

CAUGHT BETWEEN TWO WORLDS; AN ABORIGINAL RESEARCHER'S EXPERIENCE RESEARCHING IN HER HOME COMMUNITY

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INTRODUCTION

As an Aboriginal researcher who has maintained ties with her home community, I presumed that I would have relative ease of access for research purposes among members of my home community. I thought they would welcome me back and do all that they could to assist me: after all, I thought, my research was intended to help them. Alas, this was not the case. What actually transpired throughout the process of doing my doctoral research continues to be an enigma; a perplexing contrast between supposition and reality or perhaps between academia and community. My research focus was on how the Woodland Cree of Northern Saskatchewan perceive cancer as a whole: their internalization, their diagnosis, and treatment experiences as well as their world view of health and illness. I had chosen to work within my own Band, since I spoke the language and understood the culture and traditions. Lac La Ronge Band comprises 6 communities, spread out within a 300 km radius of La Ronge. What follows is a discussion about my personal experience as an Aboriginal researcher and the implications of researching in my home community.

THEORETICAL PERSPECTIVES

Aboriginal people have been the subject of research for years, often with no direct benefit to themselves, personally or collectively. This has frustrated and angered many Aboriginal communities, both in Canada and around the world. Linda Tuhiwai Smith, a Maori academic and writer notes, "the word itself, 'research,' is probably one of the dirtiest words in the Indigenous world's vocabulary" (Smith 1999: 1). Since 1969, Vine Deloria, Jr. has been writing about the damage anthropologists have wreaked upon Aboriginal communities in the United States. "The fundamental thesis of the anthropologist is that people are objects for observation, people are considered objects for experimentation, for manipulation and for eventual extinction" (Deloria 1988: 81). Furthermore, we have to be aware that "assumptions of interpretations that are derived from Native teachings framed through a Western 'lens' can be viewed as a form of assimilation" (Lambe and Swamp 2002: 433). The Indigenous researchers insist on a new paradigm of research governed by Aboriginal terms of reference and regard Western research traditions as a 'tool box' from which they can pick and choose those that fit within their paradigms (Smith 1999).

With the present trend towards increased research in Aboriginal communities, especially in the health care field, there are enormous opportunities

for Aboriginal academics and students to create positive change; both in the health status of their communities and in developing respectful and culturally specific ethical research protocols. There is a risk that our communities will not accept us in our double role as researcher and community member, because as Smith (1999: 137) so eloquently puts it, "insiders [Indigenous researchers who are community members] have to live with the consequences of their processes on a day-to-day basis for ever more, and so do their families and communities." Not only do we need to face the challenges of conducting research in our communities, we also have to convince them of the value of research and then develop processes that are not limited or directed by past legacies (Smith 1999). When doing research with Indigenous communities, Smith (1999: 128) states that "in many projects the process is far more important than the outcome. Processes are expected to be respectful, to enable people, to heal and to educate. They are expected to lead one small step further towards self-determination." Therefore, Smith (1999) recommends that Indigenous researchers must be good at defining clear research goals, and lines of relating, at developing skills to say 'no' and 'continue' and defining closure, in order to be ethical, respectful, reflexive, critical, and humble.

I had been following Fanon's process of how 'Native intellectuals' return to their people before I even knew who Fanon was. Frantz Fanon, a descendent of African slaves, was a French psychiatrist and revolutionary writer who wrote about the effects of colonial repression and culture trauma (Mborn 2004). Fanon identified 3 phases that individuals will/should go through: 1) assimilation, 2) disturbance and remembering who they are and 3) realigning themselves with their people and producing revolutionary and national literature (Smith 1999). The assimilation is something I have been going through since the early age of 6 when I was sent to the Prince Albert Indian Residential School. My love of learning continued the assimilation process as I repeatedly left my home community to continue my education, leading me from a laboratory technician certificate to a doctoral degree in community health and epidemiology. The shift into the second phase began in nursing school where I started to realize that in order to successfully complete my nursing degree I would have to shed my Cree cultural coat and don the Western medical white lab coat. I inherently knew that this wasn't the way it should be but lacked the self esteem and conviction to fight for my right to live by my Cree values and beliefs. Upon completion of my nursing degree, I slipped my Cree coat back on and began working with Aboriginal people, living and working within the two paradigms. When I returned to graduate school, I quickly be-

