Community-Building Versus Career-Building Research: The Challenges, Risks, and Responsibilities of Conducting Research With Aboriginal and Native American Communities

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Abstract—Background. The Aboriginal Women’s Cancer Care Project used a participatory research model guided by an Aboriginal advisory group. Methods. The researchers attempted to conduct cancer research with 5 culturally and geographically different communities in North America. Results. We discuss the challenges of conducting ethical research in keeping with the emergent research principles of community ownership and control of the research process and products. Conclusions. Although there are many perils for researchers and communities in conducting participatory research, clearer practice guidelines will ensure that research in Aboriginal communities will increasingly prioritize community- versus career-building outcomes. J Cancer Educ. 2005; 20:41-46.

The Aboriginal Women’s Cancer Care Project (AWCCP) was designed to increase understanding of the intersection of culture, identity, and health systems in Aboriginal and Native American women’s experience of and access to cancer care. We are investigating health and cancer beliefs, decisions, and health care experiences of Canadian Aboriginal and Native American women with breast and gynecological cancer. This exploratory qualitative study was designed to bring women’s experiences into focus to inform policy changes that address existing health disparities. In light of the many methodological challenges faced to date, in this article, we discuss the emergent challenges, risks, and responsibilities within research partnerships between researchers and Aboriginal and Native American communities. We discuss the ideals of participatory action research (PAR) and the newly asserted research principles of community: ownership, control, access, and possession (OCAP) of the research process and data. We identify that PAR and OCAP provide essential principles as guidelines that are necessary but not always sufficient for successful research collaborations. By contextualizing the research process from both the subject position of non-Native and Native researcher, we reveal the complexity of the research relationship and the dynamic issues of identity, trust, power, and sovereignty as negotiated in this cancer study.

ISSUES OF HISTORY, POWER, METHODOLOGY AND ETHICS

Participatory Action Research

PAR is defined as “systematic inquiry, with the collaboration of those affected by the issues being studied, for purposes of education and taking action or effecting social change.”1 PAR methods are viewed as appropriate and increasingly essential in conducting research with vulnerable, hard to reach, or medically underserved populations. PAR is viewed as appropriate because the research values are empowering and restorative and because of the explicit commitment that the outcomes should benefit the participants and/or their communities.2 PAR is conceptualized as a research approach that will promote the mutual production of knowledge, knowledge that is liberating rather than oppressive, knowledge that reveals and challenges systemic problems rather than reinforcing relations of dominance. Implicit in PAR is a balance of risks and benefits that should favor the needs and
with an explicit empowerment mandate. The research is an idealistic, values based, liberatory approach to research well-being of the participants over the researchers. PAR is an approach that strengthens participants’ awareness of their own strengths while building skills and knowledge in a collaborative process that supports change. Despite the explicit values of PAR to partner with and advocate for a group of marginalized or disenfranchised people, the practice of PAR is not explicit. Although there are guidelines, such as ongoing involvement of participants throughout all stages of the research, there are no clear guidelines as to how the ongoing research relationship is to be developed or how one negotiates power issues within the field. There are few if any guidelines on how power relations can either be reinforced or reshaped through PAR. What is known is largely unwritten and may ultimately be context specific. This has led to perceived and actual abuses by conventional researchers working under the PAR mantle to gain entry to communities and access to insider knowledge while still maintaining researcher control of the processes and the products of the research.

