribal

mandate (Johnson et al., 2010; Matlaub et al., 2009; Thomas, Rosa, Forcehimes, & Donovan, 2011; Wallerstein & Duran, 2006).

Similarly, each research organization and university has its own Institutional Review Board (IRB) requirements. Some tribal communities may also have a sophisticated IRB that may require project approval before any research is conducted on tribal land. Meeting the rigors of an IRB can be time consuming as well as challenging. CBCAR is not always well understood by traditional quantitative research committees. Having a good understanding of the CBCAR paradigm may require educating the IRB and/or negotiating changes in the CBCAR process that may or may not be acceptable to the tribal community. As well, changes in the CBCAR process due to IRB requirements may inhibit the tribal community's abilities to share their perspective of native values on the research process (Richmond, Peterson, & Betts, 2008; Teufel-Shone, Siyuja, Watahomigi, & Irwin, 2006; Thomas et al., 2011).

Once the research team has received tribal and IRB approval to move forward with the project, issues with community structure and participation must be addressed. Typically tribes who have participated in previous CBCAR projects will have a community advisory board. However this may not be the case for many tribes, in which case the tribe should be encouraged to establish a structure of their own which recognizes the uniqueness of the tribe and maintains equitable relationships and voice within the community (Thomas et al., 2011; Wallerstein & Duran, 2006). Each of the previous discussed issues requires that the researcher plan for long approval times. This can have significant implications on the researcher as well as project completion and dissemination of findings through publication and other means.

Data Acquisition, Interpretation and Dissemination

Data ownership and publication rights are important aspects that must be negotiated before starting a project in AI communities. CBCAR allows multiple ways to collect data as long as it honors community needs and culture (Pavlish, & Pharris, 2012). Past studies have experienced conflict when researchers attempted to administer questionnaires or focus groups rather than utilize culturally appropriate data collection tools such as “talking circles” (Johnson et al, 2010; Wallerstein & Duran, 2010). Researchers also encounter difficulties when they assume that all intellectual property rights will belong to the investigator rather than the community (Johnson et al., 2010; Thomas et al., 2011). Study disruption and discourse between the researcher and the community could have been avoided had the researcher fully disclosed from the onset their intentions and requested shared ownership and publication rights to the data collected before proceeding with the project.

Multisite Research

Researchers often find that communication and coordination as well as differences among tribal groups vary from tribe to tribe, making standardization of project protocols difficult for multisite research. Limited community resources such as personnel being utilized in multiple capacities within the community often limit the researcher’s accessibility to tribal participants making coordination of the project difficult. Many tribal communities are often located in very remote areas making project coordination of multisite projects quite challenging for researchers. Researchers have found that creating a “one size fits all” study design is not appropriate when dealing with tribal communities and that understanding that resource availability varies between tribes in the same way that cultural and traditions are different (Makosky Daley et al., 2010; Matloub et al., 2009;).

Conducting CBCAR not only benefits the community by providing the community with a method of identifying and solving community issues, but CBCAR also provides a meaningful framework to collect information and disseminated the findings back to the affected community. Subsequently, the tribe has an opportunity to improve delivery of care as well as develop additional meaningful programs specifically designed for its own people. Often researchers find that initial projects lead to further collaborative projects, which emerge between the parties (Johnson et al., 2010). Community-based research provides the community with a sustainable program implementation opportunity that can facilitate the integration of new programs into existing community resources (Wellerstein & Duran, 2010). The purpose of this project was to initiate first steps in implementing community-based collaborative action research in a Native American community.

Methodology

Design

In keeping with the principles of CBCAR, the researcher initially met with tribal administration to discuss the community needs and to evaluate community views on the future direction in health and wellness strategic planning. The researcher is well known to the tribe and has a well-established trusting relationship with individual members of both the Tribal Business Council and the community. The Tribal Business Council through a written mandate appointed a community taskforce. The taskforce consisted of the researcher, tribal medical director, tribal health department administrator as well as an individual tribal community member. The taskforce met weekly and provided weekly updates regarding project direction as well as recommendations regarding the use of CBCAR to the Tribal Business Council.

Sample and Setting

This federally recognized American Indian community in the upper Midwest consists of 274 voting community tribal members. This sovereign AI community is governed by Tribal Business Council, which consists of a Chairman, Vice-Chairman and Treasurer. The 274 voting community members elect each member of the council. The Tribal Business Council receives its direction regarding government affairs by the 274 members of the Tribal General Council.

Measures

To understand overall need of the community, the tribal general council members led by the director of strategic planning developed the survey. Although the taskforce recommended collecting the needs assessment data via traditional talking circles, the Tribal Business Council and Tribal General Council voted to adopt a traditional survey questionnaire developed by the strategic planning committee made up of executives employed by the community. The vice president of the strategic planning committee met weekly with the Tribal Chairman and Tribal Business Council who, upon completion of the final draft of the survey, brought the survey to the Tribal General Council for final approval. This process was the first of its kind in the recent history of the tribe. Since tribal members are part of the community, the survey has face validity.

