

Indigenizing Research Collaborations: An Example from the Two-Spirit HIV/AIDS Wellness and Longevity Study (2SHAWLS), Ontario, Canada

Our Story, Our Time, Our Future
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- * **Research Team**
 - * Investigators: David Brennan (PI), Art Zocole (Principle Knowledge User), Randy Jackson (Co-I) and Tony Nobis (Co-I)
 - * Research Staff: Earl Nowgesic (PhD candidate), Chavisa Brett (Research Coordinator) and George Georgievski (Undergraduate Student)
- * **Advisory Committee**
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Background

- * Aboriginal people are disproportionately represented in Canada
 - * Aboriginal peoples are “**3.8% of the Canadian population ...** and yet an estimated 4,300 to 6,100 Aboriginal were living with HIV (including AIDS) in Canada in 2008 (i.e., **8.0% of all prevalent HIV infections**)” (PHAC, 2010, p. 2).
- * Seventy-two percent of all Aboriginal people living with HIV have an AIDS diagnoses
 - * Later diagnosis
 - * Slower uptake
 - * Higher morbidity
 - * Higher mortality



Background

- * Useful but provides only a **partial description**
 - * Paints a picture of suffering/dysfunction (Lavallee & Poole, 2010)
 - * Constructs Aboriginal identity and shapes responses (Bond, 2005; Reading & Nowgesic, 2010)
 - * Can be used to justify paternalism and the idea “I’m here to help” in ways that ignore principles of self-determination
 - * Little or no information about resiliency
- * Hence, 2SHAWLS
 - * Resisting racism, homophobia, colonization and gender violence against two spirit men
 - * How do we design services that support two-spirit men’s health and their resiliency?



Goal / Objectives

To better **understand** the factors, skills, resources, knowledge and practices that contribute to **two-spirit men's health and well-being living long-term with HIV**



Methods (1)

- * Community-based research design using decolonizing and indigenous methodologies
- * Recruitment assistance was provided by the Ontario Aboriginal HIV AIDS Strategy (OAHAS) and 2-Spirited Peoples of the First Nations
- * Focus groups (re-envisioned as Sharing Circles) with 14 two-spirit male participants living at least 10 years with HIV.
 - * Held in Hamilton, Toronto and Ottawa (Ontario)
 - * **What's allowing you to live well long-term with HIV?**
 - * Honorariums, audio-recorded, verbatim transcripts



Methods (2)

- * Analysis involved several stages using the Medicine Wheel (MW) to ground our **participatory symbol-based inquiry** model
 - * The Medicine Wheel is a symbol of Anishinaabe culture that expresses the notion “all my relations.”
 - * Data were qualitatively coded
 - * Key quotes were selected and mapped onto the Medicine Wheel
 - * Themes emerged and were grouped by relationship and then mapped again onto the Medicine Wheel



Preliminary Findings

- * **Participants**
 - * Two-spirit and living with HIV for 10 or more years
 - * Aboriginal status (First Nation = 12; Métis = 2; Inuit = 0; Total = 14)
 - * Age (32 and 61 years of age; average age = 46; Age n/a = 2)
- * **Seven truths of resiliency** for two-spirit men living long-term with HIV
 - * **(1)** Worldview, **(2)** Finding One's Strength, **(3)** Walking Towards Balance, **(4)** Recognizing True Power, **(5)** Mino-bimaadiziwin (living the way of a good life), **(6)** Self-care, and **(7)** Living Our Truth



Worldview (what we believe about the world)



Note: The petroglyphs are an artistic interpretation of each of the paths/truths of resiliency (Earthlore, Ottawa, Ontario).

- * "I feel spiritually powerful so that it affects the rest of my emotional health and my physical health. I can be physically powerful, and that helps my emotional health and my mental health. I can be mentally powerful so if I see it in that balance, I really do see health knowledge, that medicine wheel balance, I really do."
- * "I find it's an awful lot about balance of mind, body, spirit and emotion. The body needs care. The spirit needs care. The emotion needs care ..."



