Table of Contents

Introduction1
Section 1: Research development and findings
An Introduction to the 2SHAWLS Article Collection
Resilience among two-spirit males who have been living with HIV long term: Findings from a scoping review
Indigenizing Scholarship to Examine Resilience Among HIV-positive Two-spirit Men: Lessons learned from the 2-Spirit HIV/AIDS Wellness and Longevity Study (2SHAWLS)29 David J. Brennan, Georgi Georgievski, Randy Jackson, Chavisa Horemans, Art Zocole, Tony Nobis
"Our Gifts are the Same": Resilient Journeys of Long-Term HIV-Positive Two-Spirit Men in Ontario, Canada
Section 2: Collaborative research processes
"A Sacred Undertaking" towards Developing an etuaptmumk (Two-eyed Seeing)-framed Collaborative Research Project and Partnership: the Sanctum 1.5 Hope Through Strength Project
Section 3: Commentary
Applying Concepts of the Life Course Approach in the Context of a Holistic Indigenous Lens to Create Recommendations for the Future of Addressing the Complexities of HIV89 Leanne Varney, Meg Miners, Rutendo Madzima

Applying Concepts of the Life Course Approach in the Context of a Holistic Indigenous Lens to Create Recommendations for the Future of Addressing the Complexities of HIV

Leanne Varney¹, Meg Miners², Rutendo Madzima³

- 1. Former Education Manager at an Indigenous-led, Community-based HIV Organization.
- 2. Former Youth Project Coordinator and Harm Reduction worker at an Indigenous-led HIV education and support organization and current YCAN Coordinator
- 3. YMCA of Northern BC. Former Community Health Educator at a Community-Based Indigenous-led HIV Organization.

Corresponding Author: Leanne Varney

Email: <u>leanne108@shaw.ca</u> Phone: (250)706-2437

ABSTRACT

The complexity of HIV highlights the need for holistic considerations in the prevention, treatment and continued care of those living with HIV. Our work spans a period when intersections between the COVID-19 pandemic, opioid crisis and HIV epidemic created a unique set of complexities for the Northern, rural, and remote populations of British Columbia. The existence of stigma and discrimination can further alienate access to appropriate care and support for those living with HIV, which over time contributes to the complexity of the disease. While the Life Course Approach is based on Western medical research and practices, there are wide overlaps with the Indigenous model of medicine and wellness which is prevalent throughout Canada. Mental, emotional, physical, and spiritual well-being are considered together, rather than as separate categories of health. The roots of drug use and other transmission methods are complex, making the prevailing Western medical approach of studying causes of an illness in isolation less than ideal. The Life Course Approach presents one possible solution to the investigation into causes of HIV transmission, as well as methods to prevent new infections. The intersection of multiple forms of oppression with HIV calls for the use of frameworks that acknowledge the complex nature of the poorer health outcomes in Indigenous populations. Policy makers and public health researchers should consider employing the Life Course Approach to properly time interventions as well as for a vehicle of reconciliation within institutions.

KEYWORDS: HIV, Life Course Approach, Reconciliation, Indigenous Lens

BACKGROUND

The Complexities of HIV

Human immunodeficiency virus (HIV) is an infectious agent that can influence multiple aspects of a person's life. Not only is there variation when examining how an individual has contracted HIV, but there is further variation introduced when researching how one lives with HIV. The virus itself targets the structure and function of the immune system; however, the effects of a weakened immune system are felt across all realms of wellbeing. The complexity of HIV highlights the need for holistic considerations in the prevention, treatment and continued care of those living with HIV. As a lifelong condition, the aspects of time and a changing body must also be taken into account when researching living with HIV.

Our work spans a period when intersections between the COVID-19 pandemic, opioid crisis and HIV epidemic created a unique set of complexities for the Northern, rural, and remote populations of British Columbia. Primarily, we sought to provide support and education to Indigenous communities, as well as those with lived experience of homelessness, addiction, and mental health conditions. The complexities associated with HIV in these populations stem from multiple avenues. Biologically, the virus is an enigma that continues to puzzle those searching for more effective therapies, and an eventual cure. Beyond the immune system infection, HIV can introduce or exacerbate the complexity of mental health in those living with HIV. Socially, stigma surrounding both HIV and HIV-related treatments continues to be perpetuated by media and other societal outlets (Card et al. 2018). The existence of stigma and discrimination can further alienate access to appropriate care and support for those living with HIV, which over time contributes to the complexity of the disease.