THE RESEARCH CHILL

Canadian Aboriginal and Native American communities are increasingly wary of external researchers, expressing concern that they are being “researched to death.” Epidemiological studies, for example, have depicted Aboriginal and Native American peoples as sick, powerless, and lacking in capacity, information that is used to reinforce unequal power relations, paternalism, and dominance and to undermine their aspirations for sovereignty. Approaching Aboriginal and Native American communities with PAR studies as a means of engaging them in research partnerships is insufficient to counterbalance the many harms created by outsider research; however, it is an important start in this process. Partnerships are more astutely understood by many Aboriginal and Native American communities as a “euphemism” for a relationship of individuals with unequal amounts of power and an uncertain balance of risks and benefits that most often favors external researchers. It is clear that western methodologies and institutional ethics processes are not enough to ensure the integrity, validity, and ethical nature of research in Aboriginal and Native American communities. Conventional academic research interests and methodologies and Aboriginal and Native American research interests and traditional forms of knowing do not make a natural fit. The clash between Aboriginal philosophies and positivist science has been described as “Jagged Worldviews Colliding.” However, Aboriginal and Native American communities have an increasing need for complementarity of methodologies, for an intercultural lens that ensures both the trustworthiness of research at the community level and external credibility to inform policy and access funding. With increasing attention to political processes of self-governance and sovereignty, Aboriginal and Native American communities are taking control of ethical review processes and decisions about which research does or does not happen in their communities. This means that researchers approaching Native American and Aboriginal communities for approval of research projects can be met with considerable skepticism, often waiting months for community approval with a very low success rate. This positive move toward increased sovereignty has resulted in a potential slowdown or “chill” on research until clearer partnership guidelines and practices are established.

PRINCIPLES OF RESEARCH
IN CANADIAN ABORIGINAL COMMUNITIES: OCAP

Increased sovereignty is expressed in part by increased control of community research. OCAP is a recently coined acronym. OCAP is a synthesis of proposed responses to grievances that have been advanced by Canadian Aboriginal peoples for many years. OCAP is a set of principles developed to ensure ethical and beneficial research that conforms to the cultures and needs of Aboriginal communities and serves to value and preserve indigenous knowledge bases. OCAP is part of a restorative process in which Aboriginal research plays a major role in restoring the power and control back to Aboriginal communities and individuals. The AWCCP is guided by the principles of OCAP to ensure that our research practices are in keeping with the laws, values, and ethics of the Aboriginal and Native American communities in which we are working and to redress the issues of power imbalances common in much of the prior research done “for” or “about” communities. However, OCAP is a “set of principles in evolution,” not an Aboriginal methodology. This is a salient point when considering the current challenges of implementing the principles of OCAP within mainstream academic research.

In the rest of the article, we describe our research project and how we experienced, as Native and non-Native researchers, both the embrace and chill of communities in relation to collaborative research. We describe our processes and our research challenges and the strategies we employed to negotiate these challenges. These challenges are in no way unique or comprehensive. We have, within the scope of this article, attempted to address those issues that were most salient: identity and subject location, development of community research partnerships, parameters of consent, control of data and participant privacy, and the vagaries of time within community-based research.

ABORIGINAL WOMEN'S CANCER CARE PROJECT

We chose a PAR model of community-based research in which members of the research population are involved at
all stages of the research process in various paid and unpaid roles. The AWCCP is an ongoing collaborative community research project in which the coprincipal investigators of this study are a non-Aboriginal Canadian assistant professor and a Native American retired academic and director of a national cancer research center. The study is coordinated by an Aboriginal project coordinator and guided by an Aboriginal and Native American advisory group (6 individuals from 5 different communities: Inuit, Mohawk, and Ojibway). The AWCCP attempted to conduct research with 5 culturally and geographically different communities including 2 reservation communities, an off-reserve urban population, and with Inuit women who were traveling from their northern communities for health services in an urban center. We are attempting to conduct in-depth, individual, open-ended qualitative interviews with 6 cancer survivors, 2 family members, and 2 health care practitioners in each community. The participants are self-identified Aboriginal and Native American women, their family members, and health care providers who belong to northern, urban, rural, or reservation communities. On request of a participant, we are also attempting to recruit elders from each community.