Finding One's Strength (accept and work with challenges in a good way)



- * "Now I've learned to accept who I am, what I am, and what I believe in. There is no rounding who you are. It is up to you to choose who you are and make it strong."
- * "I was a queer, and I was raised to believe that queers were bad. I was a queer, and I hated queers that whole thing so it's just been a long struggle. I love my Two-Spiritedness. I love my gayness. I wouldn't trade it for anything in the world. It's part of why I'm the unique individual that I am, but I remember there was a time that if I could have had it extracted and deposited I would have been at the front of the line wanting it taken away from me. Now probably my most cherished prized possession would be my unique sexuality."



Recognizing One's True Power (connecting to community for healing)



- * "It's like my whole life has been trying to learn how to love myself, and I'm there now. I finally figured out how to do it. It took other people to do it. It took me being real and vulnerable in front of other people (said in a teary voice) and seeing my reflection back at me to learn to trust me."
- * "I was [...] doing the Speaker's Bureau Program, being out there in the community [...] you build] a trust and a respect [...] because you're at the same level as them and have been through the same things. [...] It was nice because I felt people could come to me without any judgment and without any stigmas attached, but then I had to learn [to be] okay; you can be there for all these other people, but what about you?"



Walking towards Balance (putting community connection into action)



- * "It's just having it there, being able to access the support and having access to it. [...] I think if I didn't have my advocate at (name or organization) I would be a mess. [...] They really help me out a lot with so many things, not just some things. They helped me move from one city to another. They really stuck by me and encouraged me to keep living. I think, yeah, it's really important to have that support. Crisis lines don't just cut it."
- * "But I think having good support made a huge difference too like my family. If I didn't have my family, I don't think I'd be here because I'm unstable I guess."



Mino-bimaadiziwin (journey to “living the way of a good life”)



- * “[...] It doesn’t matter if you’re brand new, [...] or your diagnosis is coming up to 30 [...] that you’ve had this thing. That’s a long, long time to live with it. When I was younger, I didn’t know anything. I had to learn it, but what I’ve seen was more knowledge than I’ve ever got from a book or going to a circle. At that time, there was no circle. We didn’t have as much voice as we do today as Aboriginal people. We’ve come a long way, and we’re becoming stronger. That’s the scary part, and I think that’s what I’m feeling. It’s that now even though half of me is saying no, you’re not doing well at all, and you know you’re not. I know I’m not, but then I have the other side of myself where I say, do you know what? From then until now, I think I am stronger. I think I have a little bit more knowledge of what’s happening with me.”



Self-Care (sustaining the journey of “living the way of a good life”)



- * “I find that the best therapy for me is communing with nature... the birds will sing to me. Then somebody will walk along, and the birds will stop. Then as soon as they get a certain distance away, they’ll start again. It’s like I sit there, and I just find it so joyful because it’s just like they’re singing to me. I find its great that way. Yeah, the struggles will always be there. It’s about navigating a course through them as quickly as possible, taking on the least amount of it that you can and trying to let go of it as quickly as possible because anything that we hold onto that’s negative or with darkness in it will add to our misery...”



Living Our Truth (accepting and learning to live with our whole selves)



- * “[...] I needed to learn how to love myself, and I knew if I didn’t learn how to love myself that my dislike of myself would kill me. I started to learn how to love me ... I love my two-spiritedness. I love my gayness.”
- * “Now I’ve learned to accept who I am, what I am, and what I believe in. There is no rounding who you are. It is up to you to choose who you are and make it strong.”



Study Visualization

<http://eekanomic.com/clientArea/2shawls-beta>



Discussion

- * Our findings

- * There is a story we rarely hear: *resiliency occurs in the lives of Two-Spirit men living long term with HIV*
- * Resilience is not found in a linear progression through the Truths but is rather about locating and using these truths as a map to guide
- * Resilience is grounded in the values and perspectives of one's culture
- * Resilience is also acting on these values and beliefs.