A 35 item questionnaire was both mailed to tribal members as well as placed on the tribal member community website for direct access. The survey was administered to gather community opinion and feedback regarding community living. The goal of the survey was to provide information and direction for a community wide 2022-master plan. Items in the survey related to perceived community problems, participation in health and wellness programs, feelings of community connectedness as well as tribal initiatives. The survey contained both Likert and open-ended questions, resulting in both qualitative and quantitative data.

Procedure

Once survey was developed by the tribal general council members and the director of strategic planning; community members including researcher had provided input. The survey was mailed by the tribal council members to all tribal members residing on tribal land in April 2012. No reliability and validity of the instrument was conducted as the input from community members for the survey was deemed appropriate to maintain rigor. A notice in the community newsletter provided information regarding the survey, which was also available to community members on the community, web site. As incentive, participants were offered a “dinner for two” gift certificate to a local restaurant for returned surveys. Survey results were kept anonymous. Initial data was compiled and sorted by the strategic planning committee. A written request by the researcher was submitted to the Tribal Business Council for permission for secondary analysis of the unidentified data. IRB approval was obtained from St. Catherine University. The researcher examined all data from the needs assessment survey.

Results

The community received 64 responses (23.9% response rate). The age range of participants was 18 to 74 years with 28.3% (n=17) of respondent's age being between 25 to 34 years. Of the 64 tribal members who participated in the survey 47.5 % (n=28) were male and 52.5% (n=31) were female.

The top three issues identified in the survey which members felt were most pressing in the community were: (a) members not finishing school, (b) non-tribal gaming expansion, and (c) the loss of history and culture within their community. Other concerns included drug and alcohol use among their members, as well as the lack of use of their mental health facilities. Despite these issues, members felt that the community strengths were its medical facility,

recreational areas such as the sports arena, woodland and grasslands as well as the community gardens and organic farming.

One of the primary objectives of this research project was to introduce the community to the CBCAR process. The goal of the community was to identify common issues facing community members. Using descriptive and content analysis, themes began to emerge from the open-ended survey questions. The community wished to use these themes to guide their development of a future master plan for their community. The following six themes emerged from the community survey, which are outlined below.

Education

When asked to rank the “most significant issues facing the community”, respondents listed education as the top concern. Participants felt that education was an essential component to the community maintaining self- sufficiency. Fifty-two percent of respondents stated they use the tribal pre-school program, while 33.3 % stated that they home school their children through the tribal home school program.

Survey results show that members are concerned that many of their children are not completing their education nor are they advancing to higher education, learning a trade or receiving marketable skills that would benefit the future of the tribe. Over 50% of the respondents expressed a need for a tribal school however; others voiced concerns over the quality of the current tribal educational department. Of those indicating the need for a tribal K-12 educational program (50.8%, n=30), 80.6% (n=25) indicated that they would enroll their children in the tribal community school. Less than half the respondents (46.7%) however, indicated that they would not be willing to pay tuition for the community school.

Financial

Most members (90.2%, n=55) agree that the community should continue to diversify its financial resources into other enterprises other than the casino on the reservation in order to continue to grow its net earnings. Forty-eight (78.7%) respondents agree that the community should also diversify and grow other businesses beyond the reservation. Members ranked “finding alternative sources of revenue” as the second most important community project. Some members stated that they were concerned with “the potential of non-tribal gaming expansion in the state”. Others felt that the tribal government “should help members by investing in and starting other businesses”. Respondents also recommended that the community provide members with better financial planning resources especially to the younger members in order to better prepare the youth of the community for future financial independence.

History and Culture

Tribal history and culture seemed to be a theme that emerged throughout most areas of the community survey. Most respondents (98.4%) felt that history and culture were essential elements in keeping the community strong and intact. Members were encouraged to write their concerns regarding culture and heritage. Member wrote that they would like to see “more Dakota language programs for both young and old”, wanted more “cultural and history programs” as well as culturally appropriate art and crafts such as “beading, storytelling, quilt making and internship for future tribal positions”. Other traditional practices, which were included in the survey, were leather making, tanning hide, and pipe making as well as teaching about traditional ceremonies. Members also indicated that they felt that traditional teachings from elders about tribal history were also important in maintaining tribal culture and heritage.

Health and Wellness

The majority of the respondents indicated that they use the current tribal clinics (95.2%), pharmacy (86.7%) and wellness center (57.4%) for their health care needs. Despite the high use of the community health clinics, community members expressed the need for a “newer and more consolidated medical center”, and “better access to specialists”. Several members identified adding “assisted living” and “elder care” as community needs.

When asked to list the “top issues for the community to address”, seventeen percent (N=11) listed drug and alcohol issues as their top priority. Most respondents (48.9%) indicated that they sought mental health, counseling and other mental health support services outside of the community. Of those who did receive their services from the community mental health center (8.7%), 48% felt that the services they received ranged between outstanding to good. No one rated the services as poor.

