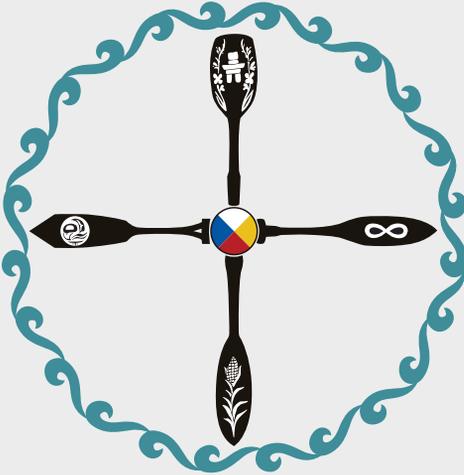


WELLNESS, IN THE CONTEXT OF ILLNESS



Alexandra King, MD, FRCPC
Simon Fraser University

World Indigenous Cancer Conference
Brisbane, QLD
April 14, 2016

I acknowledge the traditional owners of the lands on which we gather – the Jagara and Turrbal nations. I pay my respects to their Elders, past and present. I am grateful for the opportunity to visit such a beautiful place.

“Each man’s and woman’s liberty was absolute and inviolable. **A Nipissing came as near as possible to Rousseau’s perfect and ‘ideal man’.** He was untainted by civilization, did what he liked, and was moved only by natural impulses, and if, the Nipissing was not a free man and independent man, then there was no absolute freedom or independence on earth.”

– Jean Re collet in The Jesuit Relations



Desmond (Algonquin, Mattawa FN), Mary (Ojibwa / Mohawk, Nipissing FN) and daughter Mary (my mother)



Outline:

- Indigenous wellness research
- *Water Journey*: Indigenous peoples in Canada and hepatitis C
- Research methodologies



INDIGENOUS WELLNESS



5

Background



- IGIHM became interested in the Indigenous concept of wellness
- Collaborated with CIHR IAPH and FNHA to hold a Wellness Day
 - October 3, 2014
 - Unceded Coast Salish Territory (Vancouver, BC)



6

Purpose / Goals



- All Indigenous presenters exploring:
 - What is wellness?
 - Can we measure it?
 - If so, what can we do with this info?
 - ... for individuals, on their wellness journey
 - ... for health service delivery
 - ... for health system design
- Strong community voice



7

Wellness Day



- **Ann Broderstad** (NO): SAMINOR: Indicators and Resilience
- **Gail Garvey** (AU): Quality of Life and Wellness: Aboriginal and Torres Strait Islander Cancer Survivors
- **Felicia Hodge** (US): Wellness and "Un-wellness" in American Indian Communities: Predictors and Perceptions
- **Georgia Kyba** (CA): The FNHA Perspective on Wellness
- **Ted Mala** (US): Journey of Wellness
- **Gwen Phillips** (CA): Wellness from a First Nations Perspective: Moving from a Sickness System to a Wellness System
- **John Waldon** (NZ): Indigenous Health Indicator Frameworks and Measurement in New Zealand
- **Renee Williams** (AU): NACCHO: A living embodiment of the aspirations of Aboriginal communities and their struggle for self-determination
- **Asia Youngman** and **Gabriella Emery** (CA): the Cuystwi Online Youth Wellness Program

8

American Indians



- The concept of **wellness** encompasses more than just the absence of disease; it is the **balance** of one's body, mind and environment that together maintains good health
- **Illness** is seen as a **breach** of wellness practices and a **disruption** in living in balance



Alaska Natives

Vision

A Native Community that enjoys physical, mental, emotional and spiritual wellness

Mission

Working together with the Native Community to achieve wellness through health and related services



Māori



“All of the living organisms are important in maintaining balance in the natural world and therefore their presence, vitality and abundance are indicators of the wellbeing of the world.”

– J. Waldon

Māori

- 
- The mutually supporting walls of a house:
 - Family wellbeing
 - Spiritual wellbeing
 - Mental wellbeing
 - Physical wellbeing
 - These are interconnected through family relationships, the gifts from our ancestors, the wellbeing of the world we live in, and a place to call home.

Australia



Aboriginal health: not just physical wellbeing of an individual but the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their community.

It's a whole-of-life view and includes the cyclical concept of life-death-life.



Sami

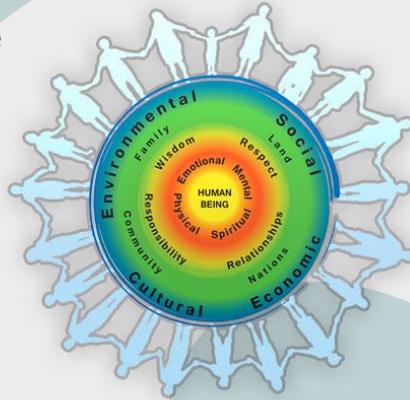


- Health is a resource and is wellbeing
- Good health is the possibility and capacity to manage all the inevitable problems, accidents and diseases every each of us meet during life
- Good health \neq absence of disease
- Good health = good ability to manage life



BC First Nations

1. Individuals, and their taking responsibility for their own health and wellness
2. Mental, emotional, spiritual and physical facets of a healthy, well and balanced life
3. Overarching values that support and uphold wellness – respect, wisdom, responsibility and relationships
4. The people that surround us and the places from which we come: nations, family, community and land
5. The social, cultural, economic and environmental determinants of our health and wellbeing
6. Strong children, families, Elders and people in communities, holding hands to demonstrate togetherness, respect and relationships



WATER JOURNEY: INDIGENOUS PEOPLES IN CANADA AND HEPATITIS C



The journey begins ...