gan to see a difference in the type of learner I was invited and expected to be: I was valued for who I was, a Cree woman who had previous knowledge. The shift into Fanon's third phase, realigning myself with my community, began to emerge during my doctoral work. Ermine's ethical space framework assisted me in making the transition from a colonialist-educated researcher to an Aboriginal researcher who chose to combine Western and Aboriginal paradigms and pedagogies. Ermine's (2004) premise is through the purposeful disconnection and contrasting of the Western and Indigenous cultures and world views. The intent is then to reconnect the entities with the notion of a bridging concept called the 'ethical space.' Through personal conversations with Ermine, I began to understand that I am a bridge between Western research and my community. Furthermore, my allegiance must always be, first and foremost, to my community. And so, being firmly ensconced in the ethical space, I took my proverbial toolbox of Western methodologies and ethical protocols in hand, and departed on my research journey back home.

OUT IN THE REAL WORLD

I did not want to embark on a project that was not in accordance with the communities' interests. Therefore, prior to developing my doctoral proposal I had, of course, consulted with community members who were in positions of authority in the health care departments as to the feasibility of my research topic, and had received unanimous encouragement. There were no established ethical protocols for research which were specific to my Band's system; therefore I proceeded to gain entry into the communities by making presentations about my research proposal to Chief and Council and seeking permission to proceed to the next step, meeting with each health committee for the 6 individual communities that comprise the Band membership. Chief and Council gave their permission and requested periodic feedback on the research as it progressed. The female Elders that sat in on the Council meetings informed me that this was a very worthwhile and important project and if necessary they would send people to be interviewed. The response of the health committees was similar. After receiving permission from these two sources, I proceeded to recruit participants.

Operating on the assumption that I would encounter the greatest number of individuals wanting to participate in my home community, I set up an office in the local health clinic. For participant recruitment, I put up posters in every location that people would be likely to see it. I contacted the local radio stations and was interviewed on air in both Cree and English. The

health clinic offered me 30 minutes to talk about the project at a Community Diabetes Education Day. I also set up a display and included pamphlets from the Canadian Cancer Society. I talked to all the clinic staff members, asking for referrals of potential participants, explaining that the University of Saskatchewan's ethics protocol prohibited me from contacting potential participants directly. I talked to people who came into the Health Clinic, informing them about my research project. I began to feel like a piranha, waiting for unsuspecting prey. Everyone I spoke to was very supportive of what I was doing but no volunteers came forward to be interviewed.

I used a different strategy when I spoke to the Elders. It is an accepted cultural practice for a person to speak with an Elder seeking help. An initial visit with the Elder gave us a chance to get reacquainted; if the Elder was interested in being interviewed, I returned the next day. I felt that the time delay would give the Elder the time and opportunity to reconsider the offer to participate. My home community has been Christianized for over 150 years, so the offer of tobacco for knowledge was seen as inappropriate. Instead, I presented each Elder who agreed to participate with a blanket at the onset of the interview, a practice that was well received.

After spending a month in my home community, I had interviewed four Elders, but had received no response from cancer survivors or their family members. I decided it was time to move on to the next community. Following a similar recruitment strategy, I had a much better response. Two participants came forward after a community presentation, three volunteered after seeing the posters or the newspaper ad, two from word of mouth and four participants came forth in a group meeting arranged by the Community Outreach Coordinator from the health clinic. The group meeting was filled with laughter, food, and sharing. The atmosphere was very different from individual interviews, it was more relaxed and the women shared their stories openly, with a minimum amount of questions and encouragement. Of the eleven participants interviewed within a two-week period, ten were either cancer survivors or family members, and one was an Elder. Once data collection was complete, this represented the best response from the six communities I visited.

Data collection continued in the other communities; the final sample size was 27: 6 Elders, 8 cancer survivors and 13 family members of someone who had had cancer. It was necessary to use a variety of recruitment methods that included speaking to Elders, community meetings, word of mouth and community health workers acting as liaisons with introductions as well as organizing group meetings.

DISCUSSION

Through a process of self reflection, journaling, and discussions with my dissertation supervisor and committee members, Elders and colleagues, revealed possible explanations for the lack of response I received from cancer survivors and family members in my home community. I don't believe there is one definitive explanation for what happened, but as with most things there were multiple possible explanations including the following.

