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Ethical Issues in Bridging Research Traditions

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FROM THE SPECIAL EDITOR

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WITH

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Change has just begun for Indigenous peoples in recent years. It has been only 34 years, for example, since Aboriginal people in Canada challenged the Federal government to enshrine Aboriginal, Métis and Treaty rights in the 1982 Canadian Constitutional document. This provided the foundation for the first step in the struggle to assert Aboriginal Justice Rights — the inception of the first Native owned and controlled justice program in Canada. Later, as a result of action taken by Native parents in the early 1970s, a policy statement was created that allowed First Nations peoples to administer their own schools, which has evolved to include urban Aboriginal schools as well. In the same time frame, Native people were lobbying for the development of cultural health-based programs such as treatment centres. In Australia, New Zealand and the United States similar changes, as a result of sometimes radical social movements, were occurring. Canadian Aboriginal people, like many Indigenous peoples globally, have only begun a process of reclamation and healing, which includes retaining (and sometimes gaining) control over different areas of their lives, a development often referred to as self-determination. Asserting our voice has been a matter of cultural survival; for many, a matter of life and death.

While research has always been part of the traditional way of knowing in Aboriginal societies, bringing the western and Aboriginal research traditions together is proving to be the next challenge Aboriginal people face. An activity that has been kept hidden away either at the university or behind government doors, surrounded by an almost mystic veil, the western research process is now becoming more accessible for at least some of the world's Indigenous people. Many Indigenous leaders and scholars understand that an important component in creating policy and systemic change lies in their participation in research processes. In fact, the need for Indigenous communities to engage in their own research processes, find their own solutions to health issues and retain control of Indigenous knowledge is so essential that peoples globally are now discussing how best to accomplish this. The most common approach for collaborative health research is Participatory Action Research (PAR), which engages community members and researchers in the research process for the purposes of empowerment and systematic change.

To this end, there are many PAR projects that have been conducted in Indigenous communities internationally; projects that are founded in the community's way of knowing, involve community members throughout the research process and produce outcomes that have a profound, sustainable and positive impact in the lives of Indigenous people. Now, however, over thirty years after the PAR movement began in Latin America, many people have found it necessary to look at PAR through critical lenses. While there have been successes, there are also challenges in the PAR approach. The purpose of this editorial is not to discredit the PAR approach, as the potential for good work remains in its process. Rather, we hope to raise awareness of the potential problems with PAR, and discuss solutions.

THE POWER IS IN THE PEN

Much of what is written about PAR exists in the academic literature and journals, authored by the researchers who have worked with Indigenous communities. This literature ranges from reports about specific projects that have been conducted, to evaluative reviews of many PAR projects for the purpose of creating "best practices" for the PAR approach. However, there is sometimes a difference between what is published about community based research and what actually happens at the community level. Cooke and Kothari (2001) in their book *Participation: The New Tyranny*, write about the back room discussions that are held by community members, who are cynical/apathetic at best and frustrated/angry at worst. Clearly, the power to report on PAR is tied into the power to construct its reality. This power is usually exercised by the academic or consultant researchers, who have both the vested interest and resources to create this literature. Unfortunately, the private and sometimes critical conversations that community people have usually never make it into print.

Perhaps the greatest gift a journal like *Pimatisiwin* can give to both academia and community is a forum to speak about all facets of community-based research. Learning from others' mistakes can be a powerful teaching; the courage of one researcher to report what went wrong can prevent those mistakes from reoccurring. Often times, the only teaching tools professors have regarding PAR are glossy accounts of a project that ran without flaw and resulted in community transformation. Possibly, if community member accounts are also brought to the forefront, a more balanced and more instructive research environment can evolve. If community members are also better prepared for the PAR process, success may be more likely.

SCHOLARSHIP AND INDIGENOUS PEOPLE

Edward Said, the author of *Orientalism* (1978), authored many texts regarding how academics and authors created what we know as the Orient. By lumping all of the middle and far eastern countries together and studying them as a whole, scholars created an “other” — a group of people that they could compare themselves to and declare superiority over. Said’s ideas are true for Indigenous peoples globally, who have often been viewed by scientists as the “other.” Academics saw Aboriginals as people who should be studied, analysed and discussed as research subjects; people who are inferior, primitive or at the very least romanticized, backward and unable to engage in high level scholarly pursuits. From this vantage point, the noble savage was provocative and provided the platform of Western superiority.

Science has struggled since this time with its superiority complex. Academically trained researchers often (and sometimes unconsciously) begin their projects believing that they must “know more” than the project participants and that they can provide answers to problems for groups of people who cannot find them themselves. PAR, in fact, arose as a challenge to traditional scholarship paradigms and is based upon a model of empowering people by changing the relationship between researcher and participant (Park 1992, Freire 1970). However, before a PAR project can engage community members and researchers on equal and common ground, specific training must occur. Indigenous people (who may have internalized the negative imagery of the “other”) must believe in their capacity to conduct research and trust that the information existing within the community is valuable. Researchers, conversely, must be trained in humility; a quality which happens to be revered in the Cree Aboriginal paradigm, but is not usually held in esteem in graduate studies. Researchers bring a tool box of techniques to a PAR project, but it is not the only way of collecting valid, reliable information in communities. Further, researchers need to be aware of power differentials that occur when they bring all of the project resources to the research table. They need to find a good way of involving community in the distribution of those resources in order to facilitate community ownership of the project.

