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Indigenizing research practices: Two Indigenous researchers share their experiences of incorporating Indigenous culture into research.

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ABSTRACT

Anita C. Benoit and Doe O'Brien-Teengs explore the use of Indigenous methodologies, Community-Based Research and the integration of the Sharing Circle, weekend retreats and the incorporation of cultural and ceremonial activities into their research activities. *Key words*: Indigenous research, Indigenous methodologies, Indigenous HIV research, Sharing circles, Indigenous partnerships

BACKGROUND

Research conducted with Indigenous peoples is often built on relationships. This article explores Indigenous methodologies through the experiences of two emerging researchers, Dr. Anita C. Benoit and Ms. Doe O'Brien-Teengs (PhD Candidate), who have partnered together on several Indigenous Community-Based HIV research projects between 2011 and 2017. Dr. Benoit was introduced to Ms. O'Brien-Teengs through a mutual colleague, Dr. Mona Loutfy, in the summer

of 2011 in the hopes that Ms. O'Brien-Teengs could help facilitate the introduction of Indigenous methodologies into Dr. Benoit's research, and to connect her to the Indigenous community in Toronto. This introduction led to a reframing of Dr. Benoit's focus towards integrating Indigenous ways of knowing and doing and enhancing our understandings of how Indigenous ways of knowing and doing happen in real time. During this time, Ms. O'Brien-Teengs was working with Dr. Saara Greene on the *Families*, *HIV and Housing Study* and integrating Indigenous methodologies and ceremony into research processes.

Through our time together, we have noticed that research conducted with and for Indigenous peoples has taken conscientious and reflective approaches which aid and promote a rapid shift for researchers to move from an Indigenous perspective to an Indigenous research paradigm. An Indigenous perspective includes an Indigenous lens, but would still use Western ways of knowing and doing. An Indigenous research paradigm (set of beliefs that guide actions) includes ontology, epistemology, axiology and methodology (Wilson, 2001). Although not necessarily complex, using these words still brings the historically defined processes of research, which could be easily understood as 'discovery', more inaccessible through academic and scientific language for Indigenous people who work in the field of HIV.

We have learned that an Indigenous research paradigm presumes we ask ourselves how we know what we know and how this affects our culture and Indigenous identity (Wilson, 2001). Indigenous epistemology specifically imagines that our Indigeneity influences our ways of thinking to gain more knowledge about our reality. Ontology on the other hand requires that we reflect on our ways of being and how we think about our reality. Axiology might be more easily understood because it includes our morals and ethics that have more overtly guided us and been clearly articulated throughout most individual's lives. The axiology within an Indigenous research paradigm requires the outcome of research be beneficial in the world, but more specifically that the benefit is deemed a benefit by the people for whom the research is intended (Marsh, Cote-Meek, Toulouse, Najavits, & Young, 2015; Wilson, 2001). Overall, an Indigenous paradigm includes Indigenous methodologies which are understood to center Indigenous knowledge and discourses, including relational accountability, which is ensured by our ethics (Kovach, 2010; Wilson, 2001).

Thus, centering one's research in Indigenous knowledge may be considered practicing an Indigenous methodology. If this is the case, does this mean that leading the research must be an Indigenous person with that knowledge? Alternatively, is the practice of grounding research methods in Indigenous principles tantamount to following an Indigenous methodology? We do not have the absolute answer to these questions, but Morgensen (2012) states that Indigenous researchers in fact focus on working within and recreating their Indigenous traditions of knowledge through their research (Morgensen, 2012). This acts as a necessary, and possibly forced evolution of Indigenous culture. As Indigenous researchers, we have explored and reflected upon our use of Indigenous knowledges in our respective research projects.

Indigenous Women's Stress Study

The goals of the Indigenous Women's Stress Study (Dr. Benoit NPI) were for First Nations, Métis and Inuit women living with and without HIV to describe their life stressors, how they managed, adapted to or modified these stressors, and their desired strategies to cope with stress. Stress was a non-stigmatizing topic that allowed the women to ease themselves into some of the key questions in the study which were to describe what role HIV had around stress or what role HIV testing and diagnosis had around stress. The study involved completing a questionnaire on socio-demographics, HIV knowledge, and mental health, including stress. Women were also asked to participate in sharing circles or one-on-one interviews to explore all three goals as well as pilot an HIV prevention workshop and stress-reducing strategies. Ms. O'Brien-Teengs played a critical role in launching the study in a good way along with Ms. Wanda Whitebird and Dr. Saara Greene. All three were present during the first research activity which was a sharing circle and completion of the questionnaire. Ms. O'Brien-Teengs and Dr. Greene facilitated the sharing circle with the ceremony and support for the women provided by Ms. Whitebird. Ms. Kerrigan Beaver was also hired for study participant recruitment and to facilitate some research activities with Dr. Benoit by modelling the earlier activities of Dr. Greene and Ms. O'Brien-Teengs with the continued support of Ms. Whitebird. The following research activities included sharing the findings of the sharing circles and interviews, as well as piloting an HIV prevention workshop and stress-reducing strategies at a retreat which was led by several members of the research team.