Housing and Land

Issues identified which dealt with housing and land acquisitions were mixed. The survey showed that no respondents were currently waiting for a land assignment and that 93.3% of the responders have already completed construction on their current land assignment. Respondents were mixed about their satisfaction regarding the land assignment process. Members commented on difficulties dealing with the tribal land department, not understanding the complexities of the process including “elders giving assigned lands back and moving back to the top of the list”. Eight-two percent of respondents felt that the community needed elder housing, 74% assisted living, and 48% felt that apartments or townhouses should be available for younger members who were just moving out from their homes and had not received their land assignments.

Tribal Government

Seventy-six percent of the respondents rated the quality of life in the community as very good or outstanding. The majority (64.1%) rated the responsiveness of tribal leaders to the needs of the community as outstanding or very good. Many respondents felt that they would like to see more tribal members engaged in the community affairs. Some felt that there needed to be more input from the community in making community decisions. Members also felt that the tribe should continue to invest in the community infrastructure such as roads, water purification systems as well as turbine for electricity in order for the community to continue to be self-sufficient.

Limitations

There were several limitations of this study. First, although all tribal members were invited to participate in the survey only 23.9% tribal members chose to participate. The information gathered, though valuable, may not represent the views of the majority of tribal members in this community. Due to the small return sample size, generalizability of these findings to other AI communities is limited. Despite the small sample size, this is the first community assessment survey that resulted in almost 24% community participation.

This study was first of its kind where community was learning and initiating steps in CBCAR. Although the survey was developed by non-tribal members but community tribal council and members had significant input. The survey did have significant input from the Tribal Chairman, Business Council and eventually final vote from Tribal General Council. This process was first part of increasing the research knowledge and capacity to work with CBCAR framework while understanding the overall wellness need of the community. This was facilitated by both tribal administration and Tribal Business Council acknowledging the possibility of CBCAR and providing the community with voice and input to engage in

community well-being. This is the first time in recent history where community have formed a partnership with a researcher to identify framework of CBCAR and have developed community work groups to address the six main themes that emerged from the survey.

Discussion

The CBCAR framework requires that the researcher understands and embrace the importance of nurturing the relationship with tribal government and community members prior to beginning any research. The investment of face-to-face time, laying down the foundation to produce meaningful data not only for the researchers but also for the communities themselves is a common theme among CBCAR studies (Johnson et al., 2010; Matloub et al., 2009; Richmond et al., 2008).

The challenges experienced in this project were found to be similar to those found in the literature. The researcher and taskforce found that not many community members understood the complexities of CBCAR. Extraneous variables including the researchers' perception of how the project should unfold had the potential of interfering with the collaboration between the researcher, community and their ideas regarding project direction, data collection and dissemination of data. This project provided a rich environment for both partners to engage in a collaborative partnership in gathering needs assessment for a community so further projects can be developed. Furthermore, this project provided the Tribal Council with much needed information about the thoughts and issues facing the community. The results of this need assessment were disseminated to the community and Tribal Council. The data using community voice provided the community with an opportunity to make culturally meaningful changes by developing a comprehensive community wide plan. While the evaluation portion of this project

has concluded, it is important to note that the researcher has continued to work with the community on several projects that have emerged as a result of the community assessment.

The CBCAR principle of including all community members and providing opportunity to hear all voices provides a rich research framework. Incorporating and engaging community in translating research into meaningful practice is crucial to sustain cultural identities.

References

- Baezconde-Garbanati, L., Beebe, L., & Perez-Stable, E. (2007). Building capacity to address tobacco-related disparities among American Indian and Hispanic/Latino communities: Concepts and systemic considerations. *Addiction 102* (suppl. 2) 112-122.
- Burhansstipanov, L., Christopher, S., & Schumacher, S. A. (2005). Lessons learned from community-based participatory research in Indian Country. *Cancer Control, 12*(suppl 2), 70-76.
- Gebbie, K., Rosenstock, L., & Hernandez, L. M. (2003). Who will keep the public healthy. Educating public health professionals for the 21st century. Washington (DC): Institute of Medicine.
- Indian Health Disparities. Retrieved from:
<http://www.ihs.gov/factshets/documents/Dispatities.pdf>.
- Jernigan, V. B. B. (2010). Community-based participatory research with Native American communities: the chronic disease self-management program. *Health Promotion Practice, 11*(6), 888-899.
- Johnson, C. V., Bartgis, J., Worley, J. A., Hellman, C. M., & Burkhart, R. (2010). Urban Indian voices: A community-based participatory research health and needs assessment. *American Indian and Alaska Native Mental Health Research: The Journal of the National Center, 17*(1), 49-70.

