

**VISIONING HEALTH:
USING THE ARTS TO UNDERSTAND
CULTURE AND GENDER AS DETERMINANTS OF HEALTH
FOR HIV-POSITIVE ABORIGINAL WOMEN (PAW)**



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Abstract

Previous research, mostly *on* HIV-positive Aboriginal women (PAW) instead of *with* them, has focused primarily on their HIV-illness experience and the gaps and needs that arise from living with HIV. This has, arguably, allowed us to develop policies and programs to meet these needs; however, it has also contributed to dominant and disempowering representations of Aboriginal women living with HIV as troubled, vulnerable and in need of outside assistance. To counter-balance these negative representations and to co-create new strengths-based, culturally-relevant and gender-specific knowledge that can inform policies, programs and services for PAW, I partnered with PAW and Aboriginal community partners to develop a project that would provide PAW with an opportunity to tell a different kind of story about themselves than has previously been told by others.

Using an Indigenist Intersectional Population Health framework that was underpinned by a strengths-based, arts-informed, culturally-grounded and decolonizing community-based participatory approach to research, we engaged 13 PAW across three sites (Toronto = 5; Montreal = 4; ‘Virtual’ group = 4) in individualized group research processes to better understand PAW’s perceptions of health instead of illness and the intersecting roles that culture and gender can play in supporting the self-defined health of PAW. We also engaged in innovative, culturally-relevant and participatory knowledge translation and exchange (KTE) and developed policy and practice recommendations from our research.

Findings from *Visioning Health* suggest that PAW have a holistic and relational view of health that is grounded in their individual and collective identity as HIV-positive Aboriginal women. Health for PAW co-researchers has physical, mental, emotional and spiritual dimensions, and is fundamentally about ‘connecting’ and ‘feeling connected’ at multiple levels including self, others, community, culture, environment and Creator. Each of these levels is interrelated and each is grounded in Aboriginal cultures and ways of knowing that see all elements of the world as interconnected. This is consistent with previously published health concepts for Aboriginal peoples; however, this is the first articulation of PAW’s perspectives on health in the literature. PAW co-researchers also identified health-enabling strategies that they use to support their self-defined health, including understanding and resisting the broader context of colonization, reclaiming their voice and identity, creating safe spaces for themselves and their peers, and (re)connecting to Spirit. Given that the vast

majority of policies and programs for PAW are based on Western concepts of health as predominantly physical, findings from this study can be used to inform strengths-based, culturally-relevant and gender-specific policies and practices that better fit the needs of PAW.

One of the most significant and unexpected findings of our study, however, is that the process of participating in our research was, in itself, health enabling. Consistent with their perspectives on health, PAW co-researchers reported that participating in Visioning Health helped them feel connected to themselves, to others, to their communities, and to their cultures. PAW co-researchers also referred to their participation in Visioning Health as ‘a healing journey’ and ‘damn good medicine’. While we did not design our project as an ‘intervention’, it is clear that Visioning Health worked as a holistic and integrated action for social change on several levels that are mutually reinforcing.

Policy and practice recommendations that flow from this research include: privileging PAW’s perspectives, grounding policy and practice in local Indigenous knowledges, highlighting PAW’s strengths instead of weaknesses, and incorporating a colonial analysis.

Acknowledgements

I would like to begin by acknowledging the traditional territory, on which I live, work and play. As a Canadian, and as a descendant of French and British Settlers on these lands, I recognize that Ottawa, the place I now call home, is the traditional, unceded and unsurrendered territory of the Algonquin People. I am thankful to the Algonquin People for allowing me to leave my footprints on their territory.

I would also like to acknowledge Kecia Larkin for coining the acronym PAW, which stands for Positive Aboriginal Woman/Women. This is an important self-identifier for HIV-positive Aboriginal women because it marks a turning point away from illness-based identities that are imposed by others towards a strengths-based self-identity that emphasizes wellness over illness. We used this acronym extensively in our work. I am grateful to Kecia for allowing us to use it.

Doris Peltier has been the most incredible research partner and collaborator on this journey. Every community-based research project needs a champion within the community; someone who believes in the project and is both willing and able to help move it forward when it loses or does not yet have momentum. Doris was that champion for *Visioning Health*, and so much more. Without Doris, I am convinced that this project would not have taken flight. With Doris, and largely because of Doris, *Visioning Health* became more than just a project. In the words of Wanda Whitebird, our Traditional Knowledge Keeper, it has become ‘a movement’. I look forward to future research collaborations with Doris – some already planned and others not yet imagined. I hope that I, and others, have finally convinced her that, yes, she absolutely is a researcher and a damn good one too!

It goes without saying that this work would not have been possible without the generosity of the PAW who participated. In alphabetical order, Candy, Doris, ES, KJ, Krista, LA, Laverne, Liz, ME, MT, Paw, Tonie and Stacy gave so generously of their time, their knowledge, their experience, and their selves that it was and is humbling to behold. It is only through their willingness to participate in this project, their ability to see beyond their own discomforts, to see the good that might come from this project that *Visioning Health* became a reality. My deepest admiration and my heartfelt thanks to all of you.

Throughout this project, Wanda Whitebird and Sharp Dopler have consistently given more than we asked of them and it was always exactly we needed. We asked them to do an

opening prayer and they created a safe space for us to come together. We asked them to do a sharing circle and they created a community of co-learners. We asked them to give us a womens' teaching and they taught us how to be healthy members of a community. We asked them to guide us through this project and they guided us through our lives. My heartfelt thanks to Wanda and to Sharp for their willingness to be drawn into this project; for their willingness to be imperfect role models and mentors for all of us; for sharing their knowledge, their wisdom, their sense of humour, and most of all their compassion with us and with me. I am honoured to call you my friends.

Thanks also to Stan and Sharla Peltier, for sharing their knowledge and laughter with us. It was under Stan's guidance that we built the first two Visioning Health Lodges. Little did we know that these would become such powerful tools of knowledge transfer and exchange.

Denise Spitzer has been the most supportive Thesis Supervisor a student could ever ask for. Thank you Denise, for encouraging me to do the project I wanted to do and giving me the space and time to do it in. Thank you for your careful read of each and every word that I wrote and for your gentle guidance through this often challenging, sometimes exciting, and always interesting process. Thank you too for the coffees, for the conversations, for the camaraderie. You have mentored me in more ways than you know.

My Thesis Supervisory Committee has also been outstanding. They too gave me the space and time I needed to figure things out and the support and encouragement I needed when I was stuck. As respected researchers in the field of Women's Health, Aboriginal Health, and Aboriginal HIV they were also inspiring role models. Many thanks to Charlotte Loppie, Renée Masching and Hélène Laperrière for helping to guide me through this process. Thanks too to Michael Orsini who generously stepped in near the end of the process to help bring this thesis to completion.

In this thesis, I use the terms Community Research Advisory Committee and Community Partners interchangeably. This amazing group of (mostly) women was always there for me, and for us, whenever we called – and we called frequently. As members of our Community Research Advisory Committee, Renée Masching of the Canadian Aboriginal AIDS Network (CAAN), Laverne Monette and then Doe O'Brien-Teengs of Oahas, Geri Bailey of Pauktuutit Inuit Women of Canada and Carrie Martin of the Native Women's

Shelter of Montreal were always willing to celebrate our latest triumph; to brainstorm solutions to our latest challenge; to offer advice where needed, or simply support. As Community Partners, this same group, along with Art Zoccole and Corena Ryan of 2-Spirited People of the 1st Nations, provided recruitment assistance, in-kind support of meeting space or staff assistance, support of *Visioning Health* participants, and just plain old fashioned cheerleading. We could not have done this project without them.

My deepest gratitude to the Aboriginal HIV Community, and CAAN in particular, for incubating and nurturing a white girl like me who had visions of doing a different kind of research. My collaboration with CAAN is more than ten years old now – I began working with them in 2002 – and in many ways, I feel like I ‘grew up’ as a researcher during this time. I came into that relationship with book knowledge and a summer’s worth of experience working in Dinétah (the Navajo Nation) doing my Master’s research in Anthropology. The staff and management of CAAN gave me the opportunity, guidance, mentorship and friendship I needed to grow that experience, to turn that head knowledge into heart knowledge, and to learn what it means to be an ally. I have had many successes at CAAN but I have also made many cross-cultural mistakes and missteps in my journey, and my friends at CAAN and in the community have always made it okay to do so. I have gained more from my relationship with this community than I will ever be able to give back.

I came to know Randy Jackson through CAAN and his fingerprints are all over this thesis. As one of my most trusted friends and collaborators, I have spent many hours with Randy talking, laughing and puzzling over issues great and small. Like what the heck is epistemology! And when’s the next yoga class? I missed him greatly when he moved to Toronto but soon learned that telephones are a wonderful thing. Thank you Randy, for your years of friendship, mentorship, and conversation. I am a better person and a better researcher for knowing you.

Renée Masching has been a friend, mentor, committee member and collaborator throughout. Again, I met Renée through CAAN (are you sensing a pattern here?) and have come to cherish the work we do together. Despite her busy schedule, Renée always has time to discuss the latest idea, the latest project, the latest issue of import. If you look closely, you’ll see her fingerprints on this thesis too.

Kevin Barlow, ex-Executive Director of CAAN, introduced me to Doris Peltier and supported this project at its earliest stages. Thank you Kevin.

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Dedication

To MT and Stacy, PAW co-researchers in this project who completed their earthly journeys within 6 months of project completion. I like to think that your participation in *Visioning Health* brought you some joy, some camaraderie, some friendship in a sometimes hostile world for HIV-positive Aboriginal women. I learned so much from both of you. I was, and continue to be, both honoured and humbled that you chose to spend some of your time with us.

To LaVerne Monette (LV) a giant in the Aboriginal HIV and AIDS movement, a tireless advocate for PAW, a warrior with an enormous heart, a natural leader, a mentor to all those who knew her. LV actively supported this project at its very earliest stages and never stopped, even when she probably should have. I spoke with LV in November 2010 about an upcoming project meeting that was taking place at her organization with her staff as facilitators. She assured me that all was well, and that while she would not be there, she would make sure that someone from her staff – the Strat Cats – would be. I found out later that LV had been speaking with me while critically ill. She passed into the spirit world about two weeks later, on World AIDS Day, December 1, 2010, just as we were beginning to meet with project participants. At many points in this project, I reflected on our process by asking myself, and occasionally one of the Strat Cats, if LV would approve of the way we were doing things. I can honestly say that I think she would have been proud of us. Thanks LV for showing us the way and for watching over us on our journey.

To the PAW who have not yet found their voice; who have not yet seen the light at the end of the tunnel. There are too many of you who cannot participate in a project like this because you do not yet feel safe enough to say to another human being, “I am HIV Positive”. It is my hope that this research will help to make your journeys just a little bit easier.

Finally, I dedicate this thesis to the *Visioning Health* co-researchers. Although you benefit little from this part of the work, I want you to know that *Visioning Health* is what it is because of you. This project became much more than I could have ever imagined because of the trust you put in me, in Doris, in the process and in each other. As individuals you are strong Indigenous women, powerful and beautiful and amazing and insightful. As a group, you are extraordinary. As a group, you co-created a vision of health that we can all aspire to. Thank you for entrusting me/us with this vision. My hope is that we can continue to work

together to photograph and film and drum and sing this vision into reality. This thesis is for you.

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Chapter 1

Introduction

Making the Road While Walking: A Dissertation Overview

It was 4:00 am when we hung the last photo in the *Visioning Health Lodge (VH Lodge)*. It had been a long day – we started building the traditional teaching lodge around 7:00 pm – and those of us left standing took a few moments each to reflect on the meaning of our co-creation and on how far we had come together. With the guidance of Traditional Elder Stan Peltier (Anishinabe)¹, and with the support of Traditional Knowledge Keeper Wanda Whitebird (Mi'gmag), we had built the Ojibwe teaching lodge in ceremony and we all knew that the spirits of our ancestors, of those who had come before us, and of the women from our team who had crossed into the spirit world, were with us. As we stood inside the lodge, surrounded by the photo-stories of health, culture and gender that had been the focus of our work together, we knew that LaVerne would be proud; that Stacy and MT were smiling². We knew that we had finally got it right; that we had finally succeeded in truly honouring the sacred stories that the *Visioning Health (VH)* co-researchers had shared with us.



VH Lodge – Washington, DC, July 2012

¹ I include the heritage of each team member the first time their name appears in this thesis. This is to honour the diversity between and within Aboriginal groups, including First Nations.

² As Executive Director of Oahas, LaVerne Monette (LV) (Anishinabe) was one of our strongest partners and most ardent supporters. She passed into the Spirit World on December 1, 2010, almost two years prior to this event but we continued to be guided by her legacy. Stacy (Anishinabe) and MT (Inuit) were PAW co-researchers in our project. They both passed into the Spirit World less than three months prior to this event.

Two hundred Indigenous³ and non-Indigenous delegates from 12 countries were expected to arrive at 8:30 am for the opening ceremonies of the Fourth International Indigenous Pre-Conference on HIV & AIDS. We went to bed that morning knowing that the *VH Lodge* – built from approximately 45 freshly harvested red willow saplings, ten feet wide by sixteen feet long by eight feet high, and filled with the photo-stories of 13 HIV-positive Aboriginal women (PAW)⁴ – would greet them in the lobby of the hotel in downtown Washington, D.C. In contrast to the dominant perception of PAW as dying, diseased and disconnected from their cultures and communities, the *VH Lodge* proudly proclaimed, “WE’RE STILL HERE! In strength and unity, with our strong cultural beliefs still intact” (Peltier, 2012, p. 10).

Our journey together, the *Visioning Health* team, had begun almost two years prior when we convened our first meeting of PAW in Toronto, Ontario - although for many of us it began long before that. Most women brought their curiosity to that meeting and their hope for something better. Stacy (Anishinabe), a potential participant, brought her eagle fan. Traditional Knowledge Keeper Wanda Whitebird brought the ancestors. Doris Peltier (Anishinabe) and I (Canadian / French / British), as co-leads on the project, brought an idea for a different kind of research project that we hoped would make a difference in women’s lives, both then and in the future. We had come to realize that the vast majority of research, mostly *on* PAW, focused on their deficits, their vulnerabilities, their ‘risk’ profile, and their needs (Peltier, et al., 2013). In short, the dominant story of PAW, propagated by research and reinforced in the media, was that PAW were either “vectors, vessels, [or] victims” of HIV (Csete, 2005); often portrayed as diseased, dysfunctional, and disengaged from themselves, their families, communities and cultures. Our idea was to create a space for

³ I use the term Indigenous throughout this thesis to refer to Indigenous peoples globally. The first inhabitants of their respective lands, indigenous peoples share an experience of colonization; of cultural and linguistic oppression; of socio-economic marginalization; and of displacement from their homelands within existing nation-states. They also share an emerging political identity and increasing activism on the global stage. When referring to the Canadian context, I use the terms First Nations or Inuit where appropriate, however, I use the term Aboriginal as an inclusive term that recognizes the First Nations, Inuit and Métis Peoples of Canada. While I recognize the current controversy around this term, the vast majority of our partners and participants refer to themselves as Aboriginal, and therefore, I use it here to honour their right to self-identification.

⁴ I acknowledge Kecia Larkin (Blackfoot and Kwa’ Kwa’ Ka’ Wakw) for coining the acronym PAW which stands for Positive Aboriginal Women. This term first appeared in print in *Environments of Nurturing Safety* (Peltier, 2010). This important self-identification marks a turning point for HIV-positive Aboriginal women in that it represents a rejection of illness-labels and the embracing of new, positive, and asset-oriented social identities.

PAW to *tell a different kind of story*; their own stories; using photos and other kinds of art; stories of what it means to be ‘healthy’ as a PAW, and the role that culture and gender can play in supporting or maintaining their health. Along the way, we hoped that women might gain some insight into their own strengths and assets and be inspired to build on those toward their vision of health and healthy communities.

In retrospect, we really had no idea what we were getting into or what the road ahead would look like. That can probably be said of any journey – or at least any journey that seems worth taking. What is important here though, is that on that day in November 2010, we all agreed to take the journey together, one step at a time, “mak[ing] the road by walking” (Horton & Freire, 1990).

Dissertation Overview

In this thesis, I offer a description of *Visioning Health* – a culturally-grounded, arts-informed, community-based participatory research project – and the process that took us from Toronto, Ontario to Washington, DC and many points in between. Following Ferguson & Thomas-Maclean (2010), I try to document the “process as it [was]” (p. 12) before it got “cleaned up in the reporting of results” (Bernard, 1988, p. 110). In other words, I present our research here in at least some of its human messiness. By doing so, I hope to honour the true nature of our emerging methodology, of our unfolding relationships, and of research that responds to the needs of community – instead of community that responds to the needs of research. I also hope to honour what Walters and colleagues (2009) call an Indigenist approach to research that is organic, iterative, flexible, responsive and process-oriented (Weber-Pillwax, 2004; Weber-Pillwax, 2001; Absolon, 2011; Hart, 2010; Kovach, 2005); an approach that “make[s] room...for life, for the unexpected, for the path that emerges rather than the one initially planned” (Kovach, 2009, p. 108). This is an academic project, however, so I ground our methodological choices in the literature. When our choices were clearly guided by participant needs (Weber-Pillwax, 2004), cultural protocols (Walters, et al., 2009), or just doing what needed to be done in the moment (Gallagher, 2008, p. 72), I explain that too.

In the end, I hope to tell a story that emphasizes both process and outcomes, further suggesting that the two are inter-related. On one level, it is the story of meaningfully

engaging with PAW in culturally-grounded, arts-informed and strengths-based research processes to understand the meaning of ‘health’, instead of illness, for PAW and the role of culture and gender in supporting PAW’s self-defined health. To my knowledge, this is the first articulation of PAW’s perspectives on health in the literature. Given that the vast majority of policies and programs for PAW are based on Western concepts of health as predominantly physical, I also suggest that findings from this study can be used to inform strengths-based, culturally-relevant and gender-specific policies and practices that better fit the needs of PAW.

On another level, this is a story of the positive changes to our research that resulted from cross-cultural research that honoured the decolonizing and Indigenist principles of respect, reciprocity, relevance, responsibility (Kirkness & Barnhardt, 1991), relationality (Wilson, 2008), and reflexivity (Walters, et al., 2009; Tuhiwai Smith, 1999). By adhering to these principles, our research changed over time, becoming more culturally-grounded, more spiritually-grounded and more focused on the process – on the way we did things (Cochrane, et al., 2008) – than on the product of our research. This meant that community-engaged culturally-relevant and participatory knowledge translation and exchange (KTE) became a much bigger part of our work together than we had originally planned.

On still another level, this is a story of the unexpected but powerful consequences of meaningfully engaging PAW in our research. We set out to explore the meaning of health for PAW using a culturally-grounded, women-centred, arts-informed and community-based participatory approach and discovered that participating in our project was itself health-enhancing. PAW co-researchers⁵ referred to our project as “a healing journey”, “lifesaving” and as “damn good medicine”.

Finally, it is a story of research that aims to reduce long term health inequities by challenging the status quo – inside and outside the academy – and by making available the tools with which PAW might begin to uncover their own strengths and assets, and by doing

⁵ Throughout this thesis, I refer to the PAW who participated in *Visioning Health* as PAW participants and PAW co-researchers. The latter is a reference to the participatory nature of our project and to the central decision-making role that was shared with all PAW participants. It is an explicit recognition of their roles as researchers, as co-creators of new knowledge, rather than passive participants.

so, heal their communities. As Elder Art Solomon once said, “When [Aboriginal] women pick up their [medicine] bundles,⁶ our nations will begin to heal” (Peltier, et al., 2013, p. 85).

I offer our experience here in partial fulfillment of the requirements of my PhD, but also in the hopes that more researchers, funders and policy-makers will see the value in arts-informed, strengths-based, culturally grounded, and participatory research that gives back to the community at least as much as it gets.

Why *Visioning Health*? Rationale, Goals and Objectives

A number of years ago, when I was working for the Canadian Aboriginal AIDS Network, (CAAN)⁷, I had the opportunity to interview LaVerne Monette, a leader in the Aboriginal HIV and AIDS movement about what she thought were the most important issues facing the community. Without hesitation, she told me that the rising rates of HIV among Aboriginal women was the most pressing issue because, ‘without our women our communities have no future’. Embedded in this idea is another idea about the centrality of women in Aboriginal communities, that ‘women are the hearts of our nations’ (Brant-Castellano, 2009); they are ‘the backbones of our communities’ (Turner, 2012, p. 21); the culture-bearers, the teachers, the healers, and the givers of life (Wolski, 2009). The threat to Aboriginal women and communities that LaVerne was responding too, however, was and is all too present.

Reports from frontline workers in Aboriginal AIDS Service Organizations (AASO’s) and multiple dozens of research studies and surveillance reports over the past three decades tell us that the on-going legacy of colonization and the inequitable distribution of social determinants of health are associated with a disproportionate number of Aboriginal women testing positive for HIV. While Aboriginal women comprise approximately 4% of the

⁶ In Aboriginal traditions, ‘medicine’ is anything that aids in creating or maintaining wellness. In this sense, laughter and friends are medicine just as much as sage, cedar or sacred tobacco. A medicine bundle can belong to an individual or a community and each medicine bundle is different. The physical manifestation of a medicine bundle might contain items such as tobacco, rocks, feathers, pipes, and other items of spiritual significance. The spiritual aspect of a medicine bundle is comprised of life lessons, experiences and sacred teachings. In this sense, an individual can be considered to have good medicine, or in some cases, to be good medicine. (Personal communication with Sharp Dopler, Doris Peltier and Wanda Whitebird).

⁷ Established in 1997, CAAN is a national not for profit organization that represents over 400 Aboriginal People living with HIV or AIDS, Aboriginal AIDS organizations, provincial/territorial associations and programs. CAAN provides a National forum for Aboriginal Peoples to holistically address HIV and AIDS, HCV, STBBIs, TB, Mental Health, aging and related co-morbidity issues; promotes a Social Determinants of Health Framework through advocacy; and provides accurate and up to date resources on these issues in a culturally relevant manner for Aboriginal Peoples wherever they reside (www.caan.ca).

Canadian female population, in 2013 they accounted for 32% of HIV reports with known ethnicity among women. Between 1998 and 2012, women accounted for 47.3% of all HIV test reports among Aboriginal peoples compared to only 20.1% for the general population. In the same time period, the proportion of Aboriginal AIDS diagnoses attributed to women was 30.0% versus 9.3% for women of other ethnicities (PHAC, 2014). According to some researchers, “Aboriginal women [are] three times more likely than men to be HIV positive” (Mehrabadi et al., 2008, p. 253), due to gendered experiences of trauma and sexual abuse.

Obviously then, the need for research, policies, programs and supports to reduce disease transmission, improve PAW’s quality of life, and slow disease progression are pressingly important (Auerbach, 2004); however, as I pointed out in a CAAN report in 2004, “there is a startling lack of gender-specific, Aboriginal-specific HIV/AIDS resources, programs and services” (Prentice, p. 3) to support Aboriginal women. Our recent reviews of the qualitative literature on women’s HIV prevention (Gahagan, Ricci, Jackson, Prentice, Mill, & Adam, 2013), and of the literature on Aboriginal women’s HIV prevention (Peltier, et al., 2013), shows this to still be true almost a decade later. Since the vast majority of HIV and AIDS research occurs within a pathogenic (the origins of disease) paradigm, there is an equally startling lack of salutogenic⁸ (the origins of health) (Antonovsky, 1996) or “health-focused” (Fleischer, et al., 2006; Bond, 2006) research that highlights women’s strengths and assets. This is despite the fact that: a) PAW, along with Aboriginal and allied researchers, are increasingly calling for strengths-based research (Peltier, et al., 2013; Peltier, 2010) and b) “evidence shows that interventions to maximize and take advantage of health assets can counter negative social and economic determinants of health, especially among vulnerable groups” such as Aboriginal women (WHO Regional Office for Europe, 2005).

Arts-informed approaches, that is, research that encourages participants to respond to research questions through creative expression, instead of, or in addition to, surveys, interviews or focus groups, have been particularly effective in highlighting the strengths and assets of various communities (Wang, 2003; Duffy, 2011; Bader, Wanono, Hamden, & Skinner, 2007), including Aboriginal communities (Castleden, Garvin, & Huu-ay-aht First

⁸ The term ‘salutogenesis’, meaning the origins of health, was coined by the medical sociologist, Aaron Antonovsky, to describe an approach that “looks prospectively at how to create, enhance, and improve physical, mental, and social well-being” (Becker, Glascoff, & Felts, 2010, p. 2) rather than disease-causing factors.

Nation, 2008; Brooks, Poudrier, & Thomas-MacLean, 2008; Moffit & Robinson Vollman, 2004), and communities of people living with HIV (Teti, Massie, Cheak-Zamora, & Binson, 2012; Teti, Murray, Johnson, & Binson, 2012; Roger, Migliardi, & Mignone, 2012; Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009; Pietrzyk, 2009; Winskell, 2009). However, while I am aware of several on-going studies that use the arts in research with Aboriginal people living with HIV and AIDS, including women, I have found no published literature of this kind to date.

To address this lack of culturally-relevant, gender-specific, arts-informed and health-focused research, I collaborated with Aboriginal community partners to develop *Visioning Health: Using the Arts to Understand Culture and Gender as Determinants of Health for Positive Aboriginal Women*. The **goal** of this community-based participatory research project was to engage PAW in generating new knowledge and knowledge products (i.e., creative works of art such as photos, paintings, poetry, etc.) that would inform the development of strengths-based, culturally-relevant and gender-specific policies, programs and services for PAW. The interrelated **objectives** were:

- (1) To explore the meanings and experiences of ‘health’ for PAW;
- (2) To identify individual and community strengths and assets that support their health;
- (3) To better understand the role of culture in supporting their health;
- (4) To better understand the intersection of gender with culture and other social determinants in supporting the health of PAW; and
- (5) To develop policy and / or practice recommendations from the findings of this research.

These objectives are consistent with the objectives of the *Federal Initiative to Address HIV/AIDS in Canada* (PHAC, 2006b) and CAAN’s *Environments of Nurturing Safety (EONS): A Five Year Strategy on HIV and AIDS for Positive Aboriginal Women* (Peltier, 2010) to include gender and culture in policy and program development and to directly engage affected communities in developing gender- and culturally responsive programs and policies that enhance PAW’s quality of life, reduce stigma and discrimination, and slow disease progression.

As noted earlier, however, our research took an unexpected turn when PAW

participants began referring to *VH* as “life-giving”, “a healing journey” and as “damn good medicine”. To explore this phenomenon we added an evaluation component to our research that I report on in this thesis. While integrated and end-of-grant KTE were always a part of our research design, at the behest of PAW participants who developed a sense of ownership over this project, and other community members who saw the value in our project, community-engaged, culturally-relevant and participatory KTE became a much larger part of our project than planned. The description of the *VH Lodge* with which I opened this chapter, is a primary example of community-engaged and culturally-relevant KTE. In this thesis, then, in an effort to honour both our original and emergent objectives, I also report on KTE.

The Journey Begins: Decolonizing the Researcher

It is difficult to say when the specific idea for this project gelled, but for me the moment the seed of the idea was planted is quite clear. I had been working with Aboriginal communities and organizations since my MA research (Cultural Anthropology) in 1998 and with the Aboriginal HIV and AIDS community since 2002. In 2004 I was invited by CAAN, the national Aboriginal AIDS service organization for whom I was working, to write a position paper on HIV and AIDS and Aboriginal women, children and families (Prentice, 2004). An advisory committee of HIV-positive Aboriginal women and Aboriginal women service providers had already been established and was responsible for providing guidance and feedback on the development of the report. After several meetings with them, plus my own research, I presented them with the first draft of the paper.

I had written the report in the style that I had been taught; a style that was typical of the health reports that I had seen or read or been a part of developing over the years. The report began with a summary of the current epidemiological data and went on to enumerate all the ways that Aboriginal women were at greater risk of contracting a variety of diseases including HIV. It concluded with a list of recommendations designed to decrease Aboriginal women’s vulnerability to HIV, many of which had come from the advisory committee in previous conversations. When it came time, however, for committee members to give feedback on the draft report, it was clear that something was missing.

The committee agreed that I had the facts correct, that the recommendations were sound, and that the report ‘flowed well’. For the committee though, it lacked heart, it lacked

context and it lacked balance. They felt that the report did a good job of delineating the negative aspects of Aboriginal women's lives in relation to HIV but it presented a one-sided picture that completely ignored the multiple strengths of Aboriginal women and the many ways in which they protect themselves, their families, and their communities from HIV transmission. One woman told me that, 'I'm so tired of reading about how 'vulnerable' I am, and how 'challenging' my life is. When do I get to read something positive about our people?' Another woman said, 'Yes, we have high rates of disease in our communities, but that's only part of the story. There are lots of good things going on in our communities. When do we get to read about those?'

By using a 'needs-based' (McKnight & Kretzman, 1992) or 'problem' based approach that is "focus[ed] on negative aspects of life as identified by outside researchers" (Wilson, 2008, pp. 16-17) – a style that is typical of a Western biomedical approach to research (Menzies, 2001) – the committee felt that I had unwittingly re-produced "[p]ortraits of Aboriginal sickness and misery [that]...can be used to justify patterns of paternalism and dependency" (O'Neil, Reading, & Leader, 1998, p. 230). Instead, this group of PAW and their advocates called for research that focused on PAW's strengths instead of their weaknesses; on their health and healing rather than their illness; on the "strength and courage of [PAW] who struggle daily to maintain and create community, to initiate and support change, to survive" (Culhane, 2003, p. 599), and to thrive (Richmond, 2007).

As a non-Aboriginal person, trained in anthropology but heavily influenced by the health sciences, this was an 'aha' moment for me; a moment that "snapped [me] into a new level of consciousness" (Aluli Meyer, 2008); that triggered the next phase of decolonizing my mind, heart, and spirit. The Advisory Committee was right of course, and as a result, we worked together to prepare a more balanced final report and I promised myself that if I ever had a chance to do my own research, I would focus on the strengths of Aboriginal women in relation to HIV rather than their challenges. For me, this was the seed of the idea for this project⁹.

In retrospect, I can see that I was guided by a positivist notion of research - what Wilson calls "dominant system research" (2008, p. 101) - in which the goal was to produce

⁹ As noted below, Doris Peltier, with whom I co-developed and co-led VH, has her own story of how she came to this project.

evidence that was valid and reliable. I tried to do that by triangulating the data, that is, using research from several sources in conjunction with interviews, and doing my best to ensure that all this information ‘lined up’ (Cho & Trent, 2006). I was successful in that. What was missing though, and what the women on the advisory committee were expressing their discomfort with, was my inattention to the relational aspect of an Indigenist approach to research (Wilson, 2008, pp. 96-125; Weber-Pillwax, 2001; Weber-Pillwax, 2004; Kovach, 2005, p. 30). By only reporting on the challenges that PAW faced and their resulting ‘vulnerabilities’, I was not being accountable to the relationships that I had established with the advisory committee, nor did what I wrote reflect a shared understanding of the topic. The women of the advisory committee had a much broader, richer, deeper and more complex understanding of the entire historical, cultural and community context of HIV among Aboriginal women, children and families that they were not seeing reflected in the draft report. Once we worked together to create a more balanced report, this relational aspect of an Indigenist research paradigm was restored and the relationship that we had embarked upon could continue to grow in a mutually respectful way. In fact, a number of women who sat on that committee so long ago were also involved in the *VH* project.

Community-Engaged Project Design: Decolonizing the Research

In 2006, I was still working with CAAN when I decided to pursue a PhD. Recalling these earlier discussions, I worked with several representatives of the PAW’s and Aboriginal HIV and AIDS communities to develop a research project that would focus on women’s ‘health’ instead of illness; on their strengths and assets instead of their vulnerabilities. The results of these initial discussions were further informed by my discovery of Aaron Antonovsky’s work on ‘salutogenesis’ in first year course work for my PhD in Population Health. For me, salutogenesis represented an alternative to the pathogenic paradigm that dominates health research, and gave me a theoretical foundation for my emerging strengths-based perspective. Together, these formed the basis of my successful application for a Canadian Institutes of Health Research (CIHR) Doctoral Training Award (2007-2010).

In 2008, I was completing PhD coursework and comprehensive exams when I was introduced to Doris Peltier, the Women’s Leadership Coordinator and Aboriginal People Living with HIV Liaison at CAAN by Kevin Barlow, the Executive Director of CAAN at

the time. Doris shared my vision of ‘a different kind of research’ that focused on PAW’s strengths instead of their weaknesses. Her perspective was informed by her own experience as a PAW and also by her experience of conducting focus groups across the country where she heard from more than 300 PAW and their service providers that more strengths-based research on PAW’s experiences was required. The results of these consultations are the basis for *Environments of Nurturing Safety (EONS): A Five Year Strategy on HIV and AIDS for Positive Aboriginal Women* (Peltier, 2010). Together, over a series of coffee, lunch and dinner dates, and several phone conversations, Doris and I began in earnest to develop the research focus, research questions and the research design. Additional community partners from CAAN, Oahas,¹⁰ and Pauktuutit Inuit Women of Canada,¹¹ helped to flesh out project details.

In the spring of 2009, we received funding from Pfizer Canada and from the CIHR funded, Anisnabe Kekandezone Network Environment for Aboriginal Health Research (AK-NEAHR) for two proposals on what it means to be ‘healthy’ as a PAW and the potential role that culture and gender can play in supporting PAW’s health. In the fall of 2009, I submitted and defended my thesis proposal based on continuing discussions with community partners and my thesis proposal committee. Our application to the University of Ottawa Research Ethics Board was approved in spring 2010 (see Appendix A) and recruitment for VH began in fall of the same year.

Scope of Research

VH was a qualitative, multi-site, strengths-based, culturally-grounded, arts-informed, and community-based participatory research project. We partnered with five Aboriginal community organizations to engage a total of 13 PAW in three research sites (Toronto [n=5], Montreal [n=4] and one ‘virtual’ site [n=4]) in group research processes. All PAW co-

¹⁰ Formerly known as the Ontario Aboriginal HIV/AIDS Strategy, Oahas was implemented in 1995 and has consistently evolved since then to respond to the changing epidemic within the Aboriginal population. The goal of Oahas is to provide culturally respectful and sensitive programs and strategies to respond to the growing HIV/AIDS epidemic among Aboriginal people in Ontario through promotion, prevention, long term care, treatment and support initiatives consistent with harm reduction (www.oahas.org).

¹¹ Pauktuutit is the national non-profit organization representing all Inuit women in Canada. Its mandate is to foster a greater awareness of the needs of Inuit women, and to encourage their participation in community, regional and national concerns in relation to social, cultural and economic development (www.pauktuutit.ca).

researchers self-identified as First Nations or Inuit, and at the time of the study, PAW co-researchers resided in five different cities and one reserve across four provinces.

So What? Contributions of *Visioning Health*

An underlying principle of community-based participatory research and of decolonizing and Indigenist methodologies is that the research must be useful or ‘relevant’ to the community in which the research is undertaken (Kovach, 2009; Weber-Pillwax, 2001). In some ways, this is a direct and overt rejection of the ‘extractive’ research practices of the past (Tuhiwai Smith, 1999), and in other ways, it is a response to the immense need in many Aboriginal communities for knowledge, policy and practice that will support communities and community members to re-build healthy communities. Aboriginal authors, for example, write about the immediacy and the urgency they feel to carry out research that ‘makes a difference’ because they often have family or friends who are struggling to stay warm, to stay housed, to stay alive inside a dominant social system that does not meet their needs (Bond, 2006; Weber-Pillwax, 2001; Kovach, 2009). In *VH*, we took this concern very seriously and designed our project to ‘make a difference’ and to meet the needs of PAW.

First and foremost, *VH* gave PAW an opportunity to tell a different kind of story about themselves than has previously been told by others. The predominance of the pathogenic paradigm in research about HIV-positive Aboriginal women has created an overall picture of suffering, dis-ease and dysfunction among Aboriginal women and communities that is an incomplete and disempowering representation of what it means to be an HIV-positive Aboriginal woman. By grounding our study in a salutogenic paradigm that is complementary to Indigenist and strengths-based approaches, findings from the *VH* project provide a counterbalance to the above by generating new policy and program relevant knowledge in the area of ‘health-focused’ research (Fleischer, et al., 2006) and by identifying individual and community-level health-protective factors for PAW. The photo-stories and new knowledge generated by this project related to the health and health assets of PAW can be used to develop culturally-grounded supports and services, including health promotion, policy, programs and materials, specifically for Aboriginal women. They can also be used to address the HIV-related stigma and discrimination that is an unfortunate and unjust part of PAW’s lives.

This project has also generated new knowledge and knowledge products related to the complex role of culture and gender in determining the health of PAW and the dynamic ways in which culture intersects with other determinants of health, such as gender, ethnicity, social support and colonization. Culture must be considered in the design of health programs and policies, including health promotion, aimed at underserved peoples such as Aboriginal women (Duran & Walters, 2004). As anthropologist Sylvia Abonyi reminds us, “effective programs and policies demand a better understanding of the role culture plays in health outcomes and how it interacts with the other health-determining conditions” (Abonyi, 2007) such as gender, poverty, and social support. The findings from *VH* contribute to that better understanding and can be used to direct gender-sensitive and culturally responsive health promotion programs and policies that are health-enabling, enhance the quality of life for PAW, reduce stigma and discrimination against PAW, and slow the progression of disease.

The art-works produced by PAW co-researchers in this project are unique contributions in themselves. As evidenced by our KTE activities, including numerous photo exhibitions and the *VH Lodge*, these innovative knowledge products elicit a powerful response as complements to health-focused research data that informs policy and decision-making around strengths-based, gender-sensitive and culturally-relevant programs and services for PAW. As health promotion products (i.e. posters, postcards, etc.), the artworks produced by PAW in this project can also be used to raise awareness of HIV and AIDS among Aboriginal women, to empower PAW, and to reduce the stigma and discrimination that PAW experience.

Visioning Health also makes several methodological contributions. The methodological and theoretical foundations of *VH* will make a valuable contribution to the field of population health research. As critical Population Health scientists have pointed out, Population Health discourse continues to be dominated by a positivist or post-positivist paradigm, by quantitative methods, and by a predominantly pathogenic approach to research (Brassolotto, Raphael, & Baldeo, 2013; Raphael, 2011). *VH* adds to other critical and qualitative studies within the field that illustrate the value of qualitative and arts-informed approaches to understanding the social determinants of health and how they intersect within the lives of non-dominant populations (Cox, et al., 2010; Orsini & Scala, 2006).

In addition, *VH* pushes the arts-informed literature towards decolonizing and Indigenist methodologies through the explicit inclusion of Indigenous knowledge and cultural protocols in arts-informed research processes. Our adaptation of the Photovoice method to other art-forms including traditional Aboriginal arts such as storytelling and drum-making is a similar contribution.

While academic institutions are being pressed by a growing number of Indigenous scholars to decolonize their classrooms and to expand their scope of what is considered “good, valid and trustworthy” research (Padgett, 2012, p. 203), those who wish to use decolonizing, Indigenist and arts-based methodologies are still pressed to defend their choices and are often judged by measures that are inappropriate to their work. In part, this is due to the ‘dominant system of research’ that Wilson refers to as a system of research that excludes “those who fall ‘outside’ the powerful majority, such people who are not men, heterosexual, physically or mentally perfect or white, or any other people who for whatever reason do not ‘fit in’ to the dominant culture” (2008, p. 35). Among other things, this system is based on sets of binary oppositions that value objectivity over subjectivity; quantitative research over qualitative; Western methods and methodologies over non-Western methods and methodologies; the written word over oral or visual forms of communication; intellect or cognitive ways of knowing over any other form of knowledge; and individual knowledge over collective or community knowledge. Decolonizing and Indigenist methodologies resist these binaries and using a decolonizing methodology is, in itself, an act of resistance. By persisting in our work and by publishing our studies, with the help of our academic committees, studies such as *VH* continue to claim space in the academy for different ways of knowing, for research that challenges the dominant system.

Finally, *VH* is one example of developing and maintaining a respectful research relationship between a non-Aboriginal graduate student and an Aboriginal community. In *Indigenous Methodologies*, Margaret Kovach suggested that it would be “valuable to hear stories of non-Indigenous faculty and graduate student researchers exploring the dynamic of their shared journey” (2009, p. 166). Likewise, Simonds and Christopher (2012) note that there is very little guidance for graduate students on how to actually ‘do’ decolonizing research. I hope that our experience can be helpful to those who follow.

To Co-Author or Not to Co-Author?

As previously noted and discussed throughout this thesis, *VH* has been a wholly collaborative and community-based research project, from idea generation to research development, to analysis and meaning-making to community-engaged knowledge translation and exchange (KTE). The extent of this collaboration is highlighted in Chapter 3 and is difficult to over-state. In fact, *VH* has been so collaborative that it seems impossible that I might be considered the sole author of this work. In my world of community-based research, putting pen to paper is only one way in which authorship might be conferred. Contributions to the actual research, to data analysis and interpretation, or to conceptualizing the research or the writing are equally valued and would all earn their actors the designation of co-author. However, authorship of a PhD dissertation – even a dissertation based on a wholly collaborative and community-based research project such as this one – is more complicated in that only one of us will earn a PhD and therefore, only one of us can be held responsible for the views expressed herein. This tension between the expectations of the academy and the everyday practices of community-based research has resulted in many interesting, sometimes awkward, and always fruitful, discussions with community partners and PAW co-researchers and has left an indelible mark on this thesis and the thesis project.

I have been and continue to be uncomfortable with sole authorship of collaborative work and the multiple ways in which it perpetuates a colonial relationship. Sole authorship confers benefits to me – such as recognition, expertise and credentials – and dismisses or renders silent the contributions of PAW co-researchers and community partners, without whom the work could not have happened. To satisfy the academy, however, and for the purpose of this thesis, I have negotiated a few strategies with PAW co-researchers and community partners that I hope honour our respective contributions and our individual needs. First and foremost, I discussed the needs and potential benefits from the research with all community partners prior to the research and with PAW co-researchers at our initial orientation sessions and on multiple occasions afterwards. I was forthright that my need (and benefit) from *VH* was permission to write about our research in a PhD dissertation that would, in turn, earn me a PhD and the potential benefits that might accrue from that. In turn, PAW co-researchers and community partners articulated their individual and collective needs that were then incorporated into the research design and methodology. These

discussions resulted in greater engagement in decision-making, more training and capacity-bridging initiatives for PAW co-researchers, conference travel and presentation opportunities for PAW co-researchers, and increased community KTE.

In Chapter 3, I detail the multiple ways that PAW co-researchers are co-creators of the new knowledge contained within this thesis. I honour their contributions to meaning-making and to this project by using *we* instead of *I* when referring to group research processes, group decisions, or the results of group analysis. I retain the use of *I* when referring specifically to decisions related to the format or writing of this thesis. In each chapter, I acknowledge the individuals who have made significant contributions to the research, to the analysis or to the formulation and conceptualization of ideas contained within that chapter. I have also committed to co-authoring journal articles on topics of interest to PAW co-researchers and community partners once the thesis work is complete.

Thesis Outline

The purpose of this chapter has been to introduce the *VH* project – what it is, how and why we got started and what we hoped to achieve. The information is primarily personal in nature and written from my perspective as the author of this thesis and academic lead on the project.

In Chapter 2, I provide the academic context for this research; our academic starting point if you will. In other words, Chapter 2 is the academic foundation on which we built our project. I begin by taking you, the reader, on a brief tour of relevant bodies of literature to situate *VH* within current fields of scholarship. After grounding this study in the literature, I then discuss its conceptual and methodological foundations. Conceptually, *VH* is built on a critical Population Health framework that foregrounds culture and gender as determinants of health and their intersections at multiple levels. This is complemented methodologically by combining a community-based participatory approach with decolonizing and Indigenist methodologies that incorporate strengths-based, arts-informed, and women-centred practices. Together, the conceptual and methodological foundations of *VH* provide a critical lens with which to explore the meaning of health, culture and gender from the perspective of PAW.

Chapter 3 outlines the methods we used to carry out this research. To meet our needs, to provide a safe and supportive environment for PAW to tell a different kind of story

about themselves than has previously been told by others, we engaged PAW in all elements of the research process, from design to dissemination. Drawing on decolonizing and Indigenist methodologies, we grounded our study in culture and cultural teachings by engaging Elders and Traditional Knowledge Keepers throughout our project. This meant that we embraced spirituality in our research processes and honored Wilson's notion of 'research is ceremony' (2008). We also used a 'strategy of inquiry' that allowed us to decolonize our research and to be rigorous but flexible in our choice of specific data collection techniques to better meet the needs of PAW participants. In Chapter 3, then, I outline the ways in which *VH* pushes the current arts-informed literature, in particular the photo-voice literature, towards decolonizing and Indigenist methodologies.

Chapters 4, 5 and 6, are focused on the PAW co-researchers' stories. In Chapter 4, I present the women's stories in their entirety, as they told them, in words and in pictures. This gives me an opportunity to centre their voices instead of my own, to acknowledge their stories as the foundation and the starting point of our analysis, and to position PAW co-researchers' as Aboriginal storytellers and therefore as active agents of change (Bell, 2010; Sium & Ritskes, 2013; Mooney-Somers, et al., 2011). It also provides a touchstone for the reader; a point of focus to return to when the women are reintroduced in later chapters through smaller bits of narrative (Oliver, 2013). In Chapter 5, I explore the research findings related to 'health' and the meaning of health for PAW co-researchers, and in Chapter 6, I look at the health-enabling strategies or protective factors identified by PAW and the complex role of culture and gender as intersecting determinants of health.

In Chapter 7, I centre the idea of research as revolution and ask what, if any, difference have we made with our research? In 2009, Walters and colleagues identified 'revolution' as one of eight guiding principles of decolonizing and Indigenist research, suggesting that research should seek to be transformative on multiple levels: for the researchers and communities who participate, for science and for society in general. In this chapter, I explore the many ways that *VH* lived up to this lofty principle.

Finally, in Chapter 8, I reflect on the findings and the impact of our research and discuss the policy and practice implications of our study. I conclude this thesis with recommendations for future research and some personal reflections on the lessons and experiences that I carry into the next leg of my research journey.

As noted above, the work that follows is largely my version of the multiple stories within *VH* – why we did it, how we did it, what we found and the impact it had on those of us who participated. My primary research partner, Doris Peltier, would tell you a slightly different version of this story, as would each of the PAW co-researchers and research team members. As Margery Wolf points out in “A Thrice Told Tale” (1992), and consistent with Indigenous notions of multiple truths (Kovach, 2009, p. 26), none of our stories are absolute ‘truth’, yet all of them are true. In the version that follows – and remembering the lessons of that earlier report on HIV/AIDS and Aboriginal Women, Children and Families – I have done my best to tell you a story of *VH* that reflects our team’s shared understanding of project events and outcomes (see Chapter 3 for a discussion of how we came to this shared understanding). In doing so, I have tried to be accountable to the relationships that I have developed with the entire *VH* team, and beyond that, to the Aboriginal HIV and AIDS community that has nurtured this project. Any errors, omissions and misinterpretations are, of course, entirely my responsibility.

Chapter 2

Visioning Health in Context: Literature Review and Guiding Frameworks

Introduction

Visioning Health is guided by an Indigenist Intersectional Population Health Framework that foregrounds the social determinants of health and their intersections. It is further informed by critical Indigenous turns in social science (Denzin, Lincoln, & Smith, 2008) that influenced the adoption of a decolonizing, Indigenist, arts-informed and community-based participatory methodology for this study. In this chapter, I present an integrated literature review with our conceptual and methodological framework. By doing so, I acknowledge the lens that guided my search and review of the literature as well as the subsequent research.

An Intersectional Population Health Approach to Understanding the Impact of HIV on Aboriginal Women: A Brief Review of the Literature

Population health is a conceptual framework that highlights inequalities in health outcomes. It encourages us to think about why some people are healthier than others (Evans, Barer, & Marmor, 1994) and urges us to look beyond health care for these answers, to the social, cultural, political and physical conditions in which people are born, grow, live, work and age (WHO, 2008). A population health perspective recognizes that health is the outcome of the unequal distribution of, and complex interplay between, interconnected societal factors, or determinants, at various levels (i.e., individual, family, community, society) and at various times across the life-course. While several lists of determinants have been developed by a range of actors and organizations, three of which are included below, they typically include income, education, social support, early life experience, healthcare, and so on (see Figure 1). These determinants are sometimes called the ‘causes of the causes’, reflecting their often indirect but significant influence on the health of individuals and populations. In the context of Aboriginal peoples, “these determinants have worked in concert with Aboriginal-specific determinants such as culture, self-determination, and colonialism to produce significant health disparities compared to non-Aboriginal Canadians” (Halseth, 2013, p. 4). These Aboriginal-specific determinants are sometimes referred to as the broader determinants of health, or ‘the causes of the causes of the causes’, and are inextricably entrenched in unequal

power relations and a history of colonization (Richmond, 2007, Loppie Reading & Wien, 2009; Halseth, 2013). In this project, we use a multi-level or socio-ecological analysis to better understand the various ways that health determinants intersect at multiple levels, i.e., individual, family, community, and society, with other determinants to shape and constrain the lives and choices of PAW.

PHAC (1996)	Raphael (2004)	Loppie Reading & Wien (2009)
Income and social status	Income and its distributions	Employment and income
Social support	Social exclusion	Racism and social exclusion
Education	Education	Education
Employment and working conditions	Employment and working conditions	
Healthy child development	Early life	
Gender		
Culture	Aboriginal status	Cultural continuity
Social environments		
Physical environments		Physical environments
Personal health practices and coping skills		Health behaviours
Health services	Healthcare services	Healthcare systems
	Housing	
	Social safety net	
	Food security	Food insecurity
		Education systems
		Community infrastructure, resources, capacities
		Environmental stewardship
		Colonialism
		Self-determination

Figure 1: Social Determinants of Health

Intersectionality, a feminist approach to research that “refers to the idea that gender is experienced by women simultaneously with their experiences of class, race, sexual orientation, size, and other forms of social difference” (Varcoe, Hankivsky & Morrow, 2007, p. 19) is an emerging paradigm in population health. Highlighting the differences between groups and seeking to illuminate a variety of interacting social factors including social location, health status, and quality of life, intersectionality highlights the interaction between multiple forms of difference and oppression that are complex, mutually constituting, and compound. While recognizing gender as an important determinant of health for PAW, intersectionality resists the homogenization of gendered experiences of HIV, and rejects the primacy of gender as *the* most important social characteristic. Instead, intersectionality is about the interpenetrating, mutually constitutive, historically and socially situated ways in which multiple social indicators interact (Yuval-Davis, 2006; Hankivsky & Christofferson, 2008). An intersectional approach then, “recognizes that people’s experiences [are] mediated by multiple identities, including race, class, ethnicity, religion, sexual orientation, gender, age, disability, citizenship, national identity, geopolitical context, and health” (NWAC, 2008, p. 8). This holistic, socio-ecological and intersecting approach is compatible with Aboriginal understandings of health; however, an intersectional population health approach also recognizes that some determinants may be more salient than others for a given population or health issue at a given socio-historical moment (Grzywacz & Fuqua, 2000; Stokols, 2000).

Culture and Gender as Intersecting Determinants of PAW’s Health

In the context of PAW, we suggest that culture and gender “exert a disproportionate amount of influence” (Grzywacz & Fuqua, 2000, p. 103) on their health. Culture was added to Health Canada’s list of health determinants in 1996 but its influence is still poorly understood (Health Canada, 1996; Taylor, 2007). In seeking to explain the various ways that culture influences the health of populations, culture is most often linked with ethnicity and then with the broader fields of “personal history...[and] wider situational, social, political, geographic and economic factors” (Health Canada, 1996, p. np). This breadth of the culture concept and the degree to which it both influences and is influenced by other areas of life is the primary reason that culture is thought to be the best example of how the various health

determinants are complex, interwoven and interdependent. More than any other determinant of health, culture draws attention to the ineffectiveness of considering physical, mental, spiritual, social, or economic health in isolation (Health Canada, 1996).