Families and HIV Housing Study

This project was funded by the Ontario HIV Treatment Network and was led by Dr. Greene. The goal of the project was to understand the housing needs of families (i.e.: mother and/or children) who are living with HIV with the hope that the shared experiences would increase our understanding of family need and that appropriate supports would eventually follow. Ms. O'Brien-Teengs was on the Community Advisory Board as the organizational representative for the Ontario Aboriginal HIV/AIDS Strategy, and then was hired as a research assistant to recruit and interview Indigenous participants in Toronto. When standard recruitment strategies failed, Dr. Greene asked Ms. O'Brien-Teengs to imagine what she could do with this research project if she could do anything. Ms. O'Brien-Teengs dreamed of integrating Indigenous cultural ceremonies and practices into community engagement with participants, and with the support of the funders, research and organizational partners that is exactly what happened.

Integrating Indigenous Methodologies

Developing relationships and refining the research process

In practice, Indigenous epistemologies and methodologies are relational. Relationality acknowledges the natural world where cycles and interactions reveal that all things are related in the universe (Fixico, 2013). What this means for researchers is that we need to nurture our relationships with individuals, community, and the world we all live in. Our projects evolved over time and were facilitated by a number of persons. Ultimately however, the foundations of relationships relied on the researchers' efforts to sustain them long-term. Establishing

community partners is a critical first step and determining community interest and willingness to make a long-term commitment to work so that research projects could become our work.

Elders, ceremony and medicines

Both research projects engaged the same traditional teacher/Elder for assistance. She was offered and accepted traditional medicines (tobacco, sage, sweetgrass and cedar) in accordance with Indigenous protocols as an understanding of mutual teaching/learning. The Elder is Mi'kmaq and has lived and worked as a support worker/women's outreach worker in Ontario for over 30 years. She is well known for providing teachings to Indigenous women and people of diverse cultures. Through many conversations regarding incorporating Indigenous ceremony into our research projects, the research teams agreed to provide any materials and space that she suggested were required. In addition, the Elder brought a medicine bundle that included a number of items that were gifted to the bundle with the understanding that the Elder would use these gifts during her work with different groups and communities which include Indigenous women living on Turtle Island.

Qualitative research methods – the sharing circle and oral tradition

Qualitative research methods regularly use focus groups to obtain data from a dynamic group of participants (Savin-Baden & Major, 2013). The Indigenous method equivalent to the focus group is the sharing circle. Although they both include a gathering of participants who share information in a group setting, the difference lies in the sacred value and meaning that a sharing circle holds for Indigenous participants, as well as the accompanying Indigenous protocols (Lavallée, 2009). These protocols involve offering tobacco or a gift to traditional teachers/Elders and participants, as well as smudging, drumming and/or singing, and feasting (Marsh et al., 2015).

Historically, these oral traditions have formed the foundation of Indigenous communities and the maintenance of cultural knowledge. The stories hold histories and life lessons which sustain the culture and identities of peoples (Archibald, 2008; Bird, 2005; Fixico, 2013). Indigenous scholar, Margaret Kovach, (2010) deliberately uses oral traditions when she uses a conversational method in research to gather knowledge (Kovach, 2010). This method relies on both the listener and the teller to exchange roles and become interactive participants in the research and cultural processes. Oral traditions can also represent holism and reveal what is central to individual and community processes (Loppie, 2007; Struthers & Peden-McAlpine, 2005). Some social science researchers who work with Indigenous populations have leaned towards phenomenology, a social science research method, because it is seen as compatible with Indigenous oral traditions (Struthers & Peden-McAlpine, 2005). It uses open-ended questions, is circular and permits the collection of information on life experiences. This notion of viewing the world in a circular pattern such as the cycle of life is aligned with many Indigenous worldviews (Absolon, 2010; Deloria, 1999).

Learning circles, healing circles, sharing circles and talking circles are spaces to facilitate knowledge sharing and are part of oral traditions (Bird, 2005; Greene, O'Brien-Teengs, Whitebird, & Ion, 2014; Lavallée, 2009; Nabigon, Hagey, Webster, & Mackay, 1999). Circle methods also enable other practices aligned with Indigenous culture to increase opportunities for

healing and knowledge sharing. Nabigon et al. (1999) deliberately created a circle format for their participants to sit together. They lit a candle in the room, which symbolized words feeding the fire and burning up negativity, while positively strengthening everyone's inner fire (Nabigon et al., 1999). In addition, circles can be used as frameworks to engage participants. Lavallée (2009) rooted her research interest and questions in the teachings of the medicine wheel, as well as using sharing circles and Anishnaabe symbol-based reflection (i.e.: paintings, drawings, sculptures, crafts, songs, teachings and stories) to collect data (Lavallée, 2009). Lastly, it is essential that Knowledge Holders - including Elders - play a key role in circles used in research to ensure that research is done in a good way (Flicker et al., 2015). Their participation in research offers an opportunity to share knowledge on how to create balance with the negative that may stem during research, engaging in power *with* versus power *over* dynamics among research team members, researchers and participants.

During the sharing circle a facilitator will offer a question or topic to the group and sometimes produce a talking device (i.e., a talking stick, an eagle feather, or stone). The facilitator will then impress upon the participants that the sharing circle is a confidential space and any story or feeling is not to be shared outside of the time and space of the activity (Lavallée, 2009; Nabigon et al., 1999). Each person speaks in turn uninterrupted, most often in a clockwise direction (Lavallée, 2009; Marsh et al., 2015; Nabigon et al., 1999). As a research method, the researcher will play a role as facilitator and must request permission from the participants and community involved on the research team to analyze and report the data shared during the circle. For the Indigenous participants, the sharing of their story is only part of the event. The ceremonial aspects of the sharing circle are often beneficial to the individual and provide an opportunity for community engagement well beyond the research activity (Lavallée, 2009; Nabigon et al., 1999). Thus, many community workers, healers, and researchers have returned to using sharing circles and other Indigenous ceremonies to encourage and support healing among Indigenous communities (Marsh et al., 2015), and also to disseminate findings from projects and reports (Lavallée, 2009).

