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“I’m here and I’m going to do what I’m going to do”: What is an HIV Older?

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ABSTRACT

With advances in anti-retroviral treatment and the increasing ability to age well with HIV, the Indigenous People living with HIV and AIDS (IPHA) community needs culturally relevant interventions that are rooted in Indigenous perspectives of wellness. The concept of HIV Olders (Indigenous knowledge holders who have lived long-term with HIV) can address this gap at a critical moment in the HIV wellness discourse and uphold the principle of the *Greater Involvement of People Living with HIV* (GIPA).

This commentary shares learnings and teachings that are intended to introduce the concept of HIV Olders to the IPHA community. An Older is an IPHA who can weave their wisdom of living with HIV to support HIV wellness interventions, regardless of the physical settings and contexts in which people may live. HIV Olders recognize that being connected to land-based teachings is a key component of resilience, community connectedness, and individual recognition. An Older possesses self-compassion, an awareness of the history of the HIV movement, and is a steward of the HIV wellness journey. Their long-term perspective provides unique insights about changing trends, patterns, and behaviours that may not be apparent to someone newly diagnosed. HIV Olders have a key role to play in designing and delivering interventions that can support wellness specifically for IPHAs. The inclusion of HIV Olders in a wellness intervention respects the lived experience of their HIV journey, values peer-to-peer engagement, and honours traditional knowledge and ceremony as a path to optimizing wellness. Weaving the wisdoms of HIV Olders

to support the IPHA community provides an opportunity for cultural continuity to be a pathway towards greater holistic (body, mind, emotion, and spirit) and “whole”-istic health.

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INTRODUCTION

“If you were going to walk 100 miles how much are you going to carry? He wanted us to think of our mind, thoughts, and spirit. To learn to walk in one with our good thoughts and teachings, not those that weigh us down like conflict and anger.”

A teaching from an Older’s Grandfather

The project *Weaving Our Wisdoms: Using a Land-Based Approach to Optimize Whole-istic Health among Indigenous People Living with HIV* (the WoW Project) was initiated in the summer of 2017 and funded in February 2018. To date, there have been two in-person meetings of community members and researchers to explore links between land-based research methodology and interventions for Indigenous People’s well-being living with HIV. Knowledge sharing during the second meeting, a retreat at Koeye Lodge near Bella Bella, BC, helped to develop the concept of an HIV Older; Indigenous knowledge holders who have lived long-term with HIV (i.e., more than 10 years) who have the wisdom and experience to support HIV wellness for other Indigenous People living with HIV and AIDS (IPHAs). In a beautiful setting, dedicated to land-based healing, we began developing a deeper understanding of how HIV Olders have been leaders in the HIV community and how their knowledge and experience could support the HIV community, and more specifically IPHAs. During the retreat we discussed how Olders engage with newly diagnosed IPHAs to support their HIV-positive status through connecting with their culture and how they might optimize their HIV wellness journey with land-based healing interventions.

This commentary follows the cadence of our conversations that was guided by the study’s steering committee. Our three esteemed HIV positive knowledge holders coined the concept “HIV Older” and will be our guides over the course of this project’s journey. The conversations we had in Koeye centered on the HIV Medicine Wheel (a conceptual model developed by one of our Olders), reflected on the qualities an HIV Older would possess, and asked questions around the HIV Olders’ role in the IPHA community.