- Makosky Daley, C., James, A. S., Ulrey, E., Joseph, S., Talawyma, A., Choi, W. S., ... & Coe, M. K. (2010). Using focus groups in community-based participatory research: Challenges and resolutions. *Qualitative health research, 20*(5), 697-706.
- Matloub, J., Creswell, P. D., Strickland, R., Pierce, K., Stephenson, L., Waukau, J., ... & Remington, P. (2009). Lessons learned from a community-based participatory research project to improve American Indian cancer surveillance. *Progress in community health partnerships: Research, education, and action, 3*(1), 47-52.
- Pavlish, C. P. & Pharris, M. D. (2012). *Community-based collaborative action research: A nursing approach*, Sudbury, MA: Jones & Bartlett Learning.
- Richmond, L. S., Peterson, D. J., & Betts, S.C. (2008). The evolution of an evaluation: A case study using the tribal participatory research model. *Health Promotion Practice, 9*(4), 368-377.
- Teufel-Shone, N. I., Siyuja, T., Watahomigie, H. J., & Irwin, S. (2006). Community-based participatory research: Conducting a formative assessment of factors that influence youth wellness in the Hualapai community. *American Journal of Public Health, 96*(9). 1623-1628.
- Thomas, L. R., Rosa, C., Forcehimes, A., & Donovan, D. M. (2011). Research partnerships between academic institutions and American Indian and Alaska Native tribes and organizations: Effective strategies and lessons learned in a multisite CTN study. *The American Journal of Drug and Alcohol Abuse, 37*(5), 333-338.
- Wallerstein, N., & Duran, B. (2010). Community-based participatory research contributions to intervention research: The intersection of science and practice to improve health equity. *American Journal of Public Health, 100*(S1), S40-S-46.

Wallerstein N. B., & Duran B. (2006). Using community-based participatory research to address health disparities. *Health Promotion Practice* 7(3), 312-323. DOI:

10.177/1524839906289376.

Walters, K. L., Simoni, J. M., & Evans-Campbell, T. (2002). Substance use among American Indians and Alaska natives: Incorporating culture in an "indigenist" stress-coping paradigm. *Public Health Reports*, 117(Suppl 1), S104-S117.

Witaya Care: Bringing Health to Tribal Communities Through Community Partnerships

Systems Change Project,
Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Nursing Practice

St Catherine University
St Paul, Minnesota

Jane Peterson

May, 2013

ST. CATHERINE UNIVERSITY
ST. PAUL, MINNESOTA

This is to certify that I have examined this
Doctor of Nursing Practice systems change project
written by

Jane Peterson

and have found it is complete and satisfactory in all respects,
and that any and all revision required by
the final examining committee have been made.

Rozina Bhimori, PhD, DNP, RN, CNP

Faculty Project Advisor

5/31/13

Date

DEPARTMENT OF NURSING

Copyright Jane Peterson, 2013

All Rights Reserved

Dedication

This project is dedicated to Chairman Stanley R. Crooks and the Shakopee Mdewakanton Sioux Community. I would like to acknowledge and thank my advisor, Dr. Rozina Bhimani for her support throughout my doctoral program my reader, Dr. Carol Geisler, and my site mentor Dr. Nancy Hawkins. Special thanks to my husband Allan and my beautiful daughters Amanda and Nicole for their support and love during the past two years while pursuing the degree of doctor of nursing practice.

Abstract

Today's health care environment calls for communities to develop collaborative partnerships that involve engagement of key community stakeholders to improve community health. Community partnerships require engagement of key community stakeholders to form alliances to work collaboratively. By providing leadership, vision and vital networking the community stakeholders can develop innovative programs to improve community health. Nurses play an important role in identifying and developing collaborative partnerships. Community-based collaborative action research led by nurse leaders has emerged as a vital strategy for developing effective and culturally relevant health interventions. This article describes the process and outcomes of a tribal/researcher collaborative project implemented to address the current health and wellness issues identified through "Witaya Care." The collaboration between the tribal community clinic and a local community hospital due to "Witaya Care," resulted into care navigation and electronic health record integration. This project represents a model of possibilities for other ethnic and community groups.

Keywords: Community-based participatory research, Indians, North American, collaboration, and partnering.

Witaya Care: Bringing Health to Tribal Communities Through Community Partnerships

Today's health care environment is rapidly transforming. This evolution of healthcare system calls for communities to develop collaborating partnerships. Community partnerships require commitment of key community stakeholders to form alliances to work collaboratively. By providing leadership, vision and vital networking the community stakeholders can develop innovative programs to improve community health. Nurses play an important role in identifying and developing collaborative partnerships. Historically, nursing has participated and placed high value on collaborative partnerships within the nursing profession and with other allied health care professionals and community leaders (Diefenbeck, Plowfield, & Herrman, 2006).

Community-based research led by nurse leaders has emerged as a vital strategy for developing effective and culturally relevant health interventions. Community-Based Collaborative Action Research (CBCAR) is defined as a collaborative and equitable relationship between a community and research organization that utilizes joint processes; engages the community in identifying issues of concern, data collection, data analysis and finally the formation of a community wide plan (Wallerstein & Duran, 2006). Community-based research continues to emerge in the literature as a transformative research paradigm, which can be used to develop, implement and sustain effective community centered strategies to eliminate marginalized population health status among American Indians (AI) (Wallerstein & Duran, 2006, 2010).

Current literature appears to be lacking in descriptive evidence of the overall impact CBCAR has on community policy change and outcomes (Minkler, Vasquez, & Shepard, 2006). This article describes the process and outcomes of a tribal/researcher collaborative project implemented to address the current health and wellness issues identified thorough a community-based collaborative action research project. The study outlines that nurses in leadership roles

have the innovation, skills and vision to bring forth meaningful and sustainable community change.

