

Athabasca University

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Essay Title

**Reducing research bias and harm in Aboriginal communities through the use of
community-based participatory action research**

by

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REDUCING RESEARCH BIAS AND HARM USING CBPR

Aboriginal¹ women are doubly marginalized because of their gender and ethnicity in all realms of Canadian society which has negatively impacted their health and wellness to a large extent (Bent, 2004; Stout, D.M., Kipling, & Stout, R. 2001). Post-colonial feminists have linked their poor health status to a severely weakened pre-colonial reverence brought about by the patriarchal agenda put forth by Euro-Canadians ever since their arrival in their Americas (Browne & Smye 2002; Green, 2007). Unfortunately, the complex history shared by Aboriginal people in general, Aboriginal women specifically, and imperial governments in Canada, extend to the research community as indicated by literature that shows Aboriginal women's concerns are seldom addressed in the research and when they are addressed, serious methodological problems are present as will be discussed in this paper (Ninomiya & Pollock, 2016; Darroch & Giles, 2014; Smith, 2012). Research based on previous studies also shows that the use of Community Based Participatory Research (CBPR) that includes Aboriginal participants and community members in all research processes, may reduce research bias and harm and improve the accessibility and quality of research when non-Aboriginal academic researchers work with Aboriginal communities, especially on topics relevant to the most vulnerable members: Aboriginal women and children (Baydala, Ruttan, & Starkes, 2015; Damon et al., 2017; Ninomiya & Pollock, 2016).

With that in mind, and considering that a vitally important component of both Aboriginal and feminist methodologies is to situate self in the research process, and to alleviate some of the concerns that many Aboriginal people have regarding researchers using research

¹ The term Aboriginal in this essay refers collectively to Canadian First Nations, Métis, Inuit and Non-Status people

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for their own gain (Smith, 2012), I have done just that as follows. In my current position as the literacy Camp Coordinator for Saskatchewan, I work directly with Aboriginal communities to ensure they receive vital programming for children and families. In January of this year I travelled to La Loche, Saskatchewan, a remote area populated by the Dene Aboriginal people to drop off books, games and snacks and to propose a literacy program. The program would give children a safe place to go this summer and raise literacy levels among children at the schools in La Loche and Clearwater First Nation. I happened to be in the area on the anniversary of the La Loche shootings. On January 22nd 2016, a 17 year old boy shot and killed two people in his home and then proceeded to the La Loche Community School where he killed two more people and injured seven (Warick, 2016). When I travel to set up and visit camps in these communities, most of which have high crime, domestic violence and suicide rates, I see major issues that are not being adequately addressed. Unfortunately, there is a legacy of mistrust between Aboriginal communities and non-Aboriginal professionals coming into the community that has developed from Canada's history of colonialism and residential schools where many promises and treaties were made with Aboriginal people and not kept (Waldram, Herring, & Young, 2006).

In line with Mohanty's (1984), critique of Western feminism as being oppressive to minority women, a literature review on research bias revealed that past research has often been used to advance colonial control over minority groups by favoring a Western European worldview and ignoring all other ways of knowing leading to a mistrust of institutions by Aboriginal people (Cochran et al., 2008). The building of adversarial relationships seeped in

mistrust can also be linked to the residential school era where children were separated from their families and cultures (Fontaine, 2010). In *Broken Circle*, Fontaine (2010) outlines a history of sexual, physical and emotional abuse perpetrated against himself and other First Nations children in a Manitoba residential school. He describes a particularly disturbing event called the *ménage*, in which young boys were called weekly into a room where their genitals were bared, washed and dried for the sexual pleasure of the priests and brothers. Giving voice to the horrors faced by women in residential school, Stout and Peters (2011), looked at the intergenerational impacts on Aboriginal professional women whose mothers and grandmothers attended residential school. In a sharing circle, the daughter of a survivor describes “how her mother witnessed the sexual abuse of her family members by the school priest” (p. 19).

In that light, a series of harmful nutritional experiments, sanctioned by the Canadian federal government, were run on children in some residential schools between 1948-1952 (Ninomiya & Pollock, 2016). Researchers were already aware of an existing problem with malnutrition within the schools when the experiments were sanctioned, essentially using the deprived conditions as “laboratories” (Ninomiya & Pollock, 2016). In addition to those atrocities, students at the Cecilia Jeffrey Indian Residential School were subject to experimental ear treatments that led to partial hearing loss in some and permanent deafness in others (Porter, 2013). Ian Mosby, the man who first exposed some of these experiments described the government response as troubling and did not believe there was a thorough attempt to get to the bottom of what was happening during that time period. He also had doubts about whether or not these known incidences were the only experiments (Porter, 2013).