Together, we have modelled Indigenous and allied authors who have described aspects of their research process (Kovach, 2010; Lavallée, 2009; Loppie, 2007; Struthers & Peden-McAlpine, 2005) and how it has adapted or is aligned with Indigenous cultures (Flicker et al., 2015; Marsh et al., 2015; Nabigon et al., 1999).

Community-based research principles

Both projects described in this article were Community Based Research Projects. Community-based research (CBR) or Community-Based Participatory Research (CBPR) (Hergenrather, Geishecker, McGuire-Kuletz, Gitlin, & Rhodes, 2010) has been described as an approach to research that engages with community in such a way that the community is just as involved and invested as the academic researcher. The basic tenets of CBR or CBPR include the following: academic researchers, organizational partners and community members are given equitable decision making power at every stage of the research project; the research team is made up of representatives of the above three groups and works collaboratively with open and respectful dialogue; there is respect for community knowledge and input; there is an understanding that multi-dimensional learning and capacity building are expected and facilitated; the research team

shares all dissemination activities (co-authoring, co-presenting); and the research team strives to provide knowledge that can benefit the community that is being researched (Braun, Browne, Ka'opua, Kim, & Mokuau, 2014; Flicker et al., 2015; Hergenrather et al., 2010; Maiter, Joseph, Shan, & Saeid, 2012; Travers et al., 2013).

Each member of the research team holds equal value on the team and has contributions to make. The researcher whose beginnings may have been in community or academia brings a variety of skills and knowledge regarding research processes.. The academic researcher often provides access to institutional Research Ethics Boards (REB) (Hergenrather et al., 2010) which are needed for research in Canada to proceed. The community members have knowledge of community customs, practices and lived experiences (Travers et al., 2013). The organizational representatives are often community members themselves or have a working knowledge of community lived experiences. They are important to the research team because they are usually the gatekeepers for the research project to community members and provide community access. Furthermore, organizational representatives understand programs and interventions and have insights into what already works and what has not worked for the organization and/or community regarding service delivery (Hergenrather et al., 2010). Although the academic researcher may initially approach the community members and organizational representatives with a research need, it is essential that the researcher take the lead from the community in developing research priorities and projects (Bird, Wiles, Okalik, Kilabuk, & Egeland, 2009; Hergenrather et al., 2010; Loppie, 2007). Often, CBR projects need approval from the community which can take place at the research team level where the community members agree to the research principles and project through their commitment and involvement (Loppie, 2007), or there is consultation and approval at a community meeting facilitated by the research team and/or community (Bird et al., 2009).

Ongoing skills building within Indigenous communities and organizations continue to enhance the equitable dialogue within the research team. Ideally, the research team works towards consensus through collaboration and capacity building (Hergenrather et al., 2010; Marsh et al., 2015). Academic and emerging researchers will often have opportunities to learn from community members and vice versa and they may design and develop the research methods for their project. For example, a researcher may learn about sharing circles in order to implement them into the design of a research project with Indigenous populations (Marsh et al., 2015). CBR appears to be the ideal research process to work with and for persons living with and affected by HIV specifically, Indigenous communities and other populations whose identities may intersect with Indigenous identity. CBR has been used to develop an Indigenous Health Epidemiology Model (Benoit et al., 2016b), construct a women living with HIV reproductive and sexual health survey (Abelsohn et al., 2015), explore HIV prevention programs in Indigenous communities (Majumdar, Guenter, & Browne, 2010), and understand the provision of services and health outcomes for trans persons (Travers et al., 2013). A number of strengths have been described in the above studies, including identifying meaningful ways to engage the populations in the research process through community advisory committees (Benoit et al., 2016b), survey working groups (Abelsohn et al., 2015), terms of references (Travers et al., 2013), and consistent team meetings and/or opportunities for feedback with diverse technologies (Abelsohn et al., 2015; Benoit et al., 2016b; Travers et al., 2013). Including Knowledge Holders such as Elders on

the research team to provide support, lead ceremony and provide teachings enabled the research teams to focus on local Indigenous knowledges (Benoit et al., 2016b; Majumdar et al., 2010). Another strength of using CBR consists of valuing community leadership which leads to privileging Indigenous voices (Benoit et al., 2016b; Majumdar et al., 2010). Also, valuing diverse expertise on a research team (e.g., Indigenous, women and/or trans persons lived experiences; Indigenous methodology; epidemiology; health and social services and supports; and HIV research) has contributed to the success of projects and capacity building opportunities (Abelsohn et al., 2015; Benoit et al., 2016b; Travers et al., 2013). Finally, hiring or providing compensation to community members has contributed to community participation in research (Abelsohn et al., 2015; Benoit et al., 2016b; Travers et al., 2013).

Although there are many positive impacts of using CBR, a number of challenges do exist. Efforts to meaningfully engage community and obtain consistent feedback has been shown to be impeded by limited access to technology and reduced communication strategies (Abelsohn et al., 2015). Although it is important to achieve a balance in terms of skills and experience on research teams, it is also important to note which community voices are missing and whose feedback has not been chosen to be included in the research process (Abelsohn et al., 2015). In addition, despite engaging community in the research process, unintentional disempowerment does occur (Abelsohn et al., 2015; Travers et al., 2013). Disempowerment can unintentionally occur through various structures within academia (e.g., research ethics boards, administration of grants, publication guidelines) and funding agencies (e.g., project roles with different payment/compensation guidelines and different decision-making roles), for example. Traditional research structures support academics to take on leadership roles irrespective of how a project may define and exercise its power structure (Travers et al., 2013). By nature, CBR projects require more time than a 'traditional' research project due to many factors such as the importance and the sometimes delicate nature of relationship-building, for example. Moreover, although honorariums are provided to community members, the amounts provided is often not able to fully compensate for the work undertaken (Abelsohn et al., 2015; Travers et al., 2013).