There is no doubt that my home community, along with the entire Band membership, is proud of me for pursuing my doctoral degree, but this, I feel is more of a tribal pride, a community pride. At the individual level, community members did not feel comfortable and may have felt they were putting themselves at risk by talking with me about such a sensitive topic. Cancer is a sensitive topic, difficult for people to discuss. This was affirmed by one of the interviewees from one community:

I think it's becoming to be more prevalent, I don't know, I think, we hid in the closet, you know and now it's coming out, just like dung beetles, you know, and I guess there's people don't like talking about it.

Small communities are usually hubs of gossip and everyone in the community knows when someone has cancer. Perhaps individuals felt that an interview with me would further compromise their perceived sense of privacy.

When asked why people weren't coming forward to talk to me, one Elder suggested that community apathy might have been a factor.

I don't know why nobody will talk. And they do that anyway, these people, when they are summoned to go somewhere, they don't go. Even when there are meetings, hardly anyone goes anymore.

The conflicting values between Western research ethics and community expectations is another possible factor. The ethical guidelines defined by the University of Saskatchewan Behavioural Research Ethics Board stated that while I could not approach potential participants directly, I could use a community liaison to speak to possible participants on my behalf. But I could not find an appropriate liaison within the health clinic because staff felt there

was no reason why I couldn't just go to the individual's house and ask each one myself. This was also reflected in the Elder's comments. When asked why she thought people weren't coming forward, she replied "maybe they are just waiting for you to go see them, to talk to you." Despite these urgings by members of the community, I could not in good conscience go to individual's homes without an invitation. The two most frequent names mentioned to me by various people in the community were the two individuals with terminal cancer. I was extremely uncomfortable with the prospect of barging in at a time of family and personal grieving to seek information for what, at the outset, would be for my personal gain. But along with the ethical conflict between the University of Saskatchewan's ethical guidelines and the community member's suggestions was my research protocol of wanting to interview cancer survivors. In retrospect, perhaps the people with terminal cancer would have appreciated an opportunity to talk with someone about their illness and their lives.

My separation from the community may also have contributed to the situation. I have been living off reserve for the past fifteen years only going home for visits on long weekends and holidays. Had I been absent from the community for so long that I had lost my sense of belonging and therefore was no longer trusted to keep the best interests of the community at heart?

Perhaps, as Smith (1999) states, my home community could not accept me in the double role of researcher and community member. Whatever the reasons that few participants came forward, I personally felt betrayed and hurt. After all, I reasoned, I wasn't doing this for my personal benefit, I was doing this ultimately to help the community, to increase the awareness of cancer, the treatment options, and to have an impact on health policy for future cancer care.

Therein lies the crux of the recruitment problem: the community had not brought this health issue forward. It had not identified or prioritized cancer as one of the areas of importance. I felt it was important and I expected cooperation so that I could elucidate the importance of it. The fact that my mother was a cancer survivor and I had walked with her on parts of her healing journey had been the impetus for my research path. In wanting to get a broader understanding of the impact cancer has on individuals and communities, I embarked on my doctoral research. But in the process, had I ultimately let down my community at the most crucial juncture, by not allowing them to decide what they wanted to be researched and working with them from the outset in determining a topic of research?

However, if I had not gone ahead with my research topic, the voices of the participants may never have been heard. The stories they shared were heart-wrenching, illuminating, and profound and have forever changed me, both as a person and as a researcher. Throughout my research journey I encountered many crossroads, diversions, and road blocks but I have come to realize that I have not been alone on this journey; my research participants have agreed to walk with me. My responsibility now lies in ensuring that their stories are allowed to touch others' lives, including my home community, members of my Band, Aboriginal communities and others.

Perhaps my home community could not accept me in the double role of researcher and community member, but being Aboriginal and being able to speak my native language did open doors in the other five communities and I was welcomed in. Aboriginal researchers will continue to have challenges researching in their home communities, and finding the balance between Western and Aboriginal world views, paradigms, and pedagogies. My experience is only one example of possible outcomes, it certainly wasn't the one I expected but it has been a tremendous learning opportunity.

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