KEY CHALLENGES AND STRATEGIES

What is largely absent from the literature are the realities, vulnerabilities, and emotional risks that each partner faces when negotiating research partnerships. Although successful research collaborations, by community standards, have been forged between external researchers and Native American communities, the trust between community and research partners is at best tenuous due in large part to the history of exploitation of Aboriginal and Native American communities by governments and research institutions. These issues of trust however are not always one-sided or fixed, as trust and participation are “conditional” and “fluid” conditions of any research process. As we reflect on the emerging challenges, risks, responsibilities, and conundrums in developing and maintaining long-term research partnerships with Aboriginal and Native American communities, we consider our own subject locations and how they influence and are impacted by the project processes and outcomes.

Identity and Subject Location: Two Voices

No one has a pure world view that is one hundred percent Indigenous or Eurocentric; rather, everyone has an integrated mind, a fluxing and ambidextrous consciousness, a pre-colonized consciousness that flows into a colonized consciousness and back again.11

As a non-Native woman (author TLM), it has been my honor and my challenge to conduct collaborative research with Aboriginal communities at different times over the past 13 years. Issues of history, identity, voice, oppression, resistance, and transformation are constant. I have been willed, and I have been scorned, trusted and mistrusted, often in cyclical patterns that resonate most strongly with potent histories rather than, I believe, with personal acts or contemporary relations. Although Brant-Castellano8 theorized about the chill in Aboriginal research and the current need to try to face challenges to continue to form collaborative research relationships with non-Natives, the very material risk of not “making it” as an Aboriginal researcher working in Aboriginal and Native American communities is not mentioned. This is not uncommon; challenges have been documented for entry and acceptance of non-Native researchers.11 However, the identity, trust, and entry issues experienced by Aboriginal and Native American researchers has rarely been acknowledged. My own location (author EB) as an Aboriginal researcher often entails a hypervigilance in both the academic and Aboriginal research communities. It is a constant balancing act in which there is little room for error and even less space for both worldviews to play out successfully. In the academic culture, there is still an expectation (obvious in most of the published literature on “capacity building”) that most or all of the capacity building in Aboriginal research is the responsibility of the community. As an Aboriginal researcher working in both cultures, it is clear that the academic and funding institutions are generally lacking in policy and practices required for conducting Aboriginal research. Conducting ethical Aboriginal research then, for Aboriginal and non-Aboriginal researchers, poses a career peril for which the material impact needs to be addressed.

Strategies

When asked why as Native and non-Native researchers we would be willing to work in such a demanding research environment, we came to realize there is no other way for us to do ethical community research. Our intercultural partnership provides us with perspective and support when faced with challenges linked to race and identity. Although the principles and practices of OCAP and PAR offer significant challenges to researchers, we believe that they also produce significantly more credible and beneficial research by, for, and about communities and individuals. We are working interculturally to form dialogue and support around the challenges of community-building research. Making the tensions conscious and sharing them first with each other and then with the research community is a strategy to address the inherent challenges of conducting research in Native American and Canadian Aboriginal communities.

Developing Community Research Partnerships

A major challenge was trying to partner with geographically and culturally different communities. Whereas many granting agencies, universities, and Aboriginal and Native American communities12 are striving to establish best practices of research in Native American and Aboriginal communities, guidelines and published accounts of research ex-
perience in conducting research in this context are still limited. For the AWCCP, each community partner had specific ethics protocols for conducting research in their community. The processes for ethics approval varied from community to community as did the manner in which researchers should approach the community itself before an ethics protocol was submitted. In one instance, the AWCCP research coordinator erroneously approached the community health advisory board first, as she had been informed of this process in approaching a community previously. Because she had breached the approach protocol with this community—by not going to band council first—she was suspected of trying to circumvent their ethics process. In another community, the project coordinator approached the band council first to discover that the health council was skeptical of her ability to work honestly with them, as they were to be approached first in that particular community. Although the band council did approve the AWCCP in that community, it took a concerted effort to reestablish the trust with the health council—which ultimately oversaw research in their community.