RESEARCH FOR WHOM?

Researchers who want to work in Indigenous communities must be willing to work from the paradigm of the community, which can only be accomplished through community consultation. Take, for example, the young man who facilitated an Aboriginal Elders’ gathering in Alberta, where he and his

organization were asking for advice from the Elders on how to proceed with justice matters in Aboriginal communities. He began by standing in front of the Elders with pen in hand, telling the group what the agenda was and how the meeting would proceed. An elderly lady in the group interrupted, and graciously said "My boy, I appreciate your help facilitating today, but don't you think that we should set the agenda?" What she was saying is that if you want information, you need to do it in a way that is meaningful for those Elders and with respect for their protocols. Both red-faced and humbled the facilitator stopped, asked the Elders how they would like to address the day's activities and the meeting proceeded with great success. Such a valuable lesson in humility and forgiveness; in fact, 20 years later he still tells that story with a red face!

Academic or student researchers who do community-based research in Indigenous country are often faced with a dilemma; having to follow University expectations versus being true to the PAR approach. How can graduate students collaborate with a community to develop meaningful research methods, if their methodology must be described in detail for their University ethics review before they enter the field? How do academics survive the "publish or perish" paradigm of their work, when many PAR projects last for years? How do academics respectfully acknowledge community members as owners of traditional knowledge, when their performance evaluations give more points for publications where their name is first? Government funded research suffers similar pitfalls. Research consultants contracted to complete community research for government, often have strict fiscal-year deadlines which are non-negotiable, regardless of what happens in the community. Clearly, there is a need to revise the way that universities and governments (in general) conceptualize conducting research in communities. In the interim, researchers need to be able to navigate through conflicting agendas throughout the research process, in a way that does not compromise the integrity of the research or its findings.

INTELLECTUAL PROPERTY ISSUES

Stated simply, government agendas regarding ownership of information, where information will be disseminated and the purposes of collecting information need to be "on the table." Projects that are tendered for the collection of traditional information from Aboriginal peoples, which, once completed, become the sole property of the government, raise ethical questions regarding whether the government (or any researcher) can own the intellectual

property of Aboriginal people. From this standpoint, regulations regarding intellectual property need to be developed to protect those knowledge keepers who share information in good faith, individuals who would be distressed if the information was used in a manner that would cause harm to their people. These regulations need to address what information the government has a right to collect and retain and what limitations need to be placed on the way information can be used.

With regard to private information of an individual, issues regarding who controls this information need to be addressed through policy development. In health research, this means managing the delicate balance between addressing collective needs (such as the duty of government to provide good health care for Aboriginal people) and the individual's right to privacy (of their individual health information). For Aboriginal people, this balance is the only shield communities and individuals have to protect against the selling of information, or the use of information without consent. Further, independent evaluation is required to monitor how the balance is being maintained and address issues as they arise in the process. Competing agendas that become problematic need to be mediated in a way that is fair for both government and Aboriginal people.

RESEARCH FUNDING

Recently, the Canadian Government has begun making resources available through funding programs specifically designed for community and/or Aboriginal social sciences research. Programs such as the CURA (Community-University Research Alliance), which is available through SSHRC (the Social Sciences and Humanities Research Council), and the Institute for Aboriginal People's Health (IAPH) are examples of an effort to engage community in meaningful ways in health research. While this is one of the strong indicators that change is underway, universities (who are struggling with under-funded social sciences departments) (Howell 2003) will most likely resist allowing research funds to be held by community organizations they partner with — dollars that they depend upon for survival. In environments where resources are scarce and the competition is fierce, it is difficult to make equity in resource allocation a priority. This can result in power and control issues in research projects with communities.

In addition, community-based research can be time intensive. When tapping into the wealth of knowledge that resides in community, often more time is required to observe protocols, ensure proper translation of concepts

that reside in other languages and/or cultures and build relationships with key stakeholders.¹ Funding needs to be sensitive to the extra time required and the resulting increased need for resources. Community cannot be expected to contribute the extra resources required; especially if the community is burdened with economic, social or systemic issues (which is often the reason research is occurring in these communities in the first place!).

CONCLUSION

The considerable self-determination efforts of the world's Indigenous peoples are beginning to pay off in the areas of justice, health, education and research. It is time now to look both appreciatively and critically at how these institutions include Indigenous people and what meaningful participation for Indigenous people involves. Specifically, clarifying the roles that Indigenous people play in these complex processes, ensuring that there is Indigenous leadership in areas where programs, research and policy affects Indigenous communities, families and individuals, and educating both Aboriginal and non-Aboriginal people in participatory processes will have a profound effect on Indigenous health and well being.

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1. Some community people who are vital to the research process may be sceptical of research and whether it can actually help their people. This is a result of experiences with or rumours of failed research in the past, or a mis-use of evidence that caused harm to the participants either directly or to their community in general.