Ownership, Control, Access and Possession principles

Almost any research that includes First Nations' people in Canada today must conform to the Ownership, Control, Access and Possession principles, otherwise known as OCAP® (FNC, 2007). OCAP principles were created in 1998 because of the oppressive legacy of colonial research and the history of the gathering of information which supported a political agenda to assimilate Indigenous populations (Schnarch, 2004). These principles were generated by and for First Nations peoples. The ideas put forward by OCAP have been adapted by Métis and Inuit Peoples to develop their own principles of self-determination. The Six Principles of Métis Health Research and the OCAS (which stands for Ownership, Control, Access and Stewardship) Principles were developed by Métis Peoples and included researchers, students and/or organizations (FNIMH, 2013; "Principles of Ethical Métis Research," 2010). Inuit Qaujimajatuqangit (IQ) translates to mean traditional Inuit Knowledge. It is critical that IQ be integrated into research with Inuit Peoples (Arnakak, 2002; FNIMH, 2013; Tester & Irniq, 2008). These principles provide similar processes as described by CBR above: Indigenous communities own the research processes, data, and dissemination. Furthermore, the research cannot be initiated, continued, or shared, without the direction of the Indigenous community

members who are involved (FNC, 2007). These Principles ensure that academic researchers do not negatively affect Indigenous populations through research projects. Another aspect of Indigenous Principles is that the research needs to be beneficial for the Indigenous community involved; whether that be through the development of a positive intervention or the preservation of an Indigenous language and culture (Schnarch, 2004). At its best, CBR will champion these principles and model equitable engagement at every opportunity in the research project.

Ideas of research

Prior to colonization in North America, Indigenous populations had their own research methods and rigour, which were often undertaken by individuals searching for his/her own answers or by 'experts' who were keepers of histories, knowledge or medicines for their communities (Marsh et al., 2015; Smith, 1999). It is important for academic researchers to understand this cultural legacy because they may encounter cross-cultural roadblocks in which the Indigenous culture does not value the same knowledge base or frameworks or vice versa (Braun et al., 2014). This may lead to misunderstandings and misinterpretations of any data collected without cross-cultural awareness (Braun et al., 2014). It is for these reasons that we chose to engage in CBR. We also chose to incorporate Indigenous ways of knowing through the practice of Two-Eyed Seeing to gain the best of both worlds and create research that would benefit Indigenous women in Ontario.

Etuaptmumk is the Mi'kmaq word for Two-Eyed Seeing, which Elders Albert and Murdena Marshall conceptualized (Martin, 2012). Two-Eyed Seeing refers to seeing the world through the lens of Indigenous knowledges and ways of knowing from one eye and European-derived knowledges and ways of knowing from the other, and using the best of both views to benefit all (Martin, 2012). Also the advantages of Two-Eyed Seeing includes not only that it recognizes the existence of multiple ways of understanding the world, but that it works from the premise of inclusivity in contrast to other knowledge systems (Martin, 2012). This concept is very important to acknowledge, given its origin from Elders and the fundamental principles of 'all my relations' - a recognition of harmony, unity and equality – a balanced and respectful approach to living in this world that was disrupted by colonization. In other words, this knowledge exchange is for the benefit of all in a changing world where perspectives may shift and change in response to the evolution of cultural growth (Martin, 2012). Two-Eyed Seeing does not require an equitable or even an equal use of the different ways of understanding our world. It requires that the diverse strengths and purposes of different perspectives are recognized and are not viewed as one dominating over the other. Instead, a user of Two-Eyed Seeing principles can and should reflect on how they understand the world without pushing aside either knowledge.

Two Research Endeavours

The Indigenous Women's Stress Study (Dr. Benoit's Project)

The Indigenous Women's Stress Study (IWSS) initially began as a basic science project. Through the development of relationships and building the research team, IWSS evolved into a more meaningful and beneficial mixed-methods research project for the community of Indigenous women who participated in IWSS. It is important to note that IWSS took place in Toronto,

Ontario, as well as in Thunder Bay, Ontario, but we will only be speaking about the process in Toronto, Ontario. IWSS had two phases and both engaged urban Indigenous women living with and without HIV.

This final project was shaped by the feedback and priorities of the community partners. Some critical feedback was to include a qualitative component so women could tell their stories and share their experiences in a sharing circle, focus group or interview. The inclusion of symbolism and the teachings of the medicine wheel also became critical aspects of the study.

During the first phase, we were interested in learning from the women how stress entered their lives and how they managed and/or desired to manage stress. We also wanted to know what their opinions were with regards to learning new stress-reducing strategies and what they thought about using biological materials to tell us something about their stress levels. Women arrived at a community agency where we shared a meal, obtained informed consent and completed a questionnaire package. The women were also able to also engage with our Elder who is a well-known and trusted traditional teacher. She began the meeting with ceremony including smudging. She sat in the circle to provide guidance and support where needed and shared teachings.