Strategies

Although we are working through and continually managing these challenges in respectful ways, there is still the process of rebuilding a very fragile community trust involved with perceived and actual breaches of community protocols. Ultimately, we developed and submitted 6 ethics research protocols; 1 for each community/institutional partner. We submitted ethics protocols for Wilfrid Laurier University; Sunnybrook and Women's College Health Sciences Center; Akwesasne New York; and Curve Lake First Nation, Ontario as well as an application to the Nunavut Research Institute and to the first reserve community. Ethics review processes varied between 2 weeks, 2 months, and 2 years across the different communities. All, except the original reserve community, have now approved the project, and the AWCCP is proceeding through each of its iterative stages in these communities.

 Individual or Community: Who Has the Authority to Give Consent?

The AWCCP has undergone numerous changes as a direct response to the challenges encountered as both a collaborative and participatory project. In our research process, we have experienced challenges in which the principles of OCAP and the laws and values of the community partners are in direct conflict with the individual wishes of community members. It was made clear to us through a number of individuals who were concerned about their own autonomy and rights being suppressed for the "good" of the community that consent is a complicated issue that is negotiated with individuals, groups, or communities. Conventionally, consent is established with individuals; however, in this study, we acknowledged the sovereignty of communities by not interviewing individuals from a community that did not provide ethics approval. A research challenge arose when several individuals (cancer survivors, a family member, and a healer) questioned our decision to abide by the decision of their community's ethics council.

Strategies

Our response to this challenge emerged from consultation with our advisory group who guided us to respect the sovereignty and governance of the local community by not, for example, interviewing individual cancer survivors off reserve. We decided not to include the members of the cancer survivors group and other cancer survivors who asked to be interviewed as research participants in the AWCCP. However, this decision to build research partnerships with communities versus individuals, and by so doing respect the sovereignty of communities, did not diminish the individual survivors’ feelings of being excluded and silenced.

The development of an emerging community research methodology needs to attend to the power and control issues within the communities themselves as well as between the researchers and Aboriginal and Native American communities. Although the conundrum of individual versus community consent needs to be acknowledged and respected by researchers, we do not believe that the academic/research community should attempt to address or circumvent these issues, which are in the domain of the communities themselves.

Privacy and Confidentiality of Data

Another challenge is ensuring the protection of participants’ rights to privacy and confidentiality. Access to and ownership of research data, as outlined in OCAP, is increasingly a primary concern for band councils in Canada and tribal groups in the United States. Community ethics protocols request that communities have access to and possession of all raw project data. The management of the confidentiality of sensitive cancer experience data is a serious responsibility of researchers. Data storage and security must be agreed on in the written consent obtained from each participant.

Strategies

Therefore, when a community explicitly requested to store all raw data in their community archive, we negotiated a middle ground with the community. First, we confirmed that we understood and supported the community's right to access and ownership of all findings but raised our concern that storage of confidential tapes and transcripts would have to be the choice of the individual research participants. We were aware that despite the principles of OCAP, some individuals might not wish their personal transcripts to be stored in their own community. We developed a process regarding access that we believed was respectful of the community’s request, a response that was transparent and clear, one that in-
dicated that access to the data would be stage dependent and that ownership of the data would remain with the participants. The community accepted our proposed solution that at differing stages, the form of the data would change and that access to data would change accordingly. We proposed that when the data is raw in the form of audio tapes and transcribed interviews, then access is reduced to the interviewers, the participants, the transcriptionist, and the primary investigators. When the data is second stage, any identifying markers are removed through a process of member checking in which interviewers review an individual’s transcripts with the individual research participants for correctness of the data and privacy of the participant. The data can then be accessed by the larger research group. In the third stage in which the data is analyzed and thematically organized into findings, then access expands to include the advisory group, the Aboriginal community (including chief and council), and the larger research community. Ultimately, it is the consent of the participants that determines whether their personal raw data will be stored with the researcher or their community.