Figure 1. View from Koeye Lodge, Bella Bella, BC

HIV Older have an important role to play in advancing and supporting the GIPA (*Greater Involvement of People Living with HIV*) principles, specifically, but not exclusively, with the IPHA community. GIPA is an inclusionary principle that upholds the right of those living with HIV and AIDS to participate in the decisions that impact their lives and values the knowledge that comes from living with HIV and AIDS (McClelland, Guta, & Greenspan, 2018; UNAIDS, 2007). There is however, a gap in GIPA research as compared to social, behavioral, and biomedical literature related to HIV and AIDS, despite its benefits related to improved quality of care, health promotion and policy development (McClelland et al., 2018, p. 196). The WoW project is rooted in a recognition that there are social, cultural, and historical determinants unique to Indigenous communities that underlie the disproportionate representation of Indigenous peoples in the HIV positive community in Canada (Flicker et al., 2015; PHAC, 2014; Reading & Wien, 2009). Yet IPHAs continue to demonstrate strength in cultivating resilience and solidarity to advocate for the inclusion of the diverse Indigenous HIV voices in the broader GIPA and policy circles. Our HIV Older are leaders in this movement. By raising up their voices in this commentary, we hope to foreground the importance of HIV Older supporting GIPA by being IPHAs living well with HIV, while foregrounding the diverse experience of the Indigenous HIV community.

Teachings from the Whale Deck: Who is an HIV Older?

The following sections are conversational summaries that were shared during the retreat in the company of the WoW team, inclusive of curious ravens, eagles, whales, and trees among others that were seen to be teachers too.

- **Self-Compassion:** An HIV Older makes space for compassion for others and for themselves. They can recognize where someone has come from and what they have been able to overcome in their lives. They also acknowledge this in themselves.
- **HIV Stewardship:** An HIV Older is a steward of their HIV; this moves beyond accepting that they live with HIV. As one Older shared, "...if I'm a steward of my HIV, I can live longer ... if someone seroconverts, if they engage with care, then there is an opportunity to still live a good life..." Stewardship is about having the ability and knowledge to develop and help others establish a "Wellness Ecosystem"; an interconnected network that comprises medical services, social services, community, nature, and culture.
- **Resilience:** An HIV Older understands the history of colonialism, violence, racism, and stigma associated with being Indigenous and being an IPHA. By recognizing what has been overcome, an HIV Older embraces their resilience and advocates for those who cannot advocate for themselves.
- **Reconciled their HIV diagnosis with living life:** An HIV Older will have faced and reconciled their life living with HIV. One of the Olders shared that when they were first diagnosed, they were told to "... make arrangements, some people only made plans two weeks in advance, because they were not sure whether they would be around much longer than that". HIV Olders will realize "I'm here and I'm going to do what I'm going to do." They recognize that there is a long history from the early years of HIV and that the landscape can shift from a perspective of victimhood and blame to one of empowerment.
- **Honour Laughter:** An HIV Older honours laughter and knows the healing powers and medicine in laughter. Laughter follows humility, gratitude, and self-compassion—it is what "lets you laugh at the lousy, crazy shit in our lives!"
- **Have Transformed their Anger into Strength:** An HIV Older has acknowledged the different layers of anger they have experienced with their diagnosis and has come to understand how it can be used to inspire advocacy in their work.
- **(Re)storing and (re)storying:** HIV Olders have come to terms with their personal stories and are willing to share their experiences to help others. This may include their stories of HIV diagnosis and disclosure and the changes that accompanied them. For example, one of our Olders spoke about the grieving processes they went through when they let their addiction die and were no longer able to drink. Wellness journeys for Olders include connecting with their culture, which may mean the end of certain lives, lifestyles, and relationships. There is a grieving process through these transitions that needs to be acknowledged and honoured, and a recognition that death is not restricted to the physical body during these times.
- **Humble and Curious:** HIV Olders have humility and feel a responsibility to share their stories, knowledge, and wisdom, yet they acknowledge the reciprocity of sharing knowledge by maintaining a curiosity towards lifelong learning. This might include being engaged in research and policy making that supports building capacity within the IPHA community.
- **Practice Self-Care:** An HIV Older recognizes that care is multi-dimensional and includes having knowledge about medications, navigating the primary care network, and understanding the science of HIV. The biomedical elements of self-care co-exist with a holistic model of health that balances the mental, emotional, physical and spiritual elements of the person. This includes maintaining a connection to culture to nurture the soul, having community ties that provide support and strength, taking time out so that you "...don't get burned out being an advocate all the time".