As anthropologist Sylvia Abonyi suggests, “defining culture is like catching smoke: you can see it, you can smell it, but you can’t quite wrap your fingers around it” (n.p.). In the limited writings on culture as a determinant of health, the term ‘culture’ is most often used uncritically and without regard for definition (Janes, 2006; Kwok, Sullivan, & Cant, 2006). When defined at all, culture is frequently used interchangeably with related, but not equivalent, concepts such as ethnicity and race (Hunt, 2005; Mill & Edwards, 2003; Thurston & Vissandjee, 2005; Vissandjee, Desmeules, Cao, Abdool, & Kazanjian, 2004). At other times, epidemiologists and other health researchers employ a definition of culture that has long been rejected by anthropologists (Dressler, 2006; Taylor, 2007).

Modern anthropologists favour a definition of culture that is focused on process and shared meaning. Culture is, indeed, “a set of integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups” (Office of Minority Health, 2013). It is also “a shared set of (implicit and explicit) values, ideas, concepts, and rules of behaviour that allow a social group to function and perpetuate itself” (Hudelson, 2004). However, culture is more than that; it is an ever-changing, adaptive lifeway; the continuously evolving product of people interacting with each other (O'Neill, 2012). Each of the cultural domains mentioned above, i.e., language, customs, beliefs, values, etc., are responsive to changes in each other and to other societal factors; thus, culture is a dynamic process of shared meaning-making in a complex world of local and global interactions.

This means then that culture is not something that only ‘others’ possess (Eckersley, 2005; Glass, 2006). All human beings are embedded in a cultural context; but like a fish in water, our own culture is often so taken-for-granted, so much a part of who we are and how we operate in the world, that for most of us it is largely invisible. Hence, products of our own culture, e.g., values, beliefs, behaviours, emotions - and in the case of dominant Euro-Canadian cultures - institutions such as universities, hospitals and health care systems, seem to us to be ‘natural’ and ‘normal’. For instance, regardless of our cultural backgrounds we sometimes forget that health, wellness and approaches to health care are all “cultural

constructs, arising from beliefs about the nature of disease and the human body” (Office of Minority Health, 2013). As Mill and Edwards point out (2003), this process-oriented conceptualization of culture as socially constructed puts it squarely in the realm of the ‘modifiable’ (in contrast to non-modifiable risk factors) and this has implications particularly for culture-based interventions.

In the context of PAW, culture as a determinant of health is referred to in the literature in three interrelated ways: 1) As an issue of inclusion/exclusion, focusing primarily on the intersecting negative effects of racism, stigma, discrimination and colonization (Barlow, 2003; Goldstone, Albert, Churchill, Schilder, Perry, & Markowski, 2000; Neron & Joffey, 2000; Mill, 1997); 2) As health-related beliefs and barriers in which ‘culture’ is taken as static, homogenized, often reified, and reduced to ‘the customs of the natives’ (Taylor, 2007). In this usage, ‘culture’ is decontextualized and often used in a form of victim blaming in which the responsibility for action/inaction is shifted to the cultural beliefs of a particular people (Racine, 2002; Taylor, 2007); and 3) as a resource for improving health outcomes. *Visioning Health* is concerned largely with culture and cultural identity as a resource for PAW (Cross, 2003). Recalling that culture is defined as a dynamic, adaptive mechanism that can be used or modified for a particular end, Aboriginal cultural traditions can be used to develop culturally-relevant education or prevention programs to help raise awareness of HIV risk and risk behaviours and to help empower women (and men) to make different choices in regards to coping strategies that put them at increased risk of HIV. Once diagnosed, cultural traditions can also be used as a spiritual resource to improve health outcomes (Pruden & Wong-Wylie, 2009; McKay-McNabb, 2006). Studies conducted in partnership with CAAN indicate that a significant number of Aboriginal people living with HIV and AIDS either connect or re-connect with their cultural traditions after receiving a positive HIV test report and further, that this helps them accept their diagnosis and to lead happier, healthier lives (Reimer, 2005; Cain, Jackson, Prentice, Collins, & Barlow, 2013; Mill, Lambert, Larkin, Ward, & Harrowing, 2008; Mill, et al., 2008; Prentice, et al., 2011; Cain, Jackson, Prentice, Collins, Mill, & Barlow, 2011).

Gender refers to the socially constructed and reinforced roles, responsibilities, attitudes, values, behaviours and relative power that society assigns to the range of constructs that might be assigned to males and females (including gay, straight, lesbian, bi-

sexual, two-spirits, transgender and inter-sexed) and that are connected to and mediated by other determinants of health such as culture, colonization, income and social status, education, social environments, and so on (Spitzer, 2005; Varcoe, Hankivsky & Morrow, 2007). As a key determinant of health, gender is critical to understanding the differential impact of HIV and AIDS on the lives of women and girls (Commonwealth Secretariat, 2002; Gahagan, Ricci, Jackson, Prentice, Mill, & Adam, 2013). However, we must also recognize that a gender-based analysis alone is often insensitive to “the multiple needs of Aboriginal women, who suffer not only from gendered discrimination, but racism and other forms of oppression” (NWAC, 2007b, p. 6; Monture-Angus, 1995; Green, 2007), including colonization (Bourassa, McKay-McNabb, & Hampton, 2004; Czyzewski, 2011; Moffitt, 2004; Loppie Reading & Wein, 2009). This intersection of historically and socially situated identities and difference has had dramatic consequences for Aboriginal women.

Gender roles in Aboriginal communities experienced a dramatic shift as a result of the imposition of Eurocentric governance systems and social values and institutions. Most Aboriginal and allied scholars agree that prior to colonization, male and female gender roles were typically complementary, balanced and egalitarian values (Weaver, 2009; Healey, 2008; Kubik, Bourassa, & Hampton, 2009). Two-spirit people also had socially ascribed roles and identities. Some Aboriginal scholars, with consideration given to the diversity among Aboriginal nations and traditions, have compared the traditional relationship between men and women to the eagle who flies to tremendous heights on the strength of one male and one female wing (Monture-Angus, 1995; Valaskakis, Dion Stout, & Guimond, 2009). If either of these wings is weaker or stronger than the other, the eagle is out of balance and cannot fly. Such were typically the traditional roles of males and females in most Aboriginal communities: if the powers of one were stronger or weaker than the other, the community could not function effectively. Historically, while men were the hunters and protectors of their communities, Aboriginal women carried “major responsibility for transmitting their cultures and assuring the well-being of their communities” (Weaver, 2009, p. 1552). Considered to be the heart of their nations (Brant-Castellano, 2009), women were teachers, healers, and givers of life (Wolski, 2009). Thus, “women were seen as sacred human beings and were protected by the men of their communities” (Hawkins, Reading, & Barlow, 2009, p. 13).

Much of this has changed, however, and Aboriginal women are frequently oppressed within their communities as well as without. Frequently the targets of racist-sexism (Hawkins, Reading, & Barlow, 2009), Aboriginal women are among the most oppressed members of Canadian society and we see the results of this in the high numbers of missing and murdered Aboriginal women (Inter-American Commission on Human Rights, 2014), high rates of domestic, physical and sexual violence perpetrated against them (Kubik, Bourassa, & Hampton, 2009; McKeown, Reid, & Orr, 2004), and higher than average HIV incidence and prevalence (PHAC, 2014).

HIV and Aboriginal Women

Three decades into the epidemic Aboriginal women continue to be inequitably impacted by HIV and scholars agree that this is fundamentally linked to the cumulative and on-going impacts of colonization as a social determinant of health for Aboriginal peoples, including the residential school systems and the social environment that created it (Pearce, et al., 2008; Ship & Norton, 2001). The effects of the imposition of these institutions and their values on Aboriginal peoples have been widely felt in the form of intergenerational or historical trauma, cultural disconnection, the interruption of traditional gender roles, and the devaluing of Aboriginal women, both within Aboriginal communities and without (Bourassa, McKay-McNabb, & Hampton, 2004; McCall & Lauridsen-Heogh, 2014). This, in turn, has had serious and well-documented consequences for Aboriginal women and HIV-positive Aboriginal women's health including higher rates of trauma-induced mental illness, substance use, sexual abuse, and intimate partner violence, incarceration, HIV infection and on-going inequities in health and socio-economic well-being (Mehrabadi, et al., 2008; Miller C. , et al., 2002; Hawkins, Reading, & Barlow, 2009; Varcoe & Dick, 2008; McKeown, Reid, & Orr, 2004; Pearce, et al., 2008; Shannon, Bright, Gibson, & Tyndall, 2007; Shannon, Kerr, Allinott, Chettiar, Shoveller, & Tyndall, 2008; Craib, et al., 2003). As a result, Aboriginal women experience poorer health indicators than their non-Aboriginal contemporaries (Dion-Stout, Kipling, & Stout, 2001), and this holds true for HIV and AIDS.

Aboriginal women comprise approximately 4% of the Canadian female population, yet in 2013, they accounted for 32% of HIV reports among women (PHAC, 2014). In 2002, women represented 39.6% of Aboriginal HIV test reports (PHAC, 2004) but since 2004,

Aboriginal women have accounted for roughly 50% of new Aboriginal HIV infections annually compared to approximately 20% for their non-Aboriginal counterparts (PHAC, 2006). On average, between 1998 and 2012, females represented 47.3% of all HIV test reports among Aboriginal peoples compared to only 20.1% for the general population (PHAC, 2014). Similarly, women comprised only 13.8% of Aboriginal AIDS diagnoses prior to 1992 (PHAC, 2004); however, since 2001, the proportion of Aboriginal AIDS diagnoses attributed to women has averaged out at 26.5%, reaching a peak of 50% in 2008, versus 9.1% for women of other ethnicities (PHAC, 2006; PHAC, 2012). Aboriginal women also tend to be diagnosed at a younger age (15-29 years) than their non-Aboriginal counterparts and comprise a larger portion of HIV transmissions from injection drug use (PHAC, 2014).

This inequitable distribution of HIV and AIDS among women is further reflected in health services research. Aboriginal women are more likely than their non-Aboriginal counterparts to be diagnosed and initiate treatment at a later stage of disease progression (Gatali & Archibald, 2003; Wood, et al., 2006); to decline HIV testing during pregnancy – particularly when under the care of a male practitioner (Wang, Larke, & Gabos, 2005); to test positive for HIV during prenatal testing (Ogilvie, Kraiden, & Patrick, 2006); to start antiretroviral therapy later in their pregnancy (King & Network, 2001); and to have a shorter time to mortality than their non-Aboriginal counterparts (Lima, et al., 2006).

Towards a Salutogenic Understanding of PAW's Health

A growing critique of Aboriginal health research, however, is that the vast majority of it has been conducted within a pathogenic paradigm that highlights the ‘problems’ of Aboriginal communities, the illness-related gaps and needs, and the risks and vulnerabilities for Aboriginal ill-health (Bond, 2006; O’Neil, Reading, & Leader, 1998; Reading & Nowgesic, 2002; Richmond, 2007). In regards to PAW, researchers have overwhelmingly focused on identifying HIV risk and vulnerability for Aboriginal women, including sexual and physical violence (Varcoe & Dick, 2008; Pearce, et al., 2008; Shannon, Kerr, Allinott, Chettiar, Shoveller, & Tyndall, 2008; McKeown, Reid, & Orr, 2004), substance use including injection drugs (Mehrabadi, et al., 2008; Pearce, et al., 2008; Craib, et al., 2003; Wood, et al., 2006), the intersections between injection drug use, sex work, violence and increased

HIV risk among women (Varcoe & Dick, 2008; Shannon, Bright, Gibson, & Tyndall, 2007; Shannon, Kerr, Allinott, Chettiar, Shoveller, & Tyndall, 2008; Hill, 2003), and engagement in sex-work (Shannon, Kerr, Allinott, Chettiar, Shoveller, & Tyndall, 2008; Mehrabadi, et al., 2007; Shannon, Bright, Gibson, & Tyndall, 2007). While this approach to HIV risk and vulnerability has contributed to our understanding of the inequitable burden of HIV and AIDS on Aboriginal women and informed public policy to address the negative health outcomes associated with these adversities, it has had the harmful consequence of contributing to a one-dimensional, stigmatizing, and ultimately pathologizing image of PAW as dying, diseased, and dysfunctional.

This is consistent with Waldram's notion of the 'traumatized Aboriginal' (2004, pp. 212-234), a discursive construction of Aboriginal lives by academics, practitioners, and politicians. Casting PAW as 'other' and as 'devia[nt] from an assumed normal state' (Shields, Bishop, & Mazawi, 2005, p. x), the knowledge produced by this kind of research "constructs an understanding of Aboriginal society that reinforces unequal power relationships" (O'Neil, Reading, & Leader, 1998, p. 230), and continues to be used to justify colonial interventions that "govern, regulate, manage, marginalize, or minoritize" PAW (Shields, Bishop, & Mazawi, 2005, p. x). While more recent examples of pathogenic research are calling for Aboriginal-led responses to the problems being studied, the implicit or explicit suggestion in much of this research continues to be that solutions to these problems can only be found in 'expert' and almost always non-Aboriginal help from outside the communities (Cochrane, et al., 2008; Menzies, 2001; Wilson, 2008; Weber-Pillwax, 2004).

To counteract this inequitable, inaccurate, and disempowering research, PAW and Aboriginal and allied scholars are highlighting the importance of salutogenic (origins of health) or strengths-based research that identifies salutary, health promoting or health-enabling strategies, including strengths and assets at the individual and community-level (Andersson, Shea, Archibald, Wong, Barlow, & Sioui, 2008; Kirmayer, Sehdev, Whitley, Dandenau, & Isaac, 2009; Peltier, et al., 2013). They are also highlighting the importance of timely access to gender-sensitive and culturally-relevant programs and services, including HIV testing (Mill, et al., 2008; Mill, Wong, Archibald, Worthington, Jackson, & Prentice, 2012; Prentice, et al., 2011; Worthington, Jackson, Mill, Prentice, Myers, & Sommerfeldt,

2010), pre-and peri-natal services (Bucharski, Brockman, & Lambert, 1996), and a range of HIV treatment options including access to Aboriginal medicines and ceremonies (Prentice, 2004; Peltier, et al., 2013; Hogg, Strathdee, Kerr, Wood, & Remis, 2005; Wardman & Quantz, 2006; Hawkins, Reading, & Barlow, 2009). This health-focused research is increasingly recognized as essential to re-orienting health services and (re)building healthy communities (Minkler, 2007; Kana'iaupuni, 2005). It is also “an important shift towards an approach that understands, explains and nurtures health. Such an approach represents a critical turn for Indigenous health researchers” (Richmond, 2007, p. 1827).

What Do We Mean By Health?

At the heart of this project is the seemingly uncomplicated concept of ‘health’. Yet, there are many ways to conceptualize health and our understanding of it has evolved over time. From the mere absence of disease or disability (a bio-medical model), ‘health’ is now frequently used interchangeably with ‘wellness’ and has come to mean the “dynamic, ever-changing process of trying to achieve our individual potential in the physical, social, emotional, intellectual, spiritual, and environmental dimensions” (Donatelle, Davis, Munroe, Munroe, & Casselman, 2003, p. 4). This last definition is most closely aligned with the approach taken in this paper; a population health approach that recognizes the limited role of primary health care in human health outcomes. A population health perspective extends our concept of health beyond the mere absence of illness to a broader definition of health as a resource that enables individuals to thrive in their daily lives and to develop the capacities to pursue their dreams (Health Canada, 1998a; WHO, 2015). This positive orientation facilitates a holistic understanding of health as a state of physical, mental, spiritual and social well-being (Health Canada, 1998b) and situates the health of PAW in the broader context of the social, cultural and policy environments that both shape and constrain their life conditions and opportunities (Kindig, 2003). As noted by the Native Women’s Association of Canada, “the population health approach is thus compatible with native ancestral laws and spiritual beliefs, in which interconnectedness and holism as keys to healing and health are central tenets” (NWAC, 2007b, p. 9).

Extending from this, and consistent with the definition above, health and wellness for Aboriginal people is generally understood to be holistic, relational, and flow from balance

and harmony between the physical, emotional, mental and spiritual elements of personal and collective life (Bartlett, 2005; Wilson, 2004; Isaak & Marchessault, 2008; Graham & Leeseberg Stamler, 2010). Health is seen as both a community and an individual responsibility in that the health of an individual is recognized as inseparable from the health of the family, the community, the society, the culture, and the environment (Bartlett, 2003; Bartlett, 2005; Deiter & Otway, 2001; Wilson, 2004). More in-depth investigations suggest that Aboriginal health and wellness is associated with self-determination and cultural preservation, including spirituality, Elders, ceremony, oral traditions, traditional healing, and a strong identity (Chandler & Lalonde, 1998; Parlee, O'Neil, & Lutsel K'e Dene First Nation, 2007; Wilson, 2004; Adelson, 2000; Dion-Stout & Kipling, 2003), social support (Wilson, 2004; Iwasaki, Bartlett, MacKay, Mactavish, & Ristock, 2008; Richmond, 2009; Richmond, 2007), and positive relationships with family and community (Bartlett, 2005; Wilson, 2004; Bartlett, 2003; Adelson, 2000; Reiken, Scott, & Tanaka, 2006).

For PAW, however, the meaning and experience of 'health' is unknown. While there are numerous studies focused on disease, co-morbidities and mortality among PAW, *VH* is the only study to date to directly explore PAW's experiences and understandings of their health, instead of focusing on their disease status and illness experiences. The concepts of 'healing' however, and of resilience, coping, or protective factors for PAW have fared slightly better. McKay-McNabb (2006), in her research with eight Aboriginal women living with or affected by HIV and AIDS identified positive steps on "the healing path" or positive ways of coping with and coming to terms with a life lived with HIV and AIDS. She found that accepting one's diagnosis, dealing with risk factors, having support and embracing new identities were important steps towards healing for PAW (McKay-McNabb, 2006; see also Mill, Lambert, Larkin, Ward, & Harrowing, 2008; Pruden & Wong-Wylie, 2009). Other authors have suggested that finding or creating 'safe spaces' where PAW can gather "in an environment free of fear and judgement" (Hawkins, Reading, & Barlow, 2009, p. 43; Peltier, 2010) was health enhancing. In studies of both Aboriginal men and women living with HIV, authors found that re-connecting with cultural or spiritual traditions, focusing on their children, and seeking support from family, friends and Aboriginal service organizations were also identified as important elements in PAW's healing journeys (Mill, Lambert, Larkin, Ward, & Harrowing, 2008; Mill, 2000; Cain, Jackson, Prentice, Collins, & Barlow, 2013;

Gahagan, Ricci, Jackson, Prentice, Mill, & Adam, 2013). This lack of health-focused research for PAW has obvious implications for policy and practice, in that just as “Aboriginal women’s health values, beliefs and practices cannot simply be subsumed under those of Aboriginal men” (Wilson, 2004, p. 2), neither can the health values, beliefs and practices of PAW be subsumed under those who are not living with HIV or AIDS. As Hawaiian scholar Kana‘iaupuni suggests in the context of Hawaiians’ health, creating a ‘vision of health’ for PAW is an important task because “in so doing, we create our own compelling vision for the future and forge our own path toward greater well-being” (2005, p. 37).

Methodological Frameworks for Exploring PAW’s Health

The methodological framework for *VH* was informed by critical Indigenist turns in the literature (Denzin, Lincoln, & Smith, 2008; Kovach, 2009; Tuhiwai Smith, 1999; Wilson, 2008) and by our team’s collective experience of research with PAW. By combining multiple approaches that spanned Western and Indigenist traditions, we were able to meaningfully engage with PAW “in ways that are consistent with the norms and values of Aboriginal cultures” (Ungar, Soto, & Thomas, 2008).

Supporting PAW’s Leadership through the Greater Involvement of People Living with HIV and AIDS (GIPA) and the Meaningful Involvement of Women Living with HIV and AIDS (MIWA)

The GIPA principle is *the* foundational principle to ensure people living with HIV are adequately and meaningfully engaged at the individual, organizational and structural levels of national and global responses to HIV. Formalized in 1994 at the Paris AIDS Summit and endorsed by 189 countries, including Canada, in 2001 as part of the United Nations Declaration of Commitment on HIV/AIDS, the GIPA principle “aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives” (UNAIDS, 2007, p. 1). However, given that women and Aboriginal women in particular, are too often invisible in the HIV epidemic and do not share in the benefits of GIPA, we are also guided by the MIWA principle (ICW, 2009) that explicitly calls for the meaningful engagement of women

living with HIV and AIDS. Together, these principles guide us to centre the voices and experiences of PAW and actively engage PAW in all phases of the research including data analysis, interpretation and KTE; to act in ways that recognize and further the self-determination and leadership of PAW; and to give priority to paid work and skills-building opportunities to PAW. In VH, PAW co-researchers gained knowledge, skills and experience in contemporary and traditional Aboriginal art-forms; in qualitative and quantitative research methods; and analyzing and sharing research results. In addition, preference for all paid positions was given to PAW co-researchers. In practice, this meant hiring a positive Aboriginal woman as our PRA and ensuring adequate honoraria for PAW co-researchers.

Community-Based Participatory Research

The long and often shameful history of research as a tool of colonization, subjugation and oppression is well documented (Willis & Saunders, 2007; Prior, 2007; Tuhiwai Smith, 1999; Denzin, Lincoln, & Smith, 2008; Kovach, 2009). For many Aboriginal communities, research is still ‘a dirty word’ that is inextricably linked with the historically twin projects of imperialism and colonialism. For Indigenous scholar Linda Tuhiwai Smith the word *research* “...is implicated in the worst excesses of colonialism” (1999, p. 1) because, “as agents of colonial power, Western scientists discovered, extracted, appropriated, commodified, and distributed knowledge about the indigenous other” (Denzin, Lincoln, & Smith, 2008, p. 5) in ways that were beneficial for the colonizer-researcher but harmful, disrespectful, obtrusive and oppressive for Aboriginal peoples (Prior, 2007; Wilson, 2008). Control over the research process lay in the researcher’s hands such that Aboriginal peoples who were the subjects of research were excluded from the process and decisions regarding the focus of research, methodology, methods, analysis, representations and distribution of the newly created knowledge. In short, Aboriginal research *subjects* were often misrepresented, objectified, essentialized and denied a voice and identity (Denzin, Lincoln, & Smith, 2008; Tuhiwai Smith, 2005). Researchers have consistently failed to provide Aboriginal peoples with an opportunity to tell their own stories, to participate in the research, or to return information to the communities from which it was taken. They – we – have failed to show respect for Aboriginal peoples, cultures, knowledge and ceremonies, often putting the needs of the researcher before the needs of the people (Cochrane, et al.,

2008; Kovach, 2009; Wilson, 2008; Masching, Allard, & Prentice, 2006; Tuhiwai Smith, 1999; Denzin, Lincoln, & Smith, 2008). For example, literally thousands of volumes of research have been collected and written about Aboriginal peoples with little or no benefit accruing to them (Cochrane, et al., 2008) and examples of researchers taking blood samples from Aboriginal peoples and using them for purposes beyond those they consented too, are unfortunately still being reported (Wiwchar, 2004; Pacheco, Daley, Brown, Filippi, Greiner, & Daley, 2013).

In response to the legacy of distrust, harm and exploitation associated with traditional research methods and the ethical challenges that stem from them, researchers are increasingly turning to Community-Based Participatory Research (CBPR)¹² approaches that equalize the power imbalance by emphasizing research *with* Aboriginal communities instead of research *on* them (Walters, et al., 2009; Israel, Schulz, Parker, Becker, Allen III, & Guzman, 2003; Minkler, 2007). The adoption of CBPR as the preferred approach to research with Aboriginal communities has been aided by the development of the National Aboriginal Health Organization's (NAHO) OCAPTM – ownership, control, access and possession - principles of Aboriginal self-determination in research (2005) and the Canadian Institutes of Health Research (CIHR) *CIHR Guidelines for Health Research Involving Aboriginal Communities* (2007), which explicitly names CBPR as the preferred research methodology. Chapter 9 of the Revised Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans is built on these same policy directions (CIHR, NSERC, and SSHRC, 2010).

CBPR has been defined as “a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each [partner] brings. It begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities” (Minkler & Wallerstein, 2003, p. 4). Although a late arrival on the research scene, CBPR has recently been described as the ‘fourth estate’ of health research, taking its rightful place alongside basic, clinical and behavioural research (Blumenthal & Yancey, 2004). CBPR for health is gaining in popularity, in part, due to

¹² CBPR is an umbrella term that includes other research approaches that share the underlying goal of social change. These include action research, participatory research, participatory action research, community-based research, etc. (Castleden, Garvin, & Huu-ay-aht First Nation, 2008; Walters et al, 2009).

synchronicity between the values of the ‘new public health’ and the values of CBPR, i.e., participation, enablement and empowerment, equity and social justice (Raphael & Bryant, 2002). More importantly, however, CBPR for health is gaining in popularity because it works (Minkler & Wallerstein, 2003).

With an underlying goal of social change, CBPR should be directed by communities and address community concerns; communities should be full and equal partners in the research process; and all partners should share in decision-making responsibilities (Kemmis & McTaggart, 2000; Israel, Schulz, Parker, Becker, Allen III, & Guzman, 2003). CBPR is a co-learning process wherein opportunities for learning on both sides (both academics and community) are actively created. For example, community members might engage in a formal process of learning about research while academics might engage in a process of developing cultural competence – an under-rated but essential skill for research with Aboriginal communities (Minkler & Wallerstein, 2003). CBPR privileges the voice and experience of participants and builds capacity in the community as an essential component of the research-partnership process (Minkler & Wallerstein, 2003; Syme, 2000). In CBPR, the conditions are created in which participants can empower themselves and increase control over their lives, i.e., the capacity of communities to identify and address issues of concern to the community is prioritized. In doing so, community members learn that they have some control over the conditions that create or mediate health. CBPR achieves a balance between research and action – this is key for community-based and population health research that prioritizes knowledge translation, policy development and research for social change. Finally, in CBPR the intersection of race, gender, class and culture are given particular attention since “these interlock and influence every aspect of the research enterprise” (Minkler & Wallerstein, 2003, p. 6).

Decolonizing and Indigenist Methodology

Decolonizing and Indigenist methodologies are compatible with CBPR. They share many of the same values but they are grounded in different worldviews (Kovach, 2009; Wilson, 2008). They explicitly recognize the colonial legacy of research (Tuhiwai Smith, 2005) and seek not only to redress issues of power, trust and ownership of research (Castleden, Garvin, & Huu-ay-aht First Nation, 2008), but also to recognize as valid Aboriginal ways of

knowing and being, to embed Aboriginal values and principles in the research design, to work towards healing and empowerment of Aboriginal peoples, and to transform relations between the researcher and the researched (Prior, 2007; Tuhiwai Smith, 1999). Decolonizing and Indigenist methodologies recognize the strengths of Indigenous knowledges within Western methodological approaches and insist on using culturally-relevant research methods that are grounded in local experience and knowledge (Denzin, Lincoln, & Smith, 2008). They emphasize process over products of research with an explicit orientation towards self-determination (Cochrane, et al., 2008; Tuhiwai Smith, 1999). This often means building relationships with Indigenous communities, investing in community capacity, reclaiming and revitalizing Indigenous practices, and challenging colonial norms and practices (Walters & Simoni, 2009). Popularized by Maori scholar Linda Tuhiwai Smith in her seminal work entitled, *Decolonizing Methodologies: Research and Indigenous People* (1999) and supported by national political and research funding bodies such as NAHO (2005) and CIHR (2007) among others, decolonizing methodologies have become a near necessity for doing research with Aboriginal peoples (Evans, Hole, Berg, Hutchinson, & Sookraj, 2009).

Borrowing from Walters and colleagues (2009), I use the term ‘indigenist’ research, instead of indigenous research, throughout this thesis to refer to a kind of research that is collaborative, decolonizing, indigenizing and frequently involves non-Indigenous partners. ‘Indigenist’ research honours Indigenous knowledge and Indigenous principles but emphasizes the way that researchers conduct their research rather than their ethnic or cultural background. Shawn Wilson also used the phrase Indigenist in his early work (2007) and in a 2014 webinar, Shawn Wilson, author of *Research is Ceremony*, supported this shift when he announced that he changed the name of his approach to research from Indigenous to Indigenist after consultation with Elders and others. He went on to compare Indigenist research to feminist research in that 1) the researcher does not have to be female to use a feminist approach and 2) just as there are many ways of doing feminist research, there are also many ways of doing Indigenist research.

Arts-Informed Approaches as Decolonizing Methodologies

As one kind of community-based participatory research (CBPR) using arts-informed methods, photovoice is one potential approach to decolonizing the research process

(Castleden, Garvin, & Huu-ay-aht First Nation, 2008). An arts-informed approach to research is one that uses various forms of creative expression, instead of or in addition to conventional interviews or focus groups, to encourage participants to respond more fully to research questions. It is consistent with CBPR and decolonizing methodologies in that it foregrounds the voices and views of participants (Knowles & Cole, 2008) and provides them with an opportunity to disrupt negative stereotypes by highlighting the strengths and assets of individuals and their communities (Wang & Burris, 1994; Wang, 1999). Arts-informed approaches engage participants in a power-sharing process of knowledge creation (Knowles & Cole, 2008). It breaks down the distinction between the researcher and the researched (Syme, 2000), and encourages reflexivity by both participants and researchers (Gotschi, Freyer, & Deive, 2008). Reflexivity is an important element of decolonizing methodologies as it encourages us to be mindful in our work and to root out discriminatory practices that might perpetuate an unequal power relationship (Tuhiwai Smith, 1999; Lavallee & Clearsky, 2006). Arts-informed approaches have also been shown to be particularly appropriate for research with Aboriginal communities because they cohere with Aboriginal notions of holism—raising alternate ways of knowing, such as feelings and intuition, to the same level as thinking or rational thought. In the Western academic tradition, the mind (thinking) is superior to the heart (feelings) and spirit (intuition). However, Aboriginal worldviews teach that thought cannot be separated from feelings, so arts-informed approaches that bring feelings and intuition into the process of knowledge production allow for a more complex, holistic and culturally-relevant understanding of any given phenomenon (Monture-Angus, 1995; Castleden, Garvin, & Huu-ay-aht First Nation, 2008; Cochrane, et al., 2008; Lavallee, 2009).

Photovoice as Decolonizing Methodology?

Photovoice is a well-established participatory action research method that typically puts cameras into the hands of community members, asks them to document in pictures their everyday life experiences, and then describe those pictures to others in the context of their everyday lives (Moffit & Robinson Vollman, 2004; Catalani & Minkler, 2009). Arising from a long tradition of using photographs in social research (Banks, 2001; Collier & Collier, 1986; Pink, 2007) and building on Paulo Freire's work on empowerment theory, feminist

theory, and community photography, photovoice was developed by Carolyn Wang and Mary Anne Burris in the 1990's and first used with rural Chinese women from Yunnan province to explore the issues that might impact their health (Wang & Burris, 1994; Wang & Burris, 1997; Wang, 1999). Photovoice, originally called Photo Novella, was developed as a technique to enable people from all walks of life to assess the strengths and concerns of their communities and to communicate these concerns to policy and decision-makers (Wang & Burris, 1994). By providing cameras to community members, photovoice allows people to: (1) visually record and reflect on their community's strengths and concerns; (2) identify and discuss important community issues in large and small groups that promote critical dialogue and produce shared knowledge; and (3) engage in discussions with policy and decision-makers (Wang & Redwood-Jones, 2001). This policy component, i.e., the explicit intention to include new voices in policy discussions, is an important element of photovoice projects and one that sets it apart from other visual methodologies (Wang, 1999; Carlson, Engebretson, & Chamberlain, 2006). An additional feature of photovoice is the inclusion of community strengths or assets as desirable subjects for discussion in addition to community challenges or deficits that are more commonly highlighted by outside researchers.

Since its inception in the 1990's, photovoice has been used for a variety of research purposes, including a needs assessment tool (Wang & Burris, 1997), program evaluation (Foster-Fishman et al 2005), empowerment education (Wang & Burris, 1994), participatory research method (McIntyre 2003), process of social change (Carlson, Engebretson, & Chamberlain, 2006; Side, 2005), health promotion program (Bader, Wanono, Hamden, & Skinner, 2007), and educational tool (Killion, 2001). Confirming the flexibility of the photovoice method and its adaptability to most research situations, photovoice has proven to be an effective method of accessing the voices of groups who do not usually have a say in decisions affecting their lives. It has also proven to be an effective method of bringing attention to the strengths of communities as well as their deficits. Among those who have used photovoice to document their community's strengths and concerns are Latina girls (Vaughn, Rojas-Guyler & Howell 2008), people with intellectual disabilities (Jurkowski 2008), people living with HIV/AIDS (Rhodes, 2006), marginally housed women (Killon & Wang 2000), transsexuals (Hussey, 2006), working class women from Northern Ireland (McIntyre 2003; Side 2005), Ugandan nurses (Fournier, Kipp, Mill, & Wallusimbi, 2007),

American nursing students (Killion, 2001), and Bedouin youth (Bader, Wanono, Hamden & Skinner 2007).

In the past few years, several articles have been published using photovoice with Aboriginal populations (Brooks, Poudrier, & Thomas-MacLean, 2008; Moffit & Robinson Vollman, 2004; Brooks, 2010; Castleden, Garvin, & Huu-ay-aht First Nation, 2008; Willson, Green, Haworth-Brockman, & Rapaport Beck, 2006; Markus, 2012; Moffit, 2012). While the study samples are geographically varied and range from urban to rural to on-reserve, all authors report that photovoice is a culturally-relevant and meaningful method of data collection and analysis, and suitable for use as a decolonizing methodology. Semi-structured interviews with 45 First Nation participants in a BC photovoice project showed that photovoice “effectively balanced power, created a sense of ownership, fostered trust, built capacity, and responded to cultural preferences” (Castleden, Garvin, & Huu-ay-aht First Nation, 2008, p. 1393). Likewise, studies with urban Aboriginal breast cancer survivors (Brooks, Poudrier, & Thomas-MacLean, 2008), pregnant Tlicho women (Moffit & Robinson Vollman, 2004; Moffit, 2012) and Native American youth (Markus, 2012) found that photovoice was a culturally-relevant and empowering method of health research with Aboriginal women and young people.

In all studies, allowing participants to choose the subjects of their photos and thereby set the agenda for the ensuing interview helped to balance the power between researcher and researched by blurring the line between them, and also increased participants’ sense of ownership over the research and research process. The responsibility for representing community issues was taken seriously by all participants, some of whom expressed awareness and satisfaction that their photographs would act as a “community-owned archive in the future” (Castleden, Garvin, & Huu-ay-aht First Nation, 2008, p. 1399). This added an extra sense of responsibility to participants to ensure that photographs were indeed representative of community life and thus, they were motivated to engage in dialogue with individuals, with family and with the wider community to ensure that individual and group perspectives were represented (Brooks, Poudrier, & Thomas-MacLean, 2008; Castleden, Garvin, & Huu-ay-aht First Nation, 2008). This, of course, had the added benefit of strengthening family and community relations by fostering a sense of common purpose. The notion of preserving knowledge for future generations was also expressed by Tlicho women

who documented traditional women's health practices. As noted by Moffit & Robinson Vollman, "as well as adding an aesthetic dimension to knowledge transmission, [photographs] may enhance the identity and visibility of past traditions" (2004, p. 195). This act of reclaiming indigenous knowledge is critical to the process of decolonization and also to the health and healing of Aboriginal communities (Battiste, 2000).

In all projects, participants reported feeling a sense of 'empowerment' from participating in the research and a renewed sense of possibility for social change. Previously feeling alone and isolated, for example, Aboriginal breast cancer survivors in Saskatchewan shared their understanding of their needs as well as their strengths, and shared their stories and narratives visually (Brooks, Poudrier, & Thomas-MacLean, 2008). Huu-ay-aht community members discussed and visually documented environmental and community health issues and organized themselves for social change. Several participants in this project reported that they continued to take photographs of community health issues long after the project was complete, and that community leadership decided to use this same technique to document other kinds of indigenous knowledge such as mat weaving and making cedar baskets (Castleden, Garvin, & Huu-ay-aht First Nation, 2008). Finally, Tlicho women talked about and reflected upon their health practices and beliefs in the context of their individual and community lives. Authors of this study hoped that they, in turn, "may generate the insight and empowerment necessary to promote policy change" (Moffit & Robinson Vollman, 2004, p. 198).

Lessons and Challenges of Photovoice with Aboriginal Communities

Photovoice has been shown to be a culturally-relevant and decolonizing community-based participatory approach to research with Aboriginal peoples. Among its many benefits, photovoice is an effective method for sharing power, fostering trust between researcher and community, facilitating a sense of individual and community ownership over the research, creating community change and building capacity. However, photovoice is not without its challenges and its limitations.

Ethical Considerations

Using participant created art works as data, including visual images, requires a re-thinking of traditional research ethics in several domains. In particular, the following considerations must be taken into account:

Free and Informed Consent – Contrary to traditional research ethics that require a single consent form from participants, Wang and Redwood-Jones (2001) recommend the use of three separate consent forms in a photovoice project: one for consent to participate in the project, one for consent from photographic subjects, and one for consent from both participant and photographic subject to publish the photo. However, in research with Aboriginal communities, additional considerations regarding the language and the medium of consent must be addressed. Brooks and colleagues (2008) suggest that the ethical norm of facilitating communication by having the written consent forms translated into the local Aboriginal language is a nice gesture and often well-received by participants. However, this is not always practical as Aboriginal languages have largely been transmitted orally and few people can read the relatively new written form of the language. Patterson, Jackson & Edwards (2006) support this notion and point out that academic consent forms are culturally inappropriate at the best of times and that oral consent is often preferred. This poses an especially difficult problem when dealing with three separate consent forms.

Anonymity – In many photovoice projects, the majority of participants choose to be acknowledged for their work, while some participants may choose to remain anonymous. Therefore, contrary to traditional research ethics that assume that anonymity is the norm for protection of research participants, the decision about how participants would like themselves and their work to be shared/credited is one that must lie in the hands of the participant. Where participants choose to be acknowledged, they must do so in full knowledge of the potential risks. Where participants choose confidentiality, any identifying information must be changed to protect their identities. This is particularly important in smaller settings, such as Aboriginal communities, where participants may be more easily identifiable. No personal information about participants should be shared publicly or with

collaborators without explicit permission from participants (Brooks, Poudrier, & Thomas-MacLean, 2008).

Privacy & Confidentiality – When the camera is used as a research tool, Wang and Redwood-Jones (2001) discuss four kinds of invasion of privacy that might occur:

1) Intrusion into a person's space – legally, we have the right in Canada to photograph an individual or individuals in public, but ethically, if a person or persons is the focus of our photo and they are identifiable, then ethically, we have an obligation to ask that person for permission to use that photo;

2) Disclosure of embarrassing facts about someone – this refers to showing someone in a negative light, intentionally or unintentionally. For example, a photo of a person at a conference may seem harmless, but not if that person was not supposed to be there, or does not want others to know that she was there;

3) Twisting the truth – this refers to taking a photo out of context to make a point or tell a story;

4) Publishing a photo for commercial gain (Moffit & Robinson Vollman, 2004).

To address these concerns, photovoice researchers should have detailed discussions with participants about the need to obtain consent *before* taking someone's photo and that consent should include information about potential uses for any photos taken. Participants should also be made aware of the many ways that privacy can be respected by taking photos in such a way that the identity of the people in the photograph is not clear, for example by taking pictures from far away, by using props such hats or umbrellas to obscure the face, or by blurring out faces after the picture is developed (Moffit & Robinson Vollman, 2004).

Safety – The safety of participants should always take precedent over the power of an image. To ensure participant safety, participants should obtain consent prior to taking a photograph and offer the photographic subject a copy of the photograph. Having information about the project available can also help to dispel questions or suspicion from the community.

(Mis)representation – Wang and Redwood-Jones (2001) have noted several issues related to representation that must be addressed in photovoice projects. First, the issue of who gets to

choose the final photos from all the possibilities must be addressed. Do participants or researchers choose? How many photos are selected? As a collection, do they represent the range of community concerns? Second, and related to the issue of privacy, is concern that the community and its members are being represented in a fair, balanced and non-sensational way. Third, is the issue of who gets to participate in the project, i.e., whose voice is being heard (or not heard) and whose perspectives are being privileged or silenced? Are participants representative of the range of life experiences in the community? (Moffit & Robinson Vollman, 2004; Castleden, Garvin, & Huu-ay-aht First Nation, 2008).

Additional Photovoice Challenges and Limitations

One of the challenges of photovoice or any photography project is that there are limits to what is observable and therefore, to what can be photographed. In the classic photovoice interview, that which is not photographed does not get discussed and therefore, entire sections of community life and experience may be left out of the discussion. For example, Brooks and colleagues (2008) report that participants could not take photos of ceremonies or spiritual objects yet they were exceedingly important aspects of their experience. For this reason, it is just as important to consider what is *missing* from participant photos as what is included (Castleden, Garvin, & Huu-ay-aht First Nation, 2008). This can easily be incorporated into the photovoice interview.

A related issue is the challenge associated with photographing intangible items or issues. For example, emotions, feelings or processes are difficult to capture on film and require a certain amount of creativity coupled with critical reflection. However, photography presents countless opportunities for creative expression, such as using scrabble blocks to spell out words (Castleden, Garvin, & Huu-ay-aht First Nation, 2008), or objects as metaphor for feelings or emotions. Among breast cancer survivors, one participant photographed a crumpled piece of paper as visual metaphor for anger (Brooks, Poudrier, & Thomas-MacLean, 2008). Fortunately, the arts in general and photos in particular, are particularly good at expressing, evoking, and representing that which cannot be easily described or expressed in linear thought and therefore, they are particularly good at expressing the ineffable. As Eisner informs us, “through art we come to feel, very often, what we cannot see directly” (2008, p. 8).

Another set of photovoice challenges concerns its relationship to social policy and change. Photovoice as developed by Wang (Wang, 1999) and Wang and Burris (Wang & Burris, 1994; Wang & Burris, 1997) and practiced by many others since then is explicit about the intention to influence policy and to do so by targeting policy and decision-makers as the appropriate agents of change, as such the responsibility for making change lies largely outside the participants although it is the participants' responsibility to bring awareness of particular issues to the policy makers. However, Side (2005) shows that not all policy-makers are interested in, or capable of enacting, change and there is little that participants can do about it if that is the case. In her study of a women's group in Northern Ireland, not a single policy-maker accepted an invitation to view the women's photos and dialogue about the issues they raised. This situation provides support for Carlson and colleagues' (2006) argument that participants can also be agents of change, and in fact, only if they are encouraged to assume agency can they be successful at raising their critical consciousness. For some photovoice projects, the goal of empowering participants may be enough. While, this is not necessarily a limitation of the photovoice method, it is important to be clear about the project goals at the outset.

Another set of challenges of the photovoice method relates to recruitment and retention of participants. Photovoice requires a significant commitment of time and effort on the part of research participants, well beyond that of a traditional research design. The photovoice research design and implementation timeline must factor in the extra time involved in recruitment, preparing for and taking photos, camera retrieval and photo development (or computer upload), organizing group meetings and reflections, and so on. Therefore, the researcher has two additional challenges: 1) she may have to work harder and be more patient to recruit and retain participants as they may be dissuaded from participating by the time involved; and 2) she must be prepared to be flexible in her timeline and diligent in her practice since seasons, the weather and random life events are additional factors to consider (Brooks, Poudrier, & Thomas-MacLean, 2008; Castleden, Garvin, & Huu-ay-aht First Nation, 2008; Moffit & Robinson Vollman, 2004). In the context of Aboriginal communities, she must also be open to learning about Aboriginal worldviews or move beyond that towards cultural humility – an ethical issue for allies involved in research involving Aboriginal communities.

A related challenge of photovoice is equipment maintenance and tracking. Cameras may be lost, broken or shelved during particularly busy times in a participant's life (Brooks, Poudrier, & Thomas-MacLean, 2008). This may be especially true of women who are also mothers and caretakers of other family members. This has implications for the project budget as well as the project timeline. This may be especially true if participants are sharing cameras. Again, the photovoice researcher must be prepared to be flexible in her timelines and diligent but open to change in her practice.

An additional challenge to using photovoice with Aboriginal communities is inherent in the classic photovoice protocol. As outlined by Wang and Burris (1994; 1997), the data are often collected in a few short weeks and the researcher has little engagement with the community. For Aboriginal communities with a legacy of distrust in research, this may be too reminiscent of the 'parachute' research that is so widely disparaged (Kovach, 2009; Tuhiwai Smith, 1999). Castleden and colleagues (2008) recommend modifying the classic photovoice protocol to enable researchers to spend significant time in the community, getting to know community members, building rapport and earning their trust. This includes adding an iterative feedback loop to the protocol that would enable community members to reflect on photos and to provide comments and feedback at multiple points in the process.

Chapter Summary

In this chapter, I have focused on the academic context for *VH*. Conceptually, *VH* is built on an Indigenist Intersectional Population Health framework that foregrounds culture and gender as determinants of health and their intersections at multiple levels. This critical approach to our research is complemented methodologically by combining a community-based participatory approach with decolonizing and Indigenist methodologies that incorporate strengths-based, arts-informed, and women-centred practices. Our arts-informed practices have been inspired by Photovoice and therefore, Photovoice was a significant focus of this chapter. Together, the conceptual and methodological foundations of *VH* provide a critical lens with which to explore the meaning of health, culture and gender from the perspective of PAW. In the next chapter, I lay out our methodological approach.

Chapter 3

“This is the way research should be done in our communities”:

Using the Arts and Culture to Decolonize Research with PAW

(with Doris Peltier¹³)

In all community approaches, process – that is, methodology and method – is highly important. In many projects process is far more important than the outcome. Processes are expected to be respectful, to enable people, to heal and to educate. They are expected to lead one small step further towards self-determination (Tuhiwai Smith, 1999, pp. 127-128).

Introduction

As outlined in the previous chapter, we used a culturally-grounded, women-centred, strengths-based, and community-based participatory approach to this research that was grounded in decolonizing and Indigenist principles. In this chapter, I operationalize these concepts and outline the methods we used to carry out our research. As noted earlier, the *VH* project responded to the community-identified need for strengths-based research among PAW, and all members of the research team were integrally involved in all aspects of the project, from design to dissemination. Our long-standing research relationships and the experiential knowledge of research team members who have worked extensively with PAW - as researchers, as service providers, or as peers - meant that a decolonizing (Tuhiwai Smith, 1999; Kovach, 2009) and community-based participatory research design (Minkler & Wallerstein, 2003; Isreal, Eng, Schulz, & Parker, 2005) was our starting point. To meet the needs of PAW co-researchers and to provide them with a safe and supportive environment in which to tell a different kind of story about themselves than has previously been told by others, we combined these with women-centred and arts-informed approaches to research. In doing so, we pushed the various bodies of literature, in particular the arts-informed, women-centred and CBPR literature, towards decolonizing and Indigenist methodologies.

¹³ Special thanks to Sharp Dopler and Carrie Martin for discussion and feedback on this chapter.

As an arts-informed, culturally-grounded, community-based participatory research project, we had several sets of ethics protocols to consider. As a baseline, we designed our project to meet (and surpass) the guidelines outlined in Chapter 9 of the Revised Tri-Council Policy Statement (CIHR, NSERC, and SSHRC, 2010, pp. 105-134) that incorporates the previously developed CIHR Guidelines for Health Research Involving Aboriginal Peoples (2007). The revised guidelines also incorporate, but do not completely replace, the OCAPTM principles (First Nations Information Governance Centre, 2007; Schnarch, 2004), and they recommend, where possible, the use of participatory, decolonizing and Indigenous methodologies. These guidelines, therefore, act as minimum standards for ethically engaging in research with Aboriginal communities.

Project Governance and Accountability

As a decolonizing and community-based participatory research project, we consider the composition and organization of our team to be a considerable strength of the *VH* project and a primary example of GIPA (UNAIDS, 1999), MIWA (ICW, 2009), of Aboriginal self-determination in research (Canadian Institutes of Health Research, 2007; CIHR, NSERC, and SSHRC, 2010) and Indigenist principles that guided our research. Our team is comprised of Aboriginal and non-Aboriginal women – both academics and community members – with a wealth of experience in Aboriginal community-based HIV and AIDS research, service provision, and lived experience of HIV. The governance and accountability structure we adopted for this project is represented by our ‘Homefires’ model as outlined below (see Figure 2).

This model is inspired by a vision of Indigenous governance and self-determination that was given to Doris Peltier following a discussion with Elders about Indigenous decision-making processes. As Doris explains:

[The Elder] took me back to a period before contact and described how we as nations would gather whenever decisions had to be made in the interests of all nations and all our communities. ... He described, upon arrival, [that] all the lodges were erected by communities in a particular formation around the central lodge - the place where all nations would gather. ... Surrounding the central

lodge were all the medicine lodges and the medicine people, and their role was to conduct ceremonies together (in unity) to support what was being discussed and decided upon in the central lodge. There was no hierarchy in their roles or within the sacred circle (Peltier, 2014)



Figure 2: Homefires Model of Visioning Health Project Governance

In this holistic, inclusive and egalitarian governance structure that honours the Indigenist principles of respect, reciprocity, relevance, responsibility and relationality, everyone has a place in the circle and everyone has a voice. Everyone in the circle is interconnected and they all work together to support activities and individuals at the centre. In our model, PAW co-researchers occupy the central position while all other team members

surround and support them in a concentric circle formation. In this model the lines between each circle are dotted to indicate that the boundaries between each group were permeable and that some members of each group were cross-appointed to other groups. The purpose of this was to ensure continuity across all groups, to ensure that the goals and objectives of each group were aligned and to foster trusting relationships between researchers and communities. The solid lines connecting PAW at the centre to two other levels indicate that these groups were in direct contact and communication.

PAW Co-Researchers

As a decolonizing and women-centred project, the *VH* Co-Researchers (PAW) and their concerns were at the centre of our project (in orange), shaping and guiding the research process and co-creating the research environment. Hence, we recognize PAW as co-researchers in our project and not simply participants; as active agents in the decision-making process instead of passive recipients of instructions. As part of our commitment to the GIPA and MIWA principles and to decolonizing methodologies that seek to democratize the research process by equalizing power relationships between the ‘researched’ and the ‘researcher’, we engaged in group research processes that would build and strengthen intra-group relationships, and actively promoted what Kirby and McKenna call “asking back”. In other words, we encouraged co-researchers “to make enquires about the research and / or the researchers” (Kirby & McKenna, 1989, p. 122) and cultivated dialogue between the Core Research Team (described below) and co-researchers regarding the nature and purpose of the research, the motivations and intentions of the research team, and any elements of the research design that may or may not be working. Informal dialogue and discussion was encouraged throughout the project, during group meetings or afterwards via Skype, email, text, or other medium. We also built in a more formal ‘asking back’ or feedback process at the end of all our group meetings. This “asking back” often resulted in prolonged discussion, group problem-solving, changes to the research protocol, re-allocation of existing funds, or application for further funds to support PAW-driven capacity-bridging activities. This helped to build trusting relationships between PAW co-researchers and between PAW co-researchers and the core research team, to cultivate a sense of co-ownership over the project and the results, and ultimately to strengthen our research project. In addition, two members

of our Core Research Team (described below) were PAW and at all times brought the interests of PAW co-researchers to the forefront.

Core Research Team

The Core Research Team (in green) was comprised of myself, Doris Peltier and KJ, our PAW Peer Research Associate (PRA). Together, we were responsible for the day-to-day operations of the project. With advice from the other committees/groups, we developed protocols for, and organized and implemented the project including carrying out group meetings, data collection, analysis and dissemination. The three members of the Core Research Team, plus our Traditional Knowledge Keeper or *oshkaabewis*¹⁴ (depending on the particular group we were working with), co-led all group meetings and met frequently after these meetings to reflect on our process and our progress. As a result of these reflections, we made on-going adjustments to ensure that we were meeting our goals of meaningful engagement of PAW through arts-informed, women-centred and decolonizing research, creating and maintaining a safe space for PAW co-researchers, and most importantly, that we were not contributing to health inequities by re-inscribing colonial practices or relationships through our research (Tuhiwai Smith, 2005).