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Unfortunately, Canada's history of putting forth actions that were fodder for building institutional mistrust between research and Aboriginal communities continued into the 21st century. Researchers deceived the Canadian Nuu-chah-nulth people of Vancouver Island into believing that their blood was being drawn for research on arthritis when it was actually used to establish ancestry (Cochran et al., 2008). Not surprisingly, this deception led to intense suspicion among the Nuu-chah-nulth people and reluctance to participate with any future researchers that may wish to engage with the community (Cochran et al., 2008). Many Aboriginal community members have reported feeling over-researched and under-represented leading to feelings of frustration (Baydala et al., 2015). Past and present experiences have led to an atmosphere of mistrust between Canadian institutions and most Aboriginal communities they wish to engage with, because many community members seem to think that "researchers are like mosquitoes; they suck your blood and leave" (Cochran et al., 2008, p. 22).

Changes *to* the community need to occur *within* the community at the grassroots level. Community-Based Participatory Research (CBPR), which grew out of a movement that fell under the banner "Nothing About Us Without Us" and fought for the emancipatory involvement of marginalized and stigmatized people in the research process, can provide community engagement in research (Damon et al., 2017). Inclusion of community members in research may reduce research bias and harm, and foster improved programming development based on those research outcomes (Hayhurst, Giles, Radforth, & The Vancouver Aboriginal Friendship Centre Society, 2015).

CBPR belongs to a family of research methods sometimes collectively called Action Research because of the inclusion of study participants in every step of the research process. Participatory action research (PAR) and community-partnered participatory research (CPPR) are just two of a variety of similar approaches that consist of two main goals that involve establishing an ethical relationship between the researcher and participants of a study while at the same time empowering the participants to evoke positive changes in their communities (Blumenthal, 2011). All of these methods are different from conventional research methodologies in that they rely on conducting research with, rather than on members of marginalized groups, which results in shared ownership of the research with the ultimate goal of taking action and creating positive change (Darroch & Giles, 2014). CBPR concentrates on research directly with communities, however proponents of this method follow the same principles of PAR² (Darroch & Giles, 2014). Defined as a collaborative approach to research that involves all partners in the research process and recognizes the strengths that each partner brings to the process, CBPR can potentially bridge the mistrust and hostility between partners and work to provide better communication and trust (Baydala et al., 2015).

By involving community members in the research process, CBPR aims to include knowledge and practices of excluded and marginalized groups by engaging them in transformative action (Chesney, 2016). CBPR is especially useful in marginalized communities that experience a disproportionate burden of environmental, health and other problems because one of the major benefits of CBPR is that community involvement contributes to a

² In this paper I have relied on examples of PAR research because of its dominance in the literature on the topic. Based on the usage in the respective cited articles, PAR and CPBR may be used interchangeably.

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more thorough understanding of the data and design of culturally relevant interventions (Baydala et al., 2015). For example, Aboriginal youth populations are one of the most marginalized groups in Canada today with a mortality rate that is three times higher than the national average and in one study, fifty-three in-service professionals, care providers and stakeholders shared their perspectives on factors contributing to the health and wellness of urban Aboriginal youth populations (Yi, Landais, Kolaheedooz, & Sharma, 2015). Of their most significant findings, was that the voices of urban Aboriginal youths are often marginalized and excluded in health-related decision making processes.

If not used carefully, action research can present its own set of problems. Communities that have been marginalized already can be further harmed through the research process (Damon et al., 2017). For example, in a heavily researched area of downtown Vancouver, peer researchers were concerned that they can be taken advantage of when offered money, especially if the results of the research are not fully explained to them (Damon et al., 2017). One participant described an incident where a researcher offered forty dollars to residents outside of a bottle depot in Vancouver's downtown East side and then asked five questions,

I never saw him again. Nobody has... People take his money anyway, right. Who knows what they want to use (the information for)? They could use the information, like, twist it against us or they could take and use it the wrong way (Damon et al., 2017, p. 88).