Like the growth rings on a tree, each ring of an Olders' experience represents a period of growth along their journey. There may even be evidence of metaphorical fires like "...when suicide happened or when my dad died", but as each stage of growth continues, another ring shows "...how resilient [the tree] is because it's not broken yet."

Being an Eagle: What is the role of an HIV Older?

"As an Older, we see a lot, and sometimes those views help us recognize what we're doing; what we need to do."

HIV Older reflection from Koeye Lodge

The HIV Olders' long term perspective provides unique insights about changing trends, patterns, and behaviours that may not yet be apparent to someone newly diagnosed with HIV. Like the eagle, an HIV Older can fly above the storm and has an eagle eye perspective over the land; they see the tiny details but also the big picture. An HIV Older tells us, "...we can see trends because we're connected to community—we see where things are starting to happen that other organizations and medical practitioners might not even know...sometimes socialization things...sometimes we're first on the ground to hear certain things."

During the Koeye Lodge discussions, the Olders decided that the role of an HIV Older should be determined by those within the IPHA community. HIV Olders are "...knowledge keeper[s] of HIV, the history..., it's almost like being a witness...like when you witness a totem pole raising—now it's my responsibility to tell anyone that looks at that pole why it's there and what it represents. As a witness, that's my job". This job is a shared responsibility to pass this knowledge to future leaders and the larger community.

The vision shared by the HIV Olders on our steering committee is "to work ourselves out of a job". To do this, the HIV Olders' role must build capacity. Building and bridging capacity will help to ensure the Indigenous HIV movement always has IPHA champions, bringing fresh faces to advocacy, education, and leadership events. The HIV Older has a responsibility to pass on their knowledge to those who share the qualities outlined above – compassion, stewardship, resilience - so that IPHAs can walk along the HIV path from peace and acceptance to service and leadership. As Olders share the knowledge in their bundles with others "...these are the ones we're gifting this knowledge to... and... it will now become their responsibility to carry it."

The Path Forward: Walking with the Land

HIV Olders have a key role to play in designing and delivering interventions that are rooted in land-based teachings and that support IPHA wellness. The embodiment of land enables those living with HIV to connect with their ancestors as they navigate the HIV journey; knowing they are never alone. Land is health, land is medicine, land is family, land is identity, land is knowing. "The land is not only a physical space, it represents the interconnected physical, symbolic, spiritual, and social aspects of [Indigenous] cultures" (Wilson, 2003, p. 83). The essence of Indigenous knowledge systems is the connection to and engagement with "place". By this definition, there are as many Indigenous knowledge systems as there are places. It is a high-

context way of knowing that flows from being in relation to place, reaching beyond the physical location of where you plant your feet, permeating through to the identity of how you exist in the world (Mellor, 2018).

Given the diversity of Indigenous Peoples and their relationships to the land, it is crucial that interventions are context based including nation, geography, urban/rural/remote, and lifestyle-specific, so that we do not presume that a single or pan-Indigenous approach will work for all IPHAs. Therefore, the wellness approaches developed by the WoW research team and the HIV Olders will be designed and facilitated in a way that is relevant and transferable to IPHAs with diverse identities and belief systems.

CONCLUSION

The inclusion of HIV Olders as an intervention for supporting IPHA wellness respects the lived experience of the Olders' journeys, values peer-to-peer engagement, supports and advocates for GIPA, and honours traditional knowledge and ceremony as a path to optimizing wellness in an intervention. Weaving the wisdoms of HIV Olders to support the IPHA community provides an opportunity for culture to be a pathway towards greater holistic (body, mind, emotion, and spirit) and "whole"-istic health. The HIV Older is a living concept; one that will grow alongside our understanding of HIV, our resources available to support wellness living with HIV, and the reconnection to teachings about wellness through the land and through culture.

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