Paradigm Shift: A Time for Innovation

American Indian inequity in education, healthcare, socioeconomics, policies both at the local and federal levels remain present in communities across the United States. There are several guiding principles, which have been described in the literature that are needed in the establishment of health equity (Wallace, 2008). One such principle is the need for a paradigm shift, which requires nurses, health care professionals and community leaders to join in a collaborative effort to enhance networking, leadership and vision towards change (Wallace). The drive to create new models of culture care requires that health care providers recognize the need for the training of culturally sensitive and competent health care providers as essential for providing culturally safe care (Leininger, 2007; Zeidler, 2011). Non-tribal professionals who provide care from a mindset of shared respect and dignity are better able to serve minority populations (Zeidler).

Past historical traumas as well as historical events have a significant impact on American Indian development both physically, mentally as well as spiritually (Gone, 2009; Yellow Horse Brave Heart, 1999). Health perception as well as historical losses influence both the individual's response to physiological changes associated with stress as well as the practice of health promotion behaviors. It is important, therefore, to determine the perception of American Indians towards community health as well as their perceived community in order to promote a healthy lifestyle and improve overall all health.

Creating and providing culturally competent health care requires a holistic model of care which incorporates cultural, spiritual, physical, emotional and social aspects of the individual

communities' values (Wallace, 2008; Zeidler, 2011). Providing culturally competent care also acknowledges and reinforces social justice framework and ensures equity through balance of power and preservation of human dignity.

The purpose of this article is to provide a model of care that provides culturally sensitive holistic care that promotes health, healing and wellbeing named "Witaya Care". This model of care emerged from a community-based collaborative action research project initiated between a tribal community and researcher. A needs assessment was developed and implemented by the tribal community members. The community needs assessment identified six community initiatives. The health and wellness initiative presented the community with an opportunity to develop culturally sensitive high quality health care, which incorporated local community health care specialists and hospital personnel. The development of the Witaya Care described in this article provides a model of care, which encourages healing, promotes wellness through cultural respect and healing of diverse ethnic groups.

Review of Literature

A review of the current literature was completed for the period 2000-2012, using electronic databases: Pubmed, Medline, CINAHL and EBSCO. MeSH terms: Community-Based Participatory Research; Indians, North American; Health Care Disparities and Needs Assessment were searched. Included were papers published in only in English. The review of literature revealed numerous challenges which emerged in the studies.

Three studies reviewed conflicts between the researcher, funder and the community (Daley et al., 2010; Johnson et al., 2010; Richmond, Peterson & Betts, 2008). Johnson et al., experienced issues when the researchers realized that they were not fully educated about CBCAR and initially attempted to design and administer a research questionnaire without the

input of the community. Following the standard practice in the CBCAR framework, the researcher and community eventually developed an agreement of understanding outlining roles and responsibilities. Daley et al. (2010) experienced conflict in choosing appropriate health issues to address. Conflict arose when study issues the researcher and funder wished to address did not match issues identified by the community. Richmond et al., (2008) also experienced similar issues. Despite Institutional Review Board (IRB) approval of the study protocol, the funder attempted to persuade the community that a rigorous quasi-experimental research design, which heavily concentrated on outcomes, needed to be instituted. This plan would require a large number of participants, random assignment as well as community buy-in. The community declined to participate and the trusting relationship, which had been cultivated, was then placed in jeopardy. Eventually the community, researcher and funder were able to reach a compromise. Resolving this conflict did cost the project several months of negotiations. However in the long run, the funder did gain insight into the challenges of collaborating with native communities and the importance of having open communication (Richmond et al., 2008).

Baezconde-Garbanati et al., (2007) found that outside funding created conflict of interest for their project. The participating communities were found to have significant economic dependence on external revenue generated from the tobacco industry. This dependence presented the researchers with significant barriers to establishing a community consensus on addressing tobacco addiction. Baezconde-Garbanati et al., found that a sense of community in both AI and Hispanic/Latino communities was a strong motivating factor for these communities in improving community health. They also identified that tribal sovereignty was a potential barrier to changing environmental smoking policies.

Another issue identified in the literature review, addressed roles and responsibilities as well as data propriety. Several research projects found that unless roles were clearly defined they were at times ambiguous and sometimes conflicting with community expectations (Thomas, Rosa, Forcehimes & Donovan, 2011; Johnson et al., 2010). Researchers found that determining project timelines, identifying clear roles and responsibilities as well as data ownership and publication rights early in the project's development is essential to the project moving forward and in a timely manner. Both studies (Thomas, Rosa, Forcehimes & Donovan, 2011; Johnson et al., 2010) experienced conflict when researchers attempted to administer either focus groups or questionnaires rather than have the community administer or conduct the data collection themselves. In addition, Johnson et al. experienced conflict when the researcher requested that all intellectual property rights go to the investigator rather than the community and tribe. This caused significant study disruption and discourse between the researcher and the community. Both studies were able to resolve their conflicts however had the researchers truly understood the CBCAR paradigm; this conflict might not have arisen.

