PROMOTING
INDIGENOUS WOMEN'S
HEART HEALTH
Lessons from Gatherings with Elders and Knowledge-Holders
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WHY WE NEEDED TO GATHER

THE PROBLEM OF HEART DISEASES IN INDIGENOUS COMMUNITIES

Heart disease is the leading cause of death among Canadians, but the burden is much higher among Indigenous peoples compared to other Canadians. Indigenous peoples are around twice as likely to develop cardiovascular diseases (CVD), are over ten times more likely to die from CVD, and experience heart attacks earlier in life than the general population.

The causes of CVD are complex as disease risk is influenced by social, economic, environmental, genetic and lifestyle factors. Known risk factors include poor diet, physical inactivity, stress, poor access to optimal medical care, elevated blood pressure and blood lipids, obesity and tobacco smoking. Nine in 10 Canadians have at least one risk factor. But, these single risk factors may underestimate true risk in Indigenous groups because each risk factor is more prevalent and there is clustering of multiple risk factors that then amplify the unequal burden of CVD. Importantly, there are also Indigenous-specific determinants of CVD risk that can vary across Indigenous communities which need to be considered.
THE IMPORTANCE OF FOCUSING ON INDIGENOUS WOMEN

Women’s heart health is generally understudied, and marginalised women are especially absent from Canada’s efforts to prevent cardiovascular diseases. According to a 2018 Heart and Stroke Foundation report, “Women’s hearts are victims of a system that is ill-equipped to diagnose, treat and support them”.

We know that women have different CVD risks and outcomes. Compared to men, women have a higher 1-year risk of dying after a heart attack, fewer women are diagnosed with CVD, and women show faster increases in obesity. There are also differences in terms of smoking and diabetes—both have a greater impact on women than men. We also know that the death rate from CVD is 76% higher in Indigenous women compared to non-Indigenous women in Canada, which represents a substantial unmet need for heart health promotion and disease prevention.

Indigenous women are one of Canada’s most vulnerable groups, and experience numerous convergent health threats from multiple forms of social and institutional discrimination based on both gender and Indigenous ethnicity among other statuses. That is, Indigenous women will have unique risk factors that contribute to their overall CVD risk. However, there is little research on the unique set of risk factors that matter most to the heart health of Indigenous women in BC or elsewhere. The plethora of unmet and poorly understood needs that exist with respect to Indigenous women and heart and brain health concerns range from prevention, diagnosis, treatment and care, medical and surgical management, institutional and community-based care, post-cardiac or stroke event recovery and rehabilitation, to cultural safety and competence of the healthcare system.

We wanted to fill the knowledge gap in heart health research and policy in Canada by explicitly focusing on Indigenous women as a unique vulnerable group. The unique contexts of Indigenous women’s lives call for more novel and integrated approaches to raise awareness and support CVD management. We employed a holistic perspective on heart health disparities of Indigenous women and on communicating heart health risk that is delivered in a culturally appropriate and respectful way.
We developed and fostered a new relationship between academic researchers and local urban Indigenous Elders to explore new ways to promote heart health among Indigenous women. Our goal was to partner with interested communities to develop an arts-based prevention program. We obtained a small grant to support stakeholder engagement as a first step to that goal. This stakeholder engagement is consistent with ethical practice for working with Indigenous communities as set out by the Tri-Council Policy Statement of Ethics, Chapter 9.

We hosted two gatherings in the format of a talking and drumming circle. Drumming is powerful in this context because: (1) it is a therapeutic agent that aims to reduce anxiety and post-traumatic stress; (2) it can be used as a tool for health communication; and it provides symbolic meaning for linking culture and health; and, (3) the beating drum is symbolic of the life-giving force of the heart; its spiritual, cultural and social meaning is found in all cultures around the world but has particular significance for Indigenous women, the heart beat of our nations.

A team of academic researchers (Dr. Annalijn Conklin, Dr. Jeffrey Reading, Dr. Karin Humphries and Rebecca Lee) met with Elders and Knowledge-Holders who live in the urban Vancouver area but come from diverse Indigenous communities across BC, including Coast Salish, Cowichan, Snuneymuxw, Squamish, Haida Gwaii, Tsleil-Waututh, Tla’amin (Sliammon), Tsimshian, Nisga’a, Gitsxaan, and Tzeachten First Nations. A representative from First Nations Health Authority (Dr. Unjali Mahotra) was invited and attended the first meeting and, the FNHA Chair in Indigenous Heart Health (Dr. Reading) was also involved in the project.