How Westernized Empirical Research Methods Fail to 'Paint the Whole Picture'

Empirical, Westernized styles of research have primarily focused on controlled environments of study, intending to reduce the likelihood of confounding variables. Using this focus, research subjects are often set within an unnatural environment that may fail to show key relationships between variables in the absence of other contributing factors. Empirical research often seeks to remove the presence of any confounding variables when life—in reality—is nothing more than a sum of intertwined confounding variables. To control or remove aspects of one's life to determine another aspect disregards the complexities that holistic worldviews strive to celebrate.

Recently, trends in research surrounding HIV have transitioned to searching for relationships between an emotional, social, physical, or mental variable and HIV status. In an attempt to qualitatively describe the complexities of diseases such as HIV, the term 'syndemic' was coined to evaluate conditions that frequently co-occur, either within a population or across a geographic or temporal context (Tsai and Burns, 2015). While this approach has highlighted some correlations, the limited search of a relationship between a few variables ignores the larger, complex picture of living with HIV. Spanning physical, emotional, mental, and spiritual realms, the disease must be evaluated in terms of each, while also recognizing the potential for intersections. When considering the use of empirical research to examine the complex impacts of HIV on daily life, there are no concrete methods to address an intersecting network of variables

in an accurate, appropriate manner. This shortcoming has been noted previously with regard to research on HIV and co-occurring conditions with a systematic review highlighting that fewer than 30 percent of studies appropriately assessed the interactions between variables that contribute to HIV-related complexities (Tsai and Burns, 2015).

Moving towards Indigenous research practices, which seek to encompass a more dynamic and individualized approach, traditional ways of knowing and Indigenous beliefs and values can be incorporated to create a research framework that is more appropriate for a given community or population (Toombs et al., 2019).

The Intersection of the Life Course Approach and Indigenous Wellness Approach

The Life Course Approach is a Western medical concept which strives to recognize environmental and lifestyle factors throughout an individual's life which contribute to disease processes. This model recognizes that individuals are not healthy right up to the point at which they become ill, but that disease trajectory is determined in many key developmental periods, from preconception to adulthood. Studies have strongly suggested that there are critical periods during infancy, childhood, and adolescence in which environmental conditions are more influential (World Health Organization, 2000). It is also accepted that there are developmental periods in childhood and adolescence in which it is easier to learn coping strategies, cognitive and social skills, values, and habits (World Health Organization, 2000). Disruption or alteration in development during these periods can, in the Life Course Approach, contribute to negative health outcomes. Early and mid-adulthood experiences are also thought to either contribute to later outcomes or interact with earlier experiences to further impact health and disease processes (World Health Organization, 2000).

The Life Course Approach calls for the identification of risk factors during these life stages and timely interventions to reduce the risk of disease and disability (Jacob et al., 2017). Generational data can also be used to predict the likelihood of disease formation (Jacob et al., 2017). As an example of the Life Course Approach, those born into adverse social conditions tend to have lower birth weight and experience poor diet, more childhood infections and be exposed to passive smoking. These factors combined can raise the risk of respiratory disease in adulthood (World Health Organization, 2000). Social factors also interact and contribute to disease processes. Repeated respiratory infections during childhood and adolescence can lead to higher school absences and poorer achievement levels, which may result in a higher likelihood of smoking and working in an occupation with more dangerous respiratory exposures (World Health Organization, 2000).

While the Life Course Approach mainly examines non-communicable disease risk, the case can be made for examining HIV with the same lens. Many risk factors contribute to the acquisition of HIV, as well as health outcomes for those infected. Intravenous drug use, access to appropriate health care and information, sexual attitudes and habits, familial and community support, overall health, and stigma levels are among those which contribute. All of these factors not only interact with each other, but are experienced over a lifetime, rather than just immediately prior to, or after, infection. By identifying protective factors which can disrupt the negative influence of various risk factors, new HIV infection rates can, potentially, be reduced

and health outcomes of those already infected can be improved. In childhood, lack of autonomy dictates that community and family, as well as individual interventions, are needed. This multi-interventional approach can also be used for adults of all ages to connect them to their families, communities, and cultural supports.