Knowledge Keepers and Counsellors: Cultural Support Team

In exchange for a traditional gift of tobacco, we also worked closely with and received on-going guidance from our Cultural Support Group (in blue) comprised of various individuals, including Wanda Whitebird, Traditional Knowledge Keeper and Aboriginal Women's Outreach and Support Worker; Sharp Dopler (Cherokee and Sac/Fox), Aboriginal Outreach and Support Worker; Carrie Martin (Mi'gmaq/Danish), Aboriginal Holistic Health Coordinator; and Stan Peltier, Traditional Elder. This group provided the cultural grounding that "nourish[ed] the researchers' [and co-researchers'] spirit during the inquiry, and ... nourish[ed] the research itself" (Kovach, 2009, p. 116). Some individuals were with us throughout the project and provided on-going advice, assistance, support, counselling,

¹⁴ According to the Ojibwe People's Dictionary (<http://ojibwe.lib.umn.edu>), *oshkaabewis*, is a ceremonial attendant or a messenger. However, it also has the meaning of 'Helper' which is grounded in the principle of generosity, one of the original Seven Sacred Teachings (Elder Lillian Pitawanakwat, 2006). This latter definition of *oshkaabewis* as Helper is an essential part of Sharp's identity as an Indigenous Two-Spirit person, and as a fire-keeper, drummer, and carrier of a peoples' pipe (Sharp Dopler, personal communication).

spiritual guidance and cultural teachings, in addition to opening/closing prayers, conducting ceremonies and co-facilitating most group meetings. Others in this group helped with specific parts of the project or conducted specific ceremonies. An additional, and extremely important, role for this group was to help us understand the parameters around sharing the Indigenous knowledge that was shared with us (Kovach, 2009, p. 116; Absolon, 2011, p. 161). While many of us – Aboriginal and non-Aboriginal – are aware that some Indigenous teachings are meant only for the person to whom they are given and some teachings are meant to be shared with others, it is not always easy to determine which is which. Having the guidance of this group was invaluable. To enhance the fluidity of our governance model and to create communication bridges between the various levels of governance, some members of this group were also part of the Community Advisory Committee.

Community Advisory Committee

Our Community Advisory Committee (in purple) was comprised of representatives from our four Community Partners. Renée Masching (Six Nations – Iroquois/Irish) has been involved in the Aboriginal HIV and AIDS movement for 19 years. She is the Director of the Research and Policy Unit at CAAN and Principle Knowledge User on numerous community-based research grants. Doe O’Brien-Teengs (Cree / Irish) is a Two-Spirit woman and was the Executive Director of Oahas for the majority of VH. When Doe was not available to attend meetings, Wanda Whitebird and / or Sharp Dopler would take her place as an Oahas representative – and sometimes they all came together! Geri Bailey is the long-time Manager, Health Programs and Policy at Pauktuutit Inuit Women of Canada. She is a trusted ally and advocate for Inuit health in Canada and has been co-Investigator on numerous community-based research grants regarding Inuit health more broadly, and HIV specifically. Carrie Martin, Holistic Health Coordinator at the Native Women’s Shelter of Montreal (NSWM)¹⁵, joined our team later in the project as a community collaborator and was also a part of our Cultural Support Team.

This group provided advice and guidance regarding research direction and design,

¹⁵The Native Women’s Shelter of Montreal is the only shelter in Montreal that provides services exclusively to Aboriginal and Inuit women and their children. The Holistic Health Project at NWSM provides culturally relevant education and works to address the needs of First Nations, Inuit and Métis women and their children who are affected by homelessness, the sex trade, HIV infection, substance abuse, and family violence.

Project Planning and Community-Engaged Sampling and Recruitment: A Relational Approach

As noted earlier in this thesis, many of the relationships that are central to the *VH* project are long-standing or had been in some stage of development prior to the beginning of the project. Others were initiated in the context of working with a particular community. Regardless of how long the relationships had been established, however, we spent a significant amount of time talking to community representatives, trying to understand the unique context and characteristics of the PAW's community we were hoping to work with, and planning an arts-informed and culturally-relevant project based on the specific needs and circumstances of that community. In each case, we continued to build our team as appropriate, including Elders or Spiritual Guides, Traditional or Cultural Resources, Aboriginal artists, community partners and others as required. With this approach, we embodied the Indigenist principles of relationality, relevance and responsibility.

Given the highly stigmatized nature of HIV in Aboriginal communities (Mill, Edwards, Jackson, Austin, MacLean, & Reintjes, 2009), the fear of public disclosure that we know accompanies that stigmatization (McKay-McNabb, 2006; McCall, Browne, & Reimer Kirkham, 2009), and the requirement of this project for participants to disclose their HIV-status to each other and to the team, we spent a significant amount of time with our partners discussing what we felt might be an appropriate and realistic sampling frame. In collaboration with community partners and collaborators, we originally planned to recruit eight to twelve PAW in Ottawa and again in Toronto. We made this decision based on the location of team members, their connections to community organizations, and their connections with PAW. Due to the intensive and immersive nature of our research process, we also took a phased approach to recruitment, beginning with Ottawa and then Toronto. We reasoned that a phased approach to recruitment would allow us to adjust our sampling strategy from one group to the next, based on lessons learned from the previous recruitment experience and from the previous group.

We used a purposive sampling strategy to engage PAW in our research. Purposive sampling is synonymous with qualitative sampling and is quite simply a deliberate process of seeking out and selecting participants based on their ability to answer the research questions. The resulting sample therefore, is not meant to be representative of, or

generalizable to, a larger population (Padgett, 2012, p. 73; Butler-Kisber, 2010, pp. 15-16). To engage PAW in our project, we developed recruitment posters (see Appendix B) and a project description (see Appendix C) that were distributed to our partner agencies. Recruitment posters were displayed inside and around community organizations and partners spoke directly to potential participants informing them of this opportunity. Using snowball sampling, we also encouraged interested participants to speak to other Positive Aboriginal Women about our project (Padgett, 2012, p. 73). Interested participants had the option of contacting me directly using a toll-free number or email address, or contacting their local service provider.

To be eligible to participate in *VH*, women must have self-identified as First Nations (status or non-status), Métis or Inuit; self-identified as a woman including two-spirit and trans-woman; self-identified as HIV-positive; been 18 years or older; and able to communicate in English. Within these parameters we also used maximum variation sampling to “capture heterogeneity across the sample population” (Padgett, 2012, p. 73) and to “honour the diversity of the Aboriginal women community, irrespective of differences in regards to nation(s), language, cultural background, age, sexual orientation, religious beliefs and most importantly life choices” (Peltier, 2010, p. 8).

Despite our careful planning, however, we were unable to recruit even one PAW participant in Ottawa. In collaboration with two Ottawa-based community partners (Oahas and AIDS Committee of Ottawa) we planned and hosted a project orientation session in September 2010 at the office/drop-in space of one of our partners. Project partners received four verbal commitments from their PAW clients but none showed up to our session. In debriefing with our partners, we decided to try again but with two differences: we held the orientation session at a neutral location that was easily accessible, and we reframed our event as an ‘evening of cultural sharing and feasting’. We brought PAW in from Toronto and Montreal to share their stories of living HIV-positive, worked with one of our partners to host a drum circle, and had ‘Indian tacos’ brought in by a local Aboriginal catering company. Despite these extra efforts though, we were unable to engage with PAW in Ottawa. In follow-up discussions, community partners and collaborators initially expressed surprise at the lack of turn-out since several of their PAW clients had expressed interest in attending. Upon reflection though, they felt that it was indicative of how unsafe PAW in

Ottawa feel; the challenges associated with irregular contact with their clients; and specifically, that a few women had negative research experiences in the past that made them reluctant to participate. In light of these experiences, in collaboration with our community partners, we decided that Ottawa was no longer a viable research site.

We then shifted our focus to Toronto, where we were somewhat more successful. Beginning in September 2010, we worked with our Toronto-based PRA and our Toronto-based community partners (Oahas and 2-Spirited People of the 1st Nations) to identify PAW for a project information session to be held in Toronto in October 2010. The session was attended by six PAW, including our original PAW-PRA. At the end of the session all six women expressed interest in participating in our project. Unfortunately though, one woman did not meet our eligibility criteria (she was not HIV+), and shortly after this meeting, our PRA withdrew from the project for personal reasons. This left us with four PAW who were interested in participating in our project. In an effort to increase our numbers and on the advice of our partner organizations, we hosted a second information session in November of 2010. The same four women attended this second session plus one more who met the eligibility criteria. After more consultations with community partners, we hired one of these women to be our new PRA (KJ) and asked our community lead (Doris Peltier), herself a Positive Aboriginal Woman, to participate in the group art-making process. In total then, we recruited six PAW for the Toronto group. One of the six, however, had a physical disability that we did our best to accommodate. While she attended the majority of group meetings, she did not participate in focus groups and she was unable to complete the art-making process. She is, therefore, not included in our final count of five Positive Aboriginal Women.

Given that Ottawa was no longer a viable research site and we had fewer participants in our Toronto group than we had hoped, we met with our Community Advisory Committee to discuss alternate recruitment sites and recruitment strategies. Through these discussions, two sites emerged as feasible alternatives. Doris made us aware that an HIV-positive sub-set of CAAN's Voices of Women (CAAN-VOW) Standing Committee,¹⁶ had expressed interest in our project. However, these women were geographically dispersed - living in four

¹⁶ The Voices of Women (VOW) is a standing committee within the Canadian Aboriginal AIDS Network (CAAN) that provides leadership in all issues relating to HIV/AIDS. CAAN-VOW is comprised of Positive Aboriginal Women and service providers from across Canada and are currently working together to carry out a 5 year National Aboriginal Women's Strategy on HIV and AIDS in Canada.

different cities in three different provinces - which forced us to think about new and creative ways of engagement. After some discussion, and given that this group of women had prior experience with teleconferences, we revised our 'strategy of inquiry' (see below) to include a combination of in-person and technology-assisted meetings. Four women expressed interest in and were eligible to participate in what we came to call the 'Virtual Group'.

Once this group was underway, Montreal became feasible as the third site for *VH* when two events coincided: Carrie Martin from NWSM approached Doris to express interest in partnering with us after hearing about *VH* at a research conference, and HIV-positive Inuit women from Montreal independently asked our Traditional Knowledge Keeper, Wanda Whitebird, for a drum-making workshop. Once we all agreed that traditional drum-making met our criteria for the 'art' in arts-informed research, and on the advice of our Community Advisory Committee, we agreed to Montreal as an additional research site. For work-related reasons, Wanda was not able to facilitate this workshop but her Ottawa-based colleague and *oshkabeewis*, Sharp Dopler – who is a drummer herself and has facilitated numerous drum-making workshops – was. Together, and on the scheduling advice of Carrie Martin, we designed a four-day drum-making workshop that incorporated all the necessary research components. Once we received approval from the University of Ottawa Research Ethics Board for modifications to our research sites, recruitment proceeded as above. Four women expressed interest in and were eligible for the Montreal group.

In total, 13 PAW participated in our study between December 2010 and November 2011. All PAW co-researchers self-identified as First Nations or Inuit: despite our best efforts, we were unable to recruit any PAW who self-identified as Métis. At the time of the study, PAW co-researchers resided in five different cities and one reserve across four provinces. They ranged in age from late 20's to late 50's and from newly diagnosed to long-term survivor. They also varied in terms of life experiences and 'where they were at' at the time of our research. For example, some women were actively engaged in sex-work, substance misuse including alcohol, and other street-involved activities; others were firmly on their healing paths; while still others were somewhere in between. Many of the women in our study were receiving social assistance but some had full-time employment and a number of others had periodic work as advisors and consultants to pharmaceutical companies, AIDS Service Organizations, and to regional or national governing bodies. They self-identified as

mothers, grandmothers, sisters, aunts, artists, activists and advocates. Most women self-identified as heterosexual but a few self-identified as transgender or two-spirited.¹⁷

In the spirit of reciprocity, each co-researcher received \$50.00 for every meeting they attended, plus bus tickets to cover their transportation costs and childcare if required. This is consistent with current practice in the Aboriginal HIV and AIDS community. We provided food and beverages at all meetings (with the exception of the 'virtual group' of course) plus cultural teachings via Elders, Traditional Knowledge Keeper or *oshkabeewis*, and opportunities to participate in cultural ceremonies (such as smudging, lodge building, sweat lodge, etc.). Opportunities for paid employment, such as our Peer Research Associate, were given to PAW. We offered opportunities to learn new skills such as digital photography, drum-making, drumming and singing, technological skills such as using Facebook and Skype, presentation and research skills, and opportunities to travel and present at national or international research conferences. We also gifted PAW co-researchers with a professionally-taken portrait of herself, with a CD of drum songs that they could learn from, with a certificate of completion/appreciation, and with a photobook of all *VH* photo-stories. We also gave back to the community that supported us by sharing our work with them in culturally-relevant and meaningful ways. See Chapter 7 for more on the impact of *VH* in the community.

Creating Safe Spaces: A Woman-Centred Approach

Using a women-centred approach allowed us to recognize that PAW have unique needs and experience many barriers to fully participating in research. We designed *VH* to enable us to address these barriers and to put the unique needs of PAW first. Given that they face a triple threat of racism, sexism and HIV-stigma in their daily lives (Hawkins, Reading, & Barlow, 2009), our primary concern was to co-create a culturally, emotionally, mentally and physically safe, supportive, non-judgemental and inviting research environment in which PAW co-researchers could feel secure. Using group research processes that facilitated and encouraged respect and support among PAW co-researchers was a starting point and having PAW on the research team and as co-facilitators of all group meetings helped to put PAW

¹⁷ Prior to completing our group processes, two trans-women dropped out of the project due to extenuating personal circumstances; they are not included in the numbers of participants and their work is not included in the analysis.

co-researchers at ease. We also ensured that co-researchers had the skills and the information they needed to protect their own privacy and confidentiality and the privacy and confidentiality of others in the group; Wiles and colleagues (2008, p. 22) refer to this as ‘internal confidentiality’. In addition to a formal consent process that occurred at the beginning of each group process, we had repeated and on-going discussions with PAW co-researchers about the implications of publicly declaring their participation in this project and of the importance of keeping the identity of others in the project private. After lengthy and on-going discussions about privacy and confidentiality in research and more specifically in arts-informed research (Boydell, et al., 2012) each PAW co-researcher made her own choice about how she wished to be identified. Some chose to use their own name, others chose to use their initials only, and still others chose to use a pseudonym.

Identifying group ‘protocols for safe participation’ at the beginning of each group process was also helpful in that engaging PAW co-researchers in discussions about ‘safety’ helped them to critically reflect on what that means and gave them a sense of ownership over the process. These protocols were agreed upon by each group and each set of protocols was different. For example, remembering the Seven Sacred Teachings (wisdom, love, respect, bravery, honesty, humility, and truth) was enough for one group, while another group came up with a list of twelve items that they felt were important.

Including culture and ceremony in our processes was an essential element of creating safe spaces for PAW co-researchers and for the team. This was the primary responsibility of our Traditional Knowledge Keeper or *oshkabeewis* (depending on the group) but we each shared in this responsibility. We signaled that respect for self, for others and for the ancestors was paramount in our research process by offering tobacco in exchange for traditional knowledge or cultural teachings, and by beginning each group meeting with prayer, a smudge and with a short ‘check-in’ or sharing circle. These small ceremonies, or “share-amonies” as Terry Tafoya (2001, p. 53) calls them, provided an opportunity for co-researchers and for team members to bring our whole selves to the project – our mind, body and spirit – to ground ourselves in our group, to acknowledge our daily challenges but to leave them behind for the time that we were together, and to re-connect with other group members on a richer and more personal level. As noted by Wilson “the purpose of any ceremony is to build stronger relationships or bridge the distance between aspects of our

cosmos and ourselves” (2008, p. 137). The purpose of our ceremonies then was to help us build stronger relationships between ourselves and other group members, between ourselves and the ideas that we were exploring, and between ourselves and the Creator. Creating opportunities through our research for PAW co-researchers to participate in other ceremonies such as sweatlodge, drum awakenings, and lodge building contributed to their over-all sense of safety.

Creating a safe space for PAW co-researchers also meant ‘meeting women where they were at’. As noted earlier in this thesis, PAW face a host of challenges that often includes histories of pain and suffering as a result of residential school experiences, sexual or intimate partner violence, intergenerational trauma, and the intersectional impact of racism, sexism, and poverty (McCall, Browne, & Reimer Kirkham, 2009). To deal with this pain on a daily basis, some women turn to alcohol or drugs and as a result we took a harm reduction approach that allowed women who used substances to participate in our project without fear of rejection, judgment or reprisal. For example, one group initially decided that a ‘protocol for safe participation’ should be to abstain from using drugs and alcohol before coming to a group meeting. However, when one brave co-researcher pointed out that this would be a barrier to her participation because she needed maintenance doses of alcohol to make it through each day, the group agreed to a new safety protocol of coming to each meeting with a clear mind - whatever that means to each individual – and respecting where other group members were at in their healing journeys.

We also made sure that co-researchers had access to counseling and support before, during, after and in between our meetings. This was provided as an in-kind contribution from our Community Partners and Cultural Support Team (Wanda Whitebird, Sharp Dopler and Carrie Martin). Finally, creating safe spaces for PAW co-researchers meant providing childcare for those who had young children or as was more often the case, making our research spaces child-friendly. In fact, the child of one member of our team was so often at our meetings that we missed him when he wasn’t there!

As a women’s project, we also wanted *VH* to “have the shape of a woman” (Doris Peltier, Personal Communication). In contrast to an in-depth interview-style project that relies on the spoken word as generated in a single meeting – or even multiple meetings – of researcher and participant, we believed that PAW co-researchers should be given the

opportunity to be fully engaged in the research process; to influence the direction and the decision-making; and be encouraged to respond to research questions fully, creatively, holistically and over time. For us, this meant actively engaging PAW co-researchers in project governance and being flexible and responsive to their needs once expressed. It also meant using culturally-grounded and arts-informed approaches that encouraged and allowed co-researchers to bring their whole selves to the project; that is, their mind, heart and spirit (Weber-Pillwax, 2001; Aluli Meyer, 2008). Grounding our project in culture and ceremony was an important element of this process in combination with arts-informed methods that validate intuitive, emotional and spiritual ways of knowing. As one co-researcher commented:

I really bared my soul in this research, I bared my soul in this and I speak well of this program because like the arts-based approach is... You can't get me in a room and use all these high tech words to me because none of that is going to relate to me and make sense to me. ... I'm an Indigenous woman and I believe in art and I believe that has a strong healing component to me.

Culturally-Grounded Data Collection: One Size Does Not Fit All

Consistent with our commitment to decolonizing and Indigenizing our research process, we developed a 'strategy of inquiry' for our study that allowed us to remain open and responsive to variations across research sites while maintaining the rigour and integrity of our methodology. Writing in the context of Indigenous research, Wilson (2008) refers to 'strategies of inquiry' as a "roadmap that helps you to get to where you want to go" (p. 39). It allows for "change and adaptation along the way" but also provides "a process or way by which I would like to get there" (p. 40). Strategies of inquiry are an intermediary between the overall methodology and the specific methods or tools that are used in a particular research project. Assuming that no two research encounters are the same, incorporating a strategy step in the research design allows the researcher – or research team in our case – to respond to the research situation by choosing the most appropriate method from a variety of methods that are designed to achieve the same ends.

It is interesting to note, however, that we did not set out to use ‘strategies of inquiry’ – at least not to the extent that we did. Rather, as noted above, they evolved in response to the research situation, to the expressed desires of PAW co-researchers, and to the particular skill sets or resources of *VH* team members. Our original research design, for example, called for a 6 week Photovoice-inspired group research process, using digital photography or other art forms (see Appendix x). Improvisation began almost immediately, however, as the recruitment challenges outlined above became clear. In reality, our research process was negotiated, messy, organic, intuitive and fluid. Honouring the Indigenist principles of respect, reciprocity, responsibility, relationality, relevance, reverence and reflexivity, it necessarily responded to the needs of the moment, of PAW co-researchers and of *VH* team members. As Paw, one of the *VH* co-researchers shared, *Visioning Health* “was a beautiful mess”.

Incorporating Art and Culture

As noted above, our ‘strategy of inquiry’ was inspired by the Photovoice process originated by Wang and colleagues (Wang, 1999; Wang & Burris, 1997) and adapted by others for use with Aboriginal peoples (Castleden, Garvin, & Huu-ay-aht First Nation, 2008; Brooks, Poudrier, & Thomas-MacLean, 2008; Palibroda, Krieg, Murdock, & Havelock, 2009; Poudrier & Thomas Mac-Lean, 2009; Markus, 2012). The *VH* innovation was to push the Photovoice process towards a decolonizing methodology by grounding our work in Indigenous knowledge, ceremony and traditional teachings, and by incorporating contemporary and traditional Aboriginal art forms (Trepanier, 2008; Muirhead & de Leeuw, 2012), research sharing circles, and researcher reflexivity as culturally resonant data collection methods.

Indigenous knowledge, ceremony and cultural teachings were foundational elements of our research process, and as discussed above, were woven throughout our project. In addition to building *VH* around the Indigenist principles of respect, reciprocity, relevance, responsibility, relationality, reverence, reflexivity and revolution, we were guided by our Traditional Knowledge Keeper, Elder and *oshkaabewis* in our daily practice. They began and ended our group meetings with prayer and shared traditional and cultural knowledge with PAW co-researchers and with the research team as appropriate. They shared cultural

protocols with us and with PAW co-researchers and offered opportunities to participate in ceremonies such as sweatlodge, drum awakenings, and lodge building. They shared stories, dreams and visions and validated these as cultural ways of knowing. Above all, however, they helped all of us to “establish respectful relationships with Spirit” (Absolon, 2011, p. 121) and with each other, and by doing so, to participate in and to understand our research as ceremony (Wilson, 2008), as sacred (Walker, 2001), “spiritual covenant” (Salois, Holkup, Tripp-Reimer, & Weinert, 2006) .

Instead of focus groups or one-on-one interviews that are typically used in the Photovoice process, we used research sharing circles (Bartlett, 2005; Rothe, Ozegovic, & Carroll, 2009) or storytelling circles (Baskin, 2005) that are both culturally resonant and revolutionary. Stories, along with traditional teachings from Elders, spiritual beliefs and ceremonies, the land, and lived experiences, are an important source of Indigenous knowledge. History, customs, values and life lessons are taught and shared through stories, as are one’s relationship to place, to Creation, and to family (Archibald, 2008; Little Bear, 2000). Stories are vessels that carry important information about how to be human, how to be Aboriginal, and how to deal with life’s challenges. Stories, therefore, are often thought of as healing or as ‘medicine’ for Aboriginal peoples (Tafoya, 2001). Contained within them are the raw materials required for healing from pain, disease, and disillusionment – or put another way, the raw materials for maintaining health and wellness. Like all medicines, however, stories do not act alone. From an Aboriginal perspective, stories require the conscious engagement of the listener and thus, they are relational (King, 2008; Simonds & Christopher, 2012). Stories invite people “to think deeply and reflect upon [their] actions and reactions” (Archibald in Kovach, 2009, p. 94), but it is the listener’s responsibility to take what they need from the story, to make the required changes in their life, to do the ‘work’ of what Joanne Archibald calls ‘storywork’ (Archibald, 2008). While storytelling is often imagined and enacted as oral, authors remind us that stories can take many forms, including written narratives, poems, visual symbols such as paintings, sculptures/structures, collage or photos, song, dance, traditional games and prayer (Muirhead & de Leeuw, 2012; Archibald & Dewar, 2010; Kovach, 2009). The *VH* stories are a combination of oral, written and visual narratives.

Using stories in our research, however, is not just culturally resonant, it is also revolutionary in that “stories are decolonization theory in its most natural form” (Sium & Ritskes, 2013, p. III). Storytelling is relational, agentic and participatory; emotional, embodied, and performed. Stories begin and end with the teller but are told in relation to, and demand responsibility from, the listener (Kovach, 2009). Using stories in our work centres the experiences of PAW and demands that their voices be heard. Their stories give space and light to issues of importance to PAW, and in these ways, stories are acts of resistance and resilience, of insurgence and resurgence (Mooney-Somers, et al., 2011; McIsaac, 2002; Sium & Ritskes, 2013). They are transformative, emancipatory and liberating – both for the teller and for those who have the ears to hear (Tafoya, 2001). They are also revolutionary and disruptive to dominant notions of scholarship, of objectivity, of intellectual rigor. Stories and storytelling challenge our notions of ‘evidence’; of what counts as knowledge. As Sium and Ritskes (2013) note, “stories as Indigenous knowledge work to not only regenerate Indigenous traditions and knowledge production, but also work against the colonial epistemic frame to subvert and recreate possibilities and spaces for resistance” (p. III).

Research-sharing circles (Bartlett, Iwasaki, Gottlieb, Hall, & Mannell, 2007) are a culturally resonant form of focus groups that embody and reflect the oral traditions of Aboriginal peoples and Aboriginal values such as egalitarianism, sharing, support, non-judgement, non-interference and spirituality (Rothe, Ozegovic, & Carroll, 2009; Lavallee, 2009; Baskin, 2005). As the name suggests, *VH* participants and researchers sat in a circle where everyone was equal and where everyone had an equal opportunity to share their thoughts. Our research sharing circles were understood to be conducted in ceremony and therefore an Elder or Traditional Knowledge Keeper was often present to open the circle with prayer and to ground the circle in respect. In the absence of an Elder, one of the PAW co-researchers volunteered to open our circles with prayer. Once the circle was opened, I, as the lead researcher, explained the purpose of the circle, asked permission to record our discussion, and then asked the first research question. Often, a talking stick, a feather or a rock, is held by the speaker and then passed to the next speaker when they are done sharing. We, however, did not use these items. Instead, our circle began with a volunteer who shared as much as she wanted. When that person indicated that she was through, another PAW co-

researcher volunteered. This process continued until everyone in the circle had an opportunity to share as much as they wished. When it was clear that the women were done sharing on that particular topic, I asked the next research question. This process continued until all the research questions were asked or until all PAW co-researchers were done sharing (Bartlett, 2005). Arising from an Indigenous worldview, the protocol of a sharing circle is that no one interrupts while another person is speaking – there is no time limit on how long each person may speak – nor do they comment on what another person has shared. Within the circle tears, fears and other emotions are welcomed (Baskin, 2005). Each person is expected to ‘speak from the heart’ while the others in the circle are expected to ‘listen from the heart’, without judgement, with an open mind and with respect for the speaker (Rothe, Ozegovic, & Carroll, 2009). This Indigenous approach to gathering information is more effective than focus group discussions in which the facilitator often determines time limits, participants do not follow a circle format, intellectual or cognitive responses are valued over emotional responses, and more reserved participants are often left out of the discussion.

All PAW participants gave their consent to participate in three audio-recorded research sharing circles (1 = health, culture, gender; 2 = selection and meaning of individual photos/drums; 3 = reflection & evaluation) that lasted between 30 minutes and 3 hours. At the request of co-researchers and to avoid participant fatigue, some of the longer research sharing circles were split over two sessions, and some of the shorter research sharing circles were combined. The ‘virtual group’ was slightly different. Since this group met by Skype© for two hours each week, it was possible to audio-record all of our discussions, with participant consent, using third-party audio recording software. Audio-recorded and transcribed discussions from the final all-groups meeting were focused on participatory analysis and ‘key messages’ that co-researchers wished to communicate with their photo-stories.

As noted in previous chapters, *reflexivity* is a core principle of decolonizing and Indigenist research (Walters, et al., 2009; Kovach, 2009). It involves “openly and honestly recognizing one’s location and experiences and deeply considering the implications of one’s power” (Kirby, Greaves, & Reid, 2010, p. 39). A reflexive research practice helps to ensure that our actions are consistent with our ethics; that when we claim to be doing decolonizing

research, for example, that our actions do not re-inscribe colonial power relationships (Tuhiwai Smith, 1999).

As individuals, a reflexive research practice helped each team member consider and account for her own location, her own experiences, and her own role in the project. It helped us process our own responses to the research and to become aware of the impact each of us may have had on each other and on the PAW co-researchers, on the direction of our discussions, and on PAW co-researchers' answers to research questions. As a team, conscious reflection on our research practices helped us to determine if we were asking the right questions in the right way, if we were meaningfully responding to the needs of the PAW co-researchers, and if we were meeting our goal of creating a safe and supportive environment for the women. It also helped us identify and clarify points of disconnection between core research team members. For example, it became clear early on in our project that members of the core research team (myself, Doris and KJ) were operating under different assumptions regarding researcher objectivity. Doris and KJ, who were both core research team members and PAW co-researchers, were uncertain about how much of their opinions and experiences they should share in our research sharing circles. As PAW co-researchers they had much to share but as researchers, they were concerned about influencing the responses of the other PAW co-researchers. In short, they were concerned about researcher bias and maintaining researcher objectivity. Once we identified this through our reflexive research practice, we were able to clarify the roles that each of us played in the research and come to the common understanding that accounting for our subjectivities was a far more agreeable goal, and far more consistent with the Indigenist principle of relational research, than attempting to maintain an impossible objectivity.

Finally, incorporating a reflexive research practice also helped us bridge the distance between the head knowledge that is so valued by academia and the heart knowledge that is equally valued by Indigenist research processes. As Sharp Dopler (personal communication) explains, "the process of reflexivity serves both the academic research and that beautiful process of ceremony... ceremony is about creating opportunities for useful reflection – sometimes alone, sometimes assisted by others. Sometimes the dialogue is internal and sometimes external." Our research practice gave us these opportunities to reflect as

individuals and as a team, to connect our heads to our hearts, and to see, feel, and respond to research situations as they arose.

To facilitate a reflexive research process (Padgett, 2012; Kovach, 2009), I captured my personal reflections, technical notes, methodological notes and analytical notes in a ‘field journal’ that was both handwritten and computer assisted. To capture similar reflections from all active research team members (core research team and cultural support group) we held regular de-briefing sessions after each group meeting. I recorded summaries of these sessions in my journal.

Strategy of Inquiry

As noted above, our strategy of inquiry was inspired by, but a significant departure from, the Photovoice process. We used the following strategy for three groups of PAW, adapting it as required for the specific needs and desires of each group.

- a. Project orientation, including welcome and opening by Traditional Knowledge Keeper, feasting and cultural protocols, ethical considerations, informed consent, discussion of overcoming potential barriers to participation, establishing a group schedule and ‘protocols for safe participation’ (see Appendix D for one example)
- b. Training and practice in chosen art-form by an Aboriginal artist
- c. Research sharing circle #1: meaning of health, culture and gender (See Appendix E for research sharing circle guide)
- d. Group meetings to provide on-going support, cultural teachings and trouble-shooting while participants create their art / take their photos
- e. Research sharing circle #2: meaning of art / photos in relation to project (see Appendix E for research sharing circle guide)
- f. Develop narratives to accompany art from transcripts of research sharing circle #2
- g. Research sharing circle #3: Participatory analysis, collaborative meaning-making and project evaluation (see Appendix E for research sharing circle guide)

- h. Culturally-relevant photo-exhibition, feast, and service-provider/community engagement event to showcase photo/drum-stories and facilitate discussion of social change
- i. Group wrap-up including celebration, ceremony and cultural teachings



Figure 3: Visioning Health Strategy of Inquiry

Wanda Whitebird was our Traditional Knowledge Keeper for the Toronto group and co-facilitated all meetings, along with myself, Doris and KJ. All group meetings opened with prayer and a brief sharing circle to ground us in our work together and cultural teachings were shared as appropriate. Group meetings also ended with prayer and a brief check-in to ensure the emotional and physical safety of all group members. This group received digital cameras, was trained in digital photography by Nadya Kwandibens, a professional Aboriginal women photographer (www.redworks.ca), and met every two or three weeks for 4 to 6 hours between January and June 2011. At the request of co-researchers, two additional

meetings and a full-day photography field trip were added for a total of six months. This group designed and hosted a culturally-relevant service-provider/community engagement event in Toronto using the Medicine Wheel¹⁸ as an organizing theme.

The second group, the Virtual Group, was co-facilitated by myself, Doris, KJ and Wanda Whitebird. This group also used digital photography, but members of this group were geographically dispersed. To accommodate their desire to participate, this group met in-person for a one and a half day project orientation and digital photography training session with myself, Doris, KJ, Wanda, and the same photographer as above, but then used Skype© to hold a series of nine weekly ‘virtual’ meetings between August and November 2011. Co-researchers were given the option of using our digital cameras or using their own. We used Skype Premium© to connect those without a reliable internet connection to the call via their landline or cellphone. This group also created a private Facebook© page to stay connected and to support each other between meetings. Traditional Knowledge Keeper, Wanda Whitebird, joined us in creating ‘virtual circles’ of safety, by opening and closing our weekly Skype© meetings with prayer and with ceremony. She was also available to group members outside our meetings for traditional counseling or to discuss cultural teachings. Our initial plan called for six meetings but three more meetings were added to accommodate co-researchers’ needs. Given the geographic diversity of this group, a single community-engagement event was not feasible. However, we worked with each co-researcher to find creative ways of presenting their photo-stories to their communities. Three of the four co-researchers in this group have presented *VH* to their local communities and two co-researchers have traveled to other cities (and other countries!) to present their photo-stories at research conferences and to engage in policy-discussions.

Our third group was slightly different. With the assistance of *oshkaabewis*, Sharp Dopler, this group learned to make, decorate and care for traditional First Nations hand-drums. These groups were co-facilitated by Sharp, myself, Doris, and KJ, with support from

¹⁸ The medicine wheel is now a ubiquitous symbol that can be used to understand a range of phenomenon, including health. It is a circle divided into four quadrants, or equal segments, which are separate but interconnected and each quadrant is assigned a different colour and different attributes. An Ojibway and Algonquin medicine wheel has quadrants that are black, yellow, red and white while a Cree medicine wheel replaces the black with blue. In many Indigenous nations, health is thought to be a balance between physical health, emotional health, mental health and spiritual health and thus, in a holistic health medicine wheel, each of the quadrants is assigned a colour and an aspect of health. Balance between these quadrants is important, as is the connection with family, community, the environment and Mother Earth (Lavallee, 2009).

Carrie Martin. To better meet the needs of PAW in Montreal, this group met for four full-days over a two-week period in September 2011 instead of weekly or bi-weekly meetings over a longer period. We used photo elicitation techniques (Weber, 2008) to initiate our first research sharing circle on health, culture and gender, asking each PAW to find a picture in a magazine that represented their views on health, culture and gender and then to tell us: 1) what is this a picture of?, 2) why did you choose it?, and 3) what does it say about health, culture and gender for PAW? The narratives that accompany their magazine photos in Chapter 4 are excerpted from these discussions. We received cultural teachings while making our hand-drums,¹⁹ drummed and sang throughout the process, provided time and materials for co-researchers to decorate their drums, and offered drum-awakening ceremonies for new drums. As I describe below, this was a powerful ceremony that had a profound effect on all of us.

When Sharp offered to do drum-awakening ceremonies for the new drums in the room, I think she was surprised when all seven of us said yes. Of the four PAW co-researchers from Montreal, three were present that day, along with Carrie, Doris, KJ, myself and Sharp. We had just spent 3 and a half days together, making and decorating our own hand drums, learning together, laughing together, eating together, singing together, crying together and telling stories together. It was fascinating to experience, in such a short time, how this group of HIV-positive Inuit women, with the support of PAW mentors, service providers and researchers, went from nervous, shy and a little bit fearful, to eager, open and happy to be together. As Sharp called for the first PAW participant to step up with her drum, it was clear that she – or any of us – had never done this before, but it was equally clear that she – and we – trusted Sharp to walk us through it. As Sharp gave instructions, laying tobacco and a pebble on the outstretched drum, the PAW co-researcher listened intently and nodded to say she was ready. Boom! Boom! Boom! Boom! Four beats of the drum and Sharp was singing the song that came to her in that moment, moving her drum over,

¹⁹ To maintain a safe space for the Montreal co-researchers and to further erase the gap between researched and researcher, we became co-learners in the drum-making process. Doris, KJ, myself and Carrie were full participants in the workshop, making our own drums, learning the songs, and participating in ceremony.

under, and around the woman's drum, causing the tobacco and the pebble to bounce and move to the vibrations. With all of us as witness, and as the song continued, the pebble moved outwards from the centre of the drum, sometimes in one direction, and then in another. When the pebble finally fell off the drum, the co-researcher noted the direction in which it had fallen and looked up at Sharp, smiling broadly, while the song came to an end. Each song was different and each drum was identified by the direction in which the pebble had travelled (north, south, east, west – or centre if it did not travel at all). This, along with the effort that each co-researcher put into making and decorating their drum, made each drum as precious and unique as the woman by whom it was made. Herein lays the power of ceremony. In that moment, with all the attention and intention in the room focused on her, each co-researcher 'knew' that they were special, they were worthy and they belonged. In that moment, their eyes shone with pride, with joy and with hope. Their fears forgotten, their insecurities gone, in that moment, each co-researcher felt loved and more importantly, loved themselves. For all of us, and perhaps especially for PAW who are typically marginalized by society; who are made to feel as if their voice does not matter; as if they do not matter; as if they do not exist – this was a profoundly healing experience.

We had our second research sharing circle, on the meaning of the artwork, at the end of the workshop after we made and decorated our hand drums. This was focused on how each co-researcher chose to paint or decorate her drum and what their drums and decorations said about health, culture and gender for PAW. The narratives that accompany photographs of their drums are excerpted from the transcripts of these discussions. Due to the high level of HIV-stigma in this community and the resulting fears around disclosure (Carrie Martin, Personal Communication), we did not host a community engagement event in this community; however, we once again worked with co-researchers from this group to find creative ways to share their drum-stories. As a result, we have supported three PAW from this group to travel to another city to present their stories at community gatherings or research conferences and one PAW who has travelled internationally to tell her story at a research conference and engage in policy-discussions.

Despite these variations in strategy of inquiry, we spent roughly the same amount of time with each group and all groups responded to the same research questions using arts-informed methods. Once all groups had completed their projects, we hosted a one and a half day in-person meeting for all co-researchers where many of them met each other for the first time. Participants shared their photo-stories (including drums) and experiences of participating in this project, and they engaged in a participatory analysis process that was designed to shift the analysis from the individual level (focusing on their own photo-stories) to the collective level (focusing on the similarities and differences between all the photo-stories). This in-person meeting culminated in a facilitated discussion of PAW co-researchers' perspectives on key findings from the project and key messages they hoped audiences and viewers of the photos would take away.

As noted above, however, decolonizing and women-centred research is about more than asking and answering questions – it is also about bridging capacities, celebrating strengths, having fun, and strengthening relationships. At the all-groups meeting, we celebrated the completion of *VH* in culturally-relevant ways such as drumming, singing, feasting and ceremony, including an optional sweat lodge.²⁰ We also presented each participant with a 'certificate of completion' that recognized the enormous amount of time, effort and dedication that each person had put into the project, and the competencies that they had achieved (see Appendix F). As one co-researcher declared with enormous pride while holding her certificate in the air, "this is my first graduation ever!"

Data Sources and Culturally-Relevant Data Management

Data for this project includes 54 photos (including photos of PAW co-researcher's drums) and their accompanying narratives, researcher fieldnotes, and transcripts from all research sharing circles, all meetings of the virtual group, and the final all-groups meeting for a total of 18 transcripts.

As the lead researcher, I kept digital copies of all transcripts, all photos and all narratives on my computer. However, as a visual arts-informed project, it was important for me to literally 'see' the data in order to understand it, and to see it holistically instead of one

²⁰ It is important to offer these healing opportunities to Positive Aboriginal Women in safe and supportive environments as many report feeling unwelcome at ceremonies in their communities – or worse, they have been told that their HIV might harm the lodge-keeper or others who participate in these ceremonies (Sharp Dopler, Personal Communication).

photo or story at a time that lacked a broader context (Lavallee, 2009; Kovach, 2009). To achieve this end, I covered the walls of my office with PAW co-researchers' photos and narratives, organized by group and by co-researcher within each group. This kept the images and narratives fresh in my mind, reminded me of who said what and took what photo, maintained the holistic and relational nature of the study, and allowed me to "live with the data" (Kirby & McKenna, 1989, p. 150) in a way that a computer assisted data management program would not allow. The use of software programs such as AtlasTI© or N6© for data management and analysis have become standard among qualitative researchers and are thought to be efficient and effective tools to manage large volumes of information by facilitating the breakdown of this information into increasingly smaller, and therefore more manageable, units. In my experience, however, and as numerous authors (Absolon, 2011; Kovach, 2009; Rogers Stanton, 2013; Simonds & Christopher, 2012) have pointed out, these software programs are built on Western notions of data analysis that fragment and decontextualize participants' narratives with the end goal of pulling apart the data so that it can be put together again in new and interesting ways (Lavallee, 2009; Kovach, 2009; Wilson, 2008). While I had originally intended to use a data management software program to assist with analysis, I found them to be awkward, constraining, and at odds with Indigenist methodologies that emphasize holism and relationality. Instead, I opted for the less linear, but more holistic and relational method of managing data mentioned above: I stored all information on my computer but we worked with hard copies of all photos, narratives, and transcripts. This allowed us to see and read PAW co-researchers' complete stories and responses in context and in relation to us and to other PAW co-researchers.

Each co-researcher retained ownership, control, access and possession of her own photos and narratives. Where possible, each co-researcher retained or was given digital copies of all their photos. For those who did not own or have access to a computer, we gave hard copies. Each co-researcher was also encouraged to think of their photo – stories as their own and to share their work with their communities. We also facilitated group ownership over the data produced in this project, by sharing digital copies of all photos and narratives with all co-researchers and by developing a *VH* Photobook that was gifted to all co-researchers and research team members. As we moved forward in our project, we also shared copies of all presentations with interested co-researchers, and where possible, worked with

co-researchers and team members to develop co-presentations for their communities (see Appendix G for a list of project outputs and co-presentations).

Collaborative Meaning-Making: Participatory Coding and Analysis

Consistent with an Indigenist and decolonizing methodology that centres Indigenous knowledge and privileges the interpretation of participants over the interpretation of researchers, we used a participatory, dialogic, and relational approach to data analysis (Jackson, 2008; Kovach, 2009; Prior, 2007; Rogers Stanton, 2013; Simonds & Christopher, 2012; Wilson, 2008) that included analytic input from co-researchers, the core research team, and members of the cultural support group. Coding and analysis was on-going, iterative, and engaged different team members at different stages of the process.

As noted by others who use the Photovoice method (Palibroda, Krieg, Murdock, & Havelock, 2009, p. 55) the first stage of data analysis is inherent in the Photovoice process: it happens naturally when participant-photographers make decisions about what photos to take and then select a limited number of these photos to share with the group. In our project, co-researchers in the photography groups made the choice of which photos to share and which photos not to share based on their own ideas of what constitutes health, culture and gender for PAW. In the drum-group, this initial stage of analysis took place when each co-researcher chose how to decorate their drum and which elements of their drum design to speak about.

In the next stage of analysis, we placed all photos and narratives for the Toronto group – the first group to complete the art-making and data collection process – and asked PAW co-researchers to collectively identify commonalities that emerged from their photos. For example, co-researchers identified ‘images of nature’, ‘images of water’, and ‘hope’ as common themes amongst their photos. We considered these commonalities to be preliminary themes in our overall data analysis. Through a process of discussion and consensus, we then sorted these themes into groups that became preliminary analytic categories. For example, ‘images of water’ and ‘images of nature’ became the analytic category of ‘connection with nature’. Each photo was associated with several themes and categories. We also asked group members if there was anything missing from the photos and added these themes to a preliminary list. Interestingly, one category of images that was missing from the Toronto

group photos was images of medications or hospitals or clinics or anything else that spoke to the medical aspects of living with HIV. Further discussion revealed that some co-researchers had intended to take those photos but for some reason or another, had not managed to do so. Initially ‘men’ seemed to be missing from the images as well, but after vigorous discussion, co-researchers saw ‘men’ and ‘maleness’ as symbolically present in images of rocks, trees, and other natural elements.

We used a similar process of participatory preliminary analysis at the end of the drum-making group. After all co-researchers had presented their drums and drum decorations, we had a facilitated discussion about the similarities and differences among them and then added any additional themes to our growing list.

The third stage of analysis took place at the All-Groups meeting once everyone had completed their projects. As noted above, all participants (except one), facilitators, our peer research associate and several members of our Cultural Support Group and Community Advisory Committee met in-person for one and a half days to share their experiences of participating in *VH*, to compare photos and to engage in participatory analysis. This was the first time that each group of PAW had seen the photos/drums of other groups so we displayed all artworks and narratives around the room and asked each co-researcher to present two photo-stories that they wished to share with the group. We then asked everyone to walk around the room and view all the remaining photo-stories. We gave each person a stack of sticky-notes and asked them to complete two tasks: 1) to identify themes within individual photo-stories; and 2) to identify themes across photo-stories. For example, in the first part of this task, a single photo-story of rocks and water elicited themes of ‘nature’ and ‘healing’. In the second part of this task, participants were asked to assign these themes to all relevant photo-stories. Each person was then asked to share their observations with the group and to identify particular photo-stories that they felt represented a particular theme. In the final phase of this group process, we asked co-researchers to identify ‘key’ themes that emerged from the photo-stories and also to identify ‘key messages’ that they hoped audiences would take away from photo exhibitions or other knowledge translation events.

All analysis discussions referred to above, from the Toronto group process, the Virtual group process, the drum group process and the All-Groups process, were audio-recorded with participants’ consent and transcribed verbatim. Themes and exemplars were also

recorded on flip-chart paper, which was later transcribed into MSWord© (see Appendix H). Following the meeting, Doris Peltier and I continued to work together to refine themes that emerged from the participatory analysis sessions and to create ‘codes’ or ‘analytic categories’ that could be applied to all data sources.

In our fourth stage of analysis, Doris, KJ, and I read the same three focus group transcripts that we chose for their diversity and their richness and collaboratively coded all three transcripts using our preliminary list of codes as a guide. We added, collapsed or deleted codes where necessary. We then split the remaining 15 transcripts amongst us to complete the coding process. Each transcript was assigned a first reader who was primarily responsible for coding that transcript and a second reader who was responsible for reading and becoming familiar with the transcript. I was either first reader or second reader on all transcripts. This made it possible to share the workload and to periodically check with another member of our coding team in instances of uncertainty. This approach proved to be very helpful, particularly when trying to code for ‘indigenous knowledge/ways of being’. As a non-Indigenous person I often missed examples of these categories that Doris or KJ picked up immediately in one of our many coding discussions.

From this point on, the ‘analysis’ phase of *VH* overlapped with, and further informed, the interpretation of our research results. Doris and I continued to collaboratively develop our interpretations for numerous co-presentations, often in partnership with KJ or other team members. This process of collaborative meaning-making was an on-going and iterative process that involved countless discussions and numerous cycles of writing, reviewing and re-writing. Lassiter (2005) calls this ‘reciprocal’ writing because it involves active collaboration between researcher and participants where ideas are being negotiated and contested in real time – as they are being written about – in contrast to the more usual style of completed researcher-prepared drafts that participants review and comment on. The manuscript for this thesis was prepared in a similar fashion: while I did the actual writing, the words you are reading are based on numerous discussions with Doris, KJ and other team members who then reviewed what I wrote, made comments or suggestions and then reviewed subsequent drafts. This collaborative and relational approach to meaning-making, interpretation and to some extent, writing, is consistent with the CBPR and decolonizing

approach that we took to this research and increases both the ‘transactional’ and ‘transformational’ validity of our research (Cho & Trent, 2006).

Validity, Trustworthiness and Credibility

While there is no universally accepted measure of validity in the qualitative research literature, or even agreement that the issue of validity is appropriate for qualitative research, most authors agree that some way of ensuring and evaluating the authenticity or credibility of the research findings is necessary (Padgett, 2012; Butler-Kisber, 2010; Creswell, 2007). According to Cho and Trent (2006), there are two general approaches to validity: transactional and transformational. They suggest that most discussions of validity are transactional and share the underlying assumption that the accuracy, trustworthiness and credibility of research findings can be improved by using two or more “techniques, methods and/or strategies...during the conduct of the inquiry” (2006, p. 322). Transactional validity therefore, is concerned with techniques for catching and correcting potential misunderstandings or misinterpretations of the data and ensuring that representations of the data are as ‘true’ or as accurate as possible. Padgett (2012) offers six “strategies for enhancing rigor and trustworthiness” (pp. 208-213): prolonged engagement with research participants; peer debriefing; triangulation or the use of multiple data sources; member checking; negative case analysis; and auditing. She further suggests that “a study’s trustworthiness depends on fairness and ethical conduct as well as rigor” (p. 218). Creswell (2007) adds ‘thick description’ and researcher reflexivity for a total of eight “validation strategies” (pp. 207-209) frequently used by qualitative researchers. Both authors suggest using at least two strategies to enhance the credibility and trustworthiness of qualitative research. They also suggest choosing those strategies that are most compatible with the purpose and design of the research.

We used several strategies to enhance the transactional validity of our study and to ensure the trustworthiness and credibility of our findings. Prolonged engagement with the community is a cornerstone of CBPR, of decolonizing and Indigenist methodologies and a cornerstone of our project. It is also an effective strategy for increasing transactional validity. Prolonged engagement builds trust and relational accountability between all research team members and facilitates a deeper level of sharing and interaction. We engaged in on-going

peer review and de-briefing with PAW co-researchers, our Core Research Team, Community Advisory Community, Cultural Support Team, and with my Thesis Supervisor and Supervisory Committee. This peer de-briefing added to the rigor of our study by giving us the opportunity to reflect on our research practices, on the meanings and interpretations that we assigned to events, and to consider different perspectives. Our reflexive research practice also added to the rigor of our study. As discussed above, our collaborative meaning-making process incorporated and went beyond member-checking as it is often practiced. In contrast to the more usual approach where the researchers develop the preliminary findings and then check back with the participants to ensure they got it right, we engaged participants in meaning-making from the beginning of our process and maintained an on-going dialogue to identify, clarify and further refine our findings. As a mixed methods study, we also used multiple methods and multiple data sources to corroborate our findings.

A transformational notion of validity goes beyond strategies and techniques to increase trustworthiness, and embraces the notion of research “as a progressive, emancipatory process leading toward social change that is to be achieved by the research endeavour itself” (Cho & Trent, 2006, pp. 321-322). This process notion of validity is consistent with the ‘research as social change’ orientation of CBPR and with decolonizing and Indigenist research that has the express intention of “changing the social condition of the researched [and] involves a deeper, self-reflective, empathetic understanding of the researcher while working with the researched” (p. 322). Criteria for accessing transformation validity include recursive and reflexive member checks as outlined above; critical reflexivity on the part of the researcher and research team; and perceptible change to the social worlds of participants (Cho & Trent, 2006, p. 332). This is consistent with Walters’ notion of research as revolution, in which “research partners and community members must actively seek to decolonize and indigenize the research process to transform science as well as themselves, their communities, and the larger society for the betterment of all” (Walters, et al., 2009, p. 154).

From a decolonizing and Indigenist perspective, issues of transactional and transformational validity overlap and are tied up with notions of process, of ethical research, of ‘researching in a good way’, and with the Indigenist principles of reciprocity, relevance, responsibility, reflexivity, and relational accountability. As noted by Kovach, attending to “validity, or relationally speaking, to credibility...means to tend to the process in a good

way, so that no matter the outcome you can sleep at night because you did right by the process” (2009, p. 52). It means conducting research as a spiritual covenant (Salois, Holkup, Tripp-Reimer, & Weinert, 2006) and incorporating steps or checks in the research framework to ensure that the research is meeting the needs of the community and accurately representing their views (Wilson, 2008). See Chapter 7 for more on transformational validity.

Community-Engaged Knowledge Translation and Exchange

Culturally-relevant and participatory knowledge translation and exchange is an essential element of CBPR, of Indigenist and decolonizing methodologies, (Masching, Allard, & Prentice, 2006; Kaplan-Myrth & Smylie, 2006) and of the photovoice process that informed our approach. As a primary example of the Indigenous principle of ‘reciprocity’, culturally-relevant and participatory KTE is one way that researchers can ‘give back’ to the communities with which we work. Following the Indigenous principle of disseminating findings to the community first, we prioritized knowledge translation and exchange to the Aboriginal community, beginning with co-researchers and the communities we worked with, project partners, and then to the extended Aboriginal HIV and AIDS community. Consistent with the Photovoice process that we adapted, we planned to host a community engagement and policy discussion event at the end of each group process, but as previously discussed, the Toronto group was the only group to host their own event in their own community. We did not host a community engagement event in Montreal due to the high level of HIV-stigma in this community and the resulting fears around disclosure (Carrie Martin, Personal Communication). Given the geographic diversity of the ‘virtual’ group, a single community engagement event for them was not feasible. However, we worked with each co-researcher from these groups to find creative ways of presenting their photo-stories and project findings to their local communities where appropriate, or to other Aboriginal audiences.

