

Original Article

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Watching the Tide come in: An Aboriginal participant reflects on participating in the HIV Research field and the University Without Walls Program

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Doris O'Brien-Teengs is of Mushkego Cree and second generation Irish Canadian heritage. She grew up in Moosonee, Ontario. She has worked for the Ontario Aboriginal HIV/AIDS Strategy in Toronto for the last eleven years as a Regional Outreach Worker and has been involved in community based research for the past nine years.

We are all situated. Who we are, how we grew up, what we do with our time, all make a difference in how well we engage and are treated in the world. I am a pale Cree girl of mixed heritage, who speaks some of her language, but not fluently. I grew up in an Aboriginal community, but not a reserve, which still had a lot of my relatives in it. Both of my parents worked through my entire childhood until their retirement. I am post-secondary educated and my writing has been published. I've had the same job for eleven years – which to some constitutes a career. I have a mortgage on a nice house, am married and have two children now in school. I am short, but not tiny. I have moments of absolute candour and deep quiet – both of which may happen at the right or wrong times, leading to interesting and challenging consequences. Most of these things add up to privilege in Canadian society and some of it contributes to privilege in my Native identity. The fundamentals of who I am I did not ask for and it is the same for everyone. No one can make these choices. Through all of this, I live in a Canadian society that is based on trying to eliminate the Aboriginal ‘problem’. The problem being there are Aboriginal peoples on resource-rich lands. The calculated and continuing attempt at assimilation of Aboriginal peoples, it can be argued, has lead to the current state of our low status in Canadian society, which includes various negative psychological and health outcomes – the one I am most concerned about is high incidence of HIV and AIDS.

I am involved in HIV Research and learned from the ground up with a great bunch of people who sat on a Community Advisory Board. This year, I participated in the University Without Walls program funded by REACH from January to June of 2010. Almost every other Monday we would participate in three hour webinars, which consisted of tutorials and group planning meetings through the internet and phone. We were assigned to debate a topic at a World Café event in Winnipeg during our one week Learning Institute, as well as prepare a presentation on a given topic. Our tutorials were given by guest speakers on Ethics, Community Based Research (CBR), HIV statistics, CIHR funding protocols, Aboriginal and “Other” non-white and culturally relevant perspectives, etc. It was a well rounded outline. Most of the Fellows were either Master’s or PhD students, and so I am assuming that a lot of the ‘academic lessons’ were a refresher for them. As for me, I enjoyed learning as much as I could about the ins and outs of applying for research funding, the processes involved before, during and after the research takes place.

I was also fascinated by the ethics discussions. We learned of the horrific events that lead to the establishment of ethics boards which would control experiments that are both physical and psychological on human subjects. As long as they are funded, the research has to be approved by at least one Research Ethics Board (REB). On principle, no subject is supposed to be harmed in any way during the research process – whether physically, emotionally or psychologically. It made me think about research that is done on Aboriginal peoples. We have come a long way in terms of how research is done for and on us, but I still think we need to be cautious. Aboriginal peoples continue to be hurt by research, both by the processes and the absence of integrated outcomes. I tried to make an impression upon my co-Fellows, stating that Aboriginal people are not to be studied and objectified, but to be wooed and engaged, leading to a lifelong relationship and commitment.

In the last few years, I have noticed that one of the reoccurring themes in the HIV research field is the engagement in Aboriginal research which has to include Aboriginal people. So, what is community based research when it is not initiated by us? Academic, public health, or institutionalized idealism? Researchers call us with the OCAP

principles in hand, as if that were enough. These principles were not born out of our philosophies, but out of necessity, a means of expressing our engagement in any research process which includes us. These are words that the colonizer has used as an expression of what he understands to be important in the research process; words this Western world promotes as normal ways of doing things. If we have to Own, Control, have Access to and Possess these things to be partners for our community, we *will* do it. But we would rather just do things ourselves in our own ways.

Sometimes we do. But when we are being romanced by funders to get involved so that community based research with non-Aboriginals about Aboriginals can get done, the lines get blurred along the way. It does not help when the funding mandates are encouraging everyone to do research on Aboriginal people, but they won't fund a lot of Aboriginal initiated research. Sometimes we need and want to know the results of research for the benefit of our people. Many Aboriginal academics and thinkers have stressed that in order for it to be meaningful, any research that is done on or for us must be analyzed by a team that includes us.

It is important to be critical of who we talk to, the language that we use, and on whose terms that conversation takes place. Any discussion of community based research that is initiated outside of the defined community is questionable. Why would anyone outside of the community want to know our health outcomes? For whose benefits? The greater public health? What about our own public health? And what about our own ideologies and methodologies? Why is the Canadian Research movement so interested in Aboriginal people, but is reluctant to let these Aboriginal ideologies and methodologies evolve in their organic way? I leave the answer to your intellect and imagination.

Would I participate in this kind of cross cultural learning exchange again and would I suggest this program for other Aboriginal people involved in the HIV research field? Absolutely! It is essential to make the contacts and have a strong sense of who is out there. We do have very strong allies! It is equally important to know who *not* to work with. Most of all, it is important to make contacts with new researchers who are still pliable to cooperative ways of thinking and working. I think that the success in this program will happen because we are new researchers and excited to engage in dialogue with one another.

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UWW is a National Interdisciplinary Learning Network connecting academics, community members and policy makers. For more information on the UWW program, including student recruitment or teaching opportunities, please contact Francisco Ibanez-Carrasco: fibanezcarrasco@ohtn.on.ca.