As first step to creating a new relationship, we opened up a dialogue to hear the voices of Indigenous women to explore heart health issues with a focus on the use of drumming as a method to communicate and improve heart health risk that is culturally safe and respectful. Insights gained from the 1st gathering led us to do an environmental scan of informational resources on heart health for Indigenous women that were available locally (e.g. cardiology departments in local hospitals, websites of relevant organisations). This work, along with regular advice from the Elders Advisory Council at the Vancouver Coastal Health Aboriginal Wellness Centre, led to our 2nd gathering where we could share-back the information that we had gathered and then identify priority actions for future collaborative projects. We used flipcharts and interactive methods for creative expression to capture new knowledge on Indigenous women’s unique needs, priorities, and capabilities.

“Drumming is powerful in this context.”

Our talking/drumming circles took place in Indigenous-owned venues and we provided two main meals catered by Indigenous-owned companies. We reimbursed participants for their travel and provided gifts of gratitude to our Elders and Knowledge-Holders. The drumming/talking circles were co-facilitated by Dr. Annalijn Conklin and Hazel Bell-Koski to follow Indigenous traditional knowledge and protocols, particularly the use of arts-based
creative expression activities. Annalijn is an academic researcher with a specialty in women’s health, social inequalities and chronic diseases, and Hazel is a professional artist and creative engagement expert from a local Indigenous organisation (IndigenEYEZ).

We wish to thank the I-HEART Centre and the BC Centre for Improved Cardiovascular Health (ICVHealth) for continued guidance and participation in this project. We especially thank the Michael Smith Foundation for Health Research (MSFHR) for the convening and collaborating (C2) award to help host these gatherings in a culturally appropriate way.
03 TALKING/DRUMMING CIRCLES

1ST GATHERING: UNDERSTANDING LIVED EXPERIENCES AND LEARNING FROM ELDERS

Held in the Chief Simon Baker Room in the Vancouver Aboriginal Friendship Centre Society on May 11, 2018 from 8 am to 4 pm.

The goal of the first gathering was to explore Indigenous women’s heart health by opening up a dialogue with Indigenous women Elders and Knowledge-Holders.

We met in talking/drumming circle for three reasons:

• To learn more about each other and build connections;

• To explore interest in an arts-based prevention program for women’s heart health; and,

• To discuss what are good ways to work together in a research project.

Elder Roberta Price graciously provided the opening and closing ceremonies.

Our day started out with a rain rhythm for grounding, introductions around the circle and a facilitated discussion of the goals of and agreements for the gathering, after which Dr. Annalijn Conklin shared her personal story.

Our first talking circle focused on Indigenous women’s heart health meaning, needs and priorities for communities, research and policy. After a break, our second circle looked at case studies of drumming for psycho-social health and Elders’ application of drumming, or other traditional practices, to promote heart health in Indigenous communities.

Following a lunch, our third circle centered on what are good ways of building a research partnership that align with First Nations principles of OCAP® (Ownership, Control, Access and Possession)—the set of standards that establish important ground rules about how Indigenous Peoples’ data should be collected and how information should be used.

The circle ended with a brief reflection on what was said and revisiting of goals and agreements and offering one word about how each was feeling in the moment. Dr. Conklin shared Hag Stones to all participants as symbolic gifts of a shared vision and reminder to keep this shared vision focused. She then led the group in a crescendo drumming of the heart beat rhythm.
2ND GATHERING: FEEDING BACK LEARNINGS AND BUILDING NEW RELATIONS

Held in the Spirit Room at the Native Education College, Vancouver, Canada, on December 16, 2018 from 10 am to 6 pm.

The goal of the 2nd gathering was to further build and strengthen new relationships and identify priorities for immediate collaborative actions.

Meeting in talking/drumming circle allowed us to:

- Share knowledge, disseminate available resources & new ideas for Indigenous material
- Learn a cultural teaching & experience music-as-medicine
- Discuss community interest to study issues related to Indigenous women’s heart health
- Raise any other issues
- Have fun together.

Elder Latash-Maurice Nahanee honoured us with opening and closing the circle.

We started our day with a rain rhythm for grounding, made introductions around the circle and had a facilitated discussion of the goals of and agreements for the gathering.

As a key objective of the 2nd talking circle, Dr. Conklin shared what was learned at the initial dialogue about concerns, needs and some strategies that were suggested for future action. Information was also shared that came from work done based on discussions at the 1st gathering. The environmental scan of available resources related to Indigenous women’s heart health (at local healthcare organisations and globally online) showed that there was very little information for patients or families. What was found was shared in a package of printed materials. This included the Diabetes Canada type 2 diabetes screening tool, a printed list of websites with resources for learning about heart disease, assessing...
your own risk, preventing poor heart health, accessing support after a diagnosis, and a heart healthy recipe for a low budget obtained from the healthcare system in the UK.