As noted above, we also encouraged and supported (technically, emotionally and financially) PAW co-researchers to present at conferences and events. This meant that the majority of our presentations and photo exhibitions, including *VH Lodges* – the innovative and culturally-relevant photo exhibition that I described in the Introduction to this thesis - were co-presented by academic and community partners, or in several cases, by community

alone. In total, we have shared our methodology and findings in 36 co-presentations with community, academic and policy-maker audiences and 17 photo exhibitions, including four *VH Lodges*.

In the Introduction to this thesis, I referred to additional KTE activities – beyond that which we had expected and planned to engage in – as an unexpected consequence of our participatory and decolonizing methodology. In fact, community-engaged KTE turned out to be one of the most important aspects of the *VH* project and one of our clearest indicators of ‘success’. I discuss this further in Chapter 7.

Chapter Summary

In this chapter I have outlined the methods and the methodology we used to meaningfully engage PAW in the *VH* research. Our axiology, or our ethics of research, and our methods were grounded in a decolonizing, women-centred, arts-informed and community-based participatory approach that foregrounded the needs and the experiences of PAW co-researchers. Our process was grounded in ceremony and in culture, and prioritized the creation of ‘safe spaces’ for PAW that were fun, engaging, non-threatening, and non-judgemental. In total, we engaged 13 PAW in three arts-informed group research processes that resulted in 54 photo-stories of health, culture and gender, including four First Nations hand drums. We have hosted 17 photo exhibitions to date, including four *VH Lodges*, and have given 36 co-presentations to community, academics, service providers and policy-maker audiences. In the following chapters, I focus on the findings from *VH*, beginning with the photo-stories that are the very heart of this project.

Chapter 4

Sacred Stories, Sacred Lives: PAW's Photo-Stories of Health, Culture and Gender

(with Candy, Doris Peltier, ES, KJ, Krista Shore, LA, Laverne, Liz,
ME, MT, PAW, Tonie Walsh and Stacy Lee Bluebird²¹)

Storytelling, oral histories, the perspective of Elders and of women have become an integral part of all indigenous research. Each individual story is powerful... These new stories contribute to a collective story in which every indigenous person has a place (Tuhiwai Smith, 1999, p. 144).

Introduction

The photo-stories in this chapter are the heart of the *VH* project. They are the PAW co-researchers answers to the core questions of our research: What does it mean to be 'healthy' as a Positive Aboriginal Woman? What strengths and assets do PAW use to be healthy? What is the role of culture in creating, maintaining or supporting PAW's health? What is the role of gender in creating, maintaining or supporting PAW's health? Of the dozens and sometimes hundreds of photos that PAW co-researchers from the Toronto and Virtual groups took over the duration of this project, and of all the magazine photos and drum decorations that the Montreal PAW co-researchers could have chosen, these are the photos and the artworks that they chose to share with each other, with me and with the world. I present them here in their entirety, much as they were presented to the group.

The narratives that accompany each photo are the result of research sharing circle #2, a photo or art-sharing session that we held near the end of each group process that focused on the meaning of the artwork in relation to health, culture and gender for PAW. These discussions were audio-recorded with permission and transcribed. At the next meeting, we returned transcripts to the women and encouraged each of them to edit her transcript into a short narrative to accompany each photo. Each PAW co-researcher had final editorial control over her own photo-story.

²¹ Special thanks to Sharp Dopler and Carrie Martin for discussion and feedback on this chapter. Carrie's insights were particularly helpful for the Montreal section.

Each group of PAW co-researchers was unique. Comprised of individuals from a diversity of backgrounds, each group had their own personality, their own preferences, their own histories, and their own way of seeing the world. While the photo-stories below are the stories of individual co-researchers, they are also the stories of individuals in relation to each other (Wilson, 2008) – in a group context – and therefore, the stories they chose to tell were influenced by the other women in the group, by our on-going discussions, and as Wang and colleagues (1994; 1997) point out, by the group reflecting back on each other's photo-stories. One purpose of this chapter then is to introduce you to each of the PAW co-researchers – after all, their stories are the heart of this project – but also to the unique character of the groups that shaped their participation in this project. To do this, I present the photo-stories first in chronological order from the first group to the last group to be completed, and within each group, in alphabetical order by first name. As noted in chapter three, each co-researcher is identified here according to her wishes. Some chose to use a pseudonym, some chose initials or a first name only, and others chose to be identified by their full name.

My intention in this chapter is to let the co-researchers' words and photos stand for themselves. As discussed in earlier chapters, this is an attempt to address what Lassiter (2005) calls "the gap between academically-positioned and community-positioned narratives" (p. 4). It is about the power and politics of representation; about whose voice and whose discourse will be privileged in the text (Potts & Brown, 2005; Kovach, 2009). The academy demands that my voice be privileged in the majority of this thesis, but in this chapter, and consistent with our decolonizing and Indigenist methodology (Kovach, 2009; Walters, et al., 2009), I choose to centre the voices of PAW co-researchers. As Oliver (2013) suggests in her study of young homeless women, "this is their chapter, their chance to share their understandings of their realities unencumbered by a so-called authoritative voice" (p. 50).

It is also an opportunity to present the PAW co-researchers and their photo-stories in a more holistic and contextual way than future data chapters will allow. Photos are necessarily snap-shots of a moment, frozen in time, often offering a single perspective on a single event. My hope for this chapter though, is that you will come to know a bit of the breadth and depth of each PAW co-researcher's experience by viewing her collection of photo-stories about her

health. A ‘typical’ Western approach to research would suggest that I divide participants’ stories into “chunks of data”, assign codes or themes to decontextualized quotes, and then provide the reader with an interpretation of the stories based on my categorization and understanding of the themes (Kovach, 2009; Absolon, 2011). I will do this in the following chapters. However, an Indigenist approach to research and data analysis guides us to let the stories stand for themselves, in their entirety and in their own context, and to let you, the reader, take from the stories what you need. For Indigenous readers, the context of the stories and who the stories belong to are important elements that provide meaning (Absolon, 2011; Lavallee, 2009; Rogers Stanton, 2013; Kovach, 2009).

Lastly, I hope that this chapter will serve as a touchstone for the reader; a place to return to, to re-read, to explore, when the women are re-introduced in later chapters through smaller bits of narrative. I purposefully limit my commentary in this chapter, choosing instead to let the women’s words resound.

Toronto Group (N=5)

The Toronto Group was the first group of women we worked with and in many ways they created the template for future groups. Our original research protocol called for five group meetings over three months; however, this group taught us that relationships, the very foundation of research in Aboriginal communities (Kovach, 2009; Schnarch, 2004), could not be rushed. While some of the women in this group knew each other or knew ‘of’ each other through the services of various Aboriginal organizations, most did not – and none knew me, or at least did not know me well. To engage in a meaningful relationship with each other and with us (the Core Research Team) this group demanded more of our time and more of ourselves than we originally thought to give. At their request, between January and May 2010, we met with this group every two to three weeks at a local community centre for four to six hours each meeting. We began each meeting with ceremony - with a prayer and a check-in/sharing circle – to ground us in our work together and to re-connect since the last time we met; we shared traditional stories and stories of our lives; we shared food, laughter, tears and fears. Near the end of our time together, we borrowed a van from one of our community partners and spent the day together driving around Toronto, visiting sites they wanted to visit, taking photos of things they wanted to take photos of. In total, we met 13

times over six months for a total of 50+ hours, in which we gradually grew to know each other, to trust each other and to look forward to our meetings together.

By the end of our group process, three things struck me about this group. The first was the degree to which they – we – had come to enjoy and look forward to our time together. During our morning check-in, women would frequently say “I almost didn’t come today but...” and then finish the sentence with how much they looked forward to the group. The second thing that struck me was the truth-value of the adage ‘laughter is the best medicine’. Despite the poverty and unstable housing these women experienced; despite their struggles with substances and the complicated lives that came along with that; despite the unimaginable abuse and neglect that many of these women had experienced as children; despite all this, there was laughter. There was laughter, there was joy, and there was genuine sharing and caring.

The third thing that struck me about this group was how frequently and naturally the discussion turned to matters of spiritual or sacred significance. Talk of dreams, spirit helpers, ancestor spirits, sacred teachings, sacred stories and ceremonies in which women had participated was common. If I left the room, I would frequently return in the middle of a story about Spider Woman and her baskets, or of spirits who visited in the night. In fact, it was this group that helped us to realize the sacred nature of the photo-stories that co-researchers were sharing with us.

In short, we learned many things from the Toronto group that we brought forward to our work with the others. They taught us that relationships were important in research; that laughter is important in relationships; that ceremony and traditional teachings were an integral part of creating safe spaces for PAW; and finally, they taught us that the photo-stories they shared with us were more than simple photo-stories. They were sacred stories of sacred lives.

Doris Peltier (Anishinabe)

Hope Amidst the Turbulence



I took this picture because it's cloudy and it's how I felt when I was diagnosed with HIV. My world was filled with turbulence and I couldn't really see a future. BUT there's hope in this picture which at first I didn't see. There is hope because there are two glimmers of light trying to break through, one beautiful glimmer is on the horizon and the other is trying to burst through the clouds. Light is very hope because there are two glimmers of light trying to break through, one beautiful

glimmer is on the horizon and the other is trying to burst through the clouds. Light is very important because light is life. For me, this is a really powerful picture, as I now recognize there is indeed hope amidst turbulence. When I was diagnosed, I didn't have hope but this picture signifies my hope and the place I have reclaimed within the environment.

Smashing the Silos

I wish I could see signs like this in our communities. This sign represents how we were at one time in terms of being a community and being a complete circle within that community. We protected each other. We watched out for each other. That's not the case anymore. As a woman living with HIV and as an activist, this is kind of what's in my heart, that we need to have this in our lives again, this whole notion of being community and protecting each and every member within our Aboriginal community, and being whole. There are three little houses in this picture. It's kind of like silos. Is community protection about protecting those silos? We've been separated and divided up and put into silos and categorized. And that's not the way we can heal. We need to come together as a community. I like the whole notion of community and protecting the people within our community but I don't like the silos. I think the whole notion of protecting and being protected within our community would have healthier outcomes, if



we went back and completed that circle again. HIV would not have such high rates in our communities. That's what this sign says to me.

Heartsong of Reclamation

I've always loved rocks. This is me sitting on this big rock by the water as I share my heart-song for a moment between me and my Creator. As I sit on this big rock by the water my spirit reclaims all that has been lost in that one precious moment. I am turning over a new leaf as I see the beauty that the Creator has put in front of us. I honor my place within this environment. I am thankful for my life. Even though I live with HIV, it is not who I am. I have a place in this environment.



Tree of Life

This is a picture of a very special tree. People might not recognize it as a tree anymore, but I do. Because no matter what we put on, if we try to be somebody else, the bottom line is you're still who the Creator made you. So



this tree is still a tree. It is not the complete tree in this picture; you don't see the base or the top of it in this picture because there's more to the story about this tree. It's not the end of the story for this tree. I recall a story my father used to tell about raising up children and he used a tree to illustrate his point. My father used to say that the time to influence how that tree is going to grow is when it's a young sapling because you can bend it.

When it's grown and solid, you can't even bend it

because it's already established its place in the world. I wasn't a very good mother with my children because I didn't know how. Now that they're adults, I'm trying to do what I can, but I can't change who they are because they're like this tree — solid, strong in their ways. As a woman, I want to be very much like this tree with more of the story to come because you don't see the whole tree in this picture.

Creator Does NOT Make Junk

'Signs, signs, everywhere there's signs. Blocking out the scenery and breaking my mind. Do this, do that, can't you read the sign' When I saw this sign I kind of thought, 'Holy shit! Look at this sign! Our beautiful Turtle Island is being recycled!' And what does this mean to me? I could look at in a very negative way or I could look at in a very positive way too. It could go either way in terms of what it means to me. Ultimately it's kind of a sad statement about how we care for the environment that we have to recycle Turtle Island. But maybe there's hope too in recycling. At least we're not throwing it away, much like our lives. The process of life is about re-birth and recycling. That's what this picture says to me. As a woman living with HIV, I can kind of relate to this sign because I'm recycling, reclaiming all those positive things. I prefer to be hopeful and look at it in a positive light.



Shaped By My Environment

This is a picture of rocks under water. The water is very clear. I think it's beautiful because all the rocks are under water. Water is powerful. The water has shaped these rocks over thousands of years to appear the way they appear in this picture. For many, many years, I felt disconnected, and today I feel very connected to my place in this world and to me that's what these rocks signify. They've been shaped by the environment much like I've been shaped by my environment, sometimes in a very negative way. It's left little marks on me that you may not be able to see (like HIV), but I'm still here, much like these rocks.



KJ (Anishinabe)

Four Little Rocks

I took this picture of a rock on the rocks. It's a rock surrounded by water and little rocks. And on the big rock are four little rocks. A white stone, a yellow stone, a red stone, and a black stone. The big rock represents my rock. It grounds me. It grounds me for the little rocks. The spirituality, the health, the physical, well, the four culture teachings. And it's surrounded by water which is healing. And that's just my whole culture. That's why I chose this one.



Medicine Bags



This picture is of a dream catcher and two medicine bags and I chose this picture because it shows the culture of a dream catcher and medicine bags. There's two of them, one for me and one for my son. This is actually his first medicine bag. And culture for me is not - well, not important in my living with HIV, but it is!

Woman's Voice

I took this picture of this girl and it looks like she's speaking. She looks proud and I think it's important for a woman to have a voice. I have a voice and I like voicing it. I think she's a beautiful woman and so am I. She looks strong, she looks proud. I'm proud of who I am. HIV does not define me but it's part of who I am, and that's ok.



Hands Praying



This picture is of hands praying. I took this picture because I pray to the Creator, and I pray to God every night. I thank the Creator and I thank God for giving me the life that he's given me. I haven't had the easiest life, and I may not know why he put things in my path that he has, but I'll know one day. There's always a reason I believe for everything that's been put in your path. And for me, it's HIV as well. That's what makes me who I am today. So I thank Creator and I pray for my health that I can stay strong and healthy.

Rocks on the Beach

This picture is of water, rocks, and I guess the sand and the land. I took this picture because it reminds me of my health. For me the rocks represent our bodies and everything we deal with on a daily basis. The water cleanses our bodies of all negativity. And it just reminds me of...it's healing, water is healing. It's like I gotta remind myself to heal myself living with HIV, and keep myself as clean as possible so that I can be healthy enough to live long and accomplish all my dreams.



Laverne (Anishinabe)

City Escape



This one is a picture of my friend's place, his 15th floor balcony. So I took a picture of this whole city, whatever I could see way in the back, because it's a safe haven for me. I was having a lot of problems at home with drugs and alcohol and people smoking crack and I kind of implemented that into my unfortunate world. And then every time I wanted to run away, this is the place I went.

Rope for Hope

Somebody had braided a tree and it was so neat the way they did it. It looked like sweetgrass. It reminds me of how we're all tied into knots but also how we can, you know, follow in a rope for hope and hang onto that. Because I always hang onto hope. That's why I took a picture of it.



Circle of Heineken

The last one I took was uh, just bottles sitting on the ground, a bunch of Heineken. [laughs]. Ask me why I took that, I guess because—it's just—a lot of people—I used to be an alcoholic, real bad, so it just reminds me of how, how messy this can look when it's in your own home. That's why I took a picture of that ... and plus I like Heineken!

Medicine Wheel

This one has like a sunset in the background on the round circle of the four colours and you can see the image of me. I chose it because it has the four colours - white, yellow, black and red – and I represent that, that culture. I'm an Aboriginal woman living with HIV.



Tonie Walsh (Anishinabe)

Lonely Street



This is just an empty street. I took this picture at 6 o'clock in the morning. I wasn't out getting anything, I was just out and about. You can see all the way down the street and it just fascinated me. This picture reminds me that it can be very lonely living with HIV. Sometimes I feel alone, even on a busy street. I feel isolation. But since being in this project I don't feel so alone.

Mosaic

This picture is of beauty. I feel very positive and happy looking at the wonders of our generation. I feel overwhelmed that something so beautiful is living in the belly of the beast. This picture says to me we are a rainbow race. We are all in this together. No matter who you are, we can be a magnificent sight for worried eyes. Just open your eyes and see us.



Turquoise Among the Reeds



This necklace is a part of me, I've had for many years. When I saw the reeds, I saw my necklace there. It's all by itself. It's pretty to look at. But it's still alone. I feel like that at times. But meeting other people with the same story makes it not feel so lonely.

Spirit Shirt

This one, the spirit shirt with all my jewellery on it? That's my culture. We're about the silver and turquoise, not gold and diamonds. I know some people like gold and diamonds but I don't. This one here, the spirit one, it's because as women we have a strong spirit. This is a choker — see how it's broken? It used to be around my neck but now it's no more. It's broken because I'm free. I'm a free spirit.



Stacy Lee Bluebird (Anishinabe)



Butterfly on Blue Cloth

This picture reminds me of Life and Death. When you live, live your life to the fullest - because when you're gone, you're gone. Life is the most beautiful thing I think.

Group of Trees

I took this picture of these trees that grew together. The three that are together and have a hole right in the middle, reminds me of that emptiness that I've had in my life. I see a lot of help because those other three trees have come to root beside me and helped me grow, nurture me. I believe there are many spirits in this world that want to help in the progress of this disease. There are many resources that are available for such cases. I believe there are many more that would like to participate. I encourage them to do so!!



Four Winds

This picture reminds me of Prayer. I took this picture of the four flags of Canada. What I really wanted to catch was the four winds that bring our prayers to the Creator. There are three flags that are going in a straight way and there's one that is half. Not everything goes straight. And I believe that myself is that little flag there, that's going half-way. Because I am infected with HIV, it's always going to be half. However, there's always others around me who will encourage me, fly with me. "Go straight. Be proud of who you are."



Tied Down

This picture represents being incarcerated; not being free to do what you would like to do. Being HIV+ meant not getting the right help, again being held back.



Montreal Group (N=4 + 2)

The Montreal Group was unique in many respects. We had not planned to work in this community, but after recruitment efforts were unsuccessful in Ottawa, Montreal became a viable alternative when Carrie Martin of NWSM overheard a conversation about our project and expressed interest in partnering with us. Following discussions with our Community Advisory Committee and Cultural Support Group that revealed that women from this community had independently been asking for a drum-making workshop, we worked with all partners to design a workshop that would meet the needs of the women and the needs of our research. The result was an intensive four day workshop (two full days per week over two weeks) that included research sharing circles focused on our research questions, drum-making instruction, traditional drum teachings, drum decorating, drum awakenings, drumming, singing, and a final research sharing circle in which the women shared the meaning of their drums and decorations with the group. The photos below are images from magazines resulting from the photo elicitation exercise described in Chapter 3 and photos of the PAW co-researchers drums. As also described in Chapter 3 and below, Doris and KJ were co-learners in this group and both facilitators and active participants in the workshop. Their drums and magazine photos are included here.

The four Montreal co-researchers were Inuit, spoke English as a second language (with Inuktitut as their first language), and had been living in Montreal for varying lengths of time. With the exception of one woman, participating in our group was their first public disclosure of their HIV-status – the first time they knowingly sat in a room with other HIV-positive women who, in turn, knew they were HIV-positive – and most had not shared their HIV-status with family or friends. Prior to *VH*, shame about their past traumas, their HIV-status, and their alcohol and other substance use, coupled with the abstinence-based zero-tolerance policies of most services, limited their ability to access the supports they wanted and needed. They struggled, therefore, with on-going shame and isolation. I cannot even imagine the strength and courage it must have taken for them to attend our first meeting - not knowing who would be there; what to expect; whether or not they might be judged. Their faith in Carrie Martin though, was clearly a deciding factor. As one woman shared, “I was always scared of my health. But thanks to Carrie Martin, I made it through, I came here. I thought I would never join you people. But I am here”.

Creating a 'safe space' for this group then, was of paramount importance. To address this, we held the workshop in a place that was familiar to the women; we had the workshop at a time that was convenient for them; we used a harm reduction approach to ensure a fun, safe, and non-judgemental environment; Carrie Martin, their support worker and our community partner, attended and participated in all aspects of the workshop; Sharp Dopler, *oskaabewis*, counselor, outreach worker, and drum-maker provided women-centred and culturally-relevant teachings and support; and finally, the disclosure and full participation of Doris and KJ in our workshop, our HIV-positive community lead and our HIV-positive Peer Research Associate, provided mentoring and positive role-modeling for the Montreal co-researchers and noticeably eased their anxiety.

Despite their initial misgivings, the women in this group were thankful for the opportunity to connect with other PAW. This peer-to-peer support allowed them to acknowledge and share their pain and their shame but also to ground this sharing in their own strength and assets. The Montreal co-researchers were cautious but hopeful; shy but excited; nervous but ready to share their experiences. Our days together were filled with laughter, with song, with stories, and with tears. When one woman disclosed an experience of sexual abuse that she had carried with her for decades, we all cried with her; her Inuk peers consoled her in Inuktitut, and the PAW co-researchers smothered her in hugs. When another brought in art-work that she had been working on for months as part of her healing journey, the others responded with praise and support. When a third revealed her fear of dying from HIV without the support of her family, the others shared her tears, her fears and their strategies for staying strong.

On the second day of the workshop one of the women took it upon herself to provide lunch for the group. Unbeknownst to us and at her own cost – both financial and physical – she packed all the ingredients for a beef stew into several shopping bags and carried them with her on public transit. She was so sick at the time that she could barely walk, yet she made the supreme effort to carry an extra 10 to 15 lbs of groceries and cooking supplies to our meeting. I cannot say for sure why she did this, but I like to think it was her way of giving back to the group and acknowledging their support. Six months later, she passed into the spirit world, but not before making arrangements for her drum to be given to her son.

Doris Peltier (Anishinabe)

Leap of Faith

This is a picture of a woman that's...she looks happy. She's right above water, she looks like she's in flight, mid-flight. She looks like she's in mid-flight and I guess what caught me is that she's at a point in her life where she's



willing to be adventurous. Because she feels confident and she feels healthy and it almost looks like she's jumping off into a new opportunity. She looks confident that she's going to a good place, a healthy place and she's willing to take that chance. And for me, I think it represents that she's at a place, a healthy place, where she's feeling physical health, mental health because the confidence is there, emotional health — she's taking that chance and she's jumped off this place and she's flying

to the next place. And her spiritual health — she's balanced. She doesn't know where she's going but she's willing to take that chance. She's healthy and she's confident and she's willing to take that leap of faith. And the water is good too. The water is very healing and very cleansing so the fact that she's going into a cleansing journey is really cool.

Possibilities

Well my drum, I left it open for possibilities. Because I am still here and there are possibilities in front of me.



But these flowers on the side that I chose to put on here, um, these are my clan colours. I come from the Deer clan, and this drum is really special for me. It's a real definite West door drum. And that's where I am heading. I will be 57 years old this year, and the Western door is looking closer and closer each year. And this drum is really special for me because of the way—the awakening ceremony that brought this drum to me, and I am going to learn lots from this drum. And that's why I put our clan colours on it. Waawaashkesh dodem, that's my clan. They are teachers. And I also put a red ribbon on it to remind me of the HIV that is in my blood and to remind others too, that this is a reality right now for us. The

HIV/AIDS red ribbon - that signifies hope. Over here, the swirls are women, around the shape of women from All Nations in Canada here. And it's a women's drum and I am just waiting for all of the possibilities that this drum is going to bring for me, so I left it blank. So that is what my drum means; it is very special, it is very humbling to get this drum. It's a real gift and we are going to learn together. This drum is going to teach me and maybe I can teach this drum too about my journey with HIV and we can journey together, and help each other. Meegwetch.

ES (Inuit)

Strong Like a Polar Bear

This is a picture of a polar bear. The polar bear looks very strong. I always wanted to be strong like a polar bear.



My brothers used to say that you should be a man to do that and I said, "no, I don't have to be a man to do that. Don't you just love the way I do things?" And they would push me to get me closer and they would say that we just want you strong like that. They figured maybe I didn't look as big as the polar bear. When I was young I used to think about how they [polar bears] grow old. And I want to grow old. With the stuff I have [HIV] I put myself down and I just try and get

up. That's it. That's all.

Grandkids Make Me Happy

I like my drum. I was thinking of the drum that we use back home but it was this kind. And I love it. It means my grandchildren, very much. I love all my kids but my grandchildren are #1....I wanna stay longer. I wanna help people like me [living with HIV]. I hope when I make noise with my drum that it's going to be happy for me. It's going to be settle down for me, this drum. My health, I've always been scared of my health. But thanks to Carrie Martin, I made it here.

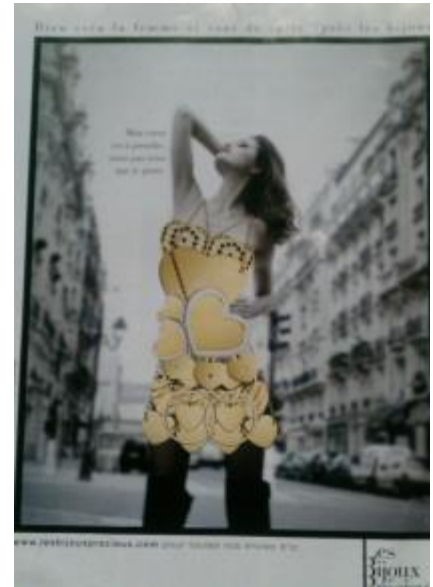


I came here. I thought I would never join you people but I'm here. It's reality to me and my kids. I'm very happy I made the drum. It keeps me busy, which I never did for a long time. That's about it.

KJ (Anishinabe)

Gold Dress

This is a picture of a woman, and she is wearing a—it looks like it's made out of gold chains, like little pendants from hearts, made into a dress. So that's my gender for me, because it's made into a dress. And it's a female. So I think the health part of it is your heart. So whether you exercise, whether you do whatever you do, to help keep yourself healthy. And she is wearing it. Because as an Aboriginal woman living with HIV, you have to keep yourself healthy to do whatever else you want to do in life. Whether it be to raise kids or whatever, prolong your life. You have to stay healthy and it starts within your life. And it's gold! Even better!



Four Directions Drum

My drum is of the four directions. First of all my drum is a centered drum from the awakening yesterday. And I put a sun and a moon on there, because it represents day and night. And there are stars, the four directions, the colours are on there. To me, that is the cultural part of my drum, and the health is, I guess the day and night. Day and night I live with HIV, so I have to take care of myself like I will take care of this drum.



LA (Inuit)

Mother Goose

I am very privileged to be part of this HIV group with these ladies and to get to know them a little bit. I made this beautiful drum which I never thought in my mind I would have ever done, and it has roots on it with flowers that are reflecting together. And those are all the ladies with HIV and the men with HIV. And I feel I belong to this HIV group now and I feel so much better. Today at least. And the hearts that are two of them, those two hearts are...I wanted to connect my heart, to take better care of myself for a long time...I've been struggling for a couple of months and I hope this creation that I made with you will help me and remind me and continue to stay healthy. And this one here is Mother Goose. I know that I am much loved, and again, I want this to remind me that I am so cared about and loved by my children that want me to continue and strive to do better. I have only one daughter with whom I can share with what I have and I hope that this can be a reminder about what you all taught me or reminded me about myself....And this four season, four elements, four colours, I thought about that a long time but I never really put a paint and make something out of it like this. And I'm adopting that and I hope that it will help me to go on and stay healthier. And the butterfly is that no matter how many struggles I go through there's always someone out there who is going through more. The sun of course is not forgetting to pray each morning, each night before I go to sleep, and wake up each morning despite how shitty I feel. And in these rooms, I feel like I grew up a little bit more. Understand my being as an HIV infected woman. I really appreciate that, for making it happen, and I hope that it can happen more often. It helped. It worked. Also, these two stars, two stars together in one. I'm two spirited. Not that I'm lesbian or gay but I'm two-spirited. I have a she within me and a she outside of me. And the younger one, when I was growing up, I stopped growing when I was sexually abused and I want to teach her, get her to take care of herself, not to be abused and taken advantage of.



MT (Inuit)

Healthy Environments

It's the words that are important in this picture. It says, "to improve their health the Starrs made a crucial decision and moved to a place where good choices are a way of life." Because mine is, I have a couple of vocal cord troubles, asthma, my feet are starting to swell and my pneumonia is coming back. But I want to improve my life. And fresh air. Go for walks. That's what I've been doing with [my boyfriend], we go by the water. I want to go vacation back home.



ME (Inuit)

Freedom!

I've been diagnosed for over 10 years and a half. I have butterflies with four directions — white, yellow, black, red, and white. The blue...I put blue because blue sky, blue water, north, south, east, west. I put a lot of hearts around my drum because we're full of hearts, such nice people, we carry our hearts every day, 24/7. Why I put so much hearts on my drum is because of the heartbeat. I put a lot of blue because blue is my favourite colour. I'm very happy to be here to do this workshop. Why this drum is important to me because it put a lot of positive feeling. And this drum, it means a lot to me. Why I put butterflies on my drum is FREEDOM! FREEDOM! They open their wings like we open our arms to each one of them to walk into our arms. Because we [PAW] go through so much, so much! We can't share our garbage with our families, we have to keep so much to ourselves. And yet we're here and share our good stories and have fun and get along. This is something. For me, this drum ain't going nowhere! Nowhere! It's all mine!



Virtual Group (N=4)

The Virtual Group, as we came to call them, was a small but mighty group of PAW who were already active in the Aboriginal HIV and AIDS movement. From all across the country, these women had already taken the crucial step to become involved in their own healing and the healing of their communities by being activists, advocates, educators and leaders. Openly HIV-positive, in their regions they held positions as counselling and support workers, as consultants to provincial governments, and as Board Members to a variety of Aboriginal AIDS Service Organizations. Some were long-term survivors (20+ years) while others were more recently diagnosed. What they all had in common though was membership in a group called CAAN VOW – CAAN’s Voices of Women Standing Committee – a group dedicated to developing leadership capacity among PAW. These women heard about the *VH* project from our community lead, Doris Peltier, who was also the staff lead for CAAN VOW. After expressing interest in our project and after discussion with our Community Advisory Committee, eligible members of CAAN VOW (not all members are HIV-positive) were formally invited to participate.

Given the geographic diversity of this group (members were from four cities across three provinces) we were challenged to come up with a means of engaging these women that was both meaningful and feasible. In consultation with them, with our Advisory Committee and with Wanda, our Traditional Knowledge Keeper, we held a 1.5 day in-person, culturally-grounded orientation meeting in Toronto in August 2011 where we met to discuss the project and problem-solve solutions. On the second day, they each received a digital camera and training in digital photography by a professional Aboriginal women photographer who is known for her strengths-based images of Aboriginal people. To make the project work, we agreed to weekly Skype-meetings from August to November 2011 to stay connected, to support each other through the process, to trouble-shoot issues related to the project, and to discuss the photos they would take. We also set up a private Facebook® page to facilitate on-going communication and photo-feedback and ensured telephone or email access to the Core Research Team and to Wanda Whitebird, our Traditional Knowledge Keeper, Counsellor and Support Worker, between meetings.

While there were many challenges associated with such a technology-dependant process – and we have argued the pros and cons elsewhere (Prentice, et al., 2011) – the

women were excited to take on this new challenge, to be learning new skills, to be connecting in this way, and to be co-researchers in our project. Despite their larger roles as activists and advocates in the community, few had had the opportunity for self-reflection and creative self-expression that VH afforded. As their photo-stories reveal, however, when given the opportunity and the support of their peers, this group of PAW did “a lot of soul searching” (PAW) and “became stronger from the experience” (Candy).

Candy (Cree)

Circle of Light

I took this picture because I love the sun.

The sun brings warmth, comfort and light.

*And that's what these wonderful ladies from
VOW have given me.*

I was alone for a long time.

I was yearning to meet people like me.

Even though we are far apart,

I feel their positive energy

and their love is like the ray of the sun.

And because of them, my healing journey begins.



Life Is A Mystery

Each step I have taken has been a struggle.

Even though I have made it this far (13 years)

*I often think of my late mother, after her HIV diagnosis,
she has chosen to go down head first.*

*I try to imagine what were her last thoughts
as she let herself go.*

Dream (Reserve in the Mist)

*Sometimes I wish this HIV diagnosis was just a bad dream
and that I will wake up soon
and I will be healthy and happy
and the world will be bright again.*



Creek

*I feel blessed every time I witness a new season.
It makes me reflect on how lucky I am to be here.
Like the footprints on the sand saying I am here*

Krista Shore (Cree)

Keeping The Circle Strong

*Young girl, my daughter, the circle with all the colours
with all the quadrants. This is a photo of two girls
holding hands, and that's to represent the circle and
the unity and being welcomed into the circle. Because I
was welcomed into the circle at a CAAN event and
that was pretty powerful.*



Sun Behind the Trees

This brings back a teaching to me, of an Elder that is very sacred in my life right now that I believe plays a very important role and that the teaching that this Elder shared with me is about the universe and about mother



nature's sacred healing energy and about the power of the creator to shine the good medicine. And to me, this light, this light is life and energy and that's good medicine and that's mother nature's sacred power and healing energy right there. And that's very sacred to me, that sacred healing energy. And I really count on that. I have been trying so hard to really rehabilitate my thinking every day when I wake up in the morning to feel happy, to feel alive, to feel energetic, to be like that

light and to let my light shine. Let my light shine that connects to my health and my gender and my culture because that connects to me and who I am as an Aboriginal woman as a spiritual being, to my identity. And to me, utilizing those teachings promotes longevity in my life. It gives me the hope. It gives me the need to thrive and all those other big things.

Pathway to the Light

You can see all the different texture and the beauty in nature and in mother earth. And you see that shadow. To me that shadow represents the darkness, and that's where I was. When I was in Toronto, there with my friends, I was in a lot of darkness and I was really, really, unhealthy in my mind and in a lot of pain. And now looking at this picture, I've since then, come out of that shadow, and that darkness and letting that darkness guard me, or hurt me, or make me feel fear or all of those negative things. So now if I see myself in this picture, I visualize myself walking past the shadow and into the light and there is light at the end of the tunnel and there is life.



Clearing the Way for Our Future Generations

To me this picture is very symbolic and very honourable to me because of each and every one of us that sits in a circle here are advocates and activists and educators and strong leaders in our community. Putting our right foot



forward, looking out for our children and our children's children and all those other generations to come after that. So that there will be a day where there will be no AIDS, zero AIDS. So that there will be a day where they have a cure for HIV/AIDS. So that there will be a day that we are safe to live in our communities, and that we are accepted in the circles. So that there will be a day when there are no children born positive.

And that to me is looking at it like we are in a big forest and we are all in this forest and we have all these trees that we have to knock down and all these barriers because of our determinants of health and we are those bulldozers, and these are our feet and we are pushing forward and we are clearing the way for our future generations. So, to me that's what that speaks in depth to me and it means a lot.

Spider Web Under the Deck

This to me is health, culture, and gender. To me it represents the web of life. I took this picture, this summer after I buried one of my bros who died of an accidental overdose. That morning I was honoured in saying a eulogy. Their family, those are my ex-in-laws and I am very close with them and they honoured me with going up there and sharing some words to bring comfort and bring some honour to my brother before we laid him at rest and I knew what I had to share. I had to share what my Elder's teachings are, talking about the web of life. Even in the bible they mention, without death there would not be life, without sadness there would not be joy, without hate there would not be love. And I had to learn about the balance and the connectivity to the world, to the universe, to the creator, to mother nature, and all those great things. So to me, that reminds me and speaks of that message that I know. And I shared that message most of all, because I could see in the crowd that I spoke to, a lot of sorrow and a lot of pain,



and a lot of people sitting there, wishing that they could have done something. Or if only they could have done something and I just comforted them not to blame themselves. That's a part of life and those are people's decisions and sometimes we are not in control of their decisions. But that it's not goodbye, and it's only see you later. You know, until we meet again.

Fireworks

This one fills me with a lot of spark and a lot of liveliness, a lot of energy, and a lot of fuel. And to have fire in life and really when I look at all the different theories that I am aware of in life because I like to combine a lot of spiritual with all the different cultures of the world and that I do know about illness that I myself I attracted my illness to myself. And I have to accept that. That I made those decisions and I attracted that illness to myself and over the years of coming out of that shame and that pain and all of that. And the more that I have, I've been empowered through education, awareness, support and to have love and compassion for my fellow people. I have come to that acceptance of my illness and that acceptance to be able to live with it. To look past just being a statistic, or all of the negative stuff attached to being positive, that we like to impose on ourselves and that we sometimes live and breathe on a day to day basis. And what I do know about health is that your health of mind contributes a lot to the health in your body, in that if you can overcome and be empowered to move forward and live and love life in health and control your daily choices and decisions in regards to your health that you can definitely have a high T-cell count which contributes to a more healthy immune system, which contributes obviously to longevity you know and all those other things. So when I look at that, I just get the excitement and the passion and really this project has really given me that and really blessed me with that. A lot of really good substance.



Child's Handprint

When I look at that handprint on that pot, I am reminded of our future generations and I am reminded of how I need to do right and to be right and to be good, and to live good and to show my kids good the best I can, for my future, for my children and my children's children that come into this world. I am reminded of the residential school impact and that syndrome that still ripples and affects our people. That contaminated our communities, our way of life, and I am reminded of how I have to work hard every day. I am also reminded of my own personal

journey inside lately. Lately I find myself really sad and really hurt and really not me. Not the strong, proud woman that I am. I often sit and think, why do I feel like a little girl? Well that's because now I am aware that I have an inner child inside of me and that I have to honour that and connected to that inner child is a lot of trauma. There is a lot of hurt. There is a lot of pain. There is a lot of things I have to bring my spirit up to the level of maturity. Maturity within myself. So that's what that speaks to me.



Liz (Gitskan)



Grandfather Rocks

Rocks make for a solid foundation. As a child I used to spend my time looking at them in the river. One or two would catch my eye and I would take it out of the water. An Elder from the east much later on in my life told me they were grandfather rocks. I didn't know what that meant until I studied various cultures from across Canada. One that stood out for me was the Historic site in Mission. Wow, good to know. They are also healing rocks that I have in my living area for good health.

Mind, Body & Soul

I spend a lot of time trying to find ways to improve my main thoughts while being in the world, to better myself, and that is looking at books on mind, body and soul. I spend my time finding things that will help me through challenging issues with myself.



Golden Angel

I remember this day vividly, as if it was yesterday. It was Easter Sunday. I went through an unexplained experience with light. It was close to this colour. But it filled me with good energy and lifted me awake. So loving, I couldn't make sense of the unexplained. I was alone then. I had given up hope and didn't see a future with pain and sorrow. That night as I slept I must have surrendered to my Creator. He came and lifted me up from my dying sleep. I am still here and doing a lot of teaching in the community I live in. My memory of that colour helps me to this day to heal any minor or major illness that I experience. Visualization is part of me. I treasure when I am out with Nature angels. Inside I breathe in calm and comfort when life gets too hectic. I get grounded from the earth beneath my feet. I revitalize and balance from the energy that flows from the roots of the trees. I think about when life was simple and no worries.



Concrete Jungle

Waiting to transfer on a bus home. It was a beautiful day. Sun was out. As I looked down I was captivated by the cement in front of me. I took the picture and wondered why did I take this picture? So many people stood at the bus stop waiting for #4 or #7 to get home. I thought concrete jungle and walking on it. Gave me migraines. I live this life of walking on concrete. I live thinking what will help me walk with comfort on this concrete? So



many thoughts came. I think about the environment, how it looks to me. Not pretty or peaceful, just a fast pace society. I learned to live in it. Concrete jungle and chaos. I learned to walk the walk with thoughts of what I was told when I first left home by my parents, Grandparents, and their family. Always told I need to get an education to live in today's society. So I persevered through the changes in my life without family. I said if this bird can do it, so can I!

Cedar Boughs



Cedar boughs after a wash in the rain. Love the freshness and scent from the tree after the rainfall. So refreshing and cleansing. Aroma-therapy. Releasing emotionally suppressed trauma. My soul-heart consciousness in action. The heart chakra is green. It's a balancing colour and encourages emotional release. GREEN: healing, peace, nurturing, new growth, fear, need for security, jealousy and envy, balance. At this moment the need for security is calling for this colour for

healing.

Paw²² (Blackfoot & Kwa' Kwa' Ka' Wakw)

Forgotten Dandelion Wishes

When I was a young girl, growing up, I was always sent out to play. Running in the bushes, and jumping down the gravel pit were some favourite games I played. I remember in the summertime, the dandelions were always a sign of hope to me. Being outside was an escape at times, and I used to wish that I would be safe. Wishing was one way of coping with the abuse at home. My mind also helped me cope, by making me forget so much of my childhood. I do not remember my childhood, and gather information from other people.



²² This co-researcher has chosen to use the acronym PAW as her pseudonym. To avoid confusion, I refer to her throughout the thesis as Paw and to Positive Aboriginal Women as PAW.

Peaceful Grey

One of my loves in life are birds. I love eagles, hawks, the mythical Thunderbird. I love them all. This was one of my bucket list pictures, to visit a Birds of Prey Centre. I watched this bird groom himself, and it was my first time being close to a Golden Eagle. It made my heart flutter...birds are my messengers.



No-Bodies Child



This discarded, stepped on, and ignored picture was found outside of a Child and Family Agency, just on the sidewalk. I found it stood out to me, because I wondered if it was the only picture a parent may have had of a child taken by child services. It made me think of how PAW get treated within today's society. We get stepped on, over, and when we assert ourselves, we are labelled as difficult, angry, irrational, etc. Ignored and disrespected as life-givers.

Dark is the Light

I took this picture, because it shows how much my family and I love the sunshine, and nature, together. I loved watching how big my shadow could be as a child. The sun warms, heals and energizes me. The shadow also represents the size I have to be as a PAW (Positive Aboriginal Woman), to manoeuvre through the multiple systems I may find myself in (i.e., medical, legal, etc.). The spirit of many PAW is indomitable, even when resilience is overwhelmed repeatedly.



Skritchies

This picture makes me think of the scars and stitches. I may have many wounds that have happened to my soul, spirit, mind, and body, but I heal. I have always healed. I don't know how, but no matter what has happened, my inner being knows how to heal...that makes me feel in awe of my body at times.



Canafrica



one year, and this is 2011...in Canada.

For over twenty years the Indigenous community and epidemiologists have predicted the human immune-deficiency virus would reach epidemic proportions, and it has. I have beared witness to this epidemic since 1988-2011, and watched as others' ignored what has been said over and over. I have watched a nine year old intravenous drug user and dealer, shoot up an older woman on a camera phone. I have a friend who has buried over nineteen friends who are HIV positive in

Shame-full

This picture makes me think of how we PAW have to hide many things to survive at times. I have carried shame for having a brain disorder, caused by trauma, and abuse. It makes me listless, hopeless, and isolated many times. I do not like big crowds, even though I have done public speaking for many years. I hid to be strong. I am not strong, I am vulnerable, sensitive, and hide so much of who I am at times, because of shame.



Chapter Summary

In this chapter, I have offered the photo-stories of PAW co-researchers in their entirety and without interpretation. Following Wilson's notion of 'relationality' (2009) I have tried to give you enough information about each group of PAW to provide a context for each co-researcher's photo-stories so that you might begin to build a relationship with each co-researcher but also with each group of women. Each group of women was unique and the dynamics of each group and the relationships that we had with each other had an impact on the kinds of photo-stories that the PAW co-researchers were willing and able to tell. These are heart-felt stories of pain and hurt, of joy and hope, of culture and healing, of resistance and resilience. These are stories told in-relation to the circumstances, to others and to the stories of others. As you read on in this thesis, I hope that you will come back to these stories to remind yourself of who the storytellers are and of this holistic and relational context.

Chapter 5

“Connecting Helps Us Heal”: PAW’s Experience of Health

(with Doris Peltier and KJ²³)

Introduction

As noted in previous chapters, the vast majority of research concerning HIV-positive aboriginal women tends to focus on the experience of illness and therefore we know very little about PAW’s experiences or perceptions of ‘health’. The PhD work of Kim McKay McNabb (McKay-McNabb, 2006) on healing for Aboriginal women living with and affected by HIV, and the limited literature on health and well-being for HIV-positive women in general (Teti, Massie, Cheak-Zamora, & Binson, 2012; Groft & Robinson Vollman, 2007) are exceptions. To address this gap, and to counter the negative images of PAW that predominate, we asked PAW co-researchers what it means to be ‘healthy’ as an HIV-positive Aboriginal woman. We draw here from the photo-stories that were highlighted in the last chapter, the sharing circle transcripts, and from field notes. Consistent with our participatory Indigenous methodology, the following analysis is based on the dominant themes identified by PAW co-researchers in our participatory analysis sessions.

What Does ‘Health’ Mean for PAW?

The PAW in this project understand health to be holistic, relational, collectivist, and integrally tied to their identity as Aboriginal women. As we might expect, health for PAW includes components of physical health, mental health, emotional health and spiritual health, but it also includes social/community and environmental dimensions. While all of these components of health are thought to be important in their own right, they are not discrete domains, and it is the sum of the parts that truly matters. Health for PAW is about the interrelatedness between these dimensions; about finding a balance between them and in relation to current life circumstances. Health, therefore, is a fluid concept for PAW co-researchers and changes with life circumstances. The notion of self-determination; of taking responsibility for, and taking control of, their health is a cross-cutting theme.

²³ Special thanks to Sharp Dopler and Carrie Martin for discussion and feedback on this chapter. Krista Shore and Kecia Larkin also reviewed this chapter.

Physical Health: “Being able to get up and do things”

Notions of physical health for the PAW in our study coalesced around the idea of “being able to, like, be just functional on a day to day basis” (KJ); and being “able to get up and do things, you know, like shower, make breakfast and eat. And to be able to walk around, like, the way that I do. I walk like almost ten miles a day or even more” (Stacy). For PAW co-researchers physical health was seen as a resource for everyday living; a tool that allowed them to live “as normal a life as possible” (Liz). As KJ explained, “as an Aboriginal woman living with HIV, you have to keep yourself healthy to do whatever else you want to do in life. Whether it be to raise kids or whatever, you have to stay healthy and it starts within your life”.

Taking responsibility for their health behaviours, including diet, exercise, being drug and alcohol free, taking medications and seeing doctors regularly were all aspects of physical health that were important for PAW co-researchers. As Stacy points out above, walking was an important activity for some PAW co-researchers while others “engage[d] in adequate exercise to achieve strength, endurance and flexibility” (Liz). For still others, diet and nutrition were cornerstones of their physical health. For those taking HIV medication, or with co-morbidities, including drug and alcohol use, understanding the impact that diet and nutrition had on their bodies was essential. Tonie, for example, used food to “give me that boost, right?” and Laverne, who was diabetic, was careful “to eat properly and try to stay away from junk food”.

Being alcohol and drug free was another important component of physical health for PAW. While drug and alcohol abuse had touched the lives of all of the women in our project in some way, most of the PAW co-researchers in our study had moved beyond this way of coping with trauma and had embraced drug and alcohol-free lifestyles. KJ shared that “Um, for me to live healthily, idealistically, in a perfect world, I think I’m getting there – drug and alcohol free.” Even those who were still using, though, said that being healthy meant being free of drugs and alcohol. Stacy, for example, considered herself an alcoholic but shared that “my vision of health would be to be drug and alcohol free, so to live longer”.

As women living with HIV, managing their HIV, having a good doctor, and taking their HIV medications was an important aspect of physical health for PAW co-researchers. For Tonie, for example, health meant “medications, good doctors. You

need good doctors, that's for one thing". KJ agreed saying, "I think also medications, doctors, um, yeah, taking care of yourself". Liz sometimes struggled with her experiences of health care but felt that seeing doctors regularly was an important part of maintaining her physical health. She shared that, "as a PAW, I really need to be vigilant, regardless of the feeling of being, um, being vulnerable, and being in vulnerable positions at the medical exams".

Being physically healthy for PAW then, was about living active, "normal", and independent lives. It was about being physically and medically healthy enough to carry out their daily activities, to "live long and accomplish all my dreams" (KJ) – and managing their HIV was only one aspect of that larger goal.

Mental Health: "Being strong about yourself"

Mental health meant a variety of things for the women in our project. For some, being mentally healthy meant successfully managing stress, depression and other mental illnesses. Paw, for example, shared that:

Physically I am probably healthier than I have been in fifteen years but my health is also determined by other factors like mental health. I have mental health issues and if I'm not managing or having that balance in my life it's really easy to make myself vulnerable to either, you know, outbursts of anger or frustration or different things that I've tried to work really hard to change in my life. ... So I really have to pay attention to that balance in my life and when I'm not taking care of myself or saying what I feel...I'm the one who suffers.

Likewise, KJ shared that: "I try to stay as stress-free as possible....Because when things get to you, it's more stressful and stress adds on to HIV; you know, your counts go haywire, at least mine do".

Taking responsibility for their health and holding health care providers, service providers, policy makers, and others to account was another measure of mental health for PAW co-researchers. Doris expressed this as "having a voice, um, being able to advocate for myself and to do the research for myself in order to be healthy". KJ explained that "I have a

voice and I like to use it”. For Paw, having access to information and learning “how to manoeuvre through a system, you know, whether it be the disability, provincial disability program or another system” was hugely important. She explained that she felt most healthy when “I feel like I have control over my health care, and my doctor and my health care providers, you know, are on the same page as me”.

For others, being mentally healthy meant taking responsibility for their thoughts and their actions; it meant rejecting “that old mindset of being a victim” (Doris); “taking responsibility for my thinking and the way I see the world” (Liz); and embracing self-determination. In *Mind, Body and Soul*, Liz shared that: “I spend a lot of time trying to find ways to improve my main thoughts while being in the world, to better myself, and that is looking at books on mind, body and soul. I spend my time finding things that will help me through challenging issues with myself”.



Mind, Body and Soul

ES said that: “I can’t blame anybody for what I got. It’s not their doing, it was my doing”. Finally, in *Fireworks*, Krista reflects passionately on what she perceives as the importance and the impact of taking responsibility for her thoughts, her actions, and her illness:

I attracted my illness to myself, and I have to accept that. ... And the more that I’ve been empowered through education, awareness, support, and to have love and compassion for my fellow people, I have come to that acceptance of my

illness and that acceptance of being able to live with it; to look past just being a statistic, or all of the negative stuff attached to being HIV-positive that we like to impose on ourselves and that we sometimes live and breathe on a daily basis. And what I do know about health is that your health of mind contributes a lot to the health of your body, in that if you can overcome and be empowered to move forward and live and love life in health and control your daily choices and decisions in regards to your health, that you can definitely have a high T-cell count which contributes to a more healthy immune system, which contributes obviously to longevity.

Rejecting the mindset of the victim though, and embracing self-determination takes courage, strength, and perseverance. As Doris explains, “it takes courage to be able to do that and it takes belief in yourself”. This is especially true when faced with multiple forms of oppression including “economic violence” (Paw), colonialism, racism, and HIV-related stigma and discrimination. For the PAW in this study then, being mentally healthy meant being “resilient” (Doris); being “strong” (Paw); being “confident” (Doris); being able to “break past those barriers, and ...make a new way” (Krista). As Stacy explains, “the strength comes from you, what you want to do with your life. You know, there is always those helpers who will always be there, but there will always be these hurdles in front of you to make you use that strength. Be strong about yourself.”

Emotional Health: “Feeling good about myself”

Emotional health for PAW co-researchers was primarily about their “ability to manage and assess [and] deal with feelings and emotions effectively” (Liz). It was about “feeling good about myself and um feeling physically and emotionally balanced and having to feel, uh, happy some days” (Liz). Feeling good, happy, confident, peaceful, joyful, hopeful, and optimistic were emotions that PAW co-researchers felt were healthy. When describing *Mosaic*, Tonie explained that: “this is health, because this makes me feel good. It makes me feel positive, it makes me feel alive”.