During the first sharing circle, I (Dr. Benoit) was an observer and watched as my more experienced colleagues (Ms. O'Brien-Teengs and another research team member) navigated the demands of the research study while ensuring the women were able to raise issues that were important to them without feeling constrained by the research objectives. I had created a medicine wheel that was placed in the middle of the floor. The women sifted through magazines, choosing images and situating these pictures on one or several quadrants of the medicine wheel. The pictures and their placement reflected a cause of stress on their mind, body, soul and/or heart. There was some laughter, and some raised their voice and with conviction discussed the impact of stress on their lives and the bigger implications. I was in awe of the generosity of the women in sharing certain life experiences and was made deeply aware that these were only some of their experiences, a snapshot of their lives.

It is important to say that while recruiting the women for this study, particularly women living with HIV, concerns around confidentiality were raised and as a result, some women participated in seven one-on-one interviews. I, along with a peer research assistant, led the remaining three sharing circles and interviews of the study.

During the second phase of the study, the information that the women shared led us to decide that a retreat would be beneficial for both the women and the project goals. The research team decided that it would be best to hold two retreats: one for women living with HIV and one for women who were either living without HIV or who do not know their HIV status. Peer facilitators were invited to the retreats.

The retreats were held over two days at a little oasis isolated from the hustle and bustle of downtown Toronto. A self-described Tudor-style hotel facilitated an air of calmness among all who attended. Women from the first phase of the project were asked to attend the retreat and a

subset agreed. Our traditional teacher conducted the ceremony for the meeting and both Ms. O'Brien-Teengs and I facilitated several of the retreat activities. At this retreat, we practiced stress-reducing strategies, incorporated traditional teachings while sewing medicine pouches, conducted an HIV workshop and also shared findings from the first phase. On day one, after the women arrived at the hotel and unpacked, everyone gathered into the meeting room where our traditional teacher conducted the welcoming ceremony. We then shared the findings from the first phase. The women were quick to highlight gaps and discuss their interpretation of the findings. The next part of the day we moved towards sharing teachings and creating a medicine pouch as a tool for discussions around HIV prevention. Afterwards, the traditional teacher closed the meeting and everyone retreated back to their rooms until dinner which was a thank you to the women. The next day of the retreat everyone gathered in the meeting room where the traditional teacher reopened the meeting. Breakfast was served and the women took the time to connect with our traditional teacher and sneak away for some private time. The remainder of the day was dedicated to practicing three stress reducing strategies. Some of the strategies were so successful that some women went from relaxing their eyes to dozing off. After lunch, a healing circle was led by our traditional teacher. After many words spoken and much laughter, drumming and singing, the retreat was closed in a good way.

Data was collected in a number of ways in this study using quantitative (Benoit et al., 2016a) and qualitative research methods. Findings from the qualitative research methods have not yet been published, but the manuscript is in preparation. The benefits of the study extend beyond the publication. The sharing circles led to women exchanging contact information – they had connected during the sharing circles and wanted to keep building their relationships. The retreat was particularly beneficial to the women because of the inclusion of stress-reduction strategies which ensured that the women saw the outcomes of their earlier participation in the study. Furthermore, the findings from the study led to securing operating funds to develop, implement and evaluate a stress-reducing strategy grounded in Indigenous culture for Indigenous women living with and without HIV.

Families, HIV and Housing Study (Ms. O'Brien-Teengs' Project)

In the Families, HIV and Housing Study, we provided a weekend retreat for HIV Positive Indigenous women away from Toronto at a Bed & Breakfast retreat centre. The goal for the project was to understand housing issues for families who were living with HIV (mother and/or children living with HIV). The original attempts at one-on-one interviews were unsuccessful and the research team decided that we needed to offer something more to show our appreciation and commitment to families living with HIV.

We provided tobacco to a traditional teacher/Elder and she was present for the entire weekend with the women. The women arrived from different locations in Northern and Southern Ontario on a Friday night. We shared a meal together and had our first ceremony of smudging and a sharing circle on the first evening. This sharing circle was not for data collection, but to bring everyone together into a shared communal space and to welcome the women. One of the women shared that when she arrived, she walked around the old house (retreat centre) and felt like she had been there before. She felt that it was a message that she was in the right place at the right time. It was an amazing moment when many of the women shared that they had the same

feeling. In this way, the first welcoming sharing circle, which was for the benefit of the women, created an immediate intimacy among the women and the research team, which would carry through the entire weekend.

The next day we engaged in a shared ceremonial activity and teaching by collectively building a sweat lodge and conducting a sweat lodge ceremony. Some women collected fire wood and built the sacred fire. Some women carried the grandfather stones from the vehicle to the sweat lodge site. The grandfather stones were collected by Ms. O'Brien-Teengs prior to driving to the retreat centre. Other women went in another vehicle to find branches which would be used to build the frame of the sweat lodge. And once the materials were gathered, four of the women, under the guidance of the Elder, built the sweat lodge. We learned that it is very hard to find Willow branches in the Ste. Catherine's area, and that Maple branches are not as pliable as willow, but when working together, anything is possible. Once it was built, and the grandfather stones were ready, the Elder conducted a sweat lodge ceremony with the women who wanted to participate. Most women went into the sweat lodge, and a couple of the women did not go in, and took on the role of fire keepers for the ceremony.

This sweat lodge ceremony was not part of the research, but was offered as part of the weekend retreat. It is part of Indigenous Principles to ensure that there will be a benefit for the participants involved in the research, and the research team made efforts to provide immediate benefits and create an intervention during the research process in the form of support and healing. One of the women who had never participated in Indigenous traditions because of colonial legacies (foster care) received knowledge of her clan and her colours. This was a significant moment for her, the traditional teacher, and the researchers who supported her journey.