Communication, coordination as well as differences among tribal groups varied from tribe to tribe making standardization of project protocols difficult for project researchers. Limited community resources such as personnel being utilized in multiple capacities in the community, also limited the researchers accessibility to tribal participants (Matloub et al., 2009). Matloub et al., and Daley et al., (2010) both found that conducting community-based research in multiple tribal sites at the same time presented unique challenges. Both researchers concluded that a "one size fits all" study design is not appropriate when dealing with different tribal communities. Both research groups realized early on that tribal communities differ not only in their available resources but also that tribes differ both in culture and traditions.

Time spent building strong tribal and community relationships are needed especially during the implementation of the project and when time came for data collection and data analysis. The researchers (Matloub et al., 2009; Thomas et al., 2011) discovered that each tribe is unique in its own way; that negotiations for the research may be complex given the differences in tribal government. Time lines often need to be adjusted to accommodate the inherent complexities of CBCAR. That having some understanding about the community prior to conducting research is imperative to the success of building and nurturing relationships with the community and its members.

Researchers recognized that although CBCAR is a time intensive study framework; this approach is a valuable approach to conducting rich research in addressing health disparities facing American Indians in the United States (Baezconde-Garbanati et al., 2007; Daley et al., 2010; Johnson et al., 2010; Matloub et al., 2009; Richmond et al., 2008; Teufel-Shone et al., 2006; Thomas et al., 2011). The researchers point out that in the past most AI communities have taken a passive role in receiving services from outsiders. However CBCAR demonstrates how communities can take ownership of the assessment, plan and outcomes of their work.

Methodology

Community Concerns

Impetus for this study originated from community concerns in one Native American community. Researcher working in the tribal community as an advanced practice nurse role learned about community's health care needs. The community voiced concern regarding fragmented care between the tribal community clinics and outside specialty clinics and hospital. Problems were also identified involving cultural insensitivity experienced by tribal members by health care staff when seeking care off tribal lands. Other health related issues such as

medication errors and duplication of diagnostic tests were also identified. Tribal members requested better and more comprehensive coordination of care especially when going to specialized clinics and hospitals throughout the city. These identified concerns are not unique to AI and have been found in the general public and described in the literature (American Nurses Association, 2012).

Research Question

In American Indian communities, how does community-based collaborative action research affect the development of community projects addressing health disparities and improved access to health care?

Purpose

A Health and wellness taskforce was created as a result of a tribal business council mandate. The taskforce consisted of a tribal community member, tribal medical administrator, wellness administrator as well as the clinic medical director and lead Family Nurse Practitioner. The aim of the health and wellness taskforce was charged with identifying and improving tribal health by creating important and sustainable community collaborative relationships between the tribe and community health resources.

Design

Community Based Collaborative Action Research (CBCAR) framework was used to conduct this study. A nurse led community-based research project was initiated in 2011 in collaboration with an upper mid-west tribal government. The researcher introduced the tribe to CBCAR and helped to facilitate the first community needs assessment in the tribal community. The tribe elected to collect data using a survey method with open-ended questions. The tribal members were active participants in the development of the questionnaire. In April 2012 the

survey was administered and data was analyzed using descriptive statistics. The follow six main areas of needs emerged from the survey; finance, health & wellness, history & culture, housing & land, tribal government and education. The result of the community-based project and identification of these six areas resulted in the formation of community member led teams. Each team consisted of a tribal administrator and five community members, who addressed a given particular community project. This particular project focused on health and wellness issues in the community.

Sample and Setting

In response to these identified concerns, a taskforce was initiated by a mandate from the Tribal Business Council. The taskforce consisted of a nurse leader, tribal medical director, and administrator and tribal community member. The taskforce worked in collaboration with the health and wellness community member team.

Data and Outcome Measures

Processes emerged organically and intertwined naturally. Using process analysis, outcomes were measured based on the number of healthcare resources and services created for the tribal community.

Results

The vision of creating a community partnership and alliances between the local health community and tribal community resulted in the creation of a “Memorandum of Understanding” between the tribe, local community hospital and specialty clinics. The initial meetings between the tribe and community hospital leadership was a historical moment for both the tribe and hospital.

Memorandum of Understanding

The “Memorandum of Understanding” was signed in May 2012. Key elements of the agreement included the following; enhance the quality of care and efficiency for tribal members; share health care information using electronic medical record coordination and interfaces; coordinate and define a network of care providers and specialists; reduce unproductive and duplication of services by implementing Care Navigation services for community members; and facilitate access of tribal health care providers to community members while members are in the community hospital system.

Witaya Care

Honoring the community culture and traditions, “Witaya Care” was initiated. The Dakota word “Witaya” which translates into English as, to assemble, to come together, to bring something or someone together. The group consulted the tribal cultural director and Dakota resource managers to help create a name representing the project. The project name “Witaya Care” was adopted. The aim of Witaya Care is to unite tribal and local medical communities as partners working together to improve the health and healing of the tribal community.