PAW co-researchers also acknowledged, however, that these positive emotions did not come without effort. Emotional health was also about seeing, feeling and

acknowledging negative, painful or hurtful events and emotions, but working to find the positive in them. As LA shared, “I always try to make things simple, as much as I can and make the negative a positive”. Doris also shared that: “I prefer to be hopeful and look at [things] in a positive light”. In fact, when viewing the entire groups’ photo-stories Doris “saw a lot of pain and fear but not helplessness or hopelessness. I saw that despite the pain and fear, there was a lot of hope and strength in all the photos”. Krista’s photo of *Pathway to the Light* is an excellent example:

You see that shadow? To me that shadow represents the darkness, and that’s where I was. I was in a lot of darkness and I was really, really, unhealthy in my mind and in a lot of pain. And now looking at this picture, I’ve since then come out of that shadow, and that darkness and letting that darkness guard me, or hurt me, or make me feel fear or all of those negative things. So now if I see myself in this picture, I visualize myself walking past the shadow and into the light and there is light at the end of the tunnel and there is life.

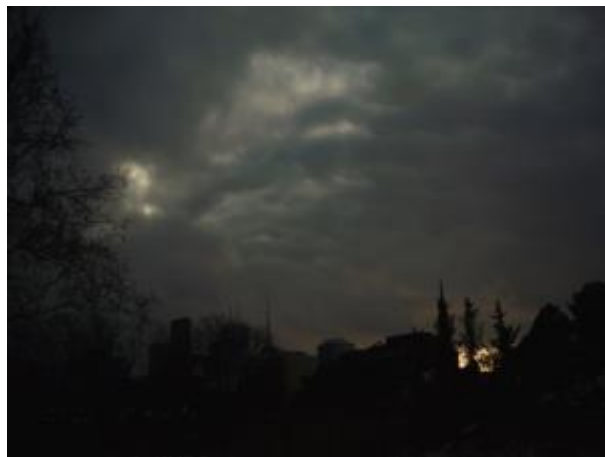


Pathway to the Light

Emotional health, then, for PAW co-researchers is about accepting and acknowledging the obstacles that are placed in their path; acknowledging the pain and

the fear that life brings, including racism, rejection and HIV-diagnosis, but despite all of this, choosing to remain open to possibility, to happiness, to joy, to hope, to beauty and to life. In *Hope Amidst The Turbulence*, Doris explains:

I took this picture because it's cloudy and it's how I felt when I was diagnosed with HIV. My world was filled with turbulence and I couldn't really see a future. BUT there's hope in this picture which at first I didn't see. There is hope because there are two glimmers of light trying to break through, one beautiful glimmer is on the horizon and the other is trying to burst through the clouds. Light is very important because light is life. For me, this is a really powerful picture, as I now recognize there is indeed hope amidst the turbulence.



Hope Amidst The Turbulence

Spiritual Health: “That’s a healthy place to be, connected to the Creator”

While spirituality meant a variety of things for the women in our study, they all agreed that it was an important dimension of PAW’s health. Liz shared that, “spirituality is important to me for good health and it has always been that way”. Laverne explained that, “my strength comes from having faith. What gives me strength is that I always have to be – God has to be in my presence or I have to acknowledge Him. That’s what gives me strength”. KJ agreed saying, “my strength comes from God as well, well my Higher Power”.

For some of the women in our project, spirituality was considered the most important health dimension of all.

I think the spiritual part is the most important part. It's what keeps me connected and able to keep moving forward; just knowing that the Creator is looking out for me, and that I am just journeying through here to go back to the Creator at some point, because, um, those other parts are only temporary. Like the physical is going to break down. The mental, probably when I am 70 years old, my brain won't be as sharp and all those parts they kind of wear down, but the spiritual actually grows stronger (Doris).

Spirituality was also the most closely aligned of all the health domains with culture for PAW co-researchers and was sometimes used as a synonym. As Doris explained, "I think spirituality is a component under culture, right? Spirituality is actually what I was talking about. That connection to the Creator". This form of spirituality is sometimes referred to as the 'red road', a form of spirituality that is embedded in First Nations traditional cultures and involves learning and practicing cultural traditions and ceremonies. As KJ shared, "when I'm on the right path and living the red road, I'm good. You know, everything goes well, everything is healthy for me. When I slip is when everything goes crazy."

For PAW co-researchers, however, the Red Road was not the only way. Many women combined their cultural traditions and practices with some form of world religion such as Christianity or Islam while others liked "to combine a lot of spiritual with Western with all the different cultures of the world" (Krista). For example, Paw explained:

I don't rely too much, like on, you know, ceremony like some people do where they go Sundance every year or go to winter ceremonies. That's not my reality. I try to create that [spiritual foundation] within my own family, so my children know, you know, have an idea of Creator and the laws of Mother Nature, [and] if you want to break it down, you know, we do talk about the bible. We're not afraid to use Christian language or terms but in the same token we are able to slide right into doing a smudge and integrating that.

Spirituality then, was practiced in a variety of ways by PAW co-researchers, but regardless of their individual beliefs or practices, all PAW co-researchers agreed that

spirituality means “connecting with your spirit” (Paw), and they all agreed that, “it’s a healthy place to be, connected to the Creator” (Doris).

Holistic Health: “You have to find the balance”

As noted above, each of these dimensions of health – physical, mental, emotional, and spiritual – is important in its own right, but optimal health for the PAW in this study was about the interrelatedness between these elements and about finding a balance between them. As noted earlier in this thesis, the symbol of the Medicine Wheel and the Medicine Wheel teachings are not pan-Aboriginal, yet the Medicine Wheel has become a ubiquitous symbol of holistic health across Turtle Island. Not surprisingly then, many of the PAW co-researchers in this project drew freely from these teachings. As Liz shared:

[W]hat does [health] mean to me? Focusing on the four aspects of myself in the medicine wheel, and focussing on the physical, emotional, spiritual, mental aspects of me. ... For myself, I adopted the use of the medicine wheel to help me keep a balance emotionally, physically, spiritually and mentally, and that’s not part of my culture but it’s something I need to do ... and that has helped me to keep a balance in my life to stay healthy, for myself.

LA, an Inuit woman for whom the Medicine Wheel has no cultural basis, painted a medicine wheel on her drum and explained: “this four season, four elements, four colours, I thought about that a long time ... and I’m adopting that and I hope that it will help me to go on and stay healthier.” Laverne, Tonie and Krista took photos of themselves or others at the centre of a giant medicine wheel and used that to represent health from a cultural perspective. Likewise, KJ created a medicine wheel from rocks and shared:

The big rock represents me, my rock. It grounds me. It grounds me for the little rocks. The spirituality, the health, the physical, well, the four culture teachings. And it’s surrounded by water, which is healing. And that’s just my whole culture. That’s why I chose it.



Four Little Rocks

Not all PAW co-researchers, however, chose to use a medicine wheel to represent holistic health. Doris chose the image below instead, explaining that:



Leap of Faith

For me, I think [this picture] represents that she is at a place, a healthy place, where she is feeling physical health, mental health because the confidence is there, emotional health – she is taking that chance and she has jumped off this place and she is flying onto the next place. And her spiritual health, she is, uh, she is balanced.

Holistic health for PAW co-researchers then, was inclusive of, but not limited to, the Medicine Wheel. For some women, the Medicine Wheel was an important model of holistic health that was culturally resonant. Others, however, felt no connection to the Medicine Wheel and preferred to think of their holistic health simply in terms of having physical, mental, emotional and spiritual dimensions.

Health as Relational and Collectivist: “I feel really like a part of the community”

Being healthy for the women in our study is about more than individual health; PAW co-researchers perceived their own health as integrally tied to the health of their communities – and their place in the community – and vice versa. This notion of collective well-being is often symbolized as a sacred circle in which each person has a place, no person is better than or less than another, and each person is equally valued. A sacred circle is strongest when all parts of the circle are in balance and when all parts are working in harmony to support other parts and to support the whole (Doris Peltier, personal communication). This notion of individual health as interconnected with the health of the collective was reflected in PAW co-researchers ideas of ‘acceptance’, ‘belonging’, and ‘giving back’ as integral aspects of their health. It was also reflected in their notions of healthy communities for PAW.

As a positive Aboriginal woman and what health means to me, is where there is acceptance, even from within your immediate circle. ...I feel supported when the acceptance is there and I guess I am talking about my family. ... To me that’s a really healthy way. (Doris)

[My family and community] show a lot of their support for me and with me and when I am home, I feel really like a part of the community. ... I don’t feel any different from any of them, and they don’t see me as being any different from them. And that um, really is a good feeling to have. (Liz)

Being ‘part of the community’ though, comes with responsibilities and these too are integral aspects of PAW’s health. A number of women spoke of their responsibilities to themselves, to their families, to their communities, and to the next seven

generations, as interrelated responsibilities that are integral to their health and to the health of their communities. As Liz explains:

I have to take time out for myself in order to be able to help others. And that's an important part of who I am as an Aboriginal woman living with HIV. ... When I contribute my skills to [my] community, I experience fulfillment, satisfaction, in applying [my] skills to the world. ... I do everything to contribute to the common welfare of the community. Seek and maintain a mutual respect with the people in my life, contribute to the wellness of my community by encouraging and elevating others to engage in a healthy lifestyle and activities.

When describing *Child's Handprint*, Krista also acknowledged the symbiotic relationship between taking care of herself and taking care of her family for the good of the community:

When I look at that handprint on that pot, um, I am reminded of our future generations and I am reminded of how you know, how I need to do right and to be right and to be good, and to live good and to show my kids good the best I can, you know, for my future, for my children and my children's children that come into this world.

Health for PAW co-researchers, then, also includes being a part of, and contributing to the creation and maintenance of, healthy communities. As Paw suggests below, healthy communities are ones that are accepting and supportive of all their members, including the most vulnerable.

Um, a healthy community for me is one that's responsive to the most vulnerable, whether that be vulnerability within a family or vulnerability within the community, so um, if you're talking about an HIV community, that means that we're connected not just on a professional level but a personal level where we support each other. [A healthy community] I think is one that you know, makes room for the ones that can't be in the circle all the time, so you know, when we

talk about drug addictions, you know, in an ideal world everybody is sitting in the circle, no matter where they're at with that right? ... So to me a healthy community is where everybody is able to be respected and have that space to say or feel whatever they, you know, they are at that moment.

Connecting to the Land: "Connecting with your spirit"

Connecting to the land, nature and the environment was another important dimension of health for the women in our study that was interrelated with all the other health dimensions. Connecting with nature, being out on the land, and understanding their natural environment was perceived to be fundamental to the health of PAW co-researchers. Doris expressed this connection as, "I am part of the environment", and after reviewing the entire groups' photos, Paw shared the following observations:

So when I looked at the pictures I thought of all the ways that we seem to interpret life through nature. Like we're so – even if we live in the city. ... So I think about, um, where people find safety, seems to be in nature. Being out, you know, which is connecting with your spirit; connecting with one's self. I seem to see a lot of that. The way that people um, what they feel like they belong to. That belonging right? ... Connecting with earth, connecting with things that we feel like we belong to including our families.

Candy also saw that connecting to nature and the environment was important to PAW co-researchers' health, and expanded on the interrelatedness between connecting with the land, connecting with families, and connecting with self.

Okay, a lot of things I noticed was the earth and how the beauty that [PAW co-researchers] seen with the nature. That's what I noticed a lot of – and their inner beauty... that we all have. And I seen a lot of uh, we are searching for that spiritual healing. Not just physical healing but I think it's also spiritual healing like emotional, physical, spiritual, mental healing. Along with all those medicine wheels and all those common colours, I seen a connection with the earth and the

families and generations because there are children there, grandfathers, ourselves. So, and tree connections – so it's like kind of related, from like the trees are connected along with the families. They are all intertwined. There is some type of connection with family and nature.

Culture, Identity & Health: “Knowing who you are...and what that good way of walking is”

An underlying theme in all of the above is the strong connection between culture, identity and health. For PAW co-researchers, “part of being healthy is knowing who you are, where you come from, and what, you know, that good way of walking is” (Stacy). While this meant something different for each of the women in our study, it primarily meant feeling connected to their culture and being “proud of who I am” (KJ) as an Aboriginal woman, and as an Aboriginal woman living with HIV. When describing the following photo, Laverne shared:



Medicine Wheel

[This is] the image of who I am in this world. ... I chose it because it has the four colours - white, yellow, black and red – and I represent that, that culture. I'm an Aboriginal woman living with HIV.

Krista too was proud of her culture and her teachings:

I feel an enormous amount of pride and honor. You know, pride, and honour and identity of who I am and where I come from as an Aboriginal First Nations woman and what that does for my health, you know, it fills me with energy, with hope, with passion, with you know, commitment, with love, with light.

Finally, when reflecting on the entire groups photos, Liz shared that “they’re all reflecting identity. And their values and their beliefs and they’re – when you look at them, they’re all part of the culture and our teachings passed to us from our Elders”.

Chapter Summary

Health for the PAW in this project then is fundamentally about ‘connecting’ and ‘feeling connected’ at multiple levels. Being healthy for PAW means being connected to oneself: physically, mentally, emotionally, and spiritually. It means being connected to others, including peers, friends, family and community by giving and receiving support, acceptance and safety. It means being connected to the land, environment and nature, regardless of where one lives. It means being connected to culture: knowing who you are, where you come from and what your traditional teachings are, and it means being connected to Spirit or the Creator. Each of these elements is interrelated and each is grounded in Aboriginal culture and ways of knowing that see all elements of the world as interconnected. In the following chapter, we explore the strategies that PAW use to support their health and the role that culture and gender play in supporting PAW’s health.

Chapter 6

“When Women Pick Up Their Bundles”:

Health-Enabling Strategies for PAW

(with Doris Peltier and KJ²⁴)

Introduction

In this chapter, I focus on the health-enabling strategies that PAW co-researchers used to support their self-defined health. The literature sometimes refers to these as ‘health protective factors’ (Duran & Walters, 2004; McIvor, Napoleon, & Dickie, 2009) but given our strengths-based approach, we prefer the term ‘health-enabling strategies’. In this chapter, we explore the findings around two primary questions: 1) what helps to create, support or maintain PAW’s health; and 2) what role do culture and gender play in creating, supporting or maintaining PAW’s health? The following themes emerged from participatory analysis and on-going discussions with Doris, KJ and other members of the *VH* team.

“Shaped By My Environment”: Understanding the Influence of Colonization and Inter-generational Trauma

While not a focus of this study, the influence of colonization on the lives of Positive Aboriginal Women was foregrounded by PAW co-researchers. When asked to consider their health and the kinds of things that support their health, many women told stories of coming to understand their lives in the broader context of colonization and its on-going impacts. They spoke of family disconnection, childhood trauma and abuse, intergenerational cycles of violence and neglect, harmful drug and alcohol use, and lateral violence in their communities. However, coming to understand these as patterns of behaviour that are rooted in, and perpetuated by, the colonial structures in which we all live was an integral part of their healing journeys, and an essential step on the path to breaking the cycle and changing those patterns.

In the following photo-stories PAW co-researchers reflect on the trauma they experienced as children and what they perceive to be the intergenerational impacts of

²⁴ Special thanks to Sharp Dopler and Carrie Martin for discussion and feedback on this chapter.

colonization on their families and themselves. In *Forgotten Dandelion Wishes*, Paw shares bittersweet and incomplete memories of her childhood.

When I was a young girl, growing up, I was always sent out to play. Running in the bushes, and jumping down the gravel pit were some favourite games I played. I remember in the summertime, the dandelions were always a sign of hope to me. Being outside was an escape at times, and I used to wish that I would be safe. Wishing was one way of coping with the abuse at home. My mind also helped me cope, by making me forget so much of my childhood. I do not remember my childhood, and gather information from other people.

In *Child's Handprint*, Krista shared her views on the interconnection between residential schools as a colonial policy, the devastating impact it has had on Indigenous communities, and her own struggles to be healthy; to heal her inner child; to come to terms with the fear and the pain and the trauma of her own childhood.

When I look at that handprint [of my child] on that pot...I am reminded of the residential school impact and that syndrome that still ripples and affects our people. That contaminated our communities, our way of life, and I am reminded of how I have to work hard every day. On the side of the remembrance and awareness of that, and our future generations, I am also reminded of my own personal journey inside lately. My inner child and being aware of that inner child, because I was looking at myself and really feeling immature. For a long time it was rotating masks and all that for survival, and lately I come to find myself to a point where I find myself really sad and really hurt and really not me. Not the strong, proud woman that I am. I often sit and think, why do I feel like a little girl? I am hurt and I want to cover my eyes and I want to run away and cry. Well that's because now I am aware that I have an inner child inside of me and that I have to honour that and connected to that inner child is a lot of trauma. There is a lot of hurt. There is a lot of pain. There is a lot of things I have to

bring my spirit up to the level of maturity. Maturity within myself. So that's what that speaks to me. (Krista)

LA also spoke of learning to heal her inner child. In *Mother Goose*, when describing the way she painted her drum, LA explained:



Mother Goose

These two stars, two stars together in one...I have a she within me and a she outside of me. And the younger one, when I was growing up, I stopped growing when I was sexually abused and I want to teach her, get her to take care of herself, not to be abused and taken advantage of.

Re-living experiences of trauma, abuse and intergenerational impacts of colonization is painful but re-framing these experiences can be decolonizing, cathartic and help to break intergenerational cycles of abuse and neglect. In *Visioning Health*, PAW co-researchers frequently saw these experiences as ‘teachings’, as painful experiences that they have learned from, grown from, and that contribute to who they are today. Tonie, who repeatedly ran away from abusive foster homes, shared that: “for me, I got a lot of strength from stuff that I went through and I made it. ... All that stuff that happened, I didn’t let it bring me

down. I got up and I said, ‘Alright, I’ll just go to another [foster home] and maybe they’ll be better.’ Never was, but you never know right? [Laughter]”.

In *Shaped By My Environment* Doris too reflected on her experiences; on how she responded to those experiences; and on the emotional and physical nicks and cuts that made her who she is today.

This is a picture of rocks under water. The water is very clear. I think it’s beautiful because all the rocks are under water. Water is powerful. The water has shaped these rocks over thousands of years to appear the way they appear in this picture. For many, many years, I felt disconnected, and today I feel very connected to my place in this world and to me that’s what these rocks signify. They’ve been shaped by the environment much like I’ve been shaped by my environment, sometimes in a very negative way. It’s left little marks on me that you may not be able to see – like HIV – but I’m still here, much like these rocks.

“We’re Still Here!”: Resistance and Resilience

On-going struggle is a reality for the majority of PAW, both before and after their HIV diagnosis. Yet, in the words of PAW co-researchers, “we’re still here!”. “We are still honouring who we are as [Aboriginal] women, no matter what is happening in our lives” (Doris). “You can beat us, you can tell us not to speak our language, but we are still spiritual beings and we are still the makers and the givers of life. We are still all those things and that all has power...So put that in your pipe and smoke it!” (Krista).

The photo-stories of PAW co-researchers speak of resistance and resilience. They speak of confronting and overcoming hardships; of adapting to new and difficult situations; of carrying on despite the challenges. As Doris observed after reviewing the groups photo-stories, “Women are survivors, no matter what. I hate using the word resilient because I think it’s overused, but there is resilience in here. [...] That true resilience comes through in these pictures”.

In *Concrete Jungle*, Liz reflects on the daily challenges she faces living in an urban centre and the teachings she carries from her parents and grandparents that help her negotiate those challenges.



Concrete Jungle

Waiting to transfer on a bus home. It was a beautiful day. Sun was out. As I looked down I was captivated by the cement in front of me. I took the picture and wondered why did I take this picture? So many people stood at the bus stop waiting for #4 or #7 to get home. I thought concrete jungle and walking on it. Gave me migraines. I live this life of walking on concrete. I live thinking what will help me walk with comfort on this concrete? So many thoughts came. I think about the environment, how it looks to me. Not pretty or peaceful, just a fast pace society. I learned to live in it. Concrete jungle and chaos. I learned to walk the walk with thoughts of what I was told when I first left home by my parents, Grandparents, and their family. Always told I need to get an education to live in today's society. So I persevered through the changes in my life without family. I said if this bird can do it, so can I!

In *Skritches*, Paw reflects on the many 'wounds' that she and other PAW have endured to their bodies, souls, minds and spirits and the tenacious way in which PAW manage to 'keep it together' and to survive.

This picture makes me think of the scars and stitches. I have seen so many Positive Aboriginal Women go through so many struggles in many times, for many different reasons and it always has to do with, you know, this sort of displacement and this disconnection from community or spirit or, you know,

sometimes family, or health, or there are so many different things, right? But um, somehow, these women have all found ways to survive. We have all found ways to kind of keep it together, and sometimes that's all it is, is just keeping it together for one day, you know, depending on what is happening in your life at that time. Um, whether it's being, you know, treated poorly, whether it's being humiliated, or being treated like you're not intelligent. You know, those are mental and spiritual scars, but I think that, you know, you always have this resiliency that I've seen so many [PAW] have and they survive. You know, we do survive.



Skritches

In *Life Is A Mystery*, Candy shares her heartache and her struggle to accept her own HIV diagnosis after the diagnosis and suicide of her mother.

*Each step I have taken has been a struggle.
Even though I have made it this far (13 years)
I often think of my late mother, after her HIV diagnosis,
she has chosen to go down head first.
I try to imagine what were her last thoughts
as she let herself go.*



Life Is A Mystery

In *Creator Does NOT Make Junk*, Doris shared her response to a ‘Turtle Island Recycling’ sign and reflected on how her experience of reclaiming all the positive things in her life might be similar to recycling.

“Signs, signs, everywhere there’s signs. Blocking out the scenery and breaking my mind. Do this, do that, can’t you read the sign.” When I saw this sign I kind of thought, ‘Holy shit! Look at this sign! Our beautiful Turtle Island is being recycled.’ It’s kind of a sad statement about how we care for the environment that we have to recycle Turtle Island - but maybe there’s hope too in recycling. At least we’re not throwing it away, much like our lives. The process of life is about re-birth and recycling. That’s what this picture says to me. As a woman living with HIV, I can kind of relate to this sign because I’m recycling, reclaiming all those positive things. I prefer to be hopeful and look at it in a positive light.

At the time of our study, Tonie had been living positive for 24 years. As a child she had endured unimaginable abuse at the hands of multiple foster parents, years of living on the streets, transactional sex and harmful substance use. She was no stranger, then, to oppression, harassment, barriers, and struggle. In the following quote, however, Tonie shares her response to these challenges and highlights her ability to survive and to thrive.

For me, I got a lot of strength from stuff that I went through and I made it. I get strength from this, from being with people like me. I just take a little bit of their strength and put it inside myself and walk away. I just take what I need, right? That's it. I don't take more than this. And you can find strength in everything; it's basically within you, right? Because if we weren't strong we would not, we would not have survived. We wouldn't be sitting here with humour. We have the ability to laugh even after what we've gone through. We still laugh and we still love and be loved.

As advocates and activists, many of the PAW co-researchers were actively engaged in HIV education, awareness and stigma reduction in their communities. In their roles as advocates and educators, they were constantly resisting stereotypes, resisting stigma, and resisting discrimination. In *Dark Is The Light*, Paw shares her experience of having to navigate the multiple health, social and legal systems that are not designed to meet her needs or the needs of PAW.



Dark Is The Light

The shadow also represents the size I have to be as a PAW (Positive Aboriginal Woman), to manoeuvre through the multiple systems I may find myself in (i.e., medical, legal, etc.). The spirit of many PAW is indomitable, even when resilience is overwhelmed repeatedly.

In *Clearing the Way for Our Future Generations*, a photo of a circle of women's feet, Krista shares her hopes for the future of her community.

To me this picture [of women's feet] is very symbolic and very honourable to me because of each and every one of us that sits in a circle here are advocates and activists and educators and strong leaders in our community. Putting our right foot forward, looking out for our children and our children's children and all those other generations to come after that. So that there will be a day where there will be no AIDS, zero AIDS. So that there will be a day where they have a cure for HIV/AIDS. So that there will be a day that we are safe to live in our communities, and that we are accepted in the circles. So that there will be a day when there are no children born positive. And that to me is looking at it like we are in a big forest and we are all in this forest and we have all these trees that we have to knock down and all these barriers because of our determinants in health and we are those bulldozers, and these are our feet and we are pushing forward and we are clearing the way for our future generations.

Krista also shares her vision for a photo that she did not take.

The picture that I wanted to take was of a woman standing behind a fence – and this is one I really wanted to do – was a woman standing behind a fence you know, but with a peace, like with a peace over her, not for the fence to really become the target of attention, but that woman standing there, like, you know, like maybe her hand up on the fence, you know, and just happy. A nice impression on her face like she is okay. You know, she is making it! You know, because we all faced oppression, we faced those God damned barriers, man. And us as Aboriginal people, we faced them even more than people in dominant society. Like I face oppression every day man! You know, and I live in it! This is my environment. But I am okay with that and I am going to break past those barriers man, and I'll make a new way. And I am going to help change things, you know? Like, just to acknowledge the oppression, but to see that woman with

that self-esteem, and that fight, and that drive, and that, you know, that everything is okay. Everything is going to be okay.

In many ways, then, the story of PAW's health is a story of adapting, resisting, overcoming, surviving and thriving. It is a story of endurance, determination, hope and healing that is grounded in culture and shaped by the environment. These photo-stories proclaim that there is no shame in struggling; that it is the teaching that is important, and the teaching here is to never give up; that "there is hope amidst the turbulence I couldn't see" (Doris).

"You Can't Tell Me Who I Am!": Reclaiming Voice and Identity

The experience of 'health' for the PAW in our study includes re-claiming voice and re-claiming identity. As previously noted, as HIV-positive Aboriginal women, all of the women of VH had intersecting life experiences that society told them were shameful, that they should not talk about, that they must suffer in silence. Throughout their childhood and much of their adult life, they had been led to believe that their voices do not matter; that they do not matter. The PAW in our study, however, were reclaiming their voices and using those voices for good. For example, Krista explained that "when I was a little kid I was told to be quiet and I was put in my place all the time. Now that I've found that I have a voice, I have a right to say it and to share with people". Tonie also shared her experience of being silenced and her steadfast refusal to do so:

Back in, uh, even now, like we're always told to be quiet. You know, "Shhhh, don't say a word." "Don't create the havoc." "Don't be..." Like now, if you raise your voice and you're firm in your convictions, then you're a bitch, you're a cunt, you're like all this stuff, you know, instead of being a woman. And I refuse to be that person, that little person.

In our all-groups discussion, Stacy added her voice to the mix, reminding us that silencing sometimes happens within Indigenous communities, as well as, without.

I just wanted to say that even in our own community, we go through that struggle too, you know, about [being silenced], you know? And we get that – not that good teaching that we should have, you know? And realizing that you have that voice, of course, but having to be quiet about it. Eh? Because I’m trying to – I had to be quiet because [pause] I was going to – my mom told me that someone is going to hurt you. And you know what? I got that hurt. But you know what? I’m still living. I’m here. I’m speaking. And this is my way, and I love it.

In *Woman’s Voice*, KJ also shares her thoughts on reclaiming her voice and the impact that has had on her health and identity.



Woman’s Voice

I took this picture of this girl and it looks like she’s speaking. She looks proud and I think it’s important for a woman to have a voice. I have a voice and I like voicing it. I’m proud of who I am. I think she’s a beautiful woman and so am I. She looks strong, she looks proud. I like to be proud of who I am. HIV does not define me but it’s part of who I am, and that’s ok.

In the following quote, Krista shares her idea for a photo that she did not take. In this untaken photo, she shares a vision for a future in which all PAW can stand tall and proud.

The picture I wanted to take was, was of a woman standing, you know, like possibly if the wind was blowing at that perhaps exact moment, of a woman standing there. An Aboriginal woman with her face – her hair blowing, long beautiful hair, and a red scarf on. And to have this picture printed in black and white and just a red scarf, just, you know, just stand out. So black and white, with that red scarf and the wind blowing, to be proud of who she is and wear red, you know? Like a badge, you know? Wear it like a badge of honour. Like, I don't have to be ashamed or disgraced because I contracted a virus. I didn't get it from any other way, but because I loved a man, and that's why I got sick. Because I really loved somebody, and I trusted them! You know, why should I be ashamed? You know? Why? But I'm not going to let it get me down, you know, and I've been trying to grow from that 'cause there is still a lot of pain there, but just if the people envisioned that pride and that strength and, you know, that freedom within; being able to be that way and feel that way.

As a long-term survivor of HIV, Paw has witnessed the consequences of having a voice or not having a voice on PAW's health. She regularly uses her voice to advocate on her own behalf and on behalf of others for better access to treatments or to services.

It can mean the difference between, sometimes I think life and death, because um, I know people that have been denied medical transportation benefits or are being denied seeing an HIV specialist so the government can save money. So people are not being assessed at the clinics in Vancouver which have the best care, because there are doctors' offices that are saying, "Well, can't you see someone else?" Or, "No." Or, you know what I mean? A lot of – some people think they can't question that or go around that, or manoeuvre, or you know what I mean? And nine times out of ten, it's the squeaky wheel that gets the oil, is kind of what I'm saying. But not having that capacity or confidence to be that squeaky wheel and then relying on other people to do it sometimes doesn't work, right? And we see that because people are falling through the cracks.

On an organizational level, PAW have been part of the HIV movement since the beginning. It is only recently, however, that they have also become part of the story. PAW have historically been silenced, ignored, or tokenized in research, in policy and in programs. However, they are now re-claiming their voices and demanding that they be heard. PAW ‘are picking up their [medicine] bundles’; claiming their space, healing their communities, and preparing the ground for a new generation of leaders. They are organizing, empowering, and educating. They are speaking up, speaking out, and re-claiming their place at the table.

As Paw shared with us:

I think what I want people to know, is that women have been a part of this movement since the beginning. I mean since the first woman became infected in the 70s, known, right? And then women like [name of HIV-positive woman], you know, and then the Community Health Representatives in the communities, even if they’re not positive, they have always been there quietly stepping aside so that other people can do their work. And I think we want our own autonomy, our own self-government, our own control over our own destiny in this movement.

Doris agreed. When recounting her experience of doing a presentation for a Health Advisory Committee, she explained:

You know, by the very fact that we were at their table, we told them, “we’re here and we’re not going away.” And that’s the same message that goes to everybody else. “We’re here and we’re not going away. You can try to make it as uncomfortable for us as you like, but we are not going away. We’re here.” You know, and so that, no one is going to make us go away. We’re taking our space. And we’re – and that space is, um – the circle is going to become complete, again.

Closely related to reclaiming voice for PAW was reclaiming identity. While some of the PAW in our project were still struggling to accept their HIV diagnosis, those who had were proud of who they were, what they had come through, and what they planned to

achieve. In *Heartsong of Reclamation*, Doris shared that “even though I live with HIV, it is not who I am”, and Tonie proudly proclaimed that “I’m proud to be who I am. I’m proud to be – and you know what? I’m HIV, so what!”

As noted previously, culture, identity and health are strongly linked for the PAW in our study, and reconnecting with culture was a significant factor in reclaiming their voice and reclaiming their identity as Positive Aboriginal Women. In the following quote, Liz shares part of her journey to reclaiming her culture and identity.

It took some time for me to feel comfortable with um, the work that I’ve been doing for the Canadian Aboriginal AIDS Network. I’ve been asked to participate [in many things] and participating in and not knowing what the smudge ceremony was when I first started and uh slowly throughout the years, it started to – I started to have a clear understanding of the ceremony and uh there were different things that I also participated in, either locally or provincially or at the national level, and that’s the sweat lodge and the various ways that, uh, each nation initiated ceremonies and with all respect for diverse cultures and, uh, their ways of doing a healing ceremony always impacted me in a good way, so that I was able to start feeling good about myself as an Aboriginal woman and as an Aboriginal woman living with HIV. So it was something that I started to learn, not just right off the bat but, you know, I found that it took some time before I really started respecting and honouring the people that were doing the healing ceremonies and starting to see the work that the Elders were doing and the communities which was very helpful for me as an Aboriginal woman to start feeling good about myself.

Krista also reflected on her initial experiences with the Aboriginal AIDS movement and the acceptance and the healing that she found at Aboriginal AIDS gatherings.



Keeping the Circle Strong

This photo is of two girls holding hands, and [the circle with all the colours with all the quadrants], that's to represent the circle and the unity and being welcomed into the circle. Because I was welcomed into the circle at a Canadian Aboriginal AIDS Network event and that was pretty powerful.

Further reflecting on her early experiences of participating in Aboriginal AIDS gatherings, Krista later added that,

I found myself in rooms where other poz people were and that was life-saving. I couldn't even begin to tell you the value of being around other poz women, feeling that connection. I can't even begin to tell you. Being in a place of not only education and awareness but love and hope.

Tonie also felt that reconnecting with her culture played a significant role in bolstering her self-esteem and reinforcing her identity.

We need to be in touch with our culture. I know I have and I'm so happy that I finally wanted to be involved in it. Now you can't get me out of it! [...] I've always walked with my head held high but now I even walk with my head held higher.[...] Because now that I am involved, going to [ceremonies], drumming

circles, going to sweats, talking to healers and medicine people, I'm like so – like stories, I'm just like a sponge. I'm just absorbing everything!

In *Spirit Shirt*, Tonie reflects proudly on her culture and the freedom that she experiences in her culture.

This one, the spirit shirt with all my jewellery on it? That's my culture. We're about the silver and turquoise, not gold and diamonds. I know some people like gold and diamonds but I don't. This one here, the spirit one, it's because as women we have a strong spirit. This is a choker – see how it's broken? It used to be around my neck but now it's no more. It's broken because I'm free. I'm a free spirit.



Spirit Shirt

As the photo-stories above attest, the PAW in our study suggested that they are rejecting externally imposed identities and awakening to their inner strength and their inner beauty. Adopting the acronym and identity of PAW, a strength and health-based identity instead of the illness-based identity of Aboriginal Women Living with HIV (AWHA) that has more usually been assigned to them, is one example of this. In our all-groups discussion, Paw also shared the following example:

We [Aboriginal women] always know our place, we always know who we are. Even if we don't know, um, somehow that always comes through and I think the more people wake up to their own identity and power and understanding that, [the stereotypes of Aboriginal women] are not who you are or what you are, you know, we're of this land and there is a lot of power in that. You know, thinking that – taking that power back, saying – like she is saying, your voice, you know, you can't tell me who I am. I am telling YOU who I am! You know, like THIS is who I am.

Reflecting on the multiple photos that she took, Krista shared just how important reclaiming voice and reclaiming identity were for her health.

Looking at these pictures...I feel an enormous amount of pride and honour. You know, pride, and honour and identity of who I am and where I come from as an Aboriginal First Nation's woman and what that does for my health, you know, it fills me with energy, with hope, with passion, with you know, commitment, with love, with light. You know, it does all that for me when I look at all these.

Reclaiming voice and identity then, are significant factors in supporting the health of PAW. The above photo-stories challenge dominant notions of PAW as dis-ordered, diseased, and dis-graced. They are life affirming photos; photos that shout out to us that there is life after diagnosis. There is passion, there is joy, there is beauty, and there is health. As Doris explains, “even though I live with HIV, it is not who I am”.

“I’m HIV-Positive, So What!”: Stigma, Discrimination and the Need for Safe Spaces

Despite the strength and resilience that is most often represented in the *Visioning Health* photo-stories, the PAW in this project, “sometimes wish this HIV diagnosis was just a bad dream/and that I will wake up soon/and I will be healthy and happy/and the world will be bright again” (Candy). Underlying this wish are the multiple experiences of loneliness, isolation, fear, pain, stigma, discrimination, rejection and shame that many PAW continue to

report. These experiences occur at the personal level, the community level, the organizational level and the systemic institutional level.

On a personal level, stigma and discrimination are a very real concern for PAW and often influence their decisions. Even in this project, for example, the photo-stories that PAW chose to tell were influenced by fears of stigma and discrimination. When we asked if there were any photos that PAW co-researchers wanted to take but did not, Liz shared that she wanted to take photos of her personal surroundings such as her cat, her partner, and her house as important supports for her health. She did not take these photos, however, “because of my neighborhood, and I am thinking because of my um, fear still that is lingering in me, that, you know, being ostracized because of being HIV. And so it is always in the back of my mind. That fear is always there.” Likewise, KJ wanted to take a photo of her son to represent that “things are possible, that you can be healthy”, but she did not take that photo out of concern for her child’s future safety. She explains:

Who knows where [the picture] could be in like five years and he may not like – he may come across it and he may not want people knowing. He may not tell his friends that I’m positive. He may not whatever, you know, and so I need to respect that for him.

Other women agreed with KJ and said they too shared similar concerns. Even though many of the PAW co-researchers were openly HIV-positive and many of them were nationally known PAW activists and advocates, they all had to consider their families and their children’s safety when making decisions around where to present and under what conditions. When looking at the entire group’s photos, Stacy made the following observation:

[T]he other thing I saw [in the photos] is people are still hiding and protecting themselves, which to me was very sad to see. But it’s the reality. You know when I talk to certain people about that... Because even those who are out are protecting those ones [who are not] and it’s constant stress; constant awareness of the fact of protecting the ones you love, protecting yourself.

Fear related to HIV-stigma and discrimination was compounded for those who were not disclosed. These fears almost kept a few women from joining our project and Wanda, our Traditional Knowledge Keeper and an outreach worker with Oahas, a provincial Aboriginal AIDS service organization, reminded us that disclosure and the HIV-related stigma and discrimination that can come with disclosure are very real concerns.

There are – some of the women I work with can't even come here yet, right? So I don't want them to be forgotten because I know there are also people that are at different places in their lives around the table. You know, and everyone needs to be met where they are at. [...] And I think that we have to remember those women that aren't in this room and, you know, I can't even get to come here. [...] [B]ecause they are not ready yet, you know, because of the stigma and discrimination, [and] you know, we meet in coffee shops and no one else knows except me and maybe one other person and we have to live with it right? I just wanted to speak about that today, so I know that you guys will never forget about them, but that they realize, the funders and government and all of those people, that these [PAW co-researchers in the room] are our leaders here but they speak for all of those who can't speak, who have yet to be able to find a place that's safe enough for them to even call somewhere. You know, I can't call someone at home. I can't leave a message on the phone saying, "Hi it's Wanda." I can't do that even, because they are just afraid it's going to - that little light is going to come on, you know, it's just a little light, right? It's the way that we have to do things.

Other PAW co-researchers shared hurtful experiences of HIV-related stigma in their communities; for example, not feeling supported by family or friends, being treated differently because of their HIV-status, or not feeling welcomed at ceremonies. Laverne, for example, shared that she used to participate in sweat lodge ceremonies before she became HIV-positive. Since her diagnosis, however, she does not feel welcome at these ceremonies and does not attend for fear of being discriminated

against. Other PAW co-researchers shared experiences of HIV stigma from Elders, from community health representatives, and from others in their communities.

Organizational or institutional stigma and discrimination was also, unfortunately, a common experience for PAW. Tonie shared the following experience of being discriminated against in a substance use treatment centre: “I had a bad experience in [treatment centre]. They didn’t want me in the kitchen. They didn’t want me using the silverware. It was just terrible. They shut me out for three weeks.” Laverne shared her experience of HIV-stigma when she cut herself and felt like she was treated as a pariah by the nurse who attended to her. Finally, in *Shame-Full*, Paw poignantly reflected on the shame that she had been made to feel in her life as a Positive Aboriginal Woman:



Shame-Full

When I looked at this picture, it made me think about um, it made me think about a lot of the shame that you know, I think, in my life I felt, and how it can touch everything around me. So it’s really about like, the emotions and even how we [as PAW] are made to hide certain things and certain parts of our lives. [...] And I think what that says about health, culture and gender for positive Aboriginal women is a lot of the times we do have to hide certain things. Um, we have to be very careful about, you know, there is a lot of mistrust there from certain systems, whether it be the child welfare system, or um basic survival, um; there are many implications for positive Aboriginal women. Um, sometimes we

even have to hide from our own culture and our own communities because of you know, because of other people.

Three decades into the epidemic then, HIV-stigma and discrimination are still a primary cause of distress for PAW co-researchers, and the primary reason that positive Aboriginal women are calling for ‘safe spaces’ to be established within each region across the country (Peltier, 2010; CAAN, 2012). ‘Safe spaces’ are an essential element of creating and maintaining health for PAW and can range from personally safe spaces, to organizational safe spaces, to institutional safe spaces. For individual women, safe spaces may mean support from family, friends and service organizations. It may mean becoming involved in Positive Aboriginal Women’s groups or PAW-centred research such as VH that make them “not feel so lonely” (Tonie), or establishing safe havens for themselves. As Laverne so powerfully shares in *City Escape*, sometimes a balcony is all it takes.



City Escape

This is a picture of my friend’s place, his 15th floor balcony. I took a picture of this whole city, whatever I could see way in the back, because it’s a safe haven for me. I was having a lot of problems at home with drugs and alcohol and people smoking crack and I kind of implemented that into my unfortunate world. And then every time I wanted to run away, this is the place I went.

Safe spaces for PAW might also include safe communities. In *Smashing the Silos*, Doris suggests that a healthy community is one in which everyone has a place in the circle. Reflecting on a photo of a neighbourhood watch sign, Doris shared the following:

This sign is about protecting our community. And uh, I wish I could see signs like this in our communities. Symbolic signs, because to me this sign represents how we were at one time in terms of being a community and being a complete circle within our community. We protected each other. We watched out for each other. That's not the case anymore. So, I think uh, as a woman living with HIV and as an activist this is what is kind of in my heart, that we need to have this in our lives again, this whole notion of being community and protecting each and every member within our Aboriginal community and being whole. ... We need to come together as a community and not as silos, like this picture here. I like the whole notion of community and protecting the people within our community. ... Maybe HIV would not be at such high rates if we went back and redid that circle.

Krista shared a similar vision of healthy communities as safe and supportive for PAW. When describing the photos she took for VH, Krista explained:

To me these pictures scream out community. You know, and the message how it takes a community to raise a child. ... The support that comes out of community is phenomenal, you know, that support is priceless. I know from personal past recent situations, you know, people coming out to support me, and no words can put a price on that. And you know, that's what we need, people... you know, my friends we live it, and we know it ourselves, but it is to push that message out that it is everybody's job to partake in the circle and to keep our circle strong for our generations and for our [future] generations to come.

On a larger scale, however, safe spaces for PAW would help also to remove structural and systemic barriers to PAW's health. This might come in the form of culturally safe health care that is also HIV-friendly. It might come in the form of HIV-friendly Elders or

traditional teachings, or as Liz explains below, this might mean creating safety in the work place so that PAW can participate fully. After all, “HIV does not mean unhealthy” (Liz) and many PAW are both willing and able to contribute their skills.

I've always wanted a normal life, to be treated as a, you know, just like, you know without being in the workplace and thinking that somebody would like to put me down and lay me down on the bed and say, “You're sick and we don't think you should be working.” You know, those things I had to fight through in the workplace, and you know, I had to show them that I could do the work and I was you know, living as normal a life as possible. ... I'm not saying I don't have it or anything. I'm just you know, I'd like to live as normal a life as possible without any repercussions anywhere ... It shouldn't have to be like that. We want to live a normal life as possible you know, without any kind of having to have people fear us when we are with them, you know and thinking that you know that they could be you know-some people have a hard time shaking my hand. You know, even around the staff sometimes you know, and educators for heaven's sake. Wow, you know, those things are really something that we need to you know-we need to be able to be in a community without having to you know, feel that withdrawing and that fear.

“Creator Gives Us What We Need”: The Importance of Spirituality

Connecting with culture and spirituality emerged as important health-enabling strategies for the PAW in this project. The on-going legacy of colonization, including the intergenerational impacts of residential schools; deliberate disruption and demonization of cultural norms, values and beliefs; repression and loss of Aboriginal languages; banning of traditional practices and ceremonies; and the forced adoption of Aboriginal children to non-Aboriginal families now known as ‘the 60’s scoop’, helped to ensure that few of the women in our study grew up with knowledge of their Indigenous culture and spirituality. As second or third generation residential school survivors, adoptees or ‘60’s scoop survivors, many PAW co-researchers were raised in Christian families or communities and, at best, were not taught their culture and spirituality, or at worst, were taught that it was evil.

Doris explained that “I didn’t know anything about our own ways, because I was raised as a Catholic and ... I was kind of brainwashed to think that our ways were not good ways. That they were evil.” She went on to explain that she and her siblings were forbidden to interact with traditional people in her community “so it kind of felt like, oh, maybe they’re not good people to go see. So I kind of left that part of my life. I didn’t want to have anything to do with traditional and cultural kind of stuff for a long time.” Paw explained that “for myself I feel like I’m caught between two places sometimes, because I don’t know my language and I wasn’t raised spiritually, I wasn’t raised traditionally”, and Tonie shared that, “I was adopted by white people. I [knew] nothing about my culture...because I didn’t learn, no one taught me”. Candy also commented that, “where I’m from we’re not spiritual people at all. They only believe in Christianity and they are at war with each other, whether being Pentecostal or some other type of Christian”.

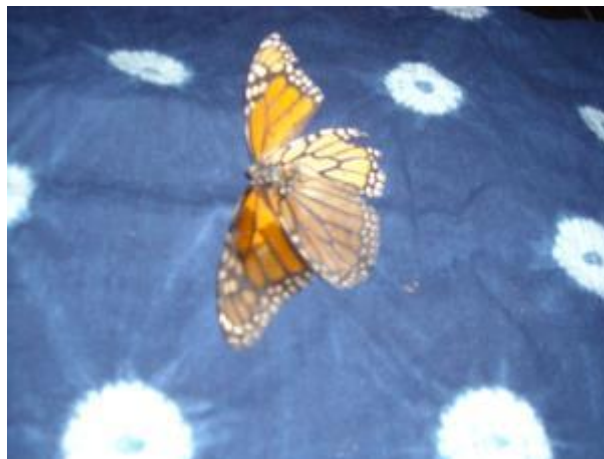
At the time of our study, however, all PAW co-researchers had re-connected with their culture and reported that culture and spirituality were important strategies for supporting their health. As Doris shared, “I wasn’t connected spiritually for a long time, you know, to the Creator, but as I’m learning [about my culture] I’m finding that when I connected to the Creator and started relearning some of the cultural ways, I find a lot of strength there. I find it’s very important”. Paw also shared that “I wasn’t raised spiritually, I wasn’t raised traditionally and I’ve taken it upon myself to learn, you know to find my own spiritual base for myself and what grounds me. KJ shared that “prayer keeps me centred I guess. I believe in prayer. Without prayer I don’t think I would be where I am today. Once I got back to praying and got back to Creator and God, my life really changed. So I think prayer has a lot to do with it.” KJ went on to share that “for me to live healthy...knowledge of my traditional teachings...I guess getting to know Elders and getting the teachings...so I guess the support of Elders and keep on track is what I need to support my healthy lifestyle.”

As the following photo-stories attest, for many of the PAW in this study, spirituality was grounded in their Indigenous culture. Specifically, PAW co-researchers talked about connecting with and honoring the Creator, Elders, ancestors and spirit helpers, including elements of the natural world such as Mother Earth and Grandfather Rocks. Prayer, participating in ceremonies, and receiving traditional teachings were also considered important health-enabling strategies for PAW.

In *Grandfather Rocks*, Liz talks about the Indigenous belief that rocks are our oldest ancestors and that they carry wisdom and healing within them.

Rocks make for a solid foundation. As a child I used to spend my time looking at them in the river. One or two would catch my eye and I would take it out of the water. An Elder from the east much later on in my life told me they were grandfather rocks. I didn't know what that meant until I studied various cultures from across Canada. They are also healing rocks that I have in my living area for good health.

In *Butterfly on Blue Cloth*, Stacy reflects on the ephemeral nature of life and the power of hope that she finds in her Indigenous teachings.



Butterfly on Blue Cloth

This picture reminds me there is a life; however, there is death too. And I respect this picture because there are four wings that remind me of the four directions. And the white reminds me that there is light, and it gives me that energy that you need to survive. I've got the blue on there because that colour signifies water which we truly need in our life to survive. And this butterfly did not make it – perhaps it didn't have that water. There's seven little flowers of white with blue in the middle. That reminds me of the seven grandfathers as well. And within that, we're always in the middle and that gives me that hope to survive.

In *Four Winds*, Stacy also shares her belief in the power of prayer, and the sacred winds of the four directions that carry her prayers to the Creator.

This picture reminds me of Prayer. I took this picture of the four flags of Canada. What I really wanted to catch was the four winds that bring our prayers to the Creator.

KJ chose a photo of “a dream catcher and two medicine bags” to represent her relationship with her son, with her culture, and with her health. She explained that, “there’s two [medicine bags], one for me and one for my son. This is actually his first medicine bag. And culture for me is not...well, not very important in my living with HIV, but...it is!” In *Rope for Hope*, Laverne refers to sweetgrass, one of the four sacred medicines that are often used in First Nations healing ceremonies. For Laverne, the braid of ‘sweetgrass’, actually made from willow, represents the hope that she finds in her Aboriginal teachings.

Somebody had braided a tree and it was so neat the way they did it. It looked like sweetgrass. It reminds me of how we’re all tied into knots but also how we can, you know, follow in a rope for hope and hang onto that. Because I always hang onto hope. That’s why I took a picture of it.

Many of the PAW in our project, however, mixed Indigenous spirituality with elements of other world religions, such as Christianity or Islam, and also with New Age spirituality. Many PAW found solace and strength in their Christian upbringing and continued to pray to a Christian God. For example, ES shared that,

one day I woke up and said, today is another day for me and God is going to do something for me. He did. He gave me [support worker]. Ever since, I have been going to all those doctors, everything by her. I am very proud of what she tells me. I tell her what’s wrong with me. I tell her everything.

KJ also shared her faith in God and the Creator and her belief in the power of prayer through her photo of *Hands Praying*.

I took this picture because I pray to the Creator, and I pray to God every night. I thank the Creator and I thank God for giving me the life that he's given me. I haven't had the easiest life, and I may not know why he put things in my path that he has, but I'll know one day. There's always a reason I believe for everything that's been put in your path. And for me, it's HIV as well. That's what makes me who I am today. So I thank Creator and I pray for my health that I can stay strong and healthy.

In *Golden Angel*, Liz shares a spiritual experience that she believes saved her life and continues to keep her healthy to this day.



Golden Angel

I remember this day vividly, as if it was yesterday. It was Easter Sunday. I went through an unexplained experience with light. It was close to this colour. But it filled me with good energy and lifted me awake. So loving, I couldn't make sense of the unexplained. I was alone then. I had given up hope and didn't see a future

with pain and sorrow. That night as I slept I must have surrendered to my Creator. He came and lifted me up from my dying sleep. I am still here and doing a lot of teaching in the community I live in. My memory of that colour helps me to this day to heal any minor or major illness that I experience.

In *Spiderweb Under the Deck*, Krista shares a teaching from her Elders but also from the Bible.

This [spider web] represents the web of life. I took this picture this summer after I buried one of my bros who died of an accidental overdose. That morning I was honoured in saying a eulogy... and I knew what I had to share. I had to share what my Elder's teachings are, talking about the web of life. Even in the bible they mention, without death there would not be life, without sadness there would not be joy, without hate there would not be love. And I had to learn about the balance and the connectivity to the world, to the universe, to the creator, to Mother Nature, and all those great things. So to me, that [photo] reminds me and speaks of that message that I know. And I shared that message most of all, because I could see in the crowd that I spoke to, a lot of sorrow and a lot of pain, and a lot of people sitting there, wishing that they could have done something ... and I just comforted them not to blame themselves. That's a part of life and those are people's decisions and sometimes we are not in control of their decisions. But that it's not goodbye, and it's only see you later. You know, until we meet again.

Laverne was Muslim and mixed her Aboriginal teachings with Islam. When describing the circumstances in which she received her spirit name, a ceremony that she describes as “very powerful for me”, she shared the following:

Because from that day I got [my spirit name], I tried to follow the two -spirited things I have in me. 'Cause I also follow them 'cause I follow my religion. I'm a Muslim too. So it's not very often you have a Native Muslim. So, it kind of plays

with my native culture and then I've got to follow this religion as well. Because I believe in that.