After the sweat lodge and a shared meal, the researchers gathered the women for the official research sharing circle. This circle included two rounds of talking. The first was guided by a question provided by the researcher regarding their housing issues, experiences and concerns. The second round was guided by a question that the women wanted to address. The women wanted to tell us about an issue all of them were dealing with, and because it was significant to them, it became significant to us as well. It is important as researchers engaging in CBR with Indigenous populations that we take the lead from the participants who are willing to open up their lives to us. When the participants took the lead in the research direction, the process became transformative both for the participants and for the researchers.

The following morning was for relaxing and packing. Before everyone left, we held a closing ceremony of smudging and another sharing circle to give everyone the opportunity to share their thoughts on the weekend. It was important to ensure that the participants felt validated and were heard. All of the women were grateful for everything that we offered and wanted to participate in any further research and community events that we could imagine.

The official data collection for this research project included a three-hour sharing circle on the topic of housing issues for families living with HIV, but the benefits for the entire weekend extended well beyond those three hours for both the researchers and the participants. The communal living and eating, as well as the multiple ceremonial activities created an intimate

sharing environment which likely increased deeper levels of trust and sharing. For more information regarding the stories shared, refer to Greene et al, (2014) "How Positive Aboriginal Women (PAW) living with HIV talk about their mothering experiences with Child and Family Services in Ontario" (Greene et al., 2014).

DISCUSSION

As Indigenous women, we were deliberate in our choices to expand our research methods to include Indigenous methodologies. We made efforts to infuse Indigenous ways of knowing and doing into our own thoughts about ourselves and our work. Our Indigenous identities may lead people to assume that we would automatically infuse Indigenous ways into our research, but as we have both been educated in the Canadian system, we had to deliberately engage with a traditional teacher and reach out to our Indigenous networks to engage with community members. It is the acknowledgement of our relations and our relationships with each other that gave us the opportunity to learn more and enhance our Indigenous methodology research practices. These are, in fact, essential parts of Indigenous ways of knowing: our connections keep us grounded in our Indigeneity and automatically engage us with Indigenous epistemologies. The use of oral story telling through sharing circle practices is a natural fit for us as Indigenous researchers who are working to connect Indigenous ways of doing into research. Furthermore, community based research has been a useful framework to integrate our culture and ceremonies.

Benoit: my thoughts:

A great sense of responsibility to the study participants, to the research team members and to the research process was exemplified in both projects which is a critical aspect of an Indigenous axiology (Hart, 2010).

I was a postdoctoral fellow only a few months into my fellowship when I met Doe. I recognized how much I could learn from her and her giving nature. My postdoctoral research project made its first and most dramatic change during this meeting and continued to evolve thereafter with feedback from other research team members. Meeting Doe facilitated the evolution of my project into a mixed methods research project. Two-Eyed Seeing, a Mi'kmaq concept, was very much inclusive of the diverse strengths of the research team in *the Indigenous Women's Stress Study* (Martin, 2012).

Sharing circles represented one of the most intimate activities I had ever been part of in research. I noticed vulnerability and support through reassurance and finding commonalities in experiences between the women. There was respectful disagreement between some of the women and also efforts to understand differing opinions. Women largely listened quietly and expressed themselves. This process was healing for the women and deepened my sense of responsibility to them.

The idea of the retreats, although not previously mentioned, stemmed from the *Families, HIV* and *Housing study*. The most important similarity of the *Indigenous Women's Stress Study* to the *Families, HIV and Housing study* was by being grounded in Indigenous culture. Our retreat did

not include building a sweat lodge which facilitated healing from the first branch picked to completion of the lodge. We instead held stress-reducing interventions. One method in particular called 'guided visual imagery' was an impactful element of the stress study retreats. The traditional teacher knew the process under a different name and described it as something that some Indigenous people were long-time practitioners of. A visualization exercise that asked the women to imagine a warm camp fire with a woman moving around the fire led to powerful comments by the women. Some shared that they recognized the person moving around the fire as a relative or a friend. It was the first time I had observed this powerful gift by the traditional teacher.

Following the last dinner of the retreat, I sat at the table once everyone had gone and drank a cup of tea. I began thinking about the research process. Throughout the research study, my focus was always on ensuring that the women could achieve a certain comfort level, that they felt respected and knew that their contributions were valued. I thought about how long it would be before the women would see the outcomes of the research study and how this could potentially dampen the women's enthusiasm for the stress-reducing and HIV prevention workshops that we designed to be grounded in culture. The traditional helper had called me a helper once before, and I hoped that it fit.

O'Brien-Teengs: my thoughts:

It is significant as Indigenous women to incorporate Indigenous methodologies and Two-Eyed Seeing into our research. Both of these projects were aligned with Indigenous epistemological concepts of relationality and connection and depended upon that for participation and outcomes (Absolon, 2010; Wilson, 2001).

I was a research assistant for the Families HIV and Housing study and a research facilitator for the weekend retreats for IWSS. I was introduced to Anita and her idea for the IWSS because I had the experience of assisting in the weekend retreat for the *Families*, *HIV and Housing study*. Both weekend retreats facilitated a sense of community among all of the attendees, including the researchers, traditional teacher and participants. The communal sharing of meals and the creation of a shared space allowed the women to connect to each other throughout the day. Thus, the connections were made and strengthened before the data collection sharing circles, thereby, increasing the likelihood of higher intimacy and mutual understanding.