In that same study, some participants also expressed concern over a lack of real connection between the researchers and the more vulnerable participants, especially women. One participant stated that "researchers unaccountable to the neighborhood and its residents were

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seen as cynically building careers on the social suffering of the community without translating research into material improvements” (Damon et al., 2017, p. 88). When communities are forgotten and marginalized, tragedy becomes, sadly, far more likely.

According to Darroch and Giles (2014), Western academic discourses that are embedded in a context of colonialism and oppression can influence how research is conducted. The academic institution is designed in such a way that it places researchers in a position of power over community members when it comes to collecting the data involved in the research – though community members are considered full partners in the research. Feminist researchers challenge biases inherent in traditional research practices and argue against patriarchal ways of understanding the world (Darroch & Giles; Green, 2007). However, non-Aboriginal researchers’ use of CBPR approaches can be critiqued as a form of colonizing Aboriginal methodologies and ways of knowing if the researchers are not being sensitive to their partners (Darroch & Giles). The marginalized group can be misrepresented by the dominant or more powerful group, in this case the researchers, which could perpetuate the myth that Aboriginal people represent a problem to be solved (Cochran et al., 2008).

In the same light, incarcerated women in Canada and the United States experience high rates of marginalization and exclusion as a result of experiences prior to incarceration, which can also be exacerbated by confinement and worsened by experiments conducted on them in prison (Chesney, 2016). Recent studies and reports have indicated that incarcerated women are not healthy, and have higher rates of mental and physical illnesses when compared to the general population and with incarcerated men (Chesney, 2016). Contributing to these

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problems, a PAR research project that took place within a Canadian women's prison with the intended goal of "improved awareness and integration of healthy lifestyles" (Chesney, 2016, p. 62) ran into ethical issues due to researcher bias over the definition of "healthy," embodied subjectives and the imbalance of power relations. Adding to their already vulnerable states, many of the participants felt failure and sadness when unable to conform to the scripted ways of becoming healthy, which was exacerbated by their incarcerated state and the intersection of other issues including poverty, abuse and racism (Chesney, 2016).

The potential of ethical issues related to researcher bias arising, even when utilizing CBPR, necessitates the use of rules and standards to guide research practices (Ninomiya & Pollock, 2016). In Canada, all research funded by a federal agency must adhere to the "Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, 2nd Edition 2 (TCPS 2)" which is the standard for all University-based research. These guides include a chapter specific to First Nations, Métis and Inuit People and the ownership, control, access, and possession principles for research with Aboriginal communities According to Ninomiya and Pollock (2016), "increasingly, national Indigenous organizations, local governments, and communities have also developed guidelines aligned with these frameworks, and reflect culture and community-specific values, knowledge, and protocols" (p. 29). In support of the thesis framing this essay, the common thread running through these guides relates to the importance of starting research on a foundation of trust that prioritizes accountability, meaningful outcomes and community-driven projects.

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Using postcolonial feminist theory and reflexivity, which acknowledges existing power dynamics and encourages the constant questioning and re-evaluating of the ways in which a more equitable balance of power between genders can be achieved, it is possible to examine power structures and focus on the experiences of marginalization, politics and the macrostructures that intersect to perpetuate oppressions (Darroch & Giles, 2014). CBPR researchers who use postcolonial feminist theory to better understand Aboriginal women's health and wellness issues pay attention to power imbalances that exist between the dominant Western research paradigm and non-Western societies (Darroch & Giles, 2014), and bring light to the fact that Aboriginal women's experiences and interests are often misunderstood and ignored in research. Darroch and Gilles' (2014), work showed that such evaluation and challenging of power throughout the research process is central to decolonization, which can work to resolve unequal power relations due to differences in class, gender and ethnicity that may exist between participants and researchers. Community engaged work necessitates an ongoing analysis of power, privilege, and oppression – a mediation of power differentials and a questioning of what work is needed, of ownership, inclusion, accountability and responsibility (Conrad, 2015). Similarly, Ninomiya and Pollock (2016) have stated that conflicts and tensions are still inevitable in CBPR, however, it is the uncomfortable moments and how they are addressed that matters. They go on to recommend that researchers must adhere to the four R's of research when working with participants – respect, reciprocity, relevance and responsibility.