She went on to explain more about her relationship to her faith:

My strength comes from having faith, eh? In a physical...I don't have to get strength from the people. I get strength from faith. Like anything I do, I make sure that, like I say, I always try to justify if that's right or wrong. Like even when I go outside to do what I do, I always ask for forgiveness to do what I do, but I have to make money. And forgive me for having this addiction, right? So I always try to justify what I do. So that's what gives me strength is that I always have to be... He has to be in my presence or I have to acknowledge Him to make sure that's okay for me to do that. That's what gives me strength.

For the PAW in our project, then, spirituality was an important health-enabling strategy. PAW co-researchers were from a variety of First Nations and Inuit communities and they held a variety of cultural and spiritual beliefs. Some women walked the 'Red Road', while others combined their cultural practices with Christianity, Islam or New Age teachings. Regardless of their individual beliefs, however, all women believed strongly, "that connection to the Creator is a real source of strength and health" (Doris) and that "our ways...actually help us to be healthy" (Doris). Other PAW co-researchers agreed, sharing that "we as Aboriginal women are spiritual beings" (Krista) and "the Creator gives us what we need" (LA) to survive and to thrive.

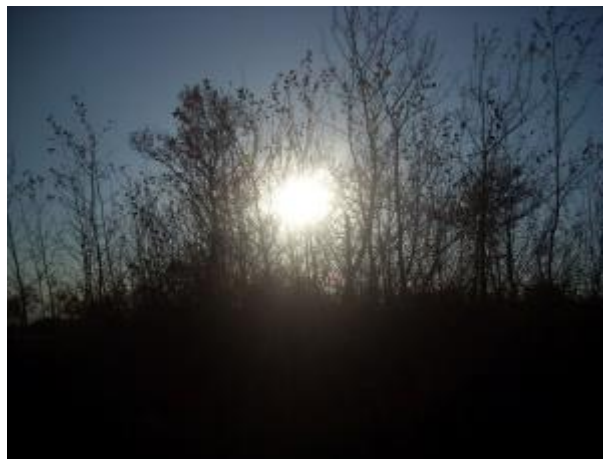
"I Get Grounded From the Earth Beneath My Feet": Healing Through Nature

As noted above, connecting to the natural environment and healing through nature is very much an element of Indigenous spirituality and one of the strongest themes to emerge from the PAW co-researchers' photo-stories. Connecting with nature and the natural environment reflects Aboriginal identity, values and beliefs and is considered by PAW co-researchers to be a cultural way of healing. As the following photo-stories attest, the women in this project draw strength, joy, inspiration and energy from nature, from 'the land' and from the natural

environment. They acknowledge, celebrate, and seek out the ‘sacred healing energy’ of Mother Earth, of ‘Grandfather Rocks’, of ‘that sacred sun’ and other elements of the natural environment.

This is true regardless of where they live. For example, Candy, whose people were hunters and lived off the land, explained that “I’ve never been in the bush because I grew up in Montreal all my life”. In fact, most of the women in our project were “city Indians” (Wanda) or “urban Indians” (Liz), having spent all or much of their lives in urban centres. This does not, however, diminish their connection to the land, to the environment, and to the natural world.

Several PAW co-researchers commented on the healing properties of the sun and the natural environment. Paw shared that, “the sun warms, heals and energizes me” and in *Sun Behind the Trees*, Krista shared the following:



Sun Behind the Trees

This brings back a teaching to me, of an Elder that is very sacred in my life right now that I believe plays a very important role and that the teaching that this Elder shared with me is about the universe and about Mother Nature’s sacred healing energy and about the power of the creator to shine the good medicine. And to me, this light, this light is life and energy and that’s good medicine and that’s Mother Nature’s sacred power and healing energy right there. And that’s very sacred to me, that sacred healing energy. And I really count on that. I have been trying so hard to really rehabilitate my thinking every day when I wake up

in the morning to feel happy, to feel alive, to feel energetic, to be like that light and to let my light shine. Let my light shine that connects to my health and my gender and my culture because that connects to me and who I am as an Aboriginal woman as a spiritual being, to my identity. And to me, utilizing those teachings promotes longevity in my life. It gives me the hope. It gives me the need to thrive and all those other big things.

Candy shares the gratitude she feels at each changing of the seasons in Creek.

*I feel blessed every time I witness a new season.
It makes me reflect on how lucky I am to be here.
Like the footprints on the sand saying I am here.*

Trees were particularly present in the photo-stories and particularly healing for PAW co-researchers. Stacy shared the following:

I believe trees, when I see them, they are looking out, not only them but little plants, the squirrels, the birds: they give us empowerment. Like, you can survive if you let it, pray for it, acknowledge all those ancestors that have passed, and your friends. Be happy who you are and walk that good path and that will let you survive.

In *Cedar Boughs*, Liz reflects on the healing she experienced from cedar.

Cedar boughs after a wash in the rain. Luv the freshness and scent from the tree after the rainfall. So refreshing and cleansing. Aromatherapy. Releasing emotionally suppressed trauma. My soul heart consciousness in action. The heart chakra is green. It's a balancing colour and encourages emotional release. GREEN: healing, peace, nurturing, new growth, fear, need for security, jealousy and envy, balance. At this moment the need for security is calling for this colour for healing.

Animals are also healing for PAW co-researchers. When asked what supports their health, both Stacy and Tonie spoke of the healing and happiness they receive from squirrels.

I always look at the trees. You know and I look at them, and there is just one tree that I look at too all the time. It's just a weeping willow. That's where I put down my tobacco. And there is always this one little black squirrel that – he comes and he peeks around, eh? And I look at him and I say, "Oh hello", and then he just looks at me and then goes scurrying away. And that's what I think being healthy, well part of being healthy is to understand who you are, where you come from and what, you know, that good way of walking is. And that little squirrel always reminds me of this. Because he is not great, he just looks around and "Nice to see you." (Stacy)

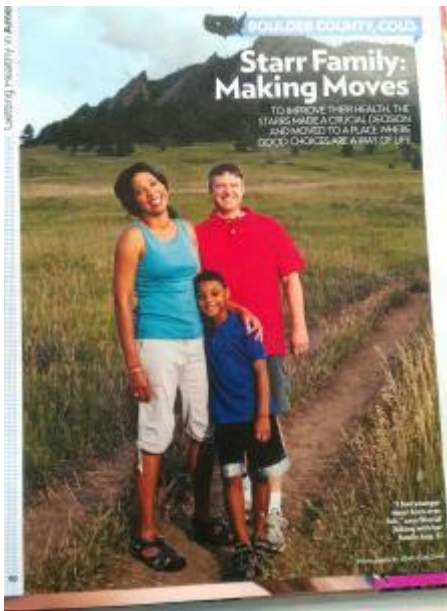
I just enjoy watching animals. Like squirrels and stuff. You know, every morning, like where I live right now on [street name], I get up at five every morning. I don't know why. I go downstairs and make myself a nice cup of coffee or tea, and I wait for the squirrels to wake up. 'Cause there's a big condominium. There's a big tree and I call it the condominium because they all come out and I make sure I have a big bag of peanuts around the tree. And I watch them come down and that's what makes me happy. (Tonie)

In *Peaceful Grey*, Paw shares her love of a different kind of animal.

One of my loves in life are birds. I love eagles, hawks, the mythical Thunderbird. I love them all. This was one of my bucket list pictures, to visit a Birds of Prey Centre. I watched this bird groom himself, and it was my first time being close to a Golden Eagle. It made my heart flutter...birds are my messengers.

For MT, an Inuit woman living in Montreal, fresh air and healthy environments were a way of supporting her health.

It's the words that are important in this picture. It says, "to improve their health the Starrs made a crucial decision and moved to a place where good choices are a way of life." Because mine is, I have a couple of vocal cord troubles, asthma, my feet are starting to swell and my pneumonia is coming back. But I want to improve my life. And fresh air. Go for walks. That's what I've been doing with [my boyfriend], we go by the water. I want to go vacation back home.



Healthy Environments

Finally, in *Heartsong of Reclamation*, Doris shares her experience of reconnecting with nature, with the Creator and with herself, as she finds healing on the waters' edge.

I've always loved rocks. This is me sitting on this big rock by the water as I share my heart-song for a moment between me and my Creator. As I sit on this big rock by the water my spirit reclaims all that has been lost in that one precious moment. I am turning over a new leaf as I see the beauty that the Creator has put in front of us. I honor my place within this environment. I am thankful for my life. Even though I live with HIV, it is not who I am. I have a place in this environment.



Heartsong of Reclamation

In our participatory analysis session, several of the PAW co-researchers commented on the link they saw between nature and healing for PAW. LA shared that “what I saw in the pictures are – the common theme was um, that nature speaks to them”. Candy also noticed “the earth and how the beauty that [PAW co-researchers] seen with the nature. [...] I seen a connection with the earth”. For Paw too, connecting to nature was a common theme:

I guess that when I looked at the pictures I thought of all the ways that we seem to interpret life through nature. Like we're so – even if we live in the city. So I think of resiliency, right? Being able to overcome um, not necessarily without scars or hurts, or you know, those pains. But somehow we always survive. I don't know how. But I think about strength and that, I think about um, where people find safety, seems to be in nature. Being out, you know, which is connecting with your spirit. Connecting with one's self.

Connecting to nature then, is a cultural way of healing and supporting PAW's health that connects them, via nature, to their culture, to the Creator and ultimately back to themselves. As Liz explains, “I treasure when I am out with nature angels. Inside I breathe in calm and comfort when life gets too hectic. I get grounded from the earth beneath my feet. I revitalize and balance from the energy that flows from the roots of the trees”.

“Water is Women’s Responsibility”: The Intersection of Culture, Gender and Health

The notion of gender and its impact on the health of PAW co-researchers was far-reaching and inextricable from the social determinants of PAW’s health mentioned above. For example, gender – the socially and culturally constructed roles, responsibilities and behaviours that are deemed appropriate for Aboriginal women – is deeply implicated in reclaiming PAW’s voice and identity; in their resistance and resilience; in their experience of stigma, discrimination and search for safe spaces; in their understanding and experience of colonization. Here, however, we foreground gender and explore the multiple ways, both positive and negative, in which gender intersects with culture and other social determinants to influence the experience of PAW’s health.

In research sharing circles, when asked directly how gender impacts their health, PAW co-researchers spoke of the pressures they feel as women to balance their own needs with the needs of others, or more usually, to put the needs of others before their own. ES shared that “being a woman, [it’s] just too difficult for me. [...] It’s not fun. You can’t do what you want to do. [...] Every morning I wake up, I pray...I am going to do things my way today. I say that every morning [but] it has to be their way”. Doris agreed with ES and further explained:

I find that too, we compromise even our own beliefs. We compromise ourselves in what we do. We make compromises all the time and that’s not returned. You know what I mean? As women, we have to compromise all the time, and I don’t know if that’s a natural thing that women do that all the time, but it’s not right. It’s not right, you know, that we have to uh, it’s like our own needs are unimportant to others. And to ourselves. ... Sometimes we don’t even think that our needs are important, you know?

Doris went on to explain that “because we are taking care of babies and taking care of stuff, our own needs aren’t being met” and that has an impact on her health. Paw agreed that “because we are life-givers, we often put our own needs last”. When describing how busy her days are, Krista exclaimed “time constraints, man, I’m busy like you wouldn’t believe! ... I’m trying to maintain a balance you know...[but] it’s a

lack of child care and taking the time, right? Because you can only do so many things when you've got four kids, you know, 'mom, mom, mom'!"

Motherhood and nurturing, however, no matter how "naturally we respond to that responsibility" (Paw), are not the only reasons that PAW co-researchers ignore or put their own needs last. Several women also identified a gendered double-standard, a kind of racist-sexism, as part of the problem on an individual and systemic level. Doris explained that "when we ask for our needs to be met, we are perceived as a pushy woman. That's hard." She goes on to say that,

just the fact that I'm a woman has an impact on my health because it seems like I have to fight for everything, when really I have those rights too you know. We have rights and those rights are denied us sometimes and it's tiresome and it does impact my health sometimes. My mental health, my physical health, when I have to fight for everything that I should – that we should also have.

Paw agrees, and with specific reference to healthcare and other services, she shares the following:

I do believe that [Aboriginal women] are treated differently in the healthcare system. Like you are not treated like you are intelligent or you understand your healthcare or that you are able to make healthy choices and I think that's very different than some of the experiences that men have had. ... I don't ever feel like [healthcare professionals] take [me] very seriously. ... So I really do feel that being not just an Aboriginal woman, but being a woman, impacts my health because I have to do that much more legwork to advocate for my own needs.

This is clearly frustrating for Paw and emotionally challenging but it also has implications for her physical health. She goes on to say that, women who advocate for themselves are called trouble-makers and risk being stone-walled by their service providers.

And then if you do assert yourself, then you're treated like you're a trouble-maker or that you are a complainer. And I've seen this happen with other women as well. If you assert yourself, you're treated like you're, you know, a pain in the butt. ... Like I'm at the point now where I don't feel like I can even go and get a second opinion because I don't really know, you know – I'm going to a walk-in clinic then basically”.

In *No-Bodies Child*, Paw speaks eloquently of the racist-sexism and the systemic oppression that PAW experience at the hands of predominantly white service providers.



No-Bodies Child

This discarded, stepped on, and ignored picture was found outside of a Child and Family Agency, just on the sidewalk. I found it stood out to me, because I wondered if it was the only picture a parent may have had of a child taken by child services. It made me think of how PAW get treated within today's society. We get stepped on, over, and when we assert ourselves, we are labelled as difficult, angry, irrational, etc. Ignored and disrespected as life-givers.

Paw believes that “our women have their children removed from them more often than other women and the way that many women are treated from the time they are born,

Aboriginal women are treated differently. We are treated as if we don't matter and that's in white society". Doris also recognized this mistreatment as systemic oppression; as racist-sexism and gendered violence resulting from centuries of colonization.

Gender, however, and its intersection with culture and other social determinants was also experienced as having a positive influence on PAW's health. Many of the women in our study self-identified as caregivers, as nurturers, as life-givers, and said that children and grandchildren were their *raison d'être*. KJ shared that "for me I guess raising my kids, would be the motivational factor to keep healthy. [I] want to watch [my son] grow up, [see] my son grow up and do all the things; [he] makes me want to keep healthy". ES painted the names of her grandchildren on her drum and shared "all that [my drum] means to me, my grandchildren, very much, because I love all my kids but my grandchildren are my number one." For Krista, mother of four, "my kids make me happy", and in *Child's Handprint*, she shares her commitment to her children and to her children's children.

I am reminded of our future generations and I am reminded of how you know, how I need to do right and to be right and to be good, and to live good and to show my kids good the best I can, you know, for my future, for my children and my children's children that come into this world.

In fact, connection to children and families, and by extension PAW co-researchers' roles as mothers, as life-givers, as caregivers, emerged as a primary theme from our participatory analysis. Reflecting on the complete collection of photo-stories Paw saw that

...connecting with things that we feel like we belong to us including our families [is important]. And I saw that in yours [ES] with what-with your drum and your granddaughters, it's a reminder of what keeps me strong every single day, and I think that's what-that's what a lot of us live for. That's the only thing that keeps us going, is our children. They save us sometimes. You know, even if we don't have them sometimes, that's what I see, you know. And I know a lot of us are

moms so it really stood out to me, 'cause I know my kids saved me and saved me from myself.

Again, as Krista shares,

I would definitely like to look for an image that paints the real um, you know, belief in our culture, where we come from and that women are life-givers, you know. A lot of our First Nations ways come from a matriarchal society and I would just like to send the message that as women we are life-givers. We have the ability to strengthen our families and we have the ability to break cycles, you know, and the ability to take our power back, so I just wanted to say that.

In many ways, PAW co-researchers' strong identity as "the makers and the givers of life" (Krista) stems from the traditional cultures and teachings of many First Nations, and particularly from women's teachings. During a discussion of gender in the Toronto groups' photos, 'water' emerged as a common theme. When asked what water meant for women, both KJ and Doris responded that "water is women's responsibility". Wanda, our Traditional Knowledge Keeper, explained:

So when the Creator was done creating creation, he handed creation over to women. So the grandmother really looked after the water of Mother Earth and we as women look after the waters of creation. 'Cause it's that water that we carry and we sit in before we are born. And it's that water that comes before life. So water is treasured and it's women's responsibility. So everywhere you look there [in the photo-stories], for us you can see the woman.

For PAW co-researchers then, gender intersects with culture and other social determinants in a variety of ways to influence PAW's health. Specifically, gender intersects with racism, with colonization, and with health and social services to create barriers to PAW's health that include lack of access, stigma, and discrimination. Gender, however, also intersects with culture to provide a strong foundation for

PAW's identity as life-givers, as care-takers, as rule-makers, as the 'hearts of the nations' (Brant-Castellano, 2009). Reclaiming these traditional roles is a health-enabling strategy for PAW.

Chapter Summary

In this chapter, we explored the health-enabling strategies that PAW co-researcher's use to create and maintain their health. Beginning with their own experiences, they described learning about and coming to understand the cumulative impact of colonization and historical trauma on their lives. Re-framing these experiences as 'teachings' or as stepping stones to becoming who they are today, proved to be empowering for many PAW and helped them to see themselves as strong Aboriginal women. Multiple experiences of stigma and discrimination led PAW co-researchers to seek out and to call for the creation of spaces that were physically, emotionally, mentally, and culturally safe. Some women sought safety in their own homes or the homes of friends and family, while others looked for safety and acceptance from families, service providers and communities. Connecting with the Creator through culture and spirituality was an important health-enabling strategy for PAW co-researchers that included connecting with the land and the environment. While most PAW co-researchers practiced a form of spirituality that was grounded in Aboriginal culture and traditions, many of them combined these traditions with some other form of spirituality including Christianity, Islam or New Age teachings. Connecting with and healing through nature was a significant support for PAW's health and helped them to resist and push-back against dominant notions of PAW as disabled, diseased and disconnected. It also helped them reclaim their voice and their identity as Positive Aboriginal Women. In the following chapter, I use Walter and colleagues notion of 'research as revolution' to look at the impact that *VH* had on PAW co-researchers and on the community. Specifically, we ask and answer the question, "did we make a difference"?

Chapter 7

Research as Revolution: Did We Make a Difference?

(with Doris Peltier²⁵)

Revolution: *A dramatic and wide-reaching change in conditions, attitudes, or operation (Oxford Dictionary, 2014); a fundamental change in the way of thinking about or visualizing something: a change of paradigm (Merriam-Webster, 2014).*

Introduction

At its core, decolonizing and community-based participatory research are about helping to create social change, or helping to create the conditions in which social change can occur. The degree to which a project has been successful at this, or not, is what Cho and Trent refer to as ‘transformational validity’ (2006). As noted in Chapter 3, transformational validity is focused on the idea of research “as a progressive, emancipatory process leading toward social change that is to be achieved by the research endeavour itself” (Cho & Trent, 2006, pp. 321-322). One way of assessing transformational validity is to assess the degree to which change has occurred as a result of the project.

Reflecting on the CBPR, decolonizing and Indigenist roots of our project, we established early on in *VH* four measures of what we considered success in our work: 1) did we do what we said we were going to do?; 2) have the PAW co-researchers benefited from their participation in our project?; 3) has the Aboriginal HIV community benefited from their participation in or support of our project?; and 4) have we, the researchers, been changed by the research? In many ways, this entire thesis has been about documenting the first measure of success. We set out to engage with PAW in the co-creation of new strengths-based, culturally-relevant, gender-specific and arts-informed knowledge. We also set out to explore what health means for PAW, what kinds of things support their health, and the role that culture and gender can play in

²⁵ Special thanks to Sharp Dopler, Carrie Martin, KJ, Krista Shore and Kecia Larkin for discussion and feedback on this chapter.

supporting PAW's health. The answers to these questions are laid out in previous chapters.

In this chapter, I take up the second and third measures of success, namely, have the PAW co-researchers and their communities benefited from participating in this project? Here, I focus on the idea of research as revolution. As noted earlier, in their excellent paper on 'Indigenist' collaborative research efforts with Native American communities, Walters and colleagues (2009) suggest that 'revolution' should be one of eight guiding principles of decolonizing and Indigenist research. In short, this means that "research partners and community members must actively seek to decolonize and indigenize the research process to transform science as well as themselves, their communities, and the larger society for the betterment of all" (p. 154). Reflecting on this and on the decolonizing and Indigenist principles of reciprocity, responsibility, and relational accountability, in this chapter I ask, did we 'give back' enough? Has participating in our research made a difference in people's lives? Has it made a difference to the Aboriginal HIV community more broadly?

In the first half of this chapter, I focus on what PAW co-researchers had to say about their experience of participating in *VH*. As noted earlier in this thesis, many of them referred to it as 'a healing journey'. In the second half of this chapter, I highlight our community-engaged, culturally-grounded and participatory knowledge translation and exchange activities (KTE) as key elements of our decolonizing and Indigenist approach to research and as key elements of our success. I address the fourth measure of success, how have I been changed by this research, in the concluding chapter.

The Benefits of Visioning Health for PAW Co-Researchers: "Good Medicine"

I'm like so passionate about this project. Everybody, like, oh my goodness. I want other people to really feel, you know like really [sigh] experience, you know, goodness, good medicine from this. 'Cause that's what [this project] is to me. It's been good medicine. - Krista

As noted in Chapter 3, at the end of each group research process we held a final research sharing circle focused on PAW experiences of participating in our project. As with

all of our research sharing circles, these were small ‘share-amonies’ (Tafoya, 2001, p. 53) that were conducted at the end of our time together with each group and again at the end of our All Groups Meeting. Questions were open ended and focused on co-researchers’ experiences of participating in *VH*: Is there anything they would like to say about their experience? What did they like about it? What did they not like about it? Answers to these questions were audio-recorded and transcribed verbatim. We also searched the remaining transcripts for comments about PAW co-researchers experiences in this project and drew from PAW co-researchers audio-recorded comments at KTE events.

Many of the *VH* co-researchers described their experience of participating in this project as ‘a healing journey’. For some it was ‘good medicine’, while others spoke of ‘inner healing’, ‘a good journey’, ‘a powerful journey’ or ‘healing in lots of ways’. Using an adaptation of the Socio-Ecological Model (CDC, 2004) as an analytical framework, we suggest that PAW co-researchers benefited from their participation in this project at four levels. Specifically, the PAW in this project talked about having the opportunity to ‘connect’ - with themselves, with others, with community, and with culture – as important and interrelated elements in their healing journey. They also reported feeling stronger, empowered, inspired and motivated to help others by sharing this project with their communities.

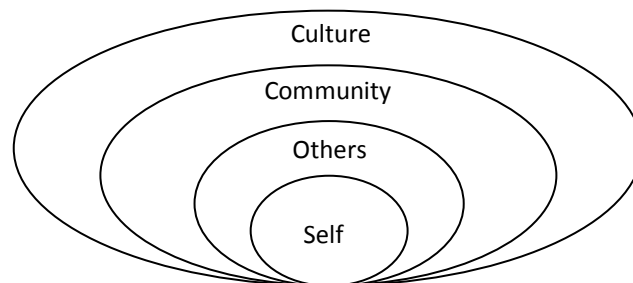


Figure 4: Socio-Ecological Model of Visioning Health Impact

Connecting with Self: “Connect[ing] the dots of my life”

For PAW co-researchers, focusing on strengths instead weaknesses; providing culturally, emotionally, spiritually and physically safe spaces; and using the arts to facilitate

introspection, critical self-reflection and dialogue were important elements of our research design that often led to healing. Candy called it “an inner healing within yourself....What is inside, you know, comes out through the pictures and the writings”. LA called it an “awakening” and explained that through this project she was “connecting myself within myself”. Krista found self-forgiveness and self-acceptance through this creative process of introspection and self-reflection. By focusing our project on strengths instead of weaknesses, Krista discovered a new and more positive perspective on her life that allowed for a renewed sense of self and self-care to emerge.

This [project] was a gateway in my life to begin to connect the dots, to forgive myself. You can go forgive somebody for stealing from you, but when you have a poor self-image and poor judgement of yourself and your identity and where you're from, it's really hard to forgive yourself. Being able to look at it not as derogatory but life giving I guess. – Krista

Critical self-reflection can be an uncomfortable process, but for those who made the effort, the pay-off was considerable. Liz commented that throughout the process “a lot of times I never really knew what my feelings were and that was really complicated, because I really didn't want to identify my feelings a lot”. For Liz though, VH was ultimately about “learning how I and my mind worked. It is about knowing when I needed to take care. How to care for myself: it's about being connected to self”. She went on to describe how she came to know herself better by reflecting on the photos she was taking. What were the photos of? How did they make her feel? Which photos was she drawn to? Soon, she realized that “I was awakening something within me that I never knew was in the back of my mind, my subconscious mind”.

Similarly, PAW shared, “I haven't really been able to help but grow from this process....I've been doing a lot of soul searching...I don't like to be really vulnerable...but I'm finding a lot more courage these days and inspiration”. She went on to say, “I wasn't really expecting sort of the emotion, and maybe that's part of um, you know, the process of healing in lots of ways because of the ability to be able to express without having to use

words.” After an emotional sharing of her photos with the group, she described feeling “raw” but “I don’t feel like trying to run away from it”.

Other women also benefited from this positive process of introspection and reflection through the arts. KJ said that “I learned a lot about myself through this project”. LA reported that “*Visioning Health* has helped me clarify what I need to work on”. Tonie commented that “taking part in this project was very positive for me. I always loved the camera. I see a lot of beauty through the lens and I’m happy to share my pics with everyone”. For Liz, *VH* “made me think differently about how I look at myself”. Stacy shared that she appreciated having access to the cameras and “having to take those pictures and using them to come alive”. Finally, Krista shared that “I feel strongly about this [project] because it gave me so much, I can’t even begin to fathom what it’s taught me about myself”. In *Fireworks*, Krista explains that she gained energy and passion from participating in our project.



Fireworks

This [picture] fills me with a lot of spark and a lot of liveliness, a lot of energy, and a lot of fuel. [...] When I look at that, I just get the excitement and the passion and really this project has really given me that and really blessed me with that. A lot of really good substance.

Another way in which PAW co-researchers connected to themselves was through gaining new skills, which in turn, led to greater self-confidence, self-esteem, and feelings of pride in their accomplishments.

I made this beautiful drum and never thought in my mind that I would have ever done. – ES

Well I feel like I had some awesome photographs, that I would like to have on, uh, that can be public. And I really think those skills are pretty awesome, and I find that I should be sharing it to the public. – Liz

Skills building in this project, however, went beyond the art works that each co-researcher produced. In our Virtual Group, we relied heavily on technology to keep us connected and for some women that meant learning to use social media and other computer programs in new ways. Despite the inevitable challenges we encountered, most women found it exciting to be learning new skills that they knew they could use in their everyday lives.

I know this is a new way of communicating. I kind of find it funny that we are talking about oral presentations and here we are on Skype and talking about uploading documents. And yeah, we are integrating into modern society, so it's kind of exciting. I'm just really excited about this way for us to meet. And I think it just inspires me more. – PAW

Connecting with Others: “I Don’t Feel So Alone Anymore”

The group process, coming together over an extended period of time in a safe and supportive environment was a key element of healing for women from all three groups. From newly diagnosed to long-term survivor, almost everyone talked about the healing that came from “not being so alone with my HIV” (LA). Tonie talked about the isolation she feels as a Positive Aboriginal Woman and how alone she often feels “even on a busy street”. Meeting regularly with a group of other PAW, however, brought a sense of belonging and social support. “Since being in this project”, she said, “I don’t feel so alone anymore”.

Candy reflected on her experience of participating in VH in a poem that she wrote to accompany her photo, *Circle of Light*:



Circle of Light

*I took this picture because I love the sun.
The sun brings warmth, comfort and light.
And that's what these wonderful ladies from [the group]
have given me.
I was alone for a long time.
I was yearning to meet people like me.
Even though we are far apart,
I feel their positive energy and acceptance
and their love is like the ray of the sun.
And because of them, my healing journey begins.*

Stacy expressed it this way:

I realize that I'm just, I'm very. I am very, very. I am very. [Nervous laughter then whispers] I am so fortunate enough to know that there are lots of women out there, especially me being Trans, and I didn't know that there are HIV women like me. And I guess it's just you know, associate, talk about things. Letting people know how we feel...I like it. I enjoy coming here. Like I make sure that I do make it.

Women were quick to point out though that while just being with other PAW was healing in itself, an important element of the group process was teaching and learning from each other. Our Traditional Knowledge Keeper, Wanda Whitebird, likened our group process to the clan mother system in which women were the leaders and decisions were made by talking and sharing amongst themselves. “So that’s a model that you’ve almost created by just being around this table together”. Stacy agreed and observed, “what we are doing right now is teaching each other, being respectful and teaching each other”. This peer mentoring aspect of our work together was further reflected at our All-Groups Meeting where women who were still struggling to accept their HIV diagnosis sat with long-term survivors and tearfully asked “how can I be strong like you?”

Talking, listening, laughing, supporting, sharing, and ‘bearing witness’ to each other’s experiences was also important.

I just really appreciate you all, um, bearing witness and um, sharing with me and I appreciate sharing everything that you guys all shared with me because I feel um, I guess I feel less alone and just more connected, you know, on many levels, right? – PAW

I want to thank you all for you know, for accepting me and inviting me in the circle, being able to share that with me because I too want to feel, you know, not alone, and that is good medicine. That is damn good medicine. – Krista

For women who felt particularly isolated, the VH groups were a lifeline. For some women, it was the first time they had been with openly HIV-positive Aboriginal women and their positive influence was palpable. LA shared that “[a]nd coming here, it’s like wow! [...] Just seeing people with what I have, it’s like I’m almost healed. [...] I feel like I belong to an HIV group, here, now, and I feel so much better.” ES said that “I was always scared of my health, but thanks to [support worker] I made it through, I came here. I thought I would never join you people, but I am here. It is

reality to me.” Likewise, when describing her drum on which she chose to paint butterflies, ME shared the following:

Why I put butterflies on my drum, it's FREEDOM! FREEDOM! And it's like they open their wings like we open our arms to every – each one of them to walk into our arms. [cries]. Because we go through so much! So much that we go through and for our family's sake we have to keep so much to ourselves and yet we are here, and sharing good stories, and have fun, and get along. This is something!



Freedom!

Some women were sad to see the groups end and searched for ways to extend their connection. Tonie shared that “it’s just something I look forward to every month, coming here. I’m going to feel a little sad when it’s going to be no more. [...] But I keep in contact with you always and, you know, hopefully I get picked for [other projects]”. Likewise, LA, a woman whose fear of disclosure almost kept her from joining our project shared this at the end of one of our small group processes:

I want to have contact with whoever is working on this project. [...] Because I was beginning to choke all the time, not knowing who am I going to talk to? Without being judged or put down or anyhow. Um, I think, yeah, I need this. I need your card, I need whatever. I am like, “Oh, they are leaving soon!” Kind of already, and um, I will try to stay in contact with everybody. When I was starting to think I don’t think I want to go on with my life anymore, about what I have. I think it has been so encouraging to accept the fact that you have HIV. I am very very thankful. – LA

Another important element of sharing their individual stories and reflecting on the similarities between them was that a collective story began to emerge. Women saw themselves in each other’s photos and drew strength from their shared experiences. As Liz reminded us, “each of our personal stories helps to explain the Big Picture.”

I am truly amazed at how much similar our experiences are and how we gain skills, you know, like from those experiences and um, the resilience is truly amazing and um, our survival is that we are still here. – Liz

Our experiences, just by this morning, we have so much in common. Not—I don’t mean a virus. The virus is the last thing on my mind right now. I don’t feel HIV positive. I feel like I am in a room full of people who think and feel the way I do. ... And that’s what gives me strength. That’s what wakes me up. – PAW

Connecting with Community: “I Want to Help People Like Me”

Almost all of the Positive Aboriginal Women in this project, even those newly diagnosed and those most isolated, made an easy connection between their own healing journey with this project and wanting to share their experiences with others to help them heal. Those new to the journey expressed a desire to “help people like me” [ME]; “to share more about [living with HIV]” [ES]; to “be more a labourer than a harvester” [LA]. In some communities, however, where HIV stigma and discrimination was high, women expressed a fear of

publicly disclosing to the communities they lived in. Some women felt safer disclosing to, and connecting with, the larger Aboriginal HIV community where they could give and receive support without fear of recrimination from their families, friends and neighbours. We supported several women, for example, who were not ‘out’ to their families or communities, to attend Aboriginal HIV events outside of their community and connect with broader networks of people such as provincial or national organizations. This allowed them to protect themselves locally while receiving support from a larger community of Aboriginal people living with and affected by HIV, learn more about HIV, and give back to the community by sharing their experiences with others.

Those who were more comfortable with their diagnosis saw this project as an opportunity to reach out to other PAW, to the general public, and to their own communities where HIV awareness was low and HIV stigma was high.

I talk about [this project] when I am able to, because I am really proud of what we do, and what we are doing...And I will on World AIDS Day, that week, I will promise that will happen, because I don't think people know what type of awesome research is being done....Research is changing and I think we need to really sort of be the champions of that. – PAW

This journey itself has a been a good journey for myself, and if other people have the opportunity to experience what I've experienced, you know, with the support, which is a big factor to play in it, I think this could be really ground-breaking in our communities in helping and healing. [...] It could be phenomenal. – Krista

According to Wanda, this was another aspect of the clan mother system that was represented by the VH group process. In the clan mother system some women emerged as natural leaders or were chosen to represent the others and to be the spokesperson for those who did not have a voice. In VH, Wanda suggested that PAW co-researchers needed to be the voice of other PAW who could not participate for reasons of access or discrimination. She went on to say that the PAW co-researchers were holding a space at the table for those who could not be there. This sense of

representing and speaking on behalf of those who cannot speak for themselves is reflected in Liz's comment. Here, she makes an explicit connection between her own journey of sharing with this project and being able to support other Positive Aboriginal Women.

Our team is our support in this room. Sharing can be scary at first but it can be very rewarding. When I tell my story I become stronger from the experience. It helps to make sense of the things that Aboriginal Women living with HIV/AIDS experience in life and share my new understanding. It helped to first understand my own life-story and my relationship to HIV/AIDS. Then new understandings are developed to create community support for newly-diagnosed Aboriginal women. – Liz

Connecting with Culture: “Awakening of Identity”

As part of our decolonizing and Indigenist methodology, our intention to use ‘culture’ and Indigenous knowledge to ground our work was explicit from the outset. The degree to which we did this, however, evolved with the project and was largely driven by the PAW co-researchers needs. The Toronto group, the first group we worked with, taught us that having a Knowledge Keeper with us at all meetings and conducting small ceremonies such as opening and closing prayers, smudge and sharing circles was an important element of providing safety for PAW co-researchers and we carried these lessons into our work with the other two groups. Again, taking our cue from the PAW co-researchers, we incorporated other ceremonies and cultural protocols as the request or the need arose. From this experience we learned that ceremonies and cultural protocols such as gifting tobacco in return for cultural teachings, smudging, research sharing circles, drumming/singing, drum awakenings, traditional teachings, a sweat lodge, and having Traditional Knowledge Keepers, *oshkaabewis* and Elders with us throughout the project provided a safe space for co-researchers to explore and express their cultural identity. Liz made this connection explicit while reflecting on what culture means to her.

It's kind of how I grew up, how I learned about how my environment works, the way I use my language, and my values, that makes me who I am. This is true with this project. Both the project and how it was developed look at how Aboriginal women learn and take in information. – Liz

Krista valued the presence of a Knowledge Keeper but also really appreciated our “culturally sensitive approach”. For her, “having the strong component of one Elder who oversaw and overlooked the whole thing, it really meant a whole lot to me”. PAW agreed that “I really feel safe with [Wanda]...and I like the idea of, you know, having Wanda with us”.

As noted in previous chapters though, PAW do not always have access to their cultural knowledge and traditions. Some did not grow up with it, and others have been denied access because of HIV-related stigma and discrimination. For many PAW co-researchers then, having the opportunity to participate in sweat lodge, to sit with and learn from Knowledge Keepers, to make their own drums and participate in drum circles was an important element of our process and revolutionary in its own right. As Wanda reminded us, “you know...we picked our drums up in 1992 here in Toronto. And now we are using drums in a research project? How did that happen!?” Other co-researchers also talked about the value of their drums and the ceremonies that we all shared in:

This drum is really special for me because of the way – the awakening ceremony that brought this drum to me. And I am going to learn lots from this drum. [...] It is very special, it is very humbling to get this drum. It's a real gift and we are going to learn together. This drum is going to teach me and maybe I can teach this drum too about my journey with HIV and we can journey together, and help each other. Meegwetch. – Doris

For me, this drum ain't going nowhere! She's all mine. All mine! It is a very special gift. It has touched my heart. – ME

This drum is really special to me. I am a drummer and for a long time I was not able to carry a drum, and for me to have this drum again is really special. So thank you. Meegwetch. – KJ



KJ's Four Directions Drum

For many co-researchers, the links they saw between culture, identity and well-being, in the groups' photos and in their analysis of the photos were unexpected. As Doris explained:

It's truly amazing you know, what I am seeing, how they connect with environment and nature and um, you know, and um, they're all reflecting their identity. And um, their values and their beliefs and they're—when you look at them they're all part of the culture and our teachings passed to us from our Elders. – Doris

Wanda also commented on the content of the photos. She felt that anyone who saw the photos would know that they were taken by Aboriginal women because of their cultural content.

This project is amazing but remember, it's going to live for centuries from now and to me [the photos] all represent hope. Hope for our community, hope for our children, our grandchildren, but ...because we're all city Indians and yet

they tell us we don't have our culture and that's so untrue! Because it's in all of those pictures; there's your spirit essence, the fact that you have the inherent right to be part of Native peoples of our country. And even if you only seen the pictures and not the narrative, another person, another Aboriginal person, no, not Aboriginal, another whatever, would know right away. – Wanda

Seeing the strong cultural content of the photos reflected back at them helped some women to re-connect with their cultural identity.

Um, looking at how spiritually and culturally connected, like that was an awakening for myself, because I looked at myself and culturally I know nothing, nothing at all....Looking at those pictures, I learned that you know, I am a culturally and spiritual being. I am a spiritual being and that was an awakening. An awakening of identity. – Krista

The Impact of Visioning Health on the Community: Community-Engaged KTE

Consistent with the Indigenous Peoples' Health Research Centre's (IPHRC) approach to knowledge translation as "sharing what we know about living a good life" (Kaplan-Myrth & Smylie, 2006; Estey, Smylie, & Macauley, 2009) and reflecting our commitment to GIPA, and to strengthening capacity among PAW, we developed a robust and integrated KTE strategy for VH that prioritized community-engaged and culturally-relevant KTE with the active engagement of PAW. We built our KTE strategy on the following fundamental beliefs:

- the results of research with Aboriginal communities should be shared first with Aboriginal communities;
- the primary beneficiaries of research with Aboriginal communities should be Aboriginal communities;
- successful KTE in Aboriginal communities requires Aboriginal involvement in all stages of the research;

- KTE must be built-in to the research process so that research has an ‘outcomes focus’ that endeavours to create social change (Masching, Allard, & Prentice, 2006);
- KTE must be locally relevant, contextualized, and use active engagement strategies instead of passive (Kaplan-Myrth & Smylie, 2006, p. 37);
- health promotion and KTE efforts for PAW must be led by PAW and be delivered in ways that are consistent with the norms and values of their cultures (Peltier, et al., 2013); and
- reducing health inequities requires the engagement of multiple stakeholders at multiple levels (Barten, Mitlin, Mulholland, Hardoy, & Stern, 2007).

For these reasons, we developed an integrated and end-of-grant KTE strategy for the VH project that prioritized KTE at several levels: 1) increasing knowledge and capacity among PAW; 2) increasing knowledge and capacity in Aboriginal communities; and 3) increasing knowledge and capacity in the broader society including academic and policy-maker audiences. Engaging all of these levels in KTE contributes to the creation of what Campbell and Cornish (2010) call “health enabling social environments”.

Since completing data collection with the first group of PAW in June 2011 and intensifying once all data collection was complete in November 2011, we have given four key note presentations to academic and community audiences; 28 conference presentations to academic, community and service-provider/policy-maker audiences; two workshops for community and service-provider/policy-maker audiences; held four policy and service-provider discussions; and hosted 17 photo exhibitions, including four *VH Lodges* that are innovative and culturally-grounded photo exhibitions hosted inside an Ojibwe-style teaching lodge that we built in ceremony, under the guidance of an Elder or Traditional Knowledge Keeper, especially for the exhibition. We have been fortunate to share our process and our findings at Aboriginal conferences and events (CAAN Annual General Meeting & Wise Practices Research Conferences; Shining Mountain Aboriginal HIV Gathering; Aboriginal Health Research Network Colloquium on Racism and Cultural Safety), at academic institutions (University of Ottawa, Concordia University, University of Victoria), at provincial (Ontario HIV Treatment Network Research Conference; Saskatchewan AIDS

Conference), national (Canadian Association of HIV Research Conference) and international (International HIV Social Sciences and Humanities Conference – South Africa; AIDS 2012 – Washington, DC) research conferences, KTE Forums (Canadian AIDS Treatment Information Exchange [CATIE] Conference; HIV Women’s Forum), and with policy maker audiences (Saskatchewan Ministry of Health and Institut national de santé publique du Québec) in twelve cities across four provinces, two states, and three countries. As a result, we estimate that many hundreds and probably thousands of people have seen our photos or attended our presentations, almost all of which (94%) have been co-developed and co-presented by myself, Doris and PAW co-researchers as part of our commitment to building research capacity and awareness among PAW. In addition, summary findings from our project and our process have been reported in two publications of conference/workshop proceedings (AHRNeTS, 2013; CHIWOS, 2012).

Early KTE

With one or two exceptions, all of our photo exhibitions were accompanied by presentations, workshops or policy dialogues and presented in ways that honoured Aboriginal culture and traditions. For example, our first photo exhibition/community forum was accompanied by a community feast (catered by an Aboriginal caterer) and hosted by a local Aboriginal Women’s Organization. Guided by the Toronto group co-researchers, all of whom were First Nations, we organized the exhibition around the Medicine Wheel Teachings in which PAW co-researchers separated their photos into themes of mental health, physical health, spiritual health and emotional health. Each set of photos was displayed against the appropriately coloured backdrop in the presence of the appropriate medicine for that quadrant: mental health = black, sage; physical health = white, cedar; spiritual health = red, tobacco; emotional health = yellow, sweetgrass (Wanda Whitebird, personal communication). In accordance with cultural protocol, fresh berries were placed on each table as a reminder of the sweetness of life and the importance of sharing and caring (Sharp Dopler, personal communication). Wanda opened our exhibition with a smudge, a prayer, and a drum-song. After a brief presentation by each of the co-researchers, attendees were invited to view the photo-stories and to ask questions of the co-researchers. We followed this with a feast and a

facilitated discussion with community members and service providers regarding potential actions or responses to the issues raised in the photographs.



Visioning Health, Toronto Group Exhibition, June 2011

Following the completion of data collection for all groups, we again used the Medicine Wheel theme for our first exhibition of all groups' photo-stories at the Ontario HIV Treatment Network Research Conference in 2011. Some of the PAW co-researchers, however, expressed discomfort with the Medicine Wheel theme. They had been taught that the Medicine Wheel had its origins in the Great Plains, and while it has become one of the most widely recognized symbol of Aboriginal holism and is commonly used in Aboriginal healing centres and in Aboriginal HIV education and awareness workshops, this symbol of holistic health did not resonate with some co-researchers whose Nations had their own symbols of holistic healing associated with the land and culture from which they hailed. Instead, PAW co-researchers decided to expand on the 'PAW' metaphor, and to connect their photo-stories with a bear paw to represent the shared experiences of Positive Aboriginal Women (PAW).

We continued to use the sacred medicines in our exhibitions and sometimes placed 'grandfather rocks' at the base of the photos to represent wisdom. Depending on the space available to us, we also used tobacco ties and grandmother cloth and hung our photos on a clothesline to honour the wisdom of the grandmothers.



**Photo Exhibitions: The Global Village at AIDS 2012, Washington, D.C.
& Institut national de santé publique du Québec**

The feedback we received on all of our exhibitions and presentations was positive. For example, Robert attended our very first photo exhibition, and said “thank you for sharing your lives and your talent with us. It is truly inspiring and raises my spirit to see such hope and joy in the midst of life”. Attending the same exhibition, Erin shared, “To all the women in this exhibit. Your voices move me, and the images resonate for my journey as part of this movement. The images you shared are important teachings to share with Aboriginal youth. I am very thankful to have been able to see these images and descriptions. Thank you all for sharing.” Kim attended the OHTN exhibition and was moved to share the following poem in our comments book:

*The photos, those that are familiar
those so new to me
Strike a chord
Build a bridge into
our shared knowing
a reminder of our human-ness
our woman-ness.
Your eyes, your sight, your images
Bring a vision into sharp focus.
Many stories
Many experiences
Many points of view –
One community
One world.*

Visioning Health Lodge

In July 2012, however, Doris came up with an idea that proved to be a game-changer. Since the first photo-sharing exercise in Toronto, we had been aware that the photo-stories that PAW co-researchers were sharing with us were more than ordinary stories of ordinary events. Contrary to what we expected, the tone of voice that co-researchers used while sharing their photos, the words they chose, the emotion they carried, and their cadence of speech, all told us that these photo-stories were deeply personal, achingly intimate, and precious beyond measure. At the culmination of their sharing, Wanda suggested that the Toronto PAW co-researchers had been seeing with and speaking through their ‘Spirit Eyes’. Indeed, they were sharing sacred stories of sacred lives, and we felt to truly honor them required a sacred space in which to host an exhibition of their photo-stories. To date, we had managed to design culturally-relevant exhibitions with the presence of spiritually significant items, but we knew that something was missing.

In the summer of 2012, to further honour our commitment to building research capacity among PAW and to “sharing what we know about living a good life” (Kaplan-Myrth & Smylie, 2006), we wrote and received a CIHR Dissemination Grant to bring eight women from our project (five PAW co-researchers, two community partners, including our Knowledge Keeper, and myself) to Washington, DC, to present our research and our photo-stories at AIDS2012 - the biggest and most prestigious AIDS conference in the world - and at the International Indigenous Pre-Conference on HIV and AIDS. While negotiating exhibition space with the organizers of the Indigenous Pre-Conference, Doris came up with the idea of displaying the photo-stories inside an Ojibwe-style teaching lodge to be built in the lobby of the conference hotel. When explaining the significance of a teaching lodge Doris shared that “traditionally, teaching lodges were and continue to be used for ceremonies and for the sharing of Indigenous teachings and Indigenous knowledge. They are sacred spaces where sacred stories are often told” (Peltier & Prentice, 2012).

As described in the Introduction to this thesis, we constructed the lodge in ceremony, under the guidance of an Elder, and with the assistance of PAW co-researchers, team members and community. Using approximately 45 red willow saplings that had been freshly harvested in Northern Ontario and transported by pick-up truck to Washington, D.C. by Elder Stan Peltier, approximately a 14 hour drive, we built a lodge that was ten feet wide by

sixteen feet long by eight feet high, and filled it with the photo-stories and drums of all 13 PAW co-researchers.



Visioning Health Lodge, Washington, D.C., July 2012

Throughout the three day Pre-Conference, PAW co-researchers gave tours of the Lodge and shared their photo-stories with conference delegates. Inside the Lodge, we hosted a three hour policy and practice circle, with traditional opening and closing by Wanda Whitebird, in which PAW co-researchers shared their experiences of participating in VH, and in which conference delegates were invited to share their ideas for addressing the issues raised. In the Indigenous Pre-Conference closing ceremonies, several key note speakers, including Sharon Day, an Ojibwe Grandmother and Executive Director of the Indigenous Peoples Task Force from the United States, and Dr. Rainer Englehardt, Assistant Deputy Minister for the Public Health Agency of Canada, Infectious Disease, Prevention and

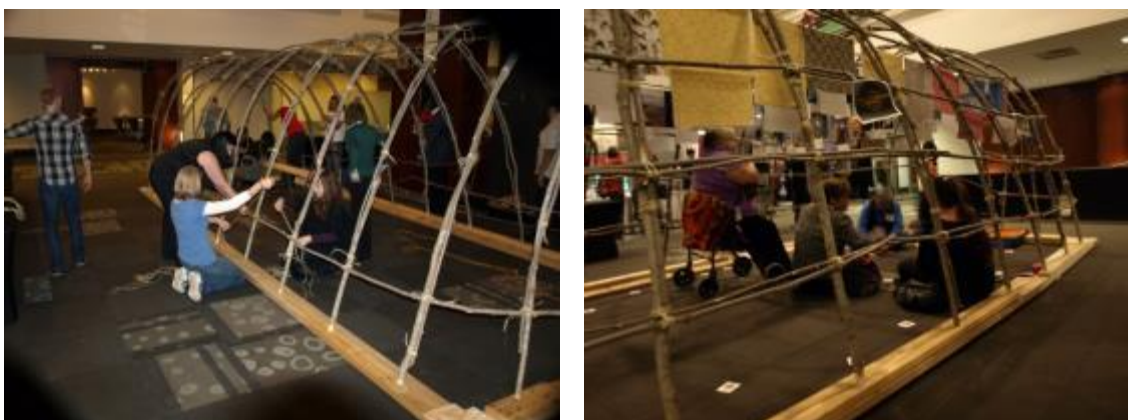
Control Branch, highlighted our *VH Lodge* as an exemplar of culturally-grounded and community-engaged KTE. We agree.

As noted earlier in this thesis, however, sacred spaces such as teaching lodges are also frequently spaces of exclusion for PAW, many of whom do not have access to these sacred spaces because of HIV-stigma, discrimination or lack of opportunity. For the PAW co-researchers in our project then, building the lodge and participating in the ceremony were acts of resistance and resilience, and the *VH Lodge* itself represented a space of resistance, resilience, restoration, and revolution. Standing in the lobby of the hotel for the duration of the Indigenous Pre-Conference, the *VH Lodge* was a strengths-based and very visible assertion of Aboriginal identity, of cultural pride, of PAW's health and wellness, and of positive resistance to oppression in all its forms, including the on-going legacy of colonialism and HIV-related stigma and discrimination. In the words of PAW co-researchers, the *VH Lodge* proudly proclaimed "I'm HIV-positive, so what!" and "You can't tell me who I am!"

Based on the success of our Washington Lodge, we were invited to build another *VH Lodge* at the Ontario HIV Treatment Network Research Conference in Toronto and again in Saskatoon at the Saskatchewan AIDS Conference in the fall of 2012. Despite our success in Washington and the obvious benefit to PAW co-researchers, given the significant time and financial resources that were required to build the Lodge, we had not intended to do it again. However, after discussions with the team, with PAW co-researchers, with Elder Stan Peltier who would once again be required to harvest the willow in Northern Ontario and then transport it Toronto and back again, and with the conference organizers who agreed to pay for all expenses including Elder honoraria and travel for several PAW co-researchers who could not attend the Washington conference, we accepted these invitations and began our planning.

The Toronto Lodge, measuring twelve feet wide by twenty-two feet long by eight feet high and prominently located at the centre of the conference venue, was our biggest *VH Lodge* and the only one that was built for a primarily non-Aboriginal audience. Consistent with our commitment to increase knowledge and capacity in the broader society including academic and policy-maker audiences, conference delegates were invited to participate in building the lodge and in the ceremony and teachings that went with it. Again, PAW co-

researchers gave tours of the Lodge and shared their photo-stories with delegates. We developed one informational poster (Peltier & Prentice, 2012) and one research poster (Prentice & Peltier, 2012) to display outside the lodge and Elder Stan Peltier and *oshkaabewis* Sharp Dopler were also available to share their traditional knowledge, teachings and drumming with those who were interested.



Visioning Health Lodge, Toronto, ON, November 2012

Drawn by the sound of Sharp's drum perhaps, by the novelty of a traditional teaching lodge inside a 5-star hotel in downtown Toronto, or by the ineffable feeling of peace and welcome that awaited those who entered, the Toronto Lodge quickly became a gathering place for Aboriginal and non-Aboriginal delegates alike. Between sessions and even during sessions, PAW co-researchers guided delegates through their photo-stories, and groups of two to twenty people gathered inside the Lodge to share stories, to share food, to share laughter, songs, ceremony and even silence when that is what was needed.