Research Takes Time

In 2001, a researcher (TLM) made links with an Aboriginal cancer support group from the first reservation community. The support group met the researcher off reserve and expressed the desire to share their stories of survival and hope with other Aboriginal communities. They discussed the possibility of conducting interviews that would lead to the development of a radio drama. Funding was sought and received for an exploratory study, and T. M. Mitchell obtained ethics review at her university. She made regular trips to the community to join the Survivors at their meetings. Ethics materials were reviewed and discussed and were left with the group members to review over the next month before signing. The researcher returned to the community the following month to obtain consent and to discuss funding and hiring issues for the project with the survivors group. After 1½ years of working with this group (but never collecting any data), the researcher was abruptly informed at another meeting in the community that she had breached all research protocols and must now seek approval from the community’s ethics review council before proceeding. She learned this for the first time despite having explicitly asked at the first and subsequent survivor group meetings if permission of chief and council was required.

Strategies

The researcher (author TLM) then chose to begin at the beginning to redress any perceived or actual breaches of protocol. She established an Aboriginal advisory group with representatives from 6 different communities including 2 from the survivor support group’s community, which included 1 member from the survivor support group. Time remains a challenge. We have had limited success in recruiting research participants (n = 10), and we have not conducted interviews with the original survivors group or interviewed individual survivors who live in the community where we did not gain band council approval. However, after 2½ years, the AWCCP has had significant achievements in building the foundation for ethical and successful research partnerships. We have developed a strong Aboriginal advisory group with representatives from 5 communities, have obtained 6 ethics approvals, and have developed partnerships with 2 reservation communities. By honoring our community research partnership and the sovereignty of the community that did not grant ethics approval, we face the difficult decision of choosing to exclude the very cancer survivors who made this research possible. However, we have clarified that in conducting PAR research, informed by the principles of OCAP, our research partnerships are formed with Canadian Aboriginal and Native American communities rather than with individuals or groups. We are confident that these research partnerships are consistent with the ethical demands of OCAP: community ownership, control, access, and possession of research processes and outputs.

LESSONS LEARNED:
COMMUNITY-BUILDING VERSUS CAREER-BUILDING RESEARCH

We have learned that history shapes all current research relationships in one way or another. Research within Aboriginal and Native American communities is constrained and defined by the historical relations of dominance, ongoing issues of achieving sovereignty and reclaiming ownership of indigenous knowledge, and prior experiences of negative research practices. Time is therefore essential in developing trust and building relationships and partnerships that are for the long-term benefit of communities that are collaborating in research. The primary condition of Aboriginal research is developing and maintaining right relationships.8 Developing community relationships and research practices that are beneficial to Aboriginal communities requires indeterminate amounts of time. The uncertain time frame and success rate of community entry, ethics review processes, recruitment, and publication presents considerable tension for university-based researchers. Although academic researchers can provide valuable research services to communities (usually without direct payment), researchers are under considerable pressure to write and publish research findings to maintain their jobs. Capacity building and structural changes must occur at the institutional and funding levels so that funding agencies, ethics review boards, and university promotion and tenure committees are informed of and responsive to the necessity of the time needed for trust building, community entry, and the building of sustainable research relationships within an OCAP era. We have learned that the liberatory and empowerment ideals of PAR are not enough and that the principles of OCAP, when conducting research in partnership with Aboriginal communities, are
essential but not yet adequately articulated in practice. Clearer guidelines combined with practice examples and lessons learned from the field will be important in shaping future research collaborations between researchers and Aboriginal and Native American communities. The difficulty in engaging OCAP principles is shaped by the dissonance between OCAP and the demands/constraints of mainstream research institutions. Although negotiating the principles of OCAP into the day-to-day practices of Aboriginal and Native American research is time consuming and fraught with perils for Native and non-Native researchers alike, authentic PAR informed by OCAP shifts existing power relations and recalibrates the balance of risks and benefits for researchers and communities.

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