Background:

- Indigenous peoples in Canada experience a disproportionately high hep C burden
- Issue must be framed within the context of historical and ongoing trauma
- Hep C treatment landscape changing dramatically
- Pressing need for hep C research agenda developed **by** and **for** Indigenous peoples

Purpose:

- Elucidate and explore culturally resonant approaches to aid Indigenous peoples in their journey of healing, wellness and self-empowerment
- Want Indigenous people to be able to take full advantage of the continuum of hep C care
- Develop a national research framework for Indigenous people in Canada and hep C



17

Research event (Vancouver, July 2015)



• Sharing circle example questions:

- What is your experience of being an Indigenous person living with hepatitis C? What have you learned that you can share for the benefit of others?
- How has your (male, female, two-spirit or transgender) Indigenous identity affected your healing journey?
- Have you encountered barriers in accessing treatment? Have you been able to navigate those barriers?

• Data analysis:

- Sharing circles were transcribed verbatim and analyzed qualitatively using a grounded theory-based approach in Nvivo 10©
- Six cross-cutting themes emerged from the collective discourse



18



RESULTS – MAJOR THEMES



19

Transformation



- Importance of finding purpose along one's healing journey
- A turning point, event, activity or cause which gave people a sense of purpose
- Unique for each individual
- Examples include cultural and spiritual involvement, volunteering, activism, providing support for others or a loved one



20



“And so, for me, hepatitis C treatment and hepatitis, believe it or not, and my HIV, actually saved my life, And I’m one of those people that will say I’m grateful.”

~ Women’s Circle 1

“[Hepatitis C] was a wake up call. A time in your life [to think about] what you do, what you want to be, what you want to do.”

~Validation Session 1



21



“I think that hep C diagnosis was a catalyst for me. Was a point of change for me. That I realized, like you said, that you didn’t ask for it. That there was only so much that my will could control. That there were things that were out of my control. And, that I could fight against it and only hurt myself further.”

~Women’s Circle 1



22



“But, I think what’s saving me right now is my spiritual journey and my roots. My original roots and my culture. The people who love me unconditionally and who support me.”

~Two Spirit Circle

“So, I started to learn culture and tradition, I started on my healing journey. I started to come out of the darkness and into the light.”

~Two Spirit Circle



23



“And so, I was volunteering at the time with women in recovery houses. And I realized when I spoke that my story motivated them. And they benefited from it. So, that was news to me, I didn’t know that I could influence people that way. So that became something I did.”

~Two Spirit Circle



24

Other themes



- Strength, resilience and hope
- Intersectionality
- Barriers across care continuum
- Conflicting priority of hep C
- Health literacy

25



RESEARCH METHODOLOGIES

26

Approaches



- Self-determination / decolonization / OCAP™
 - By us, for us
 - Indigenous research methodologies
- Two-eyed seeing
 - With allies, supporters, friendlies
 - Combining Indigenous Ways of Knowing and Western research approaches to gain a wholistic perspective



27

Ancestral wisdom



- Meaningful involvement of Elders
- Making research about ceremony
 - Smudging, tobacco protocol, song/dance/drumming
 - Feasting
- Incorporating wellness

“If you are bringing someone into darkness, you must leave them with some light.”

– Elder Sharon Jinkerson-Brass



28

Wellness ... for each person



Community wellness



Lax Xkeen



31

The Killer Whale



32

The Wolf



33

The Eagle



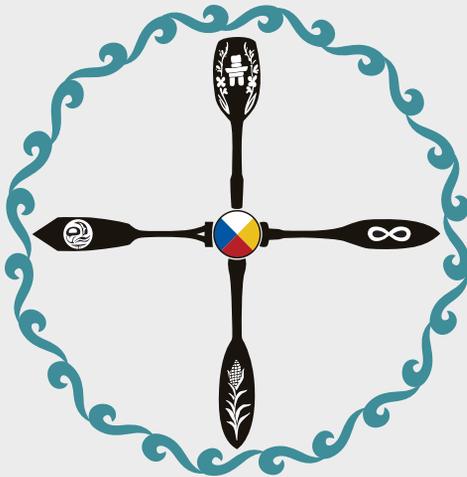
34

The Raven



35

MIIGWETCH!



I am grateful to the support of CIHR, the Michael Smith Foundation, the First Nations Health Authority of British Columbia, CanHepC and the CTN.

I also would like to acknowledge the Elders, the research teams, the contributors and the participants.

36