The last session of the conference was a sharing circle in which delegates reflected on their conference experience. Aboriginal delegates shed tears of gratitude while sharing that they had been coming to this conference for years but for the first time they felt truly welcomed when they saw the Lodge; for the first time, they felt like they belonged. For them, the Lodge provided a cultural touchstone, a place of health and healing, a safe space amidst the foreign and sometimes hostile world of researchers who often perceive Aboriginal people and Aboriginal people living with HIV as 'problems' to be fixed. Non-Aboriginal delegates though also appreciated the Lodge. Most were grateful for the

opportunity of cross-cultural learning and to be invited into what they knew to be a sacred space to participate in ceremony and cultural teachings. Reflecting on how ‘heady’ the conference is and on how much information delegates are expected to take in, non-Aboriginal conference-goers said that the Lodge gave them a space to unwind, to breathe, to process the information they were receiving. Most importantly perhaps, these delegates found that spending time in the Lodge helped them to connect their heads with their hearts, and to ground the new knowledge they were receiving in a more human and holistic framework.

In December of the same year, we built our third *VH Lodge* for the Saskatchewan AIDS Conference in Saskatoon and almost a year later, in September 2013, we built our fourth and final Lodge in Regina at CAAN’s Wise Practices Research Gathering. With these two Lodges, that continued to be built in ceremony, we continued our practice of building knowledge and capacity, and of “sharing what we know about living a good life”. PAW co-researchers continued to challenge dominant notions of what it means to be a Positive Aboriginal Woman by sharing their photo-stories of health, culture and gender with other HIV-positive Aboriginal women and men, with Aboriginal community members, and with policy-makers and service-providers, and the Aboriginal community continued to embrace our Lodges.

In Saskatoon, we worked with local Helpers to harvest the willow and have it delivered to the conference hotel; however, from this point on, the Saskatoon Lodge was the only Lodge to be built by all women, and primarily by PAW co-researchers and team members. Guided by Traditional Knowledge Keeper Wanda Whitebird, PAW co-researchers, team members and a few local PAW, worked together from 7:00 pm to 2:00 am to build this Lodge in ceremony and to house PAW photo-stories. For many of the women present, this was the first time they had ever participated in building a Lodge and it was certainly the first time they had done so without the presence of men. This proved to be a powerful experience for PAW co-researchers and team members who expressed a strong sense of satisfaction and fulfilment when completed.

During the conference, Elders and those who carried traditional teachings gathered around the Lodge to engage in nation-to-nation sharing, and the Lodge became the impromptu focal point for two sharing circles requested by conference delegates. While

opening one of these sharing circles, Wanda recalled that less than 20 years ago, when she was living in Saskatoon, the racism was so prevalent that Aboriginal people were not allowed to even be in that particular hotel. She went on to say how fantastic it was that not only were we now attending an Aboriginal HIV research conference at that same hotel, but we had also built a sacred lodge on the premises. For her, making space for Aboriginal healing and Aboriginal worldviews, for ceremonies and for teachings inside those same colonial spaces that had banned all things Aboriginal less than 20 years prior was truly revolutionary.



Visioning Health Lodge, Regina SK, November 2012

For Wise Practices, we wrote a second successful CIHR Dissemination Grant and worked with community partners to bring 15 of our 17 *VH* team members, including all but one PAW co-researcher to the conference for a project wrap-up and final celebration. We worked with a local Aboriginal youth group to harvest the willow “in a good way” and to deliver it to the conference hotel. Due to circumstances beyond our control none of our Knowledge Keepers or *oshkaabewis* could be there, but Doris as well as Elders, Grandmothers, and Knowledge Keepers at the conference gathered to collectively guide us through the ceremony and building of the Lodge. Once again, the Lodge became a focal point for conference delegates who wanted or needed a space for reflection, thought, contemplation or ceremony. Frequently, individuals or small groups of people would gather in the Lodge to do whatever needed to be done.



Visioning Health Lodge, Saskatoon SK, September 2013

With this Lodge, we also began an interactive and reciprocal process of KTE with service-providers and decision-makers. At this conference, we hosted a three hour interactive policy discussion in which PAW co-researchers shared their experiences of participating in our project, we shared our findings, and then asked delegates to participate in a mini-VH project – an arts-informed activity to explore their own ideas of health and wellness or reflection on what they had heard in our session. Delegates took photos or created collages to illustrate their ideas, wrote a short description, and shared them with the others. Art-works and photos from this session were then hung on the *VH Lodge* alongside the photo-stories of PAW co-researchers. This reflects the Indigenous notion that the health of communities and the health of individuals are integrally connected. It also extends the central metaphor of the *VH Lodge* from ‘VH for Positive Aboriginal Women’ to ‘VH for Aboriginal Communities’. It is worth noting here, that HIV-positive Aboriginal men at this conference were inspired by the *VH Lodge* to host their own discussion of what a ‘*Visioning Health* for Men’ might look like.

Chapter Summary

The primary focus of this chapter has been on assessing the ‘transformational validity’ (Cho & Trent, 2006) of *VH* using Walters and colleagues notion of ‘research as revolution’ (Walters, et al., 2009). I began by asking if our research made a difference in people’s lives. Did we ‘give back’ enough to PAW co-researchers and to the Aboriginal community more broadly? Were PAW co-researchers and community better off for having participated in our

research? Was *VH* ‘revolutionary’ in Walters and colleagues sense of the term? In other words, did we succeed in “decoloniz[ing] and indigeniz[ing] the research process to transform science as well as [our]selves, the communit[y], and the larger society for the betterment of all” (2009, p. 154)?

Drawing from data collected throughout the research process, I showed that *VH* was a health-enabling and transformational experience for PAW co-researchers, largely due to our strengths-based, arts-informed, women-centred, decolonizing and Indigenist methodology that upheld the principles of GIPA, MIWA and of Aboriginal self-determination in research. Using a socio-ecological model as an additional guiding framework, I showed that *VH* helped PAW co-researchers connect to themselves, to others, to their community and to their culture, and thus contributed to the creation of a health-enabling social environment in which PAW’s health was supported at multiple levels. In addition, our culturally-grounded, community-engaged and PAW-driven KTE process reached out to the broader community and engaged them in our research in innovative and experiential ways. In this way, we were able to create space and opportunity for new ways of doing research; for new ways of engaging PAW in research; for new ways of thinking about PAW’s health; and for new ways of “sharing what we know about living a good life”. Reflecting back, then, on the questions we asked of ourselves at the beginning of this chapter, I would suggest that yes, *Visioning Health*, had a significant impact on people’s lives, and yes, *Visioning Health* was indeed revolutionary.

In the next and final chapter of this thesis, I reflect on the findings of this project, on the process, and the policy and practice implications of *Visioning Health*. I also answer the remaining question laid down in this chapter; what did I learn from this experience? I conclude this thesis with next steps for *Visioning Health* and recommendations for future research.

Chapter 8

A Different Kind of Story: Discussion, Conclusion and Recommendations

We live by stories [and] we also live in them. One way or another we are living the stories planted in us early or along the way, or we are also living the stories we planted – knowingly or unknowingly – in ourselves. We live stories that either give our lives meaning or negate it with meaninglessness. If we change the stories we live by, quite possibly we change our lives (Ben Okri as cited in King, 2003, p.154).

Introduction

When Doris and I began developing this research back in 2008 it was the only project that we knew of that explored the meaning, experience, and pathway to health for PAW instead of the meaning, experience, and pathway to illness and of HIV specifically. It was also the only project that we knew of to use explicitly strengths-based, arts-informed, and culturally-grounded methods to explore PAW's experiences of anything.

Prior to initiating VH, PAW had been the primary focus of only two qualitative studies that produced a handful of journal articles, primarily on the risk factors and risk environments that contribute to HIV for Aboriginal women, and the barriers to care and support once they were diagnosed (Mill, 1997; Mill, 2000; Ship & Norton, 2000; Ship & Norton, 2001). PAW were also included in studies on the “challenging lifestyles” of Aboriginal men and women living with HIV (Mill, Lambert, Larkin, Ward, & Harrowing, 2008; Mill, Keenan, Lambert, Larkin, & Ward, 2008), the relationship between injection drug use and HIV among Aboriginal men and women (Harvey, et al., 1998; Spittal, et al., 2002; Craib, et al., 2003; Hogg, Strathdee, Kerr, Wood, & Remis, 2005; Wood, et al., 2008), inadequacies in HIV treatment uptake among Aboriginal people living with HIV (Lima, et al., 2006; Wood, et al., 2006; Miller, et al., 2006), the intersections between injection drug use, sex work, violence and increased HIV risk among women (Varcoe & Dick, 2008; Shannon, Bright, Gibson, & Tyndall, 2007; Shannon, Kerr, Allinott, Chettiar, Shoveller, &

Tyndall, 2008; Hill, 2003), and sexual violence and increased risk of HIV for women (McKeown, Reid, & Orr, 2004). Additionally, a few articles brought attention to the gender differences in HIV-status among Aboriginal young people who use injection drugs, highlighting that “Aboriginal women were three times more likely than men to be HIV positive” (Mehrabadi, et al., 2007; Mehrabadi, et al., 2008, p. 253). Many of these latter studies, however, failed to present a separate analysis for Aboriginal women, thus limiting their ability to contribute to a better understanding of the unique dimensions of HIV for Aboriginal women; and all shared a fundamentally pathogenic orientation that sought to understand the causes and correlates of HIV but contributed little to our understanding of health and healing for PAW.

In the intervening years, despite increasing resistance by Aboriginal scholars and community members to the pathologizing of Aboriginal lives (Ahenakew, 2011; Greensmith, 2012), and collective calls for more strengths-based research that draws attention to the strengths and assets of Aboriginal communities (Peltier, 2010), not a lot has changed. New research dedicated to PAW continues to focus on the challenges of living with HIV (McCall, Browne, & Reimer Kirkham, 2009), or the challenges of accessing care (McCall & Pauley, 2012; McCall & Lauridsen-Heogh, 2014) while studies that include Aboriginal women and Aboriginal women living with HIV in larger samples continue to focus on the structural and behavioural determinants of HIV risk (Bingham, Leo, Zhang, Montaner, & Shannon, 2014; Duff, Bingham, Simo, Jury, Reading, & Shannon, 2014; Duncan, et al., 2011; Moraros, Falconer, Rogers, & Lemstra, 2012; Rachlis, et al., 2010), mother to child transmission of HIV (Forbes, et al., 2012), or barriers to care, treatment and support (Jaworsky, et al., 2012; Carter, et al., 2014; Mill, Edwards, Jackson, Austin, MacLean, & Reintjes, 2009; Loutfy, et al., 2012; Monette, et al., 2011; Cain, Jackson, Prentice, Collins, Mill, & Barlow, 2011; Cain, Jackson, Prentice, Collins, & Barlow, 2013; Orchard, et al., 2010; Martin, et al., 2011). While a few of these latter studies dedicate limited space to ‘healing strategies’ for Aboriginal people living with HIV, and most call for culturally-relevant prevention, care, treatment and support for Aboriginal men and women, they continue to be grounded in a pathogenic paradigm that prioritizes disease over health, illness over wellness, and HIV risk factors over HIV protective factors. The doctoral work of Kim McKay-McNabb (2006) on ‘the healing path’ for Aboriginal women living with and

affected by HIV was exceptional for its strengths-based and culturally-grounded approach, as was CAAN's *Relational Care* project (CAAN, 2008); however, neither of these offered a separate analysis for HIV-positive Aboriginal women. CAAN's *Depression* project (Cain, Jackson, Prentice, Collins, Mill, & Barlow, 2008; Cain, Jackson, Prentice, Collins, Mill, & Barlow, 2011; Cain, Jackson, Prentice, Collins, & Barlow, 2013), a qualitative study of depression among Aboriginal men and women living with HIV, and *Our Search for Safe Spaces* project (Hawkins, Reading, & Barlow, 2009), a qualitative study of sexual violence among Aboriginal women living with HIV, also represent a shift away from a solely pathogenic approach to include a limited focus on health and healing for Aboriginal people living with HIV and for PAW respectively.

Research from the United States follows roughly the same pattern. While I was unable to locate a single study that focused exclusively on HIV-positive American Indian and Alaskan Native (AI/AN) women, a number of articles focused on HIV risk factors for AI/AN women including the intersections of trauma, sexual violence, and drug use (Walters & Simoni, 1999; Vernon, 2002; Simoni, Sehgal, & Walters, 2004; Saylor & Daliparthi, 2005; Evans-Campbell, Lindhorst, Huang, & Walters, 2006; Walters, Beltran, Evans-Campbell, & Simoni, 2011), HIV misinformation and alcohol use (Morrison-Beedy, Carey, Lewis, & Aronowitz, 2001), and biological, economic, social, and behavioural factors that put AI/AN women at increased risk for HIV (Vernon, 2007; Pearson & Cassels, 2014). Additionally, a few studies included women in larger samples of HIV risk factors for AI/AN (Fenaughty, Fisher, Cagle, Stevens, Balswin, & Booth, 1998; Baldwin, Trotter, Martinez, Stevens, John, & Brems, 1999; Diamond, Davidson, Sorvillo, & Buskin, 2001; Bertolli, et al., 2004; Vernon & Jumper-Thurman, 2005; Lapidus, Bertolli, McGowan, & P, 2006; Dennis, 2009; Cassels, Pearson, & Walters, 2010), and a number of studies focused on culturally-relevant HIV prevention for AI/AN (Vernon & Jumper-Thurman, 2002; Duran & Walters, 2004; Foley, et al., 2005; Gilley, 2006; Thurman, Vernon, & Plested, 2007; Lowe, 2007; Wiechelt, Gryczynski, & Johnson, 2009; Gray, de Boehm, Farnsworth, & Wolf, 2010) or culturally-relevant care, treatment and support of HIV-positive AI/AN (Hamill & Dickey, 2005; Nebelkopf & Penagos, 2005; Bien, 2005; Wright, Nebelkopf, & King, 2011; Duran, et al., 2010). These latter studies are notable for their emphasis on culturally-grounded HIV prevention, care, treatment and support that highlights individual, community and cultural

strengths; however, none provide a gendered analysis, once again rendering women invisible in the HIV epidemic, and limiting the studies' ability to contribute to our understanding of the gendered experience of HIV among American Indian and Alaskan Native women.

To date, then, *VH* remains the only study to focus on health instead of disease for PAW, on wellness instead of illness, on the strengths and strategies that PAW use to create, support and maintain their health, instead of the barriers and challenges of living with HIV. In the following pages, I reflect on the findings from *VH* and on the stories that PAW co-researchers chose to tell about their health and about themselves.

Visioning Health in Context: Reflection on the VH Findings

PAW co-researchers were a diverse group, representing a range of First Nations and Inuit identities, geographic locations, ages, gender identities, time since diagnosis, and life experiences. Each woman was unique and brought a unique perspective to our project, however, they shared three common experiences: they were Aboriginal and therefore shared a common experience of colonization, they self-identified as women, and they were HIV-positive. While we cannot claim to have identified a definitive homogenous definition of PAW's health – to do so would mask the diversity between and among PAW co-researchers – we have identified some common characteristics of health for the PAW in our project. Following Adelson (1998), I suggest that these be understood as “a depiction of an ideal state...an idealized image, a prototype against which to gauge [PAW's] state of being” (p. 14). In other words, health as we define it below is aspirational rather than concrete, an ideal to strive towards rather than an accurate representation of current realities. This is just as true of PAW's concepts of health as it is for health concepts around the world.

For PAW in this project, health was understood to be holistic, relational, collectivist, and integrally tied to their identity as Aboriginal women. Consistent with much of the literature on Aboriginal women's health (Bent, 2004; Brant-Castellano, 2009; Deiter & Otway, 2001; NWAC, 2007d; Wilson, 2004) and Aboriginal health more generally (Adelson, 1998; Graham & Leeseberg Stampler, 2010; Isaak & Marchessault, 2008; Parlee, O'Neil, & Nation, 2007; Vukic, Gregory, Martin-Misener, & Etowa, 2011), individual health for PAW includes components of physical health, mental health, emotional health and spiritual health, but it also includes family, community and environmental dimensions.

Health for PAW is about the interrelatedness between all of these dimensions; about finding a dynamic balance between them and in relation to current life circumstances. This means that health is a process rather than a state of being and the responsibility for driving that process lies with PAW. The notion of self-determination, of taking responsibility for, and taking control of, their health is a cross-cutting theme.

Health for PAW co-researchers, however, is constituted through relationships at multiple intersecting levels. According to Wilson, "...the relational way of being was at the heart of what it means to be Indigenous" and this extends beyond human relationships to encompass relationships to the land, the environment, the cosmos, and also ideas (2008, p. 80). Being healthy for PAW then means being connected or in relationship with oneself; physically, mentally, emotionally, and spiritually, and with others including peers, friends, family and community. It means being connected or in relationship to the land, environment and the natural world regardless of where one lives, and with culture through Elders, ceremonies and traditional teachings. Being healthy for PAW also means being in relationship with Spirit or Creator, in whatever way that makes sense for them. Each of these levels is interrelated, of course, and PAW's relationships at each level are bi-directional and mutually constitutive. In other words, the individual health of PAW is integrally connected to, influences, and is influenced by, the health of all other levels. As Adelson asks in her seminal work on health beliefs and Cree well-being, "can we 'be alive well' [healthy] if the land is not?" (1998, p. 13).

These findings are interesting in a number of ways. While what constitutes health for PAW is not radically different from what constitutes health for Aboriginal peoples generally, it is nonetheless, the first articulation of PAW's understanding of health in the literature. As Bartlett suggests in her study of lay definitions of health among Aboriginal women living with diabetes, while "Aboriginal populations commonly describe life as holistic and use the terms spiritual, emotional, physical, and mental (intellectual) to describe their perceptions of health and well-being...minimal academic exploration has been done to document this perception and the meaning of these terms with Aboriginal populations" (2005, p. S22). Our findings then can be considered an initial step towards documenting PAW's perceptions of health. This can, in turn, be used to design effective policy and practice that better meets the needs of PAW.

To this end, our findings highlight a clear disconnect between the vast majority of research, prevention and practice for PAW that has sought to understand and address their experiences using a far more limited and limiting concept of health than the one articulated by PAW co-researchers. Typically, these studies, policies and programs focus on deficit and disease reduction; prioritize physical health and to a lesser extent mental health while all but ignoring emotional and spiritual dimensions; and almost exclusively promote biomedical ‘fixes’ for PAW health-issues that are devoid of socio-cultural context and content (McCall, Browne, & Reimer-Kirkham, 2009). It is clear from our findings, however, that these approaches are experienced as inadequate, unbalanced, disempowering, and in some cases counterproductive. Instead, the stories that PAW co-researchers shared guide us to ground our research, our policy and our practice in PAW’s notions of health that are culturally-grounded, holistic, collectivist, and rooted in relationship at multiple levels. This is consistent with a socio-ecological model of health referred to in Chapter 2 and Chapter 7. One potential articulation of this model for PAW’s health is as follows.

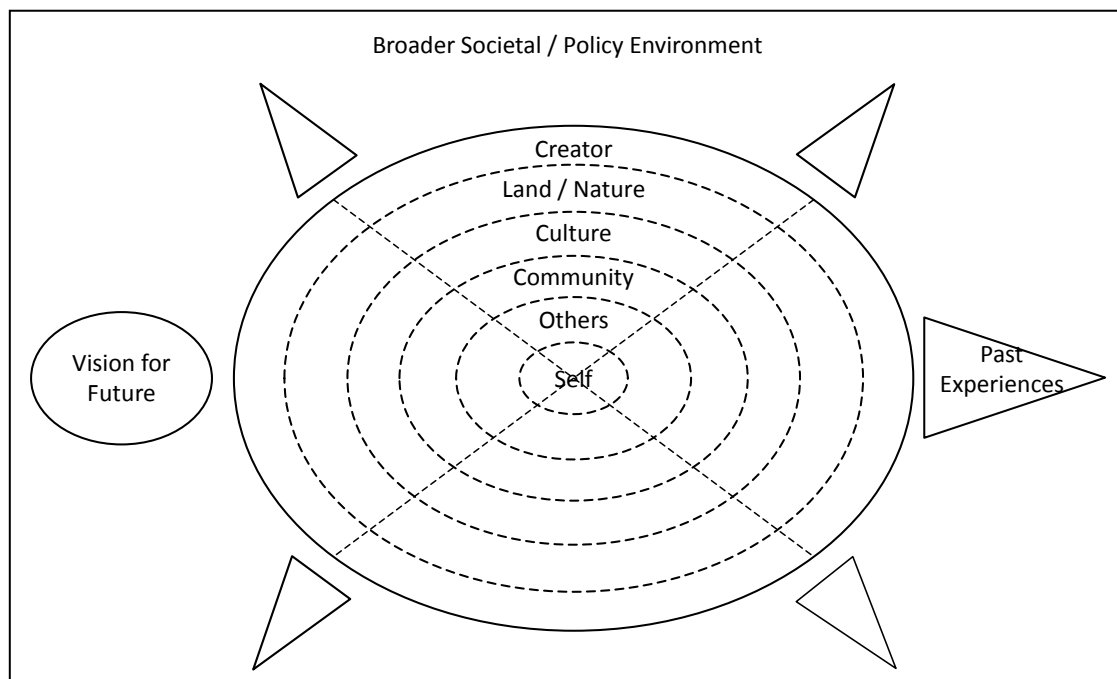


Figure 5: Socio-Ecological Model of PAW’s Health

The original inspiration for the model above was a Turtle to represent Turtle Island. However, we recognize that this may not resonate for the Inuit women in our study. Therefore, we invite you to see this model as a Bear instead of a Turtle, and to reflect on the symbolic synergies between this Bear model and the PAW acronym that positive-Aboriginal women have adopted as a culturally resonant self-identifier that is grounded in cultural strengths instead of illness. The bear represents PAW of course, and is both guided by and heading in the direction of a vision of health as articulated by PAW. The body of the bear is comprised of the multiple levels or layers of connection that influence, are influenced by, contribute to and mutually constitute PAW's health. The lines between each layer are perforated to suggest that these layers are interrelated and sometimes overlapping. The body of the bear is divided into four quadrants to represent physical, mental, emotional and spiritual dimensions of health that must be attended to but these dimensions are also interrelated and often overlapping. The tail of the bear represents the unique history and life experiences of PAW. These experiences are behind PAW but they are very much a part of who they are. They can help PAW navigate their life in a balanced equilibrium, or they can shake them off their feet. Finally, the bear itself does not exist solely in an Aboriginal universe, but must also contend with non-Aboriginal society, values, institutions and the socio-political environment. While this last aspect of PAW's health is not explicit in the discussion of PAW's health above, it is none-the-less a constant reality that PAW must contend with, and inevitably has an impact on their health.

Health-Enabling Strategies

We identified several health-enabling strategies in *VH* that PAW co-researchers use to support their self-identified health and to help them move towards their self-defined vision of thriving health. Each of these strategies is interconnected and often overlapping. While these strategies were originally identified in the photos and narratives of individual PAW, they were collectively identified by PAW co-researchers as key elements of support during our participatory analysis. Not every strategy was represented in the photo-stories of every PAW co-researcher, but every PAW co-researcher recognized the value of every strategy for creating, supporting or maintaining their health.

‘Understanding colonization’, or understanding how PAW are “shaped by [their] environment” is a key element of supporting PAW’s health and a necessary condition for moving towards greater health as defined by PAW. In our research, this was typically talked about in the context of intergenerational trauma that has on-going and sometimes devastating impacts on Aboriginal families and communities, and structural violence including deliberate disruption and demonization of cultural norms, values, beliefs, and knowledges; repression and loss of Aboriginal languages and gender roles; banning of traditional practices and ceremonies; forced adoption of Aboriginal children into non-Aboriginal families now known as ‘the 60’s scoop’; and on-going stigma and discrimination that point to deeply embedded racist and sexist policies, practices and social structures (Duff, Bingham, Simo, Jury, Reading, & Shannon, 2014; McCall, Browne, & Reimer-Kirkham, 2009; McCall & Lauridsen-Heogh, 2014; Adelson, 2000; Bourassa, McKay-McNabb, & Hampton, 2004). Coming to understand that these experiences are also gendered and are linked to “contemporary health and health behaviors including those associated with HIV risk, such as interpersonal violence and substance abuse” (Walters, Beltran, Evans-Campbell, & Simoni, 2011, p. S262; Pearce, et al., 2008; Culhane, 2003; Hawkins, Reading, & Barlow, 2009) is crucial to PAW’s healing journeys. As Krista suggested in our All-Groups meeting, “there is more to us than all of a sudden being a statistic and being HIV positive. You know, there are circumstances, there’s a pathway, there is a history”. For PAW to move towards thriving health, this negative impact of colonization and the many ways that it has shaped their lives must be understood. As Elder Lyle Longclaws once said, “Before the healing can happen the poison has to be exposed” (Peltier, et al., 2013, p. 92).

‘Resistance and resilience’ and ‘awakening voice and identity’ are related to and interconnected with ‘understanding colonization’ and in combination can be seen as a cyclical and iterative process, with each step filling out and expanding on the one before. In contrast to the dominant narratives of PAW as vulnerable, dis-eased, and dysfunctional, the PAW in our project spoke passionately about confronting the on-going negative impacts of colonization, of overcoming hardships, of adapting to new and difficult situations, and of carrying on despite these challenges. In the face of conscious and unconscious attempts to demean, belittle, pathologize, medicalize, delegitimize, erase or render their experiences invisible, PAW co-researchers regularly stand their ground and assert “We’re still here!”

From individual to collective acts of resistance, PAW co-researchers are actively pushing back and changing the “language, metaphors and images through which they come to be (re)known” (Culhane, 2003, p. 593).

Building on these acts of resistance, PAW co-researchers are also reclaiming their voice and reclaiming their identity. Connecting with culture, honouring themselves as women, and reconstituting HIV-positive status as a strength instead of weakness, as a teacher instead of a punishment, have all emerged – together – as a significant health-enabling strategy for PAW. This means standing in their strengths as PAW, being proud of who they are, and defining themselves on their own terms, not in response to an externally imposed identity. As Paw asserts and others affirmed, “you can’t tell me who I am!” Reclaiming voice and reclaiming identity for PAW was empowering, self-affirming, life-affirming and “an important strategy for individuals in terms of developing a positive sense of one’s self and promoting changes in one’s community” (McCall, Browne, & Reimer-Kirkham, 2009, p. 29; Hawkins, Reading, & Barlow, 2009). This is consistent with the findings of numerous authors (Adelson, 2000; Bent, 2004; Bourassa, McKay-McNabb, & Hampton, 2004; Deiter & Otway, 2001), including Wilson and Neville who suggest cultural strength, identity, and pride are health protective factors and that “cultural identity serves as a kind of anchor to help women deal with health and social issues” (2009, p. 10) and to move in the direction of thriving health.

“In a climate where stigma is arguably harder to cope with than the actual disease” (Burtch, 2015), safe spaces at individual, organizational and community levels, including social support, is another important strategy for supporting PAW’s health. In one of the first journal articles in Canada concerning HIV among Aboriginal women, Ship and Norton reported that stigma was a considerable barrier for women. “We are fighting for a place in society, in our communities, to feel normal, just to feel accepted and loved, and respected, let alone having to deal with ...barriers such as sexual identity or childbearing” (2001, p.78). Sadly, things have not changed much for PAW in the 15 years since that article was published. PAW co-researchers in our study are still struggling to ‘feel normal’, “to live as normal a life as possible without any kind of having to have people fear us when we are with them” (Liz). Safe spaces for PAW then, including support from children, family, peers, service providers and community, are an essential element of creating and maintaining

health for PAW. These can range from personally safe spaces, to organizational safe spaces, to institutional and community safe spaces that help to remove structural and systemic barriers to PAW's health (Hawkins, Reading, & Barlow, 2009; Peltier, 2010). Providing childcare or child-friendly spaces for PAW is one small example. Designing culturally-relevant and women-specific services is another.

While spirituality was identified as a cross-cutting theme in *VH* and a core element of PAW's health, most PAW co-researchers had gone through a period of time in their lives in which they were disconnected from their spiritual selves. Reconnecting with Spirit marked a turning point in their lives. For many of the PAW in this study, spirituality was grounded in Aboriginal cultures, including connecting with and honoring the Creator, Elders, ancestors and spirit helpers, prayer, participating in ceremonies, and receiving traditional teachings. Connecting to nature, including trees, water, animals, the Sacred Sun, Grandmother Moon, Mother Earth and Grandfather Rocks, was also considered connecting to spirit. PAW co-researchers, however, relied on a range of belief systems to enhance their health, combining Aboriginal spirituality with elements of other world religions, such as Christianity, Islam, and New Age spirituality. The importance of spirituality in supporting the health of PAW has been reported by others (Hawkins, Reading, & Barlow, 2009; McCall, Browne, & Reimer-Kirkham, 2009; Mill J. , 2000; Pruden & Wong-Wylie, 2009), however, while healing through connection to the land is reported in the Indigenous health literature generally (McIvor, Napoleon, & Dickie, 2009), its impact on the health of PAW is not well articulated.

Culture and Gender as Determinants of Health for PAW

We began this study by asking what is the role of culture and gender and their intersections in supporting the health of PAW. As evidenced above, culture and gender intersect at every moment of PAW's lives to influence the health-related choices that are available to them and their possibility of creating a healthy future. It seems painfully obvious to say that we cannot separate out the impact of gender from the impact of culture on PAW's lives, but we cannot. While we think of them as separate determinants of health, they are mutually constitutive and experienced simultaneously, not just by Aboriginal women, but by every person who has both a culture(s) and a gender. That means everyone who lives and breathes. We cannot

understand the experience of PAW by adding Aboriginal plus woman plus HIV-positive status. All of these identities are experienced holistically, simultaneously, inseparably. However, as NWAC (2007a, 2007b) and Halseth (2013) have suggested, culture, in its many guises, holds the greatest potential to both understand and intervene in Aboriginal women's lives.

Culture as colonization – As a distal determinant, culture impacts on every aspect of PAW's lives, from the moment they are born to the time they pass into the spirit world. Culture – or more to the point, the suppression of one culture by another culture, otherwise known as colonization – and its intersection with gender, plays a significant role in creating the conditions of social, economic and political marginalization that increases some Aboriginal women's vulnerability to HIV infection in the first place. Authors (Hawkins, Reading, & Barlow, 2009; Bingham, Leo, Zhang, Montaner, & Shannon, 2014; Bourassa, McKay-McNabb, & Hampton, 2004) and PAW co-researchers point to the legacy of residential schools, the loss of traditional gender roles and particularly the decentering of women from their rightful place as the 'hearts of our nations' as an indirect but primary cause of what Simoni and colleagues call the 'triangle of risk' (2004) for Aboriginal women; of sexual trauma, injection drug use, and HIV sexual risk behaviours.

Culture as a resource for improving health outcomes – Culture and gender, however, are also implicated in all of the health-enabling strategies identified in this research. From understanding colonization to reclaiming culture, traditions, ceremonies and identity, culture and gender play a central role in supporting PAW's health. The many ways that PAW interrupted and resisted the negative stories and stereotypes that other people told, and the ways in which they reclaimed their voice and identity were focused on culture. Culture also underpinned spiritual resources that PAW drew on to support their health, including connecting to/through the land and the natural environment in particularly gendered ways.

Visioning Health in the Community: Reflection on the VH Process & Impact

Not surprisingly, when PAW co-researchers came into VH they were, to varying degrees, distrustful of research and of researchers. Their own experiences and the experiences of

friends, family or peers who participated in research had taught them to expect to encounter barriers to participation such as a lack of childcare, and that the only thing to expect in return for their time and knowledge was an honorarium. They felt that neither they nor their communities had substantially benefited from participating in research and some PAW co-researchers reported being harmed in various ways. For example, meaningful emotional, cultural and financial support was often lacking in their previous research experiences and some reported feeling angry and frustrated by the often inaccessible language of research. As Krista shared, “you can’t get me in a room and use all these high tech words to me because none of that is going to relate to me and make sense to me”. They also reported feeling left out of the decision-making process and rarely received the results of the research in which they had participated. All of this, of course, raised issues of power and trust in the research relationship and ownership of the research results.

Visioning Health, however, was designed to be different. As discussed in previous chapters, this project grew from a community-identified need and was shaped by the knowledge, expertise and lived experiences of PAW, and supported by researchers, and long-time Aboriginal HIV service providers. Collectively, we had seen or been a part of numerous research projects that claimed to be engaging PAW in meaningful research processes but continued to throw up barriers to their meaningful participation. A common example is requiring PAW to use their own resources for childcare or to attend project functions and then being reimbursed. For women who typically live in poverty, and many of whom are single parents, this is akin to asking them to choose between spending their last \$20.00 on an airport taxi or dinner for their family. Equally demoralizing is creating a situation in which PAW have to *ask* for a cash advance, a situation that reinforces unequal power relations. In response to these experiences, we designed *VH* as a strengths-based, women-centred, culturally-grounded, decolonizing and Indigenist research project that welcomed children into our spaces, upheld the principles of GIPA and MIWA, and Aboriginal self-determination in research.

In practice, this meant a PAW co-lead on the project (Doris) and not just in name. Doris and I made all project-related decisions together, co-facilitated all group meetings, and spent countless hours on the phone or in person, de-briefing how things had gone the previous meeting or planning for the next one. It also meant prioritizing PAW for paid

positions, including a Peer Research Associate (KJ). KJ was invaluable in helping us organize group meetings and ensuring that group members had the information and resources they needed to come to meetings. For example, if they needed a reminder of our meeting time and place, KJ would do that. If they were out of money, KJ ensured they had bus tokens. This was an invaluable service to the project but having KJ as the point of contact for PAW co-researchers also provided a level of comfort and safety for them that, at least in the early days, I – as an unknown non-Aboriginal HIV-negative woman – could not have provided. Together, Doris and KJ also provided superb mentoring and role-modeling for PAW co-researchers at all group meetings, and equally important, they provided continuity between groups. Doris and KJ were part of the research team, but they were also project participants, which meant that they could share their experiences with each successive group of PAW and help them understand the process. This helped to create a co-learning/co-teaching environment in which all PAW were learners but they were teachers at the same time. This reflects the Circle teaching embedded in the Medicine Wheel that within the circle we are all equal; no person is higher or lower than another; we are all equidistant from the centre; and not only do we all have something to share with each other, but we all have a stake in keeping the project strong and ultimately strengthening the circle of women and community. As Paw noted, “this is a different way of doing research than has normally been done...It’s really grassroots and it’s really ground-breaking...This is setting the standard I think”.

By most accounts, *VH* proved to be a turning point in the lives of PAW co-researchers. To our surprise, PAW told us that the *process* of participating in *VH* was in and of itself, health enhancing. As noted above, health for PAW co-researchers is holistic, social-relational and primarily about feeling ‘connected’ at multiple levels, i.e., to self, others/family, community, culture, Creator, and the natural environment, and in turn, participating in *VH* increased PAW co-researchers’ feelings of connectedness at many of these levels.

At an individual level, PAW talked about gaining competence or a sense of mastery through their participation in our project. This was often related to acquiring new skills such as photography or drum-making, learning to use new technologies, or building their research skills such as data analysis or presentations. For many, however, it was also related to new

insights gained through critical self-reflection exercises that were a part of the *VH* process. Through these self-reflection exercises that were arts-informed, culturally-grounded and strengths-based, and through dialogue and co-learning, PAW talked about ‘finding their voice’, about embracing new understandings, resisting dominant and stigmatizing notions of what it means to be an HIV-positive Aboriginal woman, and telling a different kind of story about themselves than is usually told by others; one that emphasizes a positive life narrative. They also talked about feeling empowered by *VH*, about an increased sense of autonomy and agency, about self-determination, and feeling more in control of their lives. As Doris suggests, “PAW co-researchers came to realize that they ARE the medicine bundle” (Personal communication), that each one of them already had all the tools and gifts from the Creator that they needed to be healthy; that instead of looking outside of themselves for ‘expert’ help, they could draw on their own strengths and assets to take care of their own needs.

PAW co-researchers also talked about feeling connected to others as a result of participating in our project. In particular, they described the process of being together with other PAW as healing. They talked about an increased sense of belonging; a decreased sense of isolation; strong identification with other members of the group; and an expanded personal and social network that included connecting with other PAW, with the broader Aboriginal HIV community, and with their culture through teachings shared by Elders and Knowledge Keepers, and by each other through a co-learning and co-creating experience. Connecting with culture through arts-informed activities and through cultural teachings facilitated an ‘awakening of identity’ for many co-researchers as Aboriginal women and as PAW, that in turn increased their desire for more cultural knowledge. In the words of Art Solomon, through *VH* PAW co-researchers began to ‘pick up their medicine bundles’ and to begin the work of ‘healing their nations’. This was most immediately expressed through their strong desire to bring *VH* to other PAW so they too could benefit from the experience.

While we did not think of or design our project as an ‘intervention’, it is clear from the words of PAW co-researchers that *VH* was “damn good medicine”; that it worked as a holistic and integrated action for social change on several levels that are mutually reinforcing. In contrast to the majority of HIV-related programs and research that continue to be focused on influencing change at the level of the individual – despite the growing

evidence that this is not effective (Hardee, Gay, Croce-Galis, & Peltz, 2014; Peltier, et al., 2013) – *VH* helped to nurture and support PAW's health by intervening at all levels of the socio-ecological model, i.e., by helping to connect PAW co-researchers to themselves, to their peers, to their community, and to their culture. *VH*, then, can be understood as a comprehensive approach to understanding and facilitating PAW's health.

Visioning Health team members were also impacted by participating in our project. Wanda Whitebird, our Traditional Knowledge Keeper, has said publically on several occasions that being a part of this project, witnessing the artworks produced by PAW co-researchers, and witnessing the impact that participating in this project has had on co-researchers has “changed me forever”, and changed the way she views research. Prior to participating in our project, Wanda too, was skeptical of research and viewed it as a colonial project and colonial process of ‘information extraction’ that yielded little or no benefit for her community. After participating in *VH*, however, Wanda shared that, for her, research is no longer ‘a dirty word’ (Tuhiwai Smith, 1999). In fact, since completion of our project, Wanda has taken a strong interest in participating in future research projects to “make sure [the new research teams] do it right”. Other community partners have written the following in support of our project:

We have seen how the opportunity for Positive Aboriginal Women to participate in Visioning Health has proven to be an empowering experience. By sharing their stories and learning from the experiences of others, a unique and mutually supportive community has been established. [Our organization] is now citing the Visioning Health project as an exemplary model of culturally-relevant research in the Aboriginal community.

I believe this project has embraced the principles of OCAP to their fullest potential as [Tracey] has consulted with the Aboriginal community at every opportunity and has engaged PAW in the data analysis and initial Knowledge Transfer activities. [...] This project maintains OCAP and empowers PAW to show other people how research can be done with them, and not just for them.

By adhering to the Indigenous principles of KTE outlined in the previous chapter and by focusing our KTE efforts on “sharing what we know about living a good life”, *VH* also had an impact beyond those who participated or were directly involved in our research. While our early KTE efforts involving photo exhibitions and presentations were well received, it was the *VH Lodges* - innovative, culturally-grounded, community-engaged and experiential KTE vehicles – that had the most tangible and far-reaching impact. Through our *VH Lodges*, we were able to engage the Aboriginal and non-Aboriginal HIV community in our work and thus help to create a health enabling social environment for PAW. By hanging PAW co-researchers’ strengths-based photo-stories of health, culture and gender in a traditional teaching lodge – stories that resisted and countered the negative stereotypes that abound about Aboriginal women who are living with HIV – we were able to honour the sacred nature of PAW’s photo-stories and help academics, community members, service providers and policy-makers to use both their minds and their hearts to see, read, and feel the power in those sacred stories; to see and understand PAW as the beautiful, passionate, strong, funny, sometimes vulnerable and very human women, mothers, aunties, grandmothers, sisters, daughters, friends, activists, advocates, educators and artists that they are. In doing so, we believe that we have helped to create space in the academy, in the community, and in the policy environment for new ways of doing research; for new ways of engaging with PAW – and by extension other HIV-positive Aboriginal people; and for new ways of sharing information with a variety of audiences.

Implications for Policy and Practice

As long as [Aboriginal culture] remains on the margins of Western health care, Aboriginal women will not be as healthy as they could be. Because Aboriginal women have not taken part in designing the system, health care is often culturally inappropriate and sometimes ineffective (NWAC, 2007c, p. 3).

VH was a profoundly impactful project for PAW co-researchers and a poignant example of how research can ‘bring life’ to Aboriginal communities. After a century of being ‘researched to death’ (Tuhiwai Smith, 1999), *VH* is at the vanguard of a larger movement in

Aboriginal HIV research that is using Indigenous knowledge and cultures, including strengths-based approaches, to understand and to resist on-going colonial practices, to reclaim, rekindle and embrace their culture and traditions, to revitalize their communities, and to change the stories they live by. The implications of this for evidence-informed policy and practice are substantial given that policy and practice are, at least in part, reflective of the research and methodologies that inform it (NCCHPP, 2014). The following recommendations are drawn from our final sharing circle on ‘key messages’ that PAW co-researchers hoped audiences would take away from *VH* and on-going discussions with research team members.

“Get out of my chair!”: Policy and practice for PAW should be PAW-driven, with leadership by PAW

The call to date has typically been for community-based, or in some cases community-driven, policy and practice for PAW in which communities are engaged in the design, development and implementation. The experience of *VH*, however, compels us to shift this call from community-driven to PAW-driven initiatives in which PAW are directly and meaningfully engaged in all aspects. PAW leadership in policy and practice will support PAW’s self-determination and ensure that initiatives are timely and relevant to PAW’s needs. Recognizing that PAW are a diverse group with respect to their ages, times since diagnosis, experience of HIV, gender identities, nations, geographic region, and personal life experiences, this means engaging *and compensating* established and emerging PAW leaders in developing policy and practice, and investing in future PAW leaders through peer support and peer mentoring programs and capacity-building initiatives. It means not just asking PAW what they want, but also ensuring that they have the resources to make it happen. It means taking a backseat to their leadership, actually listening to what they tell us, and using our resources to support their vision. As Doris suggests and Paw confirms, “We’re here and we’re not going away”, so “Get out of my chair! I’m coming over now!”

“Shaped like a woman”: Policy and practice for PAW should be women-centred

VH has shown that gendered experiences of HIV require gendered responses. Building on the experience of *VH* and on CAAN’s five year strategy on HIV and AIDS for Aboriginal

women (Peltier, 2010), an essential component of this response moving forward should be a focus on creating culturally, physically, emotionally, spiritually and mentally ‘safe spaces’ for PAW in which they can take stock of their lives, “bear witness” (Paw) to each other’s experiences, learn about their culture, rally their resources, feed their spirits, nurture their souls, and collectively vision a healthy future. These should be non-judgemental, non-shaming spaces in which PAW can “come together to help each other, like we’re doing now...teach each other” (Stacy), and in which confidentiality is ensured. In many cities, towns and communities, it is still not safe for PAW to be openly HIV-positive, to disclose to friends and family, and in many cases healthcare and social service providers. This makes creating PAW-centred services incredibly important but extremely challenging. Policy and practice should make services more accessible for PAW by ensuring confidentiality so that “what was said here, doesn’t go out there” (LA). Following the example set by CAAN at their Wise Practices Research Gathering in 2007 wherein transwomen were publicly welcomed into the women’s circle in ceremony, in *VH*, transwomen were included in our circles.

VH has also shown, however, that the experience of gender is intricately tied to culture. As previously noted, women traditionally occupy a central place in Aboriginal communities as ‘the heart of our nations’ and this means they have a central role and responsibility in creating change not just for themselves but also for their families and communities. Elder Art Solomon’s teaching that “when women pick up their medicine bundles, nations will begin to heal” (Peltier, et al., 2013, p. 85) implies that “Aboriginal women must bring policy into focus through their nature as women. The women are the moral guardians of the society and the ones to lead initiatives for positive social change” (Kenny, 2004, p. 1). This interpretation of women’s roles as guardians of society and as agents of change is further reflected in CAAN’s five year strategy on HIV and AIDS for Aboriginal women which advocates for a women-specific but inclusive strategy that begins with women and then “ripples[s] out [to] touch the lives of all within our communities” (Peltier, 2010, p. 20). As PAW co-researchers shared, it’s about “the inclusion of our children” (Doris), “our families” (Paw), “our whole community” (Krista). “It’s not about a women’s approach, it’s about a community approach, led by women” (Doris). Policy and

practice should nurture and support the inclusion of women in leadership roles across the board.

“Good medicine”: Policy and practice for PAW should be grounded in local Indigenous knowledge and culture

With few exceptions (see CAAN’s PAW-licy Statement, 2012), policy and practice for PAW, has typically grown out of research that was grounded in non-Indigenous methodologies and modes of inquiry that often produced results that were consistent with the norms and values of a Western research paradigm but inconsistent with the norms and values of Aboriginal communities. As Kovach reminds us, “the proposition is that methodology itself necessarily influences outcomes. Indigenous research frameworks have the potential to improve relevance in policy and practice within Indigenous contexts” (2009, p. 13). Hence, a major corrective to the policy and program failure for PAW is to ground it in local expressions of Indigenous knowledge, culture, and ways of being. The success of *VH* and its impact on PAW co-researchers and community bears this out. When discussing the history of colonization and the many ways that Aboriginal culture and traditions were suppressed, Doris suggests that “we’re still living in that environment and we are still able to heal in our, you know, using our traditional ways...and that’s an important part of us, is the spiritual being that we are. That’s important.” The inclusion of localized Indigenous knowledge and culture, including Elder support, in policy and practice for PAW is further supported by a review and evaluation of 1,246 community-driven Aboriginal healing projects that found that the most effective projects included use of Elders, traditional ceremonies, individual counseling, and Western healing strategies used in conjunction with Aboriginal cultural practices. An important finding of this report is that ‘culture is good medicine’ (DeGagne, 2007).

“What are the good things?”: Policy and practice for PAW should be strengths-based

As previously noted, the vast majority of research concerning PAW is deficit-based and constructs an image of PAW as dying, diseased, dysfunctional and disconnected from their families, community and culture. This research tends to focus on the ‘problems’ of PAW that often require expert resources and high levels of dependence on hospitals and social services to ‘fix’ (Morgan & Ziglio, 2007, p. 18). In some cases, PAW even become the

problem. The policy and practice that flows from this has typically positioned PAW as passive recipients of these expert services, usually provided from outside the community, and has tended to focus on reducing PAW's engagement with 'risk factors' such as sharing needles or unsafe sex; or reducing the 'burden' of illness. All of these lead us to conceptualize PAW as helpless, reckless or irresponsible, which in turn suggests that PAW need to be protected from themselves or we need to be protected from them. In contrast, *VH* guides us to take a strengths-based approach to research and to the policy and practice that flows from it. This means "no more fear tactics" (Paw). No more policies or practices that position PAW as reckless or irresponsible. No more criminalization. Krista adds, "instead of looking at the negative and examining all the wrong things and what's wrong with us, what are the right things? What are the good things about us?" Policies and practices that build on 'the good things' constitute an important shift towards an approach that understands, explains, and nurtures health, instead of illness (Richmond, 2007), 'empowers' PAW (Paw), and positions PAW as active agents within their own lives and the lives of their communities (Brooks & Kendall, 2013).

"Arts-based approach is the best way": Policy and practice for PAW should be arts-informed

The success of *VH* and the impact it had on PAW co-researchers and community was due in no small part to our use of arts-informed approaches, coupled with strengths-based approaches and Indigenous knowledge and culture. While Western academics and decision-makers have only recognized the power of the arts for research, policy and practice relatively recently (Leavy, 2009), Indigenous communities have been using the arts, including but not limited to drumming, singing, dancing, beading, storytelling, sewing, basket-making, and carving, for functional, aesthetic, ceremonial and healing purposes for millennia (Archibald & Dewar, 2010). *VH* suggests and the literature confirms that using the arts – in conjunction with ceremony – in research, policy and practice, is an important way of communicating and transmitting knowledge for Aboriginal peoples. It also strengthens individual and collective identity, resilience and overall well-being, including enhanced self-confidence, self-esteem, and self-determination (Muirhead & de Leeuw, 2012). As Krista suggests, "I think that the government needs to acknowledge the arts-based approach and especially dealing with

Aboriginal people given the fact of all the things that go on in our communities; ADHD, FAS, all these disabilities. Arts-based approach is the best way”. This strong preference for arts-based programs is confirmed by a review of 104 Aboriginal community-designed healing projects in which 94 of them were found to include one or more creative arts in their program design (Archibald & Dewar, 2010).

“Having that information in one place when you need it is huge”: Policy and practice for PAW should be holistic and relational

The health and lives of PAW are simultaneously impacted by multiple issues that are experienced as interconnected, and therefore policies and practice for PAW that focus on singular aspects of PAW lives are ineffective. Instead initiatives to address PAW’s health must reflect PAW’s notions of health as holistic, encompassing mental, physical, emotional and spiritual elements. As Paw shared, “having access to information and resources is huge” but frequently this information is fragmented and resources are scattered, or services for one aspect of PAW lives are not inclusive of other aspects. For example, substance use treatment programs frequently do not include HIV education. Policy and practice to bring these resources together would be beneficial for PAW. Given that health for PAW is rooted in relationships with self, family, community, nature and Creator, policy and practice should also nurture and support PAW relationships at each of these levels.

“We need to talk about it”: Policy and practice for PAW should incorporate a colonial analysis

Colonization is an on-going process and continues to shape and constrain the lives and choices of Aboriginal women. Understanding this impact is a crucial step towards ‘reclaiming voice and identity’ for PAW, resisting negative stereotypes, rebuilding positive identities, and revitalizing communities. It is also a crucial step in understanding the roots of lateral violence in Aboriginal communities, and the many ways that PAW have internalized colonial oppression. Doris suggests,

*because of the oppression, we have a tendency to operate from a certain mindset.
And we are all guilty of it. There is not one person in here that is probably not*

guilty of operating within that oppressive mindset where we can hurt each other and disrespect each other...That comes from being oppressed....But we need to acknowledge that. We need to acknowledge that and change it...We need to talk about it, and acknowledge it and get past it.

Policies and practice that make space for discussions of colonization, and support PAW in understanding and overcoming the impact that colonization has on their lives, will be important for future PAW's health.

Study Limitations and Considerations for Future Research

There is no question that *VH* was successful beyond our imagination and that it was 'revolutionary' in all the ways that Walters and colleagues (2009) suggest an Indigenist research project should be. Despite the considerable strengths of *VH*, however, the study has several limitations that hinder its capacity to make a robust contribution to knowledge regarding PAW perspectives on health and to impact policy and programming. These limitations also inform opportunities for future research.

The qualitative arts-informed approach to this research was effective, and I would argue necessary, for exploring new understandings of health, culture and gender for PAW, but it was not designed to produce representative findings. This is reinforced by our purposive convenience sampling strategy and small sample size. Our sampling strategy was ideal for recruiting PAW who could speak to the issues under investigation, but our purposive convenience sample of 13 PAW means that extreme caution must be taken when extrapolating our findings to other groups of PAW. Our small sample size also means that we were forced to take a pan-Aboriginal approach to our analysis, despite our attempts to engage a diverse group of PAW, including First Nations, Métis and Inuit, with a range of ages, times since diagnosis, gender identities and regions. Future research would benefit from a larger sample size that would enable region and nation-specific interpretations of health, culture and gender for PAW as well as disaggregation of data by gender and other identifiers.

Our sampling strategy also meant that PAW self-selected for this study. This suggests that *VH* may have attracted PAW with a prior interest in culturally-grounded and arts-

informed approaches to research. Therefore, findings related to PAW participants' appreciation of such approaches must be approached with caution. In other words, culturally-grounded and arts-informed research approaches may not be appealing or successful for all PAW despite the overwhelming support for these approaches that was expressed by the PAW co-researchers in *VH*. Future research might explore, in more depth, what aspects of *VH* were or were not important for PAW participants.

