INDIGENOUS HIV LEADERSHIP: PRELIMINARY FINDINGS FROM A SCOPING REVIEW

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Conflict of Interest Disclosure

In the past 2 years I have been an employee of: **McMaster University and the Canadian Aboriginal AIDS Network**

In the past 2 years I have been a consultant for: **The Canadian Aboriginal AIDS Network and the Metro Vancouver Aboriginal Executive Council**

In the past 2 years I have held investments in the following pharmaceutical organizations, medical devices companies or communications firms: **N/A**

In the past 2 years I have been a member of the Scientific Advisory Board for: **Canadian Institutes of Health Research and the Waakabiness-Bryce Institute for Indigenous Health**

In the past 2 years I have been a speaker for: **Metro Vancouver Aboriginal Executive Council**

In the past 2 years I have received research support (grants) from: **Canadian Institutes for Health Research**

In the past 2 years I have received honoraria from: **N/A**

I agree to disclose approved and non-approved indications for medications in this presentation: **Yes**

I agree to use generic names of medications in this presentation: **Yes**

There are relationships to disclose: **No**

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BACKGROUND

- **Denver Principles** (1983)
  - Foundation for the self-empowerment and self-determination
  - Resists labels such as "HIV victims" (implies defeat) and "patients" (implies passivity, dependence, etc.)

- **Paris AIDS Summit** (1994)
  - Adopts and formalizes the Greater Involvement of Peoples Living with HIV/AIDS in all decisions affecting their lives

- **United Nation's Declaration of Commitment on HIV/AIDS** (2006)
  - 192 member states affirm their commitment to the Greater Involvement of People living with HIV/AIDS

BACKGROUND

- **Toronto Charter: Indigenous People's Action Plan on HIV/AIDS** (2006)
  - Indigenous peoples living with HIV (IPHAs) are involved to drive positive change
  - Offer a critical lens advocating for increased access to supports and services

- **Previous CAAN-led or CAAN-involved Research**
  - ***Living and Serving II (Cain et al, 2008)***
    - Stigma, disclosure, health status, the professionalization of services, decreased community activism
  - ***Sharing the Lay of the Land (CAAN, 2010)***
    - Three peer leadership models demonstrate some promise
      - One Foot Forward: A GIPA Training Toolkit (Canadian AIDS Society)
      - Positive Leadership Development Institute (Ontario AIDS Network)
      - First Nations Teaching Turtle (Manitoba Aboriginal AIDS Taskforce)

RESEARCH GOAL/OBJECTIVES

- **Rationale for GIPA Homefire**
  - IPHA involvement is central to the Indigenous HIV response
  - Need to mentor and support new leadership / those already involve carry heavy burden (at times, negatively impacting health/wellness)
  - Current GIPA models largely do not incorporate diverse Indigenous cultural contexts and may not "fit" well for mobilizing HIV-positive Indigenous leadership
- **Research Goal/Objective**
  - To develop a deeper understanding of GIPA through diverse Indigenous world views
    - Create a model of GIPA relevant to First Nations, Métis and Inuit peoples in Canada
    - Evaluate the impact health and well-being of GIPA on Indigenous persons living with HIV
    - Identify wise practices for the uptake of culture-based GIPA policy to support action to enhance the implementation of GIPA

METHODS

- **Methodological Approaches**
  - Community-based research design
  - Decolonizing and Indigenous methodologies
  - Principles of Two-Eyed Seeing

- **Method**
  - Arksey and O'Malley (2007) scoping review process
    - Stage 1: identifying the research question
    - Stage 2: identifying relevant studies
    - Stage 3: study selection
    - Stage 4: charting the data
    - Stage 5: collating, summarizing and reporting the results

SEARCH TERMS

People	Health Condition	Health & Wellness	Leadership
Aboriginal*	AIDS	Wellness	Lead*
Native	HIV	Well-being	"Authority Figure"
"First Nation"	HIV/AIDS	"Health Effects"	Overseer*
1st-Nation	"Acquired Immune	"Health Promotion"	"Front Runner*"
Inuit	Deficiency Syndrome"	"Health Benefits"	Front-runner*
Metis	"Human Immunodeficiency	Holistic	Trailblazer*
"American Indian"	Virus"	Wholistic	Pioneer*
"Native American"	"HIV Infection"	"Health Indicator*"	Innovator*
"Alaskan Native"	HIV-positive	"Social Determinants of	Pathfinder*
"Native Alaskan"	"HIV positive"	Health"	Advoc*
Indigenous	"Living with HIV"	"Wellness Model"	Negotiator*
	"Living with AIDS"	"Wellness Approach"	Helper*
	"Living with HIV/AIDS"		Intervener*
	"Living with HIV and AIDS"		Champion*
			Mentor*