An example of just how effective CBPR and similar methods can be, was revealed in a study that combined a postcolonial feminist analysis and PAR methods to study sport, gender

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and the development of programs for urban Aboriginal young women in Vancouver (Hayhurst et al., 2015). In this study, the researchers selected photovoice, a technique where participants take pictures of themselves and share stories around these pictures for the study, in recognition of the intersections of poverty, gender, racism, violence, and broader socio-political forces that impact these young women (Hayhurst et al., 2015). Knowing that these women would have diverse lived experiences, by choosing photovoice the PAR project enabled each young woman to be the author of her own story. This research highlights the broader structural forces and inequalities that relegate racialized young women to the sidelines of communities, making the need for sport and gender development programming necessary (Hayhurst et al., 2015).

According to Chesnay (2016), PAR can have an enabling effect on participants. For example, in one study that took place in the San Francisco County Jail for Women, a poststructuralist feminist lens was used to highlight participants' concerns and insights to illuminate and challenge the roles that incarceration, criminalization, gender, HIV and race have on the sexual lives of incarcerated women (Chesney, 2016). Poststructuralists conceptualize power as exercised by all rather than owned by the few, especially in Western-based societies, which is inherent in all social relations and is both repressive and productive of subjectivities, discourses and practices (Chesnay, 2016). This differs from postcolonial feminism in that post-colonialism focuses more on the historical roots of the unequal distribution of power mainly linked to colonization (Tyagi, 2014). McKibbin and colleagues (2015), use the term "intersectional feminism" to acknowledge the common feminist approach between

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poststructuralist and postcolonial feminism. The term simultaneously acknowledges diversity and recognizes the various oppressions women face such as gender, race and institutionalized violence (McKibbin, Duncan, Hamilton, Humphreys, & Kellett, 2015), which relates directly to the research conducted in the San Francisco prison as the women responded well to the poststructuralist feminist approach (Chesney, 2016). One of the main and unforeseen effects of the workshops was that participants adopted different roles, “educators, as they educated their peers; researchers, as they used various research methods to investigate HIV and risk; and students, as they learned about research methods and risk as defined by public health experts” (Chesney, 2016, p. 67). According to the PAR study results, participants felt understood, heard, supported and connected to each other.

CBPR can connect Aboriginal communities and researchers when that research is done respectfully using postcolonial feminist principles and reflexivity. In 2016, the Canadian Broadcasting Corporation (CBC) published an article on the Truth and Reconciliation Commission recommendations in action and how groups such as the “Bear Clan Patrol” and “Aboriginal Youth Opportunities” use of government funding benefit marginalized people within the community by strengthening the bonds between Aboriginal and non-Aboriginal people (Hoye, 2016; TRC, 2015). The CBC article is relevant in showing the effectiveness of participation between community and government-funded organizations, which can start with ethically driven community-based research projects. In addition to this evidence which supports the essay thesis, the acting head of the department of Native studies at the University of

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Manitoba has stated that “the people within Winnipeg’s inner city are leading the way at creating a Canada that should have always been and can be” (as cited in Hoye, 2016, para 3).

In conclusion, Canada’s history of broken promises with Aboriginal communities also extends to the research community, creating an atmosphere of distrust as evidenced by many of the studies discussed in this essay. As highlighted time and again by such findings as those found in the TRC (2015), Aboriginal community members want to make decisions for themselves, preserving culture and ways of knowing: “nothing about us, without us.” In line with the thesis put forth in this paper, PAR and CBPR can help bridge the gap between Aboriginal communities and research communities, especially when research is conducted using feminist methodologies and ethical policies. Ultimately, the results that can come from incorporating PAR and CBPR may lead to better programming that will potentially affect the entire community, especially the most marginalized.

In my work with Saskatchewan Aboriginal communities I recognize a desperate need for better programming. I also see firsthand a lack of trust in government run and funded institutions not unlike some of the examples presented in this paper. In the wake of the La Loche shootings, Saskatchewan Premier Brad Wall offered his condolences to the community, particularly the school where children should be safe, calling the event “unspeakably horrible” (Warick, 2016). Yet, in the past few days sweeping budget cuts to public schools, libraries and transit will have devastating affects across the province, particularly in rural communities like La Loche (Komadina, 2017; O’Connor, 2017; Warick, 2017). Programming and jobs in schools will be cut, especially in communities that desperately need more, not less (O’Connor, 2017). At the

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moment my own partnership with the La Loche Community School and Clearwater First Nation is potentially on the chopping block as well, which is unfortunate because it would provide eight jobs within the community and access to a safe and healthy learning environment for over one hundred children this summer. I am currently seeking funding elsewhere.

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