The sharing of cultural activities provided further bonding and spontaneous personal storytelling during the building of the sweat lodge and the sewing together of the medicine pouches. There is something about working on creating something together with our hands, which allowed for the women to relax, open up and talk to one another at a deeper level. This level of intimacy and trust was carried through to the official data collection sharing circle.

There was a high level of gratitude and personal benefit for the women who participated in both weekend retreats. The women appreciated being away from the city and/or within an oasis within the city because it was a temporary vacation from regular life's trials and tribulations. Many of the women also appreciated being included in Indigenous ceremonial practices because they had been excluded in the past because it was assumed they were under the influence of a drug or

alcohol, or they were stigmatized because of HIV. For many of the women who are regularly marginalized, these weekend retreats made them feel special and important, which had immediate benefits to their well-being.

I also experienced deeper levels of connection to the participants, and to ceremonial practices as well. It is one thing to know and understand the sweat lodge ceremony, but it is a lot more to build a sweat lodge and take care of everything at each step from beginning to end. Thus, incorporating ceremonial and cultural practices into research projects gives both researchers and participants the opportunities to engage in cultural practices more often on a day to day basis.

The biggest difference between the two projects was the location of the retreats. The *Families*, *HIV and Housing study* retreat was out on the land at a private Bed & Breakfast. We had access to an entire property and we not only communed with each other, but we connected with Mother Earth. One of the women walked around the large house several times during the first evening and when we had our first welcoming sharing circle, she said that she had a dream about this place. It was then that she (and we) knew that we were all in the right place.

The retreats in the Toronto center were private, but we were part of a larger space that held weddings and receptions. There were other guests attending weddings, and when we left our exclusive meeting area, we would see other people. In some ways, this brought us together as a group as well because we identified with each other.

CONCLUSION

Incorporating Indigenous culture into our research has worked for us as researchers. It has also created a deeper level of meaning of research for us. Our projects were not just research that was conducted to answer a question – those projects became part of our journey as Indigenous women as we engaged and participated with our Indigenous brothers and sisters across Turtle Island. These research projects contributed to the ongoing resurgence of Indigenous culture and identities within our communities, and we are grateful for these experiences.

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REFERENCES

- Abelsohn, K., Benoit, A. C., Conway, T., Cioppa, L., Smith, S., Kwaramba, G., . . . Team, C. R. (2015). "Hear(ing) New Voices": Peer Reflections from Community-Based Survey Development with Women Living with HIV. *Progress in Community Health Partnerships-Research Education and Action*, *9*(4), 561-569. doi:10.1353/cpr.2015.0079
- Absolon, K. (2010). Indigenous Wholistic Theory: A knowledge set for practice. *First Peoples Child & Family Review, 5*(2), 74-87. Retrieved from http://journals.sfu.ca/fpcfr/index.php/FPCFR/article/view/95/160
- Archibald, J. (2008). *Indigenous storywork: Educating the heart, mind, body and spirit*. Vancouver, British Columbia, Canada: UBC Press.
- Arnakak, J. (2002). Incorporation of Inuit Qaujimanituqangit, or Inuit traditional knowledge into the Government of Nunavut. *J Aboriginal Econ Dev, 3*, 33-39. Retrieved from http://iportal.usask.ca/docs/Journal%20of%20Aboriginal%20Economic%20Development/JAED_v3no1/JAED_v3no1_Article_pg33-39.pdf
- Benoit, A. C., Cotnam, J., Raboud, J., Greene, S., Beaver, K., Zoccole, A., . . . Loutfy, M. (2016a). Experiences of chronic stress and mental health concerns among urban Indigenous women. *Arch Womens Ment Health*, *19*(5), 809-823. doi:10.1007/s00737-016-0622-8
- Benoit, A. C., Younger, J., Beaver, K., Jackson, R., Loutfy, M., Masching, R., . . . Canadian Observational Cohort, C. (2016b). A comparison of virological suppression and rebound between Indigenous and non-Indigenous persons initiating combination antiretroviral therapy in a multisite cohort of individuals living with HIV in Canada. *Antivir Ther*. doi:10.3851/IMP3114
- Bird, L. (2005). *Telling our stories. Omushkego legends & histories from Hudson Bay*. Peterborough, Ontario, Canada: Broadview Press.
- Bird, S., Wiles, J. L., Okalik, L., Kilabuk, J., & Egeland, G. M. (2009). Methodological consideration of story telling in qualitative research involving indigenous peoples. *Glob Health Promot, 16*(4), 16-26. doi:10.1177/1757975909348111
- Braun, K. L., Browne, C. V., Ka'opua, L. S., Kim, B. J., & Mokuau, N. (2014). Research on indigenous elders: from positivistic to decolonizing methodologies. *Gerontologist*, *54*(1), 117-126. doi:10.1093/geront/gnt067
- Deloria, V. (1999). Spirit & Reason. Golden, Colorado, Unites States: Fulcrum Publishing.
- Fixico, D. (2013). *The American Indian mind in a linear world: American Indian studies & traditional knowledge*. New York, New York, United States: Routledge.
- Flicker, S., O'Campo, P., Monchalin, R., Thistle, J., Worthington, C., Masching, R., . . . Thomas, C. (2015). Research Done in "A Good Way": The Importance of Indigenous Elder Involvement in HIV Community-Based Research. *Am J Public Health, 105*(6), 1149-1154. doi:10.2105/AJPH.2014.302522
- FNC. (2007). First Nations Centre. OCAP: Ownvership, Control, Access and Possession. Retrieved from Ottawa: http://cahr.uvic.ca/nearbc/documents/2009/FNC-OCAP.pdf
- FNIMH. (2013). First Nations, Metis and Inuit Health Research Strategic Planning Committee Framework for research engagement with First Nations, Metis and Inuit Peoples. Winnipeg, Manitoba, Canada: University of Manitoba.
- Greene, S., O'Brien-Teengs, D., Whitebird, W., & Ion, A. (2014). How Positive Aboriginal Women (PAW) living with HIV talk about their mothering experiences with Child and Family Services in Ontario. *Journal of Public Child Welfare*, 8(5), 467-490. doi:10.1080/15548732.2014.948253