The team designed a logo representing “Witaya Care” using the Native American medicine wheel. The medicine wheel was drawn as figures representing people joined together by hands forming the medicine wheel and the colors represent the races black, white, red and yellow. The wheel was strategically placed at a 45-degree angle so that no one race could be interpreted as having more power over any other race. The medicine wheel with its colors does not divide people racially but unites all nations while at the same time providing encouragement, togetherness and balance, so that all nations are united as one (Castellano, 2000; Lowe & Struthers, 2001).

Program Initiatives

Six program initiatives were developed by the Witaya Care team; development of unique treatment plan identifier for hospital patients, electronic health record and radiology integration, creation of a Care Navigation program, facilitation of tribal providers credentialing at the community hospital, implementation of cultural sensitivity training to local community clinics and hospital. These initiatives were created by the multidisciplinary collaborative team, which included the tribal leadership, medical director, health clinic director/nurse practitioner, tribal member, medical administrator, hospital president, hospital medical director, hospital vice president of patient services, and vice president of institutional technology (IT). Other disciplines were called in for their expertise and to collaborate depending on the project needs.

Unique Treatment Plan Identifier

With the development of the “Witaya Care” program, a brochure was created which defines the Witaya Care program to the tribal community members. The brochure also provides the member with an opportunity to agree to participate in the Care Navigation program. Once the member has consented to participate in the navigation program both the community electronic health record and the community hospital records are flagged with a unique treatment plan identifier. The identifier is flagged when the member makes contact with a non-tribal health care clinic. The unique treatment plan then allows the care navigator to assist with coordination of care between the patients’ home clinic and the hospital or specialty clinic’s coordinator.

Electronic Health Record and Radiology Integration

The community hospital and tribal clinic as well as surrounding specialty clinics created an interface, which allows for real-time patient data to be exchanged among providers. This sharing of patient approved data has enabled providers to reduce the duplication of diagnostic

tests and has improved communication between facilities in a timely matter. Patient results or specialty visit notes that used to take days or a week to be received by primary care providers now takes hours. The information is now available in patient electronic health record and reflects changes in medications or patient status. This project has also provided other area clinics with a template for integrating their electronic health records with the community hospital as well.

Care Navigator

The Care Navigation program was instituted to provide coordination between tribal clinics and the non-tribal community hospital to decrease care fragmentation and therefore decrease medical costs by eliminating duplication of services and diagnostic tests. The pilot program was initiated involving an APRN and an RN who worked as a team following tribal member patients with chronic diseases. During this pilot phase, the tribal clinic patients' who were hospitalized in the local community hospital were identified through "Witaya care" process. Once tribal patients were identified; APRN/RN team pinpointed potential medication errors, side effects, and duplication of tests, exacerbation of co morbidities for prompt intervention. The Care Navigator processes led by APRN/RN team prevented hospital admissions and decreased in-patient hospital days. The Care Navigation team also provided intense care coordination during hospital stays by synchronizing discharge planning and post-discharge interventions. Home visits were conducted 24 thru 72 hours post hospitalization and Care Navigator team collaborated with other providers by accompanying patients to outside specialty clinic visits. Utilization of the APRN improved response time to patient issues due to the autonomy of the advanced practice nurse. Due to this flexibility to individualized care plans, patient advocacy, prescription accuracy and quick interventions according to the needs of the

patients and their families resulted in significantly reducing in-patient hospital admissions by 50% resulting in a decrease in hospital cost.

Hospital Credentials

Prior to this collaborative project, clinic providers were credentialed through the community hospital that only allowed the provider to only order diagnostics through the hospital. Patients admitted to the hospital were managed solely by hospital providers. Through the memorandum of understanding between the tribe and the community hospital, tribal clinic providers now have full credentials to admit and manage tribal patients while they are in the hospital. This change in policy has made access to care for tribal patients easier.

A significant deterrent for American Indian people in accessing hospital care is the lack of trusting relationship with strange hospital personnel and health care providers. Tribal members often feel isolated from their community when going to the hospital. By providing tribal providers with full credentials to the community hospital, patients are now able to have better continuity of care, but are also able to access their community provider whom they have developed a trusting relationship with over time. This new policy also allows the tribal provider to nurture relationships with local community specialists. By being present in local hospital meetings the community of tribal providers and non-tribal providers has improved. This collaborative partnership has also improved identification of barrier to care and has provided culturally sound solutions in overcoming obstacles to care.

Cultural Sensitive Training

Tribal members continue to experience and feel the effects of past and present cultural insensitivity. In order to improve community relations and tribal members experience while in the care of non-American Indian medical providers, Witaya Care developed cultural sensitivity

training for the community hospital staff. The tribal cultural director conducted the training. Initial training was provided for all the hospital leadership. Throughout the year training was extended to include all department heads and nursing staff.

Witaya Care also developed a hospital policy allowing AI patients to burn sage during their hospital stay. The development of this policy required the use of multidisciplinary team engagement including the fire marshal, hospital security, nursing staff and hospital administrators. Despite encountering several obstacles the policy was adopted hospital wide. To date this project and the project leaders have provided American Indian specific culturally sensitivity training to over 300 nurses. The cultural leadership team has also been invited to several community conferences held to provide continued training for local teachers, social workers and community mental health workers. Taskforce colleagues have expressed that this continued training has moved the community to genuine understanding and acceptance that is fundamental to the continued strengthening relationship of respect and recognition between the tribal community and health community. The power of culturally based care to heal and promote wellness in the community is a major breakthrough both for health care and the tribal community.