An unexpected finding from our study was that the very act of participating in our research was health-enhancing. This suggests that *VH* has excellent potential as a health promotion intervention for PAW; however, the lack of a rigorous evaluation component potentially limits its contribution to knowledge. Future research would benefit from an intervention research design that clearly and adequately measures the impact on PAW of participating in *VH*. This might be conceived as a mixed method design that includes a quantitative pre- and post-study research component that would allow us to reliably attribute benefit to participation in the *VH* project. It might also be conceived as a wholly qualitative research design that is firmly grounded in Indigenous approaches to research, and uses Indigenous approaches to evaluate the impact. The latter research design might include storytelling, body mapping, or other arts-informed and culturally-resonant approaches to evaluation.

Future research would benefit from an even more participatory approach to analysis and writing than I was able to undertake for this thesis. While we engaged PAW co-researchers in participatory analysis and interpretation at several stages of this research, future research would benefit from more time and resources being allocated to these activities. Doris (community lead and PAW co-researcher) and KJ (Peer Research Associate and PAW co-researcher) were active partners in the analysis and interpretation of findings which were then 'member checked' with PAW co-researchers, our Community Partners / Community Advisory Committee (see Chapter 3 for more details on this), and several members of the Aboriginal HIV and AIDS community. In addition, Doris, and community partners, Sharp Dopler, Carrie Martin, and Renee Masching, all of whom were engaged in the day-to-day activities of *VH* provided excellent feedback on multiple thesis drafts. However, as Jones and Jenkins (2008) point out in their excellent article on 'working the Indigene-Colonizer hyphen', a written product is necessarily reflective of the hand that it is

written by, regardless of how many discussions the writer has with a collaborator. Hence, despite my best efforts to ‘centre the voices of PAW’ and to ‘privilege PAW perspectives’, the resulting thesis is still largely my interpretation of findings and events, and therefore, it is still largely a reflection of uneven power relations. Future journal articles, book chapters, a community report and future research related to *VH* will benefit from a truly collaborative co-writing process that extends the benefits of CBPR and decolonizing methodologies through to the writing stages of the research (Jackson, et al., 2011).

Finally, we estimate that many hundreds of policy and decision-makers at all levels, including community organizations, health centres, and municipal, provincial and federal government departments have viewed the *VH* photo-stories and many have engaged with us in formal or informal discussions. The impact on policy-makers though, and the concrete social change that we would like to see, is unclear. Future research might again borrow from a Photovoice model by incorporating additional group meetings in which we engage PAW co-researchers in developing and implementing PAW-led action plans that have a clear link to the social change they would like to see happen as a result of the research (Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009). This approach might also benefit from engaging policy and decision-makers at earlier stages of the work to facilitate buy-in at all stages of KTE.

What Is Next For *Visioning Health*?

Since the completion of data collection in November 2011, *VH* has taken on a life of its own. We had planned to share our results with communities, of course, but we did not expect the enthusiasm with which *VH* was embraced by communities. We did not expect the volume of invitations we received to present our work at conferences, to communities, to classrooms, and to service providers, both nationally and internationally, nor did we expect that we would still be receiving invitations to present our work all this time later.

Visioning Health has clearly struck a chord with PAW and with communities and several of them have expressed a desire to partner with us on a *VH* research project in their regions. Building on the results of this research, and picking up on the findings of Chapter 7 on the impact of *VH* on PAW, we have committed to working with several communities and Aboriginal AIDS Service Organizations to develop *VH* as an intervention research project,

with culturally-relevant psychometric measures and qualitative and quantitative assessment tools. It is of paramount importance, however, that this new study stays true to our values of putting the needs of the women first, of supporting PAW leadership in research, of grounding our study in Indigenous knowledge and worldviews, and of using arts-informed and strengths-based approaches. This proposal has already been submitted for funding consideration and incorporates potential links to a *Visioning Health for Men* project as well as built-in accountability and sustainability mechanisms.

To date, and consistent with our Indigenist approach to research and to KTE, we have concentrated our time and our effort on sharing *VH* with Aboriginal communities, including PAW and other community members, researchers, service providers and policy-makers, via presentations, workshops and photo exhibitions including the innovative and culturally-relevant *VH Lodge*. We have also shared our results with non-Aboriginal researchers, policy-makers, service providers and funders, however, this has largely been limited to presentations. To address this gap in the literature, and as noted above, I will be working with PAW co-researchers and team members to develop co-written journal articles and book chapters to share our findings and our process with others. We are also planning to develop a *VH* website and a PAW-authored community report.

Thesis Limitations: What Is Missing?

In addition to sharing our findings and our process in co-authored journal articles, post-thesis writing also offers an opportunity to address themes and issues that arose in *VH* that were perhaps tangential to the thesis, or for some reason I had deemed ‘beyond the scope of this work’. This does not mean, however, that these themes and issues are not important in a broader context. There are a number of issues that I think will be important to consider in the months ahead and that offer excellent opportunities for co-writing with PAW co-researchers and *VH* team members.

As discussed throughout the thesis, the *VH* process was inspired by Photovoice but evolved into a unique approach to research with PAW when we responded to their unique circumstances and began to incorporate Indigenous knowledge and ceremony in a more meaningful way. While we used a fairly standard Photovoice protocol for the Toronto group, our processes for the Montreal drum-making group and ‘Virtual’ group were unique. While

hand-drumming is a significant element in many First Nations healing practices and has been the subject of a few studies (Winkelman, 2003; Goudreau, Weber-Pillwax, Cote-Meet, Madill, & Wilson, 2008; Dickerson, Robichaud, Teruya, Nagaran, & Hser, 2012), to my knowledge it has never before been used as a research method. A more nuanced discussion of our drum-making process than was possible for this thesis will be a valuable contribution. The same can be said of the technology-assisted process we used to engage with PAW who were geographically dispersed. The technology-assisted process we engaged in was far from perfect, fraught with challenges, and required an enormous amount of commitment and effort from all parties. For all of its challenges though, this mode of engaging with PAW across the country in culturally-grounded and arts-informed research also offers multiple benefits. Perhaps the biggest of these is simply enabling the participation of PAW who would otherwise be left out of the project.

Another element that is intentionally missing from the thesis but would make a significant contribution to the literature and to practice is our *VH Lodge* as Indigenous methodology, experiential learning, and culturally-relevant KTE. There is no doubt that the Lodge was our most impactful KTE tool for PAW, for community, for academics and for policy-makers, but exploring or theorizing why this might have been was beyond the scope of this thesis. Yes, it was visually arresting, culturally-relevant, and we think unique in the world of KTE for Aboriginal HIV research results; but is that all there was to it? Were the ceremonial aspects of the lodge important to the impact? A potentially important and enriching area of further exploration will be to look at the *VH Lodge* as experiential learning, as culturally-grounded and participatory KTE, and as Indigenous methodology.

Perhaps the hardest paper to write will be one that complicates the *VH* process and the relationships that were central to its success. Looking back on the completed thesis, I am aware that in my enthusiasm to help you see how amazing the women at the heart of our project are, and how important our PAW-driven, culturally-grounded, arts-informed and community-based participatory research process is for future research, policy and programming, I neglected to share with you many of the challenges we faced along the way and the bumps on the road to project completion. Looking back on the completed thesis, I see that despite my intention to discuss our “process as it [was]” (Ferguson & Thomas-Maclean, 2010, p. 12) before it got “cleaned up in the reporting of results” (Bernard, 1988, p.

110), I still managed to smooth out the rough edges of our time together. To leave you with the impression that we anticipated and planned for every challenge, that we did everything right, and that there were no conflicts or missteps along the way, would not only be an outright lie but it would also do all of us – the research team, PAW co-researchers, the Aboriginal HIV community and the academy, including any students who might pick up this thesis – a significant disservice.

Visioning Health was many things, but easy was not one of them. A PAW co-authored paper, or perhaps two, that explores the tensions that arose throughout the project, some that we resolved and some that we did not; some that needed to be resolved and some that needed to not; will be a valuable contribution to the literature and to practice. It will also honour the courage of PAW co-researchers and team members and our commitment to the core values and to the goals of *VH*. That each of us were willing and able to be uncomfortable, to be challenged, to be vulnerable, and ultimately to learn from our interactions with each other is a testament to the relationships we had established, to the *VH* process, and to the safe guards we put in place along the way. While *VH* was far from perfect, and fraught with challenges, we all faced those challenges with courage, with humility, with generosity and with love. Exploring these challenges together, in a co-authored journal article, will enhance our understanding of ourselves, our team dynamic, and also contribute to a broader discussion of community-based research and decolonizing methodologies (see Elliot, Krawczyk, Gurney, Myran, Rockthunder, & Storm, 2015 for an excellent example).

Another area that I chose not to explore in this thesis is the issue of allyship, solidarity, or what it means for a non-Aboriginal researcher to be engaged in decolonizing and Indigenist research. This was and continues to be an animating theme in my own work, and has an indelible impact on the projects I choose to engage with and how I choose to engage. Questions that I continually ask myself include: What is or should be my role, as a non-Aboriginal person, in Aboriginal research? Am I the right person to be doing this work? Would *VH* (or other projects that I have had the honor to work on) be better served by an Aboriginal lead? Why am I doing this work? What am I getting out of it – besides a PhD? How can we better balance the benefits of participating in research between all team members? Am I taking space or making space for Aboriginal and PAW leadership? How can

I best use my privilege as a white, heterosexual, middle-class, able-bodied woman to create a more equitable society? What knowledge can I / should I claim as a result of participating in Aboriginal research? How do I, as a non-Aboriginal person, respectfully engage with Indigenous knowledge and ceremony? How do I reconcile, or not reconcile, the multiple perspectives that are held by Aboriginal individuals regarding the engagement of non-Aboriginal people in Aboriginal traditions and ceremony, including Aboriginal research protocols? While I believe that these are important, in fact essential, questions for any non-Aboriginal researcher engaged in Aboriginal research to be asking of themselves – and to continue to ask of themselves – I chose not to include a lengthy discussion of this issue in the thesis because *VH* was not about me. *Visioning Health* was about creating an opportunity for PAW to tell their own stories of health, culture and gender and I feel strongly that to have made myself a larger part of this thesis than I already am would have privileged my story instead of theirs and shifted the goals of the research. However, it is an issue that impacts the research and is therefore, worth pursuing in a separate article that offers perspectives from both sides of the issue. I look forward to co-authoring a paper with Doris and other members of the research team regarding our respective experiences of working across cultures, across HIV-status, and across knowledge systems.

Visioning Health in the Academy: Reflection on VH Conceptual Frameworks

As discussed in Chapter 2, *VH* was guided by an Indigenist Intersectional Population Health Framework and underpinned by a strengths-based arts-informed and community-based participatory approach to research. Using these complementary approaches, while complicated, emphasized the strengths of Indigenous and Western approaches and was designed to enable us to do our work “in ways that are consistent with the norms and values of Aboriginal cultures” (Unger, Soto, & Thomas, 2008, p. 125). In many ways, our conceptual framework served us well, however, as our project evolved, I began to question our choices. I reflect here on a few key issues.

The Population Health framework in which *Visioning Health* was situated offered us three key advantages: 1) A definition of health as a state of complete physical, mental, and social well-being, and not just the absence of illness; 2) A concept of health as the outcome of complex, overlapping, and integrated social structures in which people are born, grow,

live, work and age. These social determinants of health include social, environmental, political, cultural, economic, and behavioural processes that are influenced by the distribution of money, power and privilege; and, 3) A socio-ecological model of health that recognizes the complex interplay between multiple levels of influence, including individual, interpersonal, community and societal factors. As noted by NWAC (2007b), this offered us a way of understanding health that seemed compatible with Indigenous concepts of health as holistic, relational and interconnected and gave us a starting point for our research. As our project progressed, however, a number of issues arose with the Population Health framework that I/we were unable to reconcile.

A central tenet of *VH* is that the pathogenic paradigm that underlies the majority of health science research including the PAW's literature is steeped in and perpetuates colonial norms that are ultimately harmful for PAW's health. With epidemiology as its core science, however, the field of Population Health is a primary culprit of this pathogenic paradigm (Raphael, 2011). The vast majority of the Population Health literature speaks more aptly of the social determinants of illness, instead of the social determinants of health, and tends to view them as ahistorical and decontextualized behavioural risk factors leading to fragmentation and pathologizing of PAW's health experiences (Brassolotto, Raphael, & Baldeo, 2013). In those instances when structural determinants are acknowledged as influencing health, PAW are still pathologized and disempowered by constructing them as 'vulnerable', 'marginalized', or 'at risk'. This is at odds of course with our strengths-based approach and became increasingly challenging over the course of the project as PAW co-researchers expressed their disdain for the deficit-approach to research.

Another challenge to our model was the dissonance between the positivist or post-positivist perspective that underlies much of the Population Health literature, particularly the literature focused on association and causation, and the Indigenous knowledges and worldviews that guided our project. Wilson explains a fundamental difference between Western and Indigenous research paradigms:

One major difference between those dominant paradigms and an Indigenous paradigm is that those dominant paradigms build on the fundamental belief that knowledge is an individual entity: the researcher is an individual in search of

knowledge, knowledge is something that is gained, and therefore, knowledge may be owned by an individual. An Indigenous paradigm comes from the fundamental belief that knowledge is relational. Knowledge is shared with all creation. It is not just interpersonal relationships, or just with the research subjects I may be working with, but it is a relationship with all of creation. It is with the cosmos; it is with the animals, with the plants, with the earth that we share this knowledge. It goes beyond the idea of individual knowledge to the concept of relational knowledge...you are answerable to all your relations when you are doing research (2008, p. 56).

As noted earlier, following the lead of the women, our research became more grounded in Indigenous knowledges, relational knowledge, as we went along, and inclusive of more ways of knowing. While this was necessary for our project and helped us create a space where knowledge of all kinds could be shared, grow and flourish, it challenged the positivist and post-positivist underpinnings of our Population Health approach. This is both important and troublesome because as Castellano writes about research with Aboriginal communities,

Fundamental to the exercise of self-determination is the right of peoples to construct knowledge in accordance with self-determined definitions of what is real and what is valuable. Just as colonial policies have denied Aboriginal people access to their traditional lands, so also colonial definitions of truth and value have denied Aboriginal peoples the tools to ascertain and implement their knowledge (2004, p. 102).

While I do not believe that this dissonance negatively impacted our research – Margaret Kovach (2009) offers the pragmatic term ‘strategic concession’ for such troubling epistemological tensions, a kind of safe zone where ideas in tension can co-exist, and Andreotti and colleagues refer to this as ‘epistemological pluralism’ (Andreotti, Ahenakew, & Garrick, 2011) – future research and writing will benefit from an exploration of these issues.

A final challenge for us in using a Population Health paradigm was the considerable overlap between what *is* health for PAW, and what *determines* health for PAW. While this may be simply a function of language, it might also point us back to the hierarchical and positivist underpinnings of the field and its on-going obsession with causality. While I cannot claim to have reconciled these tensions, I raise them here in the interests of future research and writing.

The socio-ecological model, on the other hand, proved to be a valuable framework for analyzing and conceptualizing the *VH* findings. While it too is grounded in a Western worldview, its similarity to the Medicine Wheel and to holistic approaches to health that acknowledge the interrelatedness of all things made it familiar to PAW co-researchers and therefore easily adapted.

Similarly, from a Western academic perspective intersectionality is the best hope we have of understanding complex identities. In fact, NWAC (2007a) suggests that incorporating Aboriginal women's perspectives in any [research] initiative must include an "intersectional approach [which] recognizes that people's experiences...are mediated by multiple identities, including race, class, ethnicity, religion, sexual orientation, gender, age, disability, citizenship, national identity, geopolitical context, and health" (p. 7). Clark and colleagues (2013) also remind us that intersectionality is not a new concept to Indigenous peoples, and that, "there is increasing recognition that the concept of intersectionality complements growing discussions about the complexity and multiplicities involved in being indigenous, in the category of indigeneity, and in indigenous people's health and well-being" (p. 41 quoting de Leeuw & Greenwood, 2011,p.54).

Nonetheless, while I suggest that intersectionality 'worked' well enough in our study, in some ways it was an uncomfortable fit. Intersectionality is a Western academic word that is alienating to the uninitiated and therefore privileges the voice and interpretation of academics. *VH*, however, was designed as a community-based participatory and decolonizing research project in which PAW co-researchers and team members were actively engaged in project design, implementation, analysis, meaning making and KTE. This required multiple and on-going discussions about every aspect of the research including conceptual framework and analysis. When we discussed intersectionality, however, it

inevitably proved to be a divisive term rather than one that brought us together, again raising the question of whose voice and whose paradigm was being privileged.

Finally, we began this study with a decolonizing methodology but at the end of this project I question the utility of this approach for culturally-grounded strengths-based research. For me, a decolonizing methodology, while hugely important and influential, is inherently a deficit-based approach that privileges a Western worldview. By its very name, it is a reaction to colonization and therefore affirms colonization as the standard of practice. To focus on decolonizing approaches is to resist, challenge or Indigenize Western methods but it does little to articulate and think through an alternative. Indigenist and Indigenous methods, on the other hand, “emanates from, honours and illuminates [Indigenous] worldviews” (Wilson, 2008, p. 54). Indigenous methods are unapologetic and work to make space in the academy for Indigenous ways of knowing, being and doing, on an equal footing with – not in opposition to - Western methods. While much work has been and is being done on this front, my hope is that *VH* can contribute to this on-going discussion.

Visioning Health and Me: Researcher Reflections

The fourth and final question from Chapter 7, the last criteria for Walters and colleagues notion of research as revolution (2009), Cho and Trent’s transformational validity (2006), and Wilson’s ‘Indigenist research methods’ (2007; 2008) is how have I been changed by the research? What have I learned along the way? My learning can be summarized in two short phrases: “it’s ok”, and “get out of the way”.

When I began this journey called *Visioning Health* I really had no idea what I was getting into. Part of that was intentional, of course, and built into our decolonizing and Indigenist methodology that made space for dialogue, for learning, for change, and for adaptation to the needs of PAW co-researchers and to the research environment. As previously discussed, we built in a number of mechanisms, including cultural, community, methodological and PAW accountability mechanisms, that would help us respond to change when required. This ensured that while I, or we, may not have always had the answers in the moment, we did have a way and a means of discussing the issue and coming to some kind of resolution. This worked well for us and I would definitely take a similar approach to future research.

This is what I have come to call my “it’s ok” principle. As numerous authors have suggested, in community-based, arts-informed, and Indigenist research, things seldom go according to plan (Gallagher, 2008; Ferguson & Thomas-Maclean, 2010; Kovach, 2009). It is necessary to have a plan, of course, but it is equally necessary to be open to changing and adapting that plan to suit the evolving needs of participants or the particular research situation. Community-based, arts-informed and Indigenist research makes space for participants in the decision-making process and is therefore unpredictable, messy, organic and fluid. It frequently produces moments of uncertainty, of anxiety, of potential conflict; however, it is the job of the researcher, along with others on the team, to make the most of those moments, and to adapt the research to the changing circumstances. Resisting this change is counter-productive and potentially alienating for research participants who may feel that their needs are not being recognized. Embracing this change, and working together to find a solution that honors the needs of research participants and the needs of the research is really the only way to move forward. Hence, “it’s ok” became a guiding principle. “It’s ok” if our recruitment plan did not work. “It’s ok” if PAW co-researchers have a different idea of how that meeting should go. “It’s ok” if we did not anticipate this or that situation. Whatever it is, “it’s ok”. Find another way.

An aspect of the research I was not prepared for, however, is what some have called “the longest journey – the 18 inches from your head to your heart”. Despite my knowing that an Indigenist approach to research is a holistic approach that requires an investment of heart and mind, I did not fully understand what this would mean. As a researcher, I am a product of my up-bringing and a product of a Western academic tradition that privileges intellect over emotion, cognitive knowing over sensory knowing, logic over intuition, waking knowledge over dreaming knowledge, and empirical knowledge over cultural knowledge (Wilson, 2008). In research settings, we also tend to privilege ‘serious’ talk over humour, deep discussion over fun, saving laughter and merriment for when the recorder is turned off. Engaging with an Indigenist paradigm though, demands that we bring all of these elements to the work, not just some of them. It demands that we engage as humans, “feeling, living, breathing, thinking, [laughing], humans” (Wilson, 2008, p. 58), not just as researchers. For those of us who are trained in Western academic traditions, this can be difficult despite our best intentions, despite our evidence-informed reasons for doing so, and despite our own

inner knowing that tells us to stand aside. “Get out of the way”, then, became a constant reminder to set aside my personal, academic and cultural predispositions towards prioritizing intellect and to embrace more holistic and human ways of knowing and being. This includes learning to trust my instincts and to follow my ‘gut’. It means making greater space for emotion and intuition in decision-making, and ceremony in daily practice. It also means letting go of a life-time habit of perfectionism and learning to trust the process. As Wanda repeatedly shared with us, whatever happens is meant to be. Therefore, “get out of the way” means letting go of the illusion of control and learning to accept what is.

Lastly, “get out of the way” means being willing to be changed by the process. It means going in to the research each day with an open mind and an open heart and letting oneself be impacted by the stories that are told, by the experiences that are had, by the joy and the pain that is shared. It means fully immersing oneself in the research, yes, but more importantly in the process of relating to people as people. It means dropping one’s guard, allowing oneself to be vulnerable, and humbly travelling those 18 inches from one’s head to one’s heart.

Each Ending Is A New Beginning

Following cultural protocols, we began and ended each *VH* meeting with a prayer. Often it was offered by an Elder or Traditional Knowledge Keeper, but often it was offered by one of the PAW co-researchers. I would like to bring this thesis to a close in the same way. The following prayer was offered by Krista Shore, PAW co-researcher, as a mental, emotional and spiritual balm, a salve if you will, at the end of a very challenging but ultimately satisfying meeting. With Krista’s permission, I offer it here in the same spirit: to acknowledge the journey that we have taken together; to acknowledge the challenges and discomforts that we experienced as we grew to know each other and to know ourselves; to acknowledge the good work that we have done together and the faith, hope, love and humility in which we have done it.

Thank you Creator for giving us an opportunity to come together in unity and as one ... and to get our work done ..., together for our community, for ourselves, for our children, for the world, to make the world a better place. I just ask that

you, you know, put that sacred healing and energy around each and every one of [us] ... and that you fill us with that love and that light, with that sacred healing and energy, and that you carry any pain, any worry, any discomfort that may have come from our project, you carry that away and you take it away to a place where it won't come back. I just ask that you keep us all together and you help us keep our circle strong. And you help us moving forward together in love, faith, hope, happiness, humility and all those other good teachings that we are aware of, so that we can make our future brighter. Miigwetch. (Krista Shore)

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Appendix A: University of Ottawa Ethics Certificate

File Number: H10-09-01

Date (mm/dd/yyyy): 02/02/2010



Université d'Ottawa **University of Ottawa**
Service de subventions de recherche et d'éthologie Research Grants and Ethics Services

Ethics Approval Notice Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Denise	Spitzer	Social Sciences / Women's Studies	Supervisor
Tracey	Prentice	Health Sciences / Others	Student Researcher

File Number: H10-09-01

Type of Project: PhD Thesis

Title: Visioning Health: An Arts-informed Approach to Understanding Culture and Gender as Determinants of Health for Aboriginal Women Living with HIV/AIDS

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
02/02/2010	02/01/2011	Ia

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:
N/A

1

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Université d'Ottawa University of Ottawa
Service de subventions de recherche et déontologie Research Grants and Ethics Services

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement and other applicable laws and regulations in Ontario, has examined and approved the application for ethical approval for the above named research project as of the Ethics Approval Date indicated for the period above and subject to the conditions listed the section above entitled "Special Conditions / Comments".

During the course of the study the protocol may not be modified without prior written approval from the REB except when necessary to remove subjects from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the study (e.g. change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, information/consent documentation, and/or recruitment documentation, should be submitted to this office for approval using the "Modification to research project" form available at:
http://www.rges.uottawa.ca/ethics/application_dwn.asp

Please submit an annual status report to the Protocol Officer 4 weeks before the above-referenced expiry date to either close the file or request a renewal of ethics approval. This document can be found at:
http://www.rges.uottawa.ca/ethics/application_dwn.asp

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5841 or by e-mail at: ethics@uOttawa.ca.

Germain Zongo
Protocol Officer for Ethics in Research
For Dr. Daniel Lagarec, Chair of the Health Sciences and Sciences REB

Appendix B: Recruitment Poster

Visioning Health!

Do you self-identify as an **Inuit, First Nations or Métis woman living with HIV or AIDS?**

Would you like to learn about photography or other art forms?

Do you live in or near [regional location]

Are you 18 years or older?

***Come JOIN US in exploring the many ways that
culture and gender support your health and wellness!***

In this research project you will have an opportunity to:

Learn to create contemporary or traditional Aboriginal art

Have an opportunity to tell your story of health and wellness

Celebrate your culture and your gender through the arts

Share your artwork with your community and with policy-makers/service-providers

Contribute to the development of an intervention for Positive Aboriginal Women

Make a difference in the lives of Aboriginal women living with HIV or AIDS!

**This is an inclusive research project! Heterosexual, bi-sexual, lesbian, queer, two-spirited
and trans women welcome!**

For more *confidential* information on how to get involved in this exciting project,
please call or Skype:

[National Coordinator contact info]

Or

[Local regional community research coordinator]

Appendix C: Project Description



Visioning Health!



Project Description - Participants

Researchers from the University of Ottawa (UO) (Tracey Prentice, PhD Candidate/Lead Researcher and Denise Spitzer, Research Supervisor) along with members of the Ontario Aboriginal HIV/AIDS Strategy (OAHAS) (Doe O'Brien-Tessens), Pauktuutit Inuit Women's Association (Geri Bailey) and the Canadian Aboriginal AIDS Network (CAAN) (Renée Masching and Doris Pelletier) are working together on a project called, "Visioning Health: Arts and Aboriginal Women Living with HIV or AIDS". In this project, Inuit, Métis and First Nations women living with HIV/AIDS are using pictures and other types of art, such as drum-making, to tell stories about their health and wellness. Some artworks will be shown to the public through the Internet or in displays, presentations and reports about the project. We will also ask people who make public policy and representatives of Aboriginal AIDS Service organizations to look at our results and take actions to change or develop policies and programs to meet the health and wellness needs of Aboriginal women living with HIV or AIDS in Canada.

Eight to twelve (8 to 12) participants in Toronto, Ottawa and Montreal, will be asked to commit to 5 to 7 meetings of approximately 4 hours each (total of approximately 30 hours) to learn about digital photography and other types of art, such as drum-making, and how to use art to tell stories about what health and wellness means to them and about their hopes for health and wellness for themselves and their communities. Participants will also have the opportunity to tell stories about the importance of culture and gender in supporting their health and wellness. Participants will choose artworks for use in reports, presentations, and websites that highlight community strengths, promote community action and advocate for policy change. All participants will receive \$50.00 per meeting (there will be a maximum of 7 meetings) in return for their time and knowledge and also to help offset any costs they might have to attend these meetings.

If you have any further questions or concerns about this study please contact:

Tracey Prentice, Institute of Population Health, University of Ottawa, Ottawa, Ontario

Tel: **1-888-568-1706** (toll free) OR Email: [REDACTED]

OR

[local contact]

*Funding for this project has been provided by a Doctoral Training Award from the Canadian Institutes of Health Research, Community-Based HIV/AIDS - Aboriginal Stream, and an Unrestricted Educational Grant from Pfizer Canada.



Appendix D: Protocols for Safe Participation (Toronto Group)

(as decided at first Toronto meeting on November 26, 2010. The alcohol ‘rule’ was subsequently revised)

- Follow the Seven Grandfather Teachings
- Respect yourself and each other
- Follow the Eagle Feather Teaching = only one person speaks at a time; please do not add to someone’s story without permission.
- Confidentiality is key!! Please do not talk about the people in the group or what gets said in the group to those outside the group. When talking to your friends, family or others, please do not tell them the names of other members of the group.
- To whom and when to disclose one’s HIV-status is a decision that only the individual can make. Please do not disclose for others in the group.
- Remember that a willingness to disclose your HIV-status is not required to participate in this project. We will show you ways of participating without revealing your identity (you also do not have to use your real name)
- Practice non-judgement. Everyone has a right to their own opinions. Please do not judge others for something they may say or do – accept that it may be different from your way of saying or doing things, but do not judge.
- We do not have to agree on everything. It’s quite alright to agree to disagree on some things.
- Please come to meetings with a clear mind. This means abstaining from alcohol and drugs until after the meeting is over.
 - If you do come to a meeting under the influence you will politely be asked to leave and come to the next meeting with a clear mind.
- Give each other support when needed
- Discuss safety plans at the end of each meeting, ie, make sure everyone is safe when they leave.
- Please arrive on time.

Appendix E: Research Sharing Circle Guide

As reflected in the Data Collection Protocol, participants will have several opportunities to participate in sharing circles. Each of these sharing circles will be facilitated discussions. The Sharing Circle (Focus Group) Interview Guides are as follows:

Sharing Circle 1: Meaning & Experience of Culture, Gender and Health

This facilitated discussion will be conducted with each group of AWHAs, one in Ottawa and one in Toronto.

1. As a First Nations, Métis or Inuit woman living with HIV or AIDS, what does ‘health’ mean to you? ‘Wellness’?
2. What kinds of things help to keep you or make you healthy? What kinds of things keep or make your community healthy?
3. What kinds of things make you unhealthy? What makes communities unhealthy?
4. How do you think being an Aboriginal woman affects your ability to be healthy or well?
5. Is there a role for culture in supporting the health of Aboriginal women living with HIV or AIDS? Gender? Why are these important?
6. What are the most important things that First Nations, Métis or Inuit women living with HIV or AIDS can do to improve their health and wellness? The health of their communities?

Sharing Circle 2: Meaning of Photos/Artworks

These questions will be asked of all participants once they have chosen photos or artworks that they would like to share with others in their group. Ideally, this will be a facilitated discussion; however, there may be occasion to ask these questions in a one-on-one interview.

1. What is this a photo/artwork of? (please describe)
2. Why did you take this photo/create this artwork?
3. What does it mean to you/why is it important?
4. What do you think it says about culture, gender and health for Aboriginal women living with HIV or AIDS?
5. Is there anything that you wanted to take a photo of, or wanted to express in artwork but weren’t able to? Can you tell us about that? Why were you not able to express it in photos/artworks?

Sharing Circle 3: Similarities & Differences Across Groups/Cultures

This facilitated discussion will be conducted once each group has chosen their photos/artworks and have come together again as one group to view each other’s works.

1. What are your overall impressions of the other groups collected works? Is there anything that stands out for you?
2. What are some of the similarities you see between the two groups collected works?
3. What are some of the differences you see between the two groups collected works?
4. If we look at the two collections as a whole, what do you see as the main messages coming out of this? What are these photos/artworks saying about health and wellness for First

Nations, Inuit and Métis women living with HIV or AIDS? About the role of culture in supporting the health of First Nations, Inuit and Métis women living with HIV or AIDS? The role of gender in supporting the health of First Nations, Inuit and Métis women living with HIV or AIDS?

5. Is there anything missing from these photos/artworks that you think is important to talk about?
6. What would you like to see happen with these photos/artworks?
7. What do you see as the policy and practice implications of these photos/artworks?
8. How did you feel about participating in this arts-informed project?
9. What do see as the benefits of this approach? The challenges?

Evaluations

Evaluations will be conducted in this project in numerous ways: (1) on-going evaluations via graffiti walls at all sharing circles/focus groups/community gatherings, (2) workshop evaluations after orientation session, (3) evaluation questions in Sharing Circle 3, (4) evaluations after each of the community gatherings by participants, community, & policy-makers.

Appendix F: Certificate of Completion

Certificate of Contribution

This is to acknowledge that

has been a key contributor to the success of the Visioning Health Project on the health of Positive Aboriginal Women (PAW)

Many thanks from your community

& PARTNER AGENCIES: OAHAS, CAAN, PAUKTUUIT & U Ottawa

8 hours of photography training
50+ hours of photography & project development



Appendix G: Project Outputs

CONFERENCES, WORKSHOPS AND PUBLIC PRESENTATIONS

1. Reading, C., Larkin, K. (2014, November). Visioning Health: Arts-Informed Research with HIV-Positive Aboriginal Women. *PEER Training Institute*, Victoria, BC, November 28. **[Invited]**
2. Prentice, T., Peltier, D., Larkin, K. (2014, November). “Damn Good Medicine”: Visioning Health for Positive Aboriginal Women. *Centre for Aboriginal Health Research (CAHR) Learning Institute*, University of Victoria, Victoria, BC, November 3-7. **[Invited]**
3. Prentice, T., Peltier, D., Whitebird, W. (2014, October) Guest Lectures. School of Social Work, McMaster University, Hamilton, ON, October 23 and 24. **[Invited]**
4. Prentice, T. (2014, July). “Connecting Helps Us Heal”: Using the Arts and Culture to Decolonize Research with HIV-Positive Aboriginal Women. *National Gathering of Graduate Students, Network Environments for Aboriginal Health Research*, Simon Fraser University, Burnaby, BC, July 13-14.
5. Prentice, T., Beaver, K., Peltier, D. (2013, November). “Connecting Helps Us Heal”: Using the Arts and Culture to Decolonize Research with HIV-Positive Aboriginal Women. *Ontario HIV Treatment Network Research Conference*, Toronto, ON, November 18.
6. Prentice, T., Peltier, D. (2013, October). “Visioning Health for Positive Aboriginal Women: VH as Intervention?” *Canadian HIV Trials Network Bi-Annual Meeting, Prevention for Vulnerable Populations Core*, Montreal, QC, October 21. **[Invited]**
7. Prentice, T., Peltier, D., Beaver, K., Benson, E., Walsh, T. (2013, September). “Visioning Health: Positive Aboriginal Women’s Perceptions of Health, Culture and Gender”. *Wise Practices IV: Research to Action*, Saskatoon, SK, September 26.
8. Peltier, D. (June, 2013). “Women’s Leadership Report – focus on Visioning Health”. *Canadian Aboriginal AIDS Network Board and Staff Meeting*, Vancouver, BC, June 25.
9. Prentice, T., Shore, K. (2013, February). “Developing Research Partnerships and Working with Allies: The Visioning Health Experience”. *HIV/AIDS Community-Based Research Workshop. Canadian Association of HIV Researchers CBR Workshop*, Saskatoon, SK, February 28-March 1. **[Invited]**

10. Peltier, D., Larkin, K. (2012, December). "Visioning Health: Positive Aboriginal Women's Experiences of Health, Culture and Gender". Oral presentation at *Aboriginal AIDS Awareness Event, Celebrating Aboriginal Women*, Victoria, BC, December 5 & 6. **[Invited]**
11. Prentice, T., Beaver, K., Shore, K., Benson, E. (2012, September). "Visioning Health for Positive Aboriginal Women (PAW): One Experience of Meaningful Engagement". Oral presentation at *CHIWOS Advisory Committee Meeting*, Tiny, ON, September 17. **[Invited]**
12. Prentice, T., Peltier, D. (2012, July). "This is the way research should be done in our communities": Using the Arts to Meaningfully Engage Positive Indigenous Women in HIV-Community Based Research. Oral presentation at *Indigenous Pre-Conference on HIV & AIDS: To See and Be Seen*, Washington, DC, July 21.
13. Prentice, T., Peltier, D., Shore, K., Beaver, K., Benson, E., Martin, C., Whitebird, W. (2012, July). Visioning Health: Creating Action for Social Change for HIV-Positive Aboriginal Women. Policy Discussion Circle at *Indigenous Pre-Conference on HIV & AIDS: To See and Be Seen*, Washington, DC, July 21.
14. Peltier, D., Martin, C., Prentice, T., Shore, K. (2012, July). "Creating Safe Spaces for Women Living with HIV: Utilizing an Indigenous Sharing Circle Model to Engage and Build Capacity for POZ Women". Workshop at *XIX International AIDS Conference*, Washington, DC, July 23.
15. Prentice, T., Beaver, K., Shore, K., Benson, E., Sharky, E. (2012, July). "Visioning Health: Positive Aboriginal Women share their experiences of meaningful engagement in HIV-CBPR". Panel Discussion at *Indigenous Networking Zone, Global Village, XIX International AIDS Conference*, Washington, DC, July 24. **[Invited]**
16. Prentice, T., Beaver, K., Shore, K., Benson, E. (2012, July). "Visioning Health: Positive Aboriginal Women share their experiences of meaningful engagement in HIV-CBPR". Panel Discussion at *North American Networking Zone, Global Village, XIX International AIDS Conference*, Washington, DC, July 24. **[Invited]**
17. Peltier, D. (2012, May). Visioning Health: Positive Aboriginal Women's Perceptions of Health, Culture and Gender. Keynote presentation at *Shining Mountain – Aboriginal HIV Gathering*, Red Deer, Alberta, April 3 & 4. **[Invited]**

18. Prentice, T., Beaver, K. (2012, April). Visioning Health: One Example of Meaningful Engagement. Workshop presented for CHIWOS Aboriginal Research Training. *Canadian HIV Treatment Network Bi-Annual Meeting*, Montreal, QC, April 19. **[Invited]**
19. Prentice, T., Peltier, D. Visioning Health Researchers (2012, April). “Finding Our Place in the Environment”: Art and Positive Aboriginal Women’s Perceptions of Health. Paper presented at *Canadian Association of HIV Researchers Conference*, Montreal, QC, April 19-22.
20. Peltier, D., Prentice, T. Visioning Health Researchers (2012, April). “They Have to Want to Be There”: New Approaches to Meaningfully Engage HIV-Positive Aboriginal Women in Community-Based Research. Poster Presentation at *Canadian Association of HIV Researchers Conference*, Montreal, QC, April 19-22.
21. Whitebird, W. (2012, March). Visioning Health: Arts and Positive Aboriginal Women. Oral presentation at *HIV Women’s Forum*, Windsor, ON, March 28. **[Invited]**
22. Prentice, T., Peltier, D. (2012, March). Visioning Health: HIV-Positive Aboriginal Women’s Perspectives on Health, Culture and Gender. Feature presentation at *Women’s Health Research Day*, University of Ottawa, March 20. **[Invited]**
23. Prentice, T., Peltier, D. (2012, February). Visioning Health: Racism and Cultural Safety in the Context of Health for HIV-Positive Aboriginal Women. Oral presentation at *Colloquium on Aboriginal Health, Racism and Cultural Safety, Aboriginal Health Research Networks Secretariat*, University of Ottawa, Ottawa, ON, Feb. 1. **[Invited]**
24. Peltier, D. (2012, January). N’GINAAJIIWIMI: A Decolonizing Perspective on the Impacts of HIV and AIDS on Aboriginal People. Feature presentation at *Concordia University Lecture Series*, January 26. **[Invited]**
25. Shore, K. (2012, January). Thru the Lens: Positive Aboriginal Women’s Perceptions of Health, Culture and Gender. Oral presentation to *HIV/BBP/IDU Program, Population Health Branch, Saskatchewan Ministry of Health*, January 2012. **[Invited]**
26. Shore, K., Prentice, T., Beaver, K. (2011, December). Thru the Lens: Positive Aboriginal Women’s Perceptions of Health, Culture and Gender. Oral presentation at *Saskatchewan AIDS Conference*, Regina, SK, Dec. 2.

27. Peltier, D., Martin, C. (2011, December). Visioning Health: Positive Aboriginal Women's Perceptions of Health, Culture and Gender. Oral presentation at *Aboriginal AIDS Awareness Week – Women's Day*, Montreal, Quebec, December 2. **[Invited]**
28. Peltier, D., Prentice, T. and the Visioning Health Team. (2011, November). Visioning Health: Art and Positive Aboriginal Women's Perceptions of Health, Culture and Gender. Oral presentation at *Ontario HIV Treatment Network Research Conference*, Toronto, Ontario, November 14.
29. Prentice, T., Beaver, K., and the Visioning Health Team. (2011, November). Visioning Health: Technology, Tradition, and Enhancing Knowledge for Positive Aboriginal Women. Oral presentation at *Ontario HIV Treatment Network Research Conference*, Toronto, Ontario, November 14.
30. Whitebird, W. (2011, October). Visioning Health: Arts and Positive Aboriginal Women. Oral presentation at *Aboriginal Storytelling Session at CATIE's Knowledge Exchange Forum*, Toronto, ON, October 19. **[Invited]**
31. Prentice, T., Peltier, D. (2011, July). Visioning Health: Arts and Aboriginal Women Living with HIV. In *Seeking Safe Spaces: Aboriginal Women's Experiences of Racist Sexism in HIV/AIDS Services*. Panel presentation at *Women's Worlds Conference*, Ottawa, ON, July 3-7.
32. Prentice, T., Jackson, R. (2011, June). Is Photovoice a Culturally-relevant Methodology for Research with Aboriginal Women Living with HIV? Oral presentation at *1st International HIV/AIDS Social Science and Humanities Conference: Locating the Social*, Durban, South Africa, June 11-13.
33. Prentice, T., Spitzer, D., Jackson, R. (2010, May). Photovoice as De-Colonizing Methodology for Health Research with Aboriginal Peoples. Oral presentation at *Canadian Association of Health Services and Policy Research (CAHSPP)*, Toronto, ON, May 10 – 14.
34. Prentice, T. (2010, March). Arts-Based Approaches to De-colonizing Research with Aboriginal Peoples. Oral presentation at *Forum for Aboriginal Studies Research - University of Ottawa, Toward De-colonizing Methodologies: An Interdisciplinary Workshop*, Ottawa, ON, March 4. **[Invited]**

35. Prentice, T., Peltier, D. (2009, June). Visioning Health: An Arts-Based Approach to Understanding Culture and Gender as Determinants of Health for Aboriginal Women Living with HIV/AIDS. Oral presentation at *Canadian Aboriginal AIDS Network Annual General Meeting & Skills Building*, Winnipeg, MB, June 23-25.
36. Prentice, T. (2009, April). Visions of Health: An Arts-Based Approach to Understanding Culture and Gender as Determinants of Health for Aboriginal Women Living with HIV/AIDS. Oral presentation at *1st Forum for Aboriginal Study and Research - Student Colloquium*, University of Ottawa, Ottawa, ON, April 14.

PHOTO EXHIBITIONS WITH COMMUNITY ENGAGEMENT

Visioning Health Lodge

With the guidance of an Elder, we built an Anishinabe Teaching Lodge in the lobby of the conference hotel. We exhibited the photos inside the lodge and offered other cultural activities.

1. With the Women's Bundle & Ceremony. *Wise Practices IV: Research to Action...*, Saskatoon, SK, September 23-27, 2013.
2. With the Women's Bundle & Sharing Circles. *Saskatchewan AIDS Conference*, Regina, SK, November 28-29, 2012. **[Invited]**
3. With traditional drumming and singing. *Ontario HIV Treatment Network Research Conference*, Toronto, ON, November 13-15, 2012. **[Invited]**
4. With the Women's Bundle & Policy Discussion Circle. *Indigenous Pre-Conference on HIV and AIDS: To See and Be Seen*, Washington, DC, July 20 & 21, 2012.

PHOTO EXHIBITIONS

Visioning Health Photo Exhibition: Positive Aboriginal Women's Perceptions of Health, Culture and Gender.

1. *Institut national de santé publique du Québec*, Montréal, Québec, September 4 – November 4, 2012.
2. *Global Village, AIDS2012*, Washington, DC, July 22-27, 2012.

3. *Shining Mountain – Aboriginal HIV Gathering*, Red Deer, Alberta, April 3 & 4, 2012.
[Invited]
4. *Women’s Health Research Day*, University of Ottawa, May 20, 2012. **[Invited]**
5. *Colloquium on Aboriginal Health, Racism and Cultural Safety, Aboriginal Health Research Networks Secretariat*, University of Ottawa, Ottawa, ON, Feb. 1, 2012.
[Invited]
6. *Aboriginal AIDS Awareness Week – Women’s Day*, Montreal, Quebec, December 2, 2011. **[Invited]**
7. *National Launch of Aboriginal AIDS Awareness Week*, Ottawa, Ontario, December 1, 2011. **[Invited]**
8. *Saskatchewan AIDS Conference*, Regina, Saskatchewan, December 1 & 2, 2011.
9. *Ontario HIV Treatment Network Research Conference*, Toronto, Ontario, November 14 & 15, 2011.
10. *SisterSong Conference, Let’s Talk About Sex*, Miami, Florida, July 13-17, 2011.
[Invited]
11. *Native Women’s Centre of Toronto, Grand Opening Celebration*, June 24, 2011, Toronto, ON. **[Invited]**
12. *Canadian Aboriginal AIDS Network’s 13th Annual General Meeting and Skills Building*, Quebec City, Quebec, June 7-9, 2011.
13. *Native Women’s Centre of Toronto*, Toronto, ON, June 3, 2011.

NON-PEER REVIEWED PUBLICATIONS & KNOWLEDGE PRODUCTS

1. Prentice, T., Peltier, D. (2012, November). “Visioning Health: A Community-Based Participatory Research Project, by, for and with Positive Aboriginal Women” [Poster]
2. Peltier, D., Prentice, T. (2012, November). “The Visioning Health Lodge”. [Poster]
3. Prentice, T., Peltier, D., & Visioning Health Team. (2012, September). “Visioning Health: Positive Aboriginal Women’s (PAW’s) Experiences of Health, Culture & Gender. Project Summary”. [Pamphlet]
4. Peltier, D. (2012, Summer). “A Traditional Teaching Lodge Built in Washington at Indigenous Preconference: A Definitive Message that Conveyed – “WE ARE STILL HERE!!!” Canadian Aboriginal AIDS Network Newsletter, Summer.

5. Prentice, T., Peltier, D., & Visioning Health Team. (2012, April). "Visioning Health: Positive Aboriginal Women's (PAW's) Experiences of Health, Culture & Gender". [Brochure]
6. Prentice, T., Peltier, D., & Visioning Health Team. (2012, April). "Visioning Health: Arts and Aboriginal Women Living with HIV. A Photo Exhibition". [Reprint - Postcards, Series of 4]
7. Prentice, T., Peltier, D., & Visioning Health Team. (2011, November). "Visioning Health: Arts and Aboriginal Women Living with HIV. A Photo Exhibition". [Brochure - Revised]
8. Prentice, T., Peltier, D., & Visioning Health Team. (2011, June). "Visioning Health: Arts and Aboriginal Women Living with HIV. A Photo Exhibition". [Brochure]
9. Prentice, T., Peltier, D., & Visioning Health Team. (2011, June). "Visioning Health: Arts and Aboriginal Women Living with HIV. A Photo Exhibition". [Postcards, Series of 4]

FUNDING

1. CIHR Doctoral Training Award. September 2006 to August 2009
2. Pfizer Unrestricted Educational Grant. September 2009
3. AK-NEAHR Seed Funding. 2010 to 2012
4. OHTN Studentship Award. September 2009 to August 2012
5. CIHR Dissemination Grant. July 2012 to June 2013
6. CIHR Dissemination Grant. July 2013 to June 2014

Appendix H: Key Themes from All-Group Meeting

(from flipchart)

- Pain and Fear, Hope and Strength (DP – Hope Amidst the Turbulence)
- Mediated by My Environment
- Strength / Inner Strength
- My Essence
- Quintessential
- Heartsong
- Sacredness
- *My Environment Shapes Me
- Perception
- *Adapting Inner Child / My Inner Child
- Aloneness
- My Choices
- Helpers / Help
- Roar! (KL – Canafrica)
- My Rock, Earth, Life
- Expressions of my Spirit
- Togetherness (KB – 4 Little Rocks & LD – Braid)
- Warmth (?) (TW – Turquoise)
- Health (LD – Medicine Wheel)
- Glad to be alive (TW – Mosaic)
- Change (SB - Butterfly)
- Defined (DP – Shaped by My Environment)
- Dark / Light (many images)
- Going back (CG – Dream Pic)
- Tenderness (KB – Woman’s Voice)
- Walking forward and returning (CG – Stairs)
- *Life Thru Nature/ Safety / Connection with Spirit, Self, Creator / Belonging (EB – Pavement)
- Resilience / Overcoming / Always Survive
- Strength
- Responsibility
 - o Different/Multiple roles (KS – Girls = Empty Vessels & Possibilities)
- *Possibilities
- Standing Tall No Matter How We Look / Protector (DP – Totem)
- Expression of Voice / Soul
- *Vulnerability - but not in a negative way (DP – Drum = Deer clan; Deer can be fierce but sensitive)
- Needing/Wanting Safety (KL – Birds of Prey & DP – Drum)
- Connecting to Earth/Family
 - o Reminder of what keeps us strong
 - o Sometimes kids are the only thing to live for, ie, they save us from ourselves
- Standing out in colour (TW – Turquoise)

- Different ways of reconnecting with life; one way is not the same for all (KB – 4 Rocks)
- Fragility, softness, gentle, living out its purpose (SB – Butterfly)
- Physical and Emotional Aspects of Life
- Spiritual and colourful world we live in (TW – Mosaic)
- Water is women's responsibility (DP – Shaped by my environment)
- Protection / Safety (SB - Group of Trees)
- Rocks are Ancient and Our Tie to the Past
- Standing Strong No Matter How we Look (DP – Tree/Totem)
- Earth
 - o Beauty
 - o Nature
 - o Inner Beauty (TW – Turquoise)
- Searching for Spiritual Healing
 - o Physical, Emotional, Spiritual, Mental Health (LD – Medicine Wheel)
- Connection with Earth, Families, Grandfather (Photos of Trees, Nature)
- Isolation & Rejection
- Freedom of Speech
- Intergenerational
- Inner Child (KS – Vase, KL – Dandelion)
- Nature Speaks to Us / Nature as Helper
- Womb, Struggles That Pay Off (SB – Butterfly)
- Learning More About HIV – Sharing More
- Labourer instead of Harvester
- Turning – to +
- Identifying Needs and Getting them Met
- Healing
- We All Have Answers in Our Heart
- Shaped By Environment
- Creator Gives Us What We Need / Everything We Have
- No Shame in Struggles / Struggling
- Remember / Recognize What Keeps Me Sane
- Family – Disclosure
- Strength to Move Forward but Remember I'm a Labourer
- Hope
- Culture
 - o Spirit Essence
 - o Inherent Right
- *Feet
- *Stairs
- *Handprint on Pot – Reminds us that we were children, have children, grandkids
- Values
 - o Uniqueness
 - o *Awakening (KB & TW – Graffiti, KS – Handprint)
 - o Urban youth (Graffiti)
- *Culture – I Am a Spiritual Being / Culturally Aware

- Making + from –
 - o Flexibility / freedom of msg to meet my needs
- Social Determinants of Health
 - o Environment
 - o Identity
- Respect for Land (doesn't really occur to others)
- Struggles but the teaching is important
- Teaching Each Other
- *Environment is not accepting so connecting with family is so important
- *7 Grandfather Teachings
- *Love
 - o Connections to community & family
- Struggle with isolation and loneliness
- Finding way thru difficult times
- Process can be difficult
- Connecting with Nature and Environment
 - o Reflecting identity and values and beliefs
 - o *Connecting helps us heal
- *Inner Child
 - o Trusted Adult / everyone but taken away by harsh environment
 - o Reconnecting makes us feel better
- Everything feels dark and hope to see the light cuz I am so tired of isolation at home and feel very lonesome (DP – Hope Amidst the Turbulence)
- Amazed at similarity of experience
- *Resiliency
- Survival – I'm still here!

Sticky Notes on Photos

- Birds seen as helpers – cultural
- Reflection – CG Stairs – look at life from the top/after yo've climbed
- Circle of Light – cultural
- Candy creek – culturally appropriate techniques used to heal
- Krista Pathway – environment/nature used to heal
- Krista feet – individual steps
- Krista spidersweb – family roots, thoughts/advice from Elders, cultural
- Krista sun behind the trees – teachings from Elders, cultural
- Krista girls – family, identity, cultural, teachings from ASOs, girls looking for where they belong
- Liz Books – searching for healing, mental health
- Liz cedar – cultural
- Liz birds – adaptation – being able to survive in any environment, Elders advice taken into consideration
- Liz Angel – beauty
- ES drum – showing what's important, what keeps us strong – family

- ME drum – social interaction
- KB drum – reaching, believing in the stars
- KL Skrtiches – DoH
- KL Shame-full – pain, shame, isolation, mental health
- KL Dark is the Light – identity, strength, endurance