Note: The asterisk (*) is a wildcard placeholder expanding the search term to include all derivatives (e.g., lead* for leads, or leader, or leaders)

DATABASES

Name	Results
JSTOR	45
Web of Science	74
EBSCO	47
Proquest	123
USASK iPortal	15
Native Health Database	9
Duplicates	60
TOTAL	**253**

INCLUSION/EXCLUSION CRITERIA

- **Inclusion**
  - Does the article have an exclusive focus on Indigenous peoples?
  - Does the article have an exclusive focus on HIV/AIDS?
  - Does the article include a focus on leadership?
  - Does the article discuss health/wellness?
- **Exclusion**
  - Is the article published in a language other than English?
  - Is the article published before 1990?

- **Results**
  - First level screening of article abstracts resulted in 16
  - Second level screening of full articles resulted in **12 articles for inclusion**

PRELIMINARY FINDINGS

- **Barriers to Leadership**
  - **HIV-related stigma** (Hatala et al, 2018; Monchalin et al, 2016a)
    - Fears of persecution, rejection, and/or discrimination
    - Representing the costs of HIV leadership, creates doubt about whether to assume a leadership role
    - May be internalized and impacts self-acceptance
    - Reluctance to disclose HIV-status in the context that includes a perquisite for leadership involvement
  - **Traditional Indigenous Roles** (Flicker et al, 2015; Monchalin et al 2016a)
    - Current leadership model reflect colonial understandings of power that destabilize traditional models of leadership
    - Few Indigenous models of traditional leadership / but needed
    - Involvement of Elders is essential in terms of need for mentorship

PRELIMINARY FINDINGS

- **Facilitators of Leadership**
  - **Transformation of identity / adopting a helper's role** (Piot et al, 2015; Sowell & Phillips, 2010)
    - Leadership often requires HIV disclosure
    - Able to advocate for culturally safe and health relational practices
    - Opens healthy dialogue focused on prevention, access to health services, and resisting HIV-stigma
    - Leads to a greater focus on community health as opposed to individual level experiences focused on the self, the need for disclosure, and HIV stigma

- **Features of Indigenous Leadership** (Flicker et al, 2015; Monchalin et al, 2016b))
  - **Elder involvement** provides wisdom, knowledge, ceremonial guidance to "selflessly serve their community" helping to bridge HIV research knowledge with Indigenous community values
  - **Youth involvement** is a foreword thinking strategy aimed at mentoring and building the next generation of HIV leadership / builds on the idea that "we are in the age of the 7th generation where youth will rise up and restore balance to the nations"

PRELIMINARY FINDINGS

- **Features of Indigenous Leadership** (continued)
  - **Confidence in Leadership Roles**
    - Inward journey of awareness of oneself
    - Transformed to connect with larger communal and political issue
  - **Humility in Leadership Roles**
    - Understanding that one's actions are intended to serve the larger community, rather than for individual gain
    - "… a good leader is not necessarily someone who is looking for a leadership title. Rather, the focus of a good leader should be on things that benefit the community, rather than themselves" (Monchalin et al, 2016a)
  - **Recognition of Traditional Indigenous Worldviews**
    - Leadership involves using ceremonial and traditional practices
    - Requires mentorship and resources

PRELIMINARY FINDINGS

- **Health Implications of Being in a Leadership Role**
  - Positive health impact of leadership (Greeff et al, 2008; Piot et al, 2015; Monchalin et al, 2016a; Monchalin et al, 2016b; Sowell & Phillips, 2010)
    - Reduces isolation while creating opportunities for social inclusion
    - Leadership leads to continued learning about what it means to live as a healthy Indigenous person (i.e., increased Indigenous knowledge, increased access to social support, knowledge that prevents HIV transmission, increased access to health care, etc.)

IMPLICATIONS/DISCUSSION

- Challenging HIV-related stigma
  - Training and education needed to combat
- Need for Elder Involvement
  - Requires uniting and drawing on the strengths of community grounded in the traditional values of "All My Relations"
- Need for training and mentorship opportunities grounded in Indigenous cultural values and ways of being