Conclusion

The success of Witaya Care depends on the successful collaborative efforts of multiple disciplines providing unparalleled networking, leadership and vision. Community-based research has empowered both tribal and community leaders who historically may have had adversarial relationships to address a wide variety of community issues by combining their resources. A concerted and synchronized relationship and collaborative interaction from multiple disciplines is needed to continue to facilitate and expand the Witaya Care project.

This unique team continues to meet regularly and is currently working to incorporate more community partnerships to address tribal mental health issues. Ten years ago the idea of community individual both tribal and non-tribal coming together for a mutually accepted goal or mission would not have been possible. This experience has demonstrated to those involved in the process that building relationships, which enhance the formation of collaborative partnerships, is possible even among the most unlikely of communities. This project has also demonstrated that networking, leadership and vision are the strengths and core values necessary in keeping a community partnership engaged. This project provides a platform and model in engaging diverse communities in addressing health disparities through their own community lens.

References

- American Nurses Association. (2012). The Value of Nursing Care Coordination: A White Paper of the American Nurses Association. Retrieved from: www.nursingworld.org/carecoordinationwhitepaper
- Baezconde-Garbanati, L., Beebe, L., & Perez-Stable, E. (2007). Building capacity to address tobacco-related disparities among American Indian and Hispanic/Latino communities: Concepts and systemic considerations. *Addiction, 102* (suppl. 2) 112-122.
- Daley, C.M., James, A.S., Ulrey, E., Joseph, S., Talawyma, A., Coi, W.S., Greiner, K. A., & Coe, M.K. (2010) Using Focused Groups in Community-Based Participatory Research: Challenges and Resolutions. *Qualitative Health Research, 20*(5) 697-706.
- Diefenbeck, C. A., Plowfield, L. A., & Herrman, J. W. (2006). Clinical immersion: A residency model for nursing education. *Nursing Education Perspectives, 27*(2), 72-79.
- Gone, J. P. (2009). A community-based treatment for Native American historical trauma: Prospects for evidence-based practice. *Journal of Consulting and Clinical Psychology, 77*(4), 751.
- Johnson, C. V., Bartgis, J., Worley, J. A., Hellman, C. M., & Burkhart, R. (2010). Urban Indian voices: A community-based participatory research health and needs assessment. *American Indian and Alaska Native Mental Health Research: The Journal of the National Center, 17*(1), 49-70.
- Leininger, M. (2007). Theoretical questions and concerns: Response from the theory of culture care diversity and universality perspective. *Nursing Science Quarterly, 20*(1), 9-13.
- Lowe, J., & Struthers, R. (2001). A conceptual framework of nursing in Native American culture. *Journal of Nursing Scholarship, 33*(3), 279-283.

- Matloub, J., Creswell, P. D., Strickland, R., Pierce, K., Stephenson, L., Waukau, J., ... & Remington, P. (2009). Lessons learned from a community-based participatory research project to improve American Indian cancer surveillance. *Progress in community health partnerships: research, education, and action*, 3(1), 47-52.
- Minkler, M., Vasquez, V. B., & Shepard, P. (2006). Promoting environmental health policy through community based participatory research: a case study from Harlem, New York. *Journal of Urban Health*, 83(1), 101-110.
- Richmond, L. S., Peterson, D. J., & Betts, S.C. (2008). The Evolution of an Evaluation: A Case Study Using the Tribal Participatory Research Model. *Health Promotion Practice*, 9(4), 368-377.
- Thomas, L. R., Rosa, C., Forcehimes, A., & Donovan, D. M. (2011). Research partnerships between academic institutions and American Indian and Alaska Native tribes and organizations: Effective strategies and lessons learned in a multisite CTN study. *The American Journal of Drug and Alcohol Abuse*, 37(5), 333-338.
- Teufel-Shone, N. I., Siyuja, T., Watahomigie, H. J., & Irwin, S. (2006). Community-based participatory research: conducting a formative assessment of factors that influence youth wellness in the Hualapai community. *Journal Information*, 96(9), 1623-1628.
- Wallace, B. (2008). *Toward Equity in Health: A New Global Approach to Health Disparities*. New York, New York: Springer Publishing Company.
- Wallerstein, N., & Duran, B. (2010). Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *Journal Information*, 100(S1).

- Wallerstein N. B., & Duran B. (2006). Using Community-Based Participatory Research to Address Health Disparities. *Health Promotion Practice, 7*(3), 312-323. DOI: 10.1177/1524839906289376.
- Yellow Horse Brave Heart, M. (1999). Gender differences in the historical trauma response among the Lakota. *Journal of Health and Social Policy, 10*(4), 1-21.
- Zeidler, D. (2011). Building a Relationship: Perspectives from One First Nations Community. *Canadian Journal of Speech-Language Pathology and Audiology, 35*(2) 136-143.