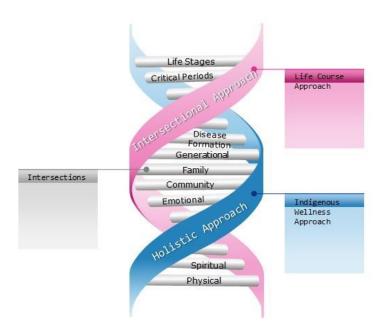
While the Life Course Approach is based on Western medical research and practices, there are wide overlaps with the Indigenous model of medicine and wellness which is prevalent throughout Canada. There are many diverse practices and beliefs among the Indigenous people of Canada and many of those practices are passed down orally, making them difficult to quantify from a research perspective. There are, however, several common themes which Indigenous wellness/medicine approaches have in common. Mental, emotional, physical, and spiritual wellbeing are considered together, rather than as separate categories of health. This holistic healing approach involves the use of herbal remedies, ceremonies, and connections to the earth and nature to correct an imbalance or weakness in this interrelated health matrix (Robbins & Dewar, 2011). Plant, animal and mineral-based medicines, physical/hands-on, and energy-based techniques are all used to achieve or promote balance (First Nations Health Authority, 2021).

Rather than occurring in isolation, Indigenous healing practices involve family, community, and culture. Relationships are at the heart of wellness; with self and others, both in one's family and the wider community, as well as with the land, nature and cultural history and practices (First Nations Health Authority, 2021). While these healing and wellness practices have been in place for many generations, they were severely disrupted by colonization and the banning of rituals and ceremonies, such as the Pot Latch and dancing (Robbins & Dewar, 2011). Some traditions were taken underground, but generations of Indigenous people had their medicinal education disrupted or halted, leading to the current need to rebuild the knowledge base.

HIV infections among BC's Indigenous population are growing faster than the general population. While Indigenous people make up 4% of residents, they comprise more than 13% of new HIV infections, as well as half of the babies infected with HIV (Jackson & Reschney, 2014). One of the major routes of infection involves the use of injection drugs (Jackson & Reschney, 2014). The roots of drug use and other transmission methods are complex, making the prevailing Western medical approach of studying causes of an illness in isolation less than ideal. The Life Course Approach presents one possible solution to the investigation into causes of HIV transmission, as well as methods to prevent new infections.

The Indigenous approach to medicine and healing, while overlapping greatly with the Life Course Approach, provides even more promise, particularly to Indigenous individuals. Historical trauma in the form of colonization and residential schools has dampened Indigenous wellness practices but has not erased them. The ongoing ties to land, family, and culture promise to provide a blueprint for not only the study of causes of HIV transmission rates, but ways to prevent new transmissions through social protections. By supporting involvement for Indigenous people in culturally, traditionally relevant practices from the beginning of life throughout adolescence and adulthood, the protective factors which lead to overall wellness and community engagement can have a similar protective influence on HIV transmission rates and health outcomes related to HIV infection. While the relationship between Indigenous people and

traditional wellness practices continues in Northern BC and throughout Canada, supports need to be strengthened to allow the full participation of individuals and the growth of research.



RECOMMENDATIONS

Capacity Bridging acknowledges that all parties bring skills and knowledge to a collaborative experience (Pacific AIDS Network, 2017). The term highlights a realization in research and the scientific discovery that other forms of knowledge are relevant and equal in weight to empirical research.

The intersection of multiple modes of oppression that leaves Indigenous people globally experiencing poorer health outcomes than non-Indigenous peoples calls for the use of frameworks that acknowledge the complex nature of HIV transmission in these populations (Nanibaa et al., 2019). The COVID-19 pandemic, coupled with the legacies of colonialism has further increased the health disparities experienced by Indigenous communities in British Columbia. This has been further exacerbated by the ongoing opioid crisis. Young Indigenous people using drugs in BC are dying at an alarming rate, particularly young women and those using injection drugs (Jongbloed et al., 2017). This presents a problem that requires solutions that go beyond the cause and effect model science so often relies on.

The Life Course Approach considers the temporal and social contexts in an individual's present and past to find explanations for current patterns of health and disease (World Health Organization, 2000). The Life Course Approach takes the social determinants of health into account as well as an individual's experiences throughout their lifespan. It is the authors' view that it is a suitable vehicle for capacity bridging in HIV research in Indigenous populations in Canada.

As former health educators, the HIV prevention and awareness exercises we engaged in focussed on encouraging safe sexual practices and improving individual decision-making. However, our direct engagement with Indigenous people living with HIV while also engaging in Intravenous Drug Use (IDU) told a more complex story that cannot be explained sufficiently without mentioning colonialism, residential schools, trauma and discrimination. Health disparities research often focuses on individual biological and psychosocial consequences and leaves out the family, community, population, or societal levels (Jones, et al., 2019). Indigenous models of being also employ a lens that incorporates the emotional, physical, spiritual and mental aspects as visually represented by the medicine wheel. If Indigenous peoples define wellbeing as more than physical health or the absence of disease, then HIV prevention efforts, particularly in this community, are insufficient outside of a Life Course Approach (King et al., 2021).