- Hart, M. A. (2010). Indigenous worldviews, knowledge and research: The development of an Indigenous research paradigm. *Journal of Indigenous Voices in Social Work, 1*(1), 1-16. Retrieved from http://hdl.handle.net/10125/15117
- Hergenrather, K. C., Geishecker, S., McGuire-Kuletz, M., Gitlin, D. J., & Rhodes, S. D. (2010). An introduction to Community-Based Participatory Research. *Rehabilitation Education*, 24(3 & 4), 225-238. doi:10.1891/088970110805029804
- Kovach, M. (2010). Conversational method in Indigenous Research. *First Peoples Child & Family Review,* 5, 40-48. Retrieved from https://fncaringsociety.com/sites/default/files/online-journal/vol5num1/Kovach pp40.pdf
- Lavallée, L. F. (2009). Practical application of an Indigenous research framework and two qualitative Indigenous research methods: sharing circles and Anishnaabe symbol-based reflection *International Journal of Qualitative Methods*, 8(1), 21-40. doi:10.1177/160940690900800103
- Loppie, C. (2007). Learning from the grandmothers: incorporating indigenous principles into qualitative research. *Qual Health Res, 17*(2), 276-284. doi:10.1177/1049732306297905
- Maiter, S., Joseph, A. J., Shan, N., & Saeid, A. (2012). Doing participatory qualitative research: development of a shared critical consciousness with racial minority research advisory group members. *Qualitative Research*, 13(2), 198-213. doi:10.1177/1468794112455037
- Majumdar, B., Guenter, D., & Browne, G. (2010). HIV prevention in an aboriginal community in Canada. *J Assoc Nurses AIDS Care*, *21*(5), 449-454. doi:10.1016/j.jana.2010.01.002
- Marsh, T. N., Cote-Meek, S., Toulouse, P., Najavits, L. M., & Young, N. L. (2015). The application of Two-Eyed Seeing decolonizing methodology in qualitative and quantitative research for the treatment of intergenerational trauma and substance use disorders. *International Journal of Qualitative Methods*, 14(5), 1-13. doi:10.1177/1609406915618046
- Martin, D. H. (2012). Two-eyed seeing: a framework for understanding indigenous and non-indigenous approaches to indigenous health research. *Can J Nurs Res, 44*(2), 20-42. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/22894005
- Morgensen, S. L. (2012). Destabilizing the Settler Academy: The Decolonial Effects of Indigenous Methodologies. *American Quarterly, 64* (4), 805-808. doi:10.1353/aq.2012.0050
- Nabigon, H., Hagey, R., Webster, S., & Mackay, R. (1999). The learning circle as a research method: the trickster and windigo in research. *Native Social Work Journal*, *2*(1), 113-137. Retrieved from http://142.51.24.159/dspace/handle/10219/461
- Principles of Ethical Métis Research. (2010). *Métis Cente Our health: Strengthened by Sharing.*Retrieved from http://www.naho.ca/metis/
- Savin-Baden, M., & Major, C. H. (2013). *Qualitative Research: The essential guide to theory and practice*. New York, New York: Routledge Taylor & Francis Group.
- Schnarch, B. (2004). Ownership, control, access, and possession (OCAP) or self-determination applied to research: a critical analysis of contemporary First Nations research and some options for First Nations communities. *Journal of Aboriginal Health, January*, 80-95. Retrieved from http://www.naho.ca/jah/english/jah01_01/journal_p80-95.pdf
- Smith, L. T. (1999). *Decolonizing methodologies: research and indigenous peoples*. London, England; New York, New York; Dunedin, New Zealand: Zed Books; University of Otago Press; St. Martin's Press.
- Struthers, R., & Peden-McAlpine, C. (2005). Phenomenological research among Canadian and United States indigenous populations: oral tradition and quintessence of time. *Qual Health Res, 15*(9), 1264-1276. doi:10.1177/1049732305281329
- Tester, F. J., & Irniq, P. (2008). Inuit Qaujimajatuqangit: Social History, Politics and the Practice of Resistance. *Arctic, 61*, 48-61. Retrieved from <Go to ISI>://WOS:000262800700007

Travers, R., Pyne, J., Bauer, G., Munro, L., Giambrone, B., Hammond, R., & Scanlon, K. (2013). 'Community control' in CBPR: Challenges experienced and questions raised from the Trans PULSE project *Action Research*, *11*(4), 403-422. doi:10.1177/1476750313507093

Methodology.pdf

Wilson, S. (2001). What is an Indigenous research methodology? . Canadian Journal of Native Education, 25(2), 175-179. Retrieved from file:///C:/Users/AnitaC/Downloads/WilsonS_What%20is%20an%20Indigenous%20Research%20