For years there has been acknowledgement as well as evidence of how the legacies of colonialism continue to impact negatively on the health outcomes of Indigenous communities; however, there has been no alleviation of this status and the inequities persist. For example, HIV rates are significantly higher among Canadian Indigenous intravenous drug users compared to non-Indigenous IDUs (Minichiello et al., 2013), and it has been found that drug use is often entered into to cope with past traumas. Public Health policymakers in Canada should seriously consider if they can afford to approach any serious attempt to improve the health of Indigenous people outside of this Life Course Approach. Whether it is non-communicable diseases like diabetes or communicable diseases like tuberculosis there is a linkage to structural violence that should no longer be ignored. One-message health campaigns that seek to target the entire population as a homogenous group will not produce results. True capacity bridging involves partnering with Indigenous communities, in a culturally specific way that allows them to take the lead in efforts to reduce HIV rates of transmission in the community. The following approaches are recommendations on how to practically use the Life Course Approach to achieve this.

1. Taking A Cross-Generational Approach to Youth HIV Prevention Efforts

The Life Course Approach seeks to aim interventions at a time when they would lead to the greatest reduction in health risk. In addition, a 2-generation approach can be undertaken, emphasizing a joint focus on the child and the parent, recognizing the importance of the family (Jones et al., 2019). This works well with Indigenous models that frame individual well-being within the larger framework of the family and the community. For example, educators working with high-risk youth from turbulent family dynamics could partner with Indigenous community structures and use the resources available in the education system to provide the necessary, culturally safe, interventions that curtail any further harm to the individual.

2. Embedding Reconciliation into Institutional Practice

Studies looking at third-generation Holocaust survivors and how they handled their intergenerational trauma found that rather than forgetting, focussing on the resilience of their ancestors helped move past pathological symptoms (Kahane-Nissenbaum, 2011). Further, leaving this storytelling experience to just Indigenous people is a half-baked attempt at true healing and reconciliation. Spaces for a conversation about past injustices should be mainstreamed because leaving one group alone to process the legacy of colonization is

dishonest—it was an experience that shapes the current reality of every Canadian, whether for better or for worse. It is through these interactions that a Life Course Approach can become a widespread lens that can be employed before discrimination and stigma to understand how the behaviour of two seemingly similar individuals will differ based on their genetics, past experiences, and socioeconomic position (Jones et al., 2019).

"Discussing the implications and apologizing for the violence that happened from the perspective of a bystander, their descendants or their representative and showing the apologies to broader audiences in spaces where people can discuss the extent of complicity and complexity of perpetrators and bystanders is a valuable strategy for teaching several aspects of life following political trauma" (Volks and Musungu, 2016).

Instances of discrimination and racism have been uncovered within health care institutions in British Columbia. The clinical education of health care professionals is incomplete without considerable modules on reconciliation and understanding of Indigenous culture and history. When doctors and nurses are allowed to be ignorant of the Life Course and intergenerational factors that influence the health of the patients they interact with daily, it is nearly impossible for sufficient amounts of empathy and cultural safety to be produced. Discrimination is only further increased in environments where poverty combines with already stigmatizing conditions like HIV and substance use (Brown et al., 2016).

CONCLUSION

Empirical scientific research, though valuable, is insufficient in dealing with complex issues such as HIV within the Indigenous populations of Northern BC who are facing intersectional forms of oppression. It is our opinion that the Life Course Approach provides an opportunity for capacity bridging where current efforts of HIV prevention with Indigenous worldviews are concerned. Policymakers should employ the Life Course Approach to target individuals in key moments to maximize harm reduction. Additionally, the institutional practice should be embedded in cultural safety and decolonization by using the Life Course Approach as a tool for teaching and creating empathy instead of discrimination.

REFERENCES

- Browne, A.J., Varcoe, C., Lavoie, J. et al. Enhancing health care equity with Indigenous populations: evidence-based strategies from an ethnographic study. BMC Health Serv Res 16, 544 (2016). https://doi.org/10.1186/s12913-016-1707-9
- Card, K.G., Hawkins, B.W., Mortazavi, L., Gregory, A., Hon Ng, K., Lachowsky, N.J. (2019) Stigma, the Media, and Pre-exposure Prophylaxis for HIV Prevention: Observations for Enhancing Knowledge Translation and Resisting Stigma in the Canadian Context. AIDS and Behavior, 23, pp 1877-1887.
- First Nations Health Authority (FNHA) (2021) First Nations perspective on health and wellness. https://www.fnha.ca/wellness/wellness-for-first-nations/first-nations-perspective-on-health-and-wellness
- Jacob, C. M, Baird, J, Barker, M, Cooper, C, & Hanson, M. (2017) The importance of a life-course approach to health: Chronic disease risk from preconception through adolescence and adulthood: White paper World Health Organization life-course-approach-to-health.pdf (who.int)
- Jackson, S. & Reschney, J. (2014) HIV specific research in northern Canada, Moving Mountains conference presentation <u>HIV-Specific Research in Northern Canada</u> (pacificaidsnetwork.org)
- Jones, N. L., Gilman, S. E., Cheng, T. L., Drury, S. S., Hill, C. V., & Geronimus, A. T. (2019). Life Course Approaches to the Causes of Health Disparities. American Journal of Public Health, 109(S1), S48–S55. https://doi.org/10.2105/AJPH.2018.304738
- Jongbloed, K., Pearce, M. E., Pooyak, S., Zamar, D., Thomas, V., Demerais, L., ... & Spittal, P. M. (2017). The Cedar Project: mortality among young Indigenous people who use drugs in British Columbia. CMAJ, 189(44), E1352-E1359. Retrieved June 5, 2021, https://doi.org/10.1503/cmaj.160778
- Kahane-Nissenbaum, M. C. (2011). Exploring intergenerational transmission of trauma in third generation Holocaust survivors. Retrieved June 1, 2021 from https://repository.upenn.edu/cgi/viewcontent.cgi?article=1017&context=edissertations_sp
- King, M., Smith, A., & Gracey, M. (2009). Indigenous health part 2: the underlying causes of the health gap. The lancet, 374(9683), 76-85. Retrieved May 25, 2021 from 10.1016/S0140-6736(09)60827-8
- Minichiello, V., Rahman, S., & Hussain, R. (2013). Epidemiology of sexually transmitted infections in global Indigenous populations: data availability and gaps. International journal of STD & AIDS, 24(10), 759-768. Retrieved June 5, 2021 from https://journals.sagepub.com/doi/10.1177/0956462413481526

- Nanibaa'A, G., Hudson, M., Ballantyne, L. L., Garba, I., Martinez, A., Taualii, M., ... & Rainie, S. C. (2019). Genomic research through an Indigenous lens: understanding the expectations. Annual review of genomics and human genetics, 20. Retrieved April 4, 2021 from https://doi.org/10.1146/annurev-genom-083118-015434
- Pacific Aids Network, 2017. Capacity Bridging: Reciprocity at Work in Research. Retrieved June, 5, 2021 from https://pacificaidsnetwork.org/2017/07/25/capacity-bridging-reciprocity-workresearch/
- Rachlis, B. (2018) HIV prevention and care among rural and remote Indigenous communities in Canada hiv prevention and care interim report final.pdf (ahacentre.ca)
- Robbins, J.A. & Dewar, J. (2011) Traditional Indigenous Approaches to Healing and the modern welfare of Traditional Knowledge, Spirituality and Lands: A critical reflection on practices and policies taken from the Canadian Indigenous Example. The International Indigenous Policy Journal 2 (4)
- Toombs, E., Drawson, A. S., Chambers, L., Bobinski, T. L., Dixon, J., Mushquash, C. J. (2019). Moving Towards an Indigenous Research Process: A Reflexive Approach to Empirical Work With First Nations Communities in Canada. The International Indigenous Policy Journal, 10(1). Retrieved from: https://ir.lib.uwo.ca/iipj/vol10/iss1/6 DOI: 10.18584/iipj.2019.10.1.6
- Tsai, A., Burns, B.F.O. (2015) Syndemics of Psychosocial Problems and HIV Risk: A Systematic Review of Empirical Tests of the Disease Interaction Concept. Social Science and Medicine, 139, p26-35. Retrieved from https://www.sciencedirect.com/science/article/pii/S0277953615300034?casa_token=Xym_o3RJLVpMAAAAA:Ep-FSg-6edBH6z1LXJW_mqMIUcJ7QcbrZkrQR4htpj_teoggo3rTZUywu4541_uJNDzKoiz7g
- Volks, C., & Musungu, S. (2016). Building empathy by watching apologies: Perceptions of facilitators regarding bystanders and perpetrators. South African Journal of Higher Education, 30(4), 112125. https://doi.org/10.20853/30-4-677
- World Health Organization (2000). The implications for training of embracing: a life course approach to health. Retrieved Jun 5.2021 from: https://www.who.int/ageing/publications/lifecourse-training-en.pdf