We then invited participants to learn a cultural teaching of rattle-making, led by Elder Marr. This arts-based activity was both an opportunity for personal ceremony and reclaiming traditional ways of knowing, and also a form of music-as-medicine since rattles are a common percussion instrument for Indigenous women to play at gatherings and in ceremonies across communities.

We started our day with a rain rhythm for grounding.

After lunch, we started again with a drumming-based activity using each person’s name and the collective singing of the Grandmother song that was led by Elders Roberta and Marr. Then the second half of the day involved two facilitated discussions. The first focused on practical suggestions that were made for creating an Indigenous women’s educational resource, and the second looked into what communities want to study first among the many needs and knowledge gaps, with examples of possible funding opportunities. We ended the day again with the heart-beat drumming and a statement of gratitude.
**Emotional domain of heart health**

A key issue that arose from the stories that were shared at the 1st gathering was the importance of the emotional domain of health. Several Elders described personal losses and spoke about Indigenous women having ‘heart sickness’, meaning trauma that manifests in disease because the heart is broken. Each one told their story of losing parents/grand-parents at a young age due to residential schools and this separation was a major source of inter-generational trauma. The forced internalization of anger, fear and rage was another source of heart sickness because residential schools did not allow Indigenous children to express emotion. The following quotes illustrate the important role of the emotional domain of Indigenous women’s heart health.

> There is heart sickness from losing children & parents

> Diabetes is the grieving of the blood from losing our children

> Are we grieving our cultural losses & passing our broken hearts to our children & grandchildren?

**Lack of safety in healthcare**

Cultural safety training of healthcare staff is pivotal to the heart health of Indigenous women. The stories of Elders revealed a shared experience of misdiagnosis and mistreatment by healthcare professionals. One Elder shared her story of being taken to hospital and being given antibiotics for what was assumed to be an infection when in fact she was having a heart attack. Despite insisting that the treatment was wrong, her concerns were dismissed and the misdiagnosis had serious consequences for her. Other stories of mistreatment and racism involved healthcare providers making assumptions about substance use (e.g. alcoholism) as the cause of illness rather than providing an adequate medical assessment, or forcing an Elder to be discharged and take a taxi home in the middle of the night because no family member could provide transportation despite the Elder expressing safety concerns due to a history of being assaulted. Cultural safety in healthcare also extends to food and nutrition, as one Elder described being forbidden by hospital staff from bringing traditional food like salmon for hospitalized community members.

**Education & awareness**

It was clear from the stories shared that there is a need for education and awareness to help support Indigenous women’s heart health. Many Elders spoke about how they wanted to know what is plaque and how it affects their bodies, and how they were not told how to care for their own bodies (e.g. nutrition, exercise) nor how to care for themselves. Some Elders had been diagnosed with heart problems, or had had a heart attack, but they were not told by their doctors how to live with the disease and this...
lack of knowledge contributed to their fear about the unknown and what could happen. This highlighted the importance and need for prevention conversations, or Indigenous women’s stories around health.

Once you have knowledge about the disease and prevention, you can alleviate the fear about it

Another common concern that was raised about education and awareness related to diet. Several women Elders described how they were not told how to eat differently after receiving diagnoses or being hospitalized after a heart attack. There is also a need for more knowledge in terms of how Indigenous communities can teach themselves to eat differently, how to make good food available and how to eat healthy under time pressures of busy lives. In the discussions about diet for CVD prevention, several Elders remarked that the modern diets among Indigenous communities in the urban environment are disconnected from traditional foods. Hunting moose and foraging for berries, for example, were examples of traditional food practices of the ancestors who previously led active lives and did not suffer from chronic diseases before about 100 years ago. High levels of physical activity are part of these food practices, and the role of physical activity for prevention was highlighted by one Elder’s story of giving her grand-son a Fitbit which inspired him to be more active to reach his 10,000 steps a day.

Food is integral to healing

Culture & ceremony as prevention

The passing on of traditional knowledge about healthy eating and the cultural practices of ceremony were described as important factors for preserving the health of Indigenous women and their communities. Several Elders shared stories about learning traditional practices of their ancestors from their own grandparents, such as foraging for plants and medicines, highlighting the importance of sharing knowledge across generations to preserve cultural knowledge so local urban Indigenous communities can stay healthy in several domains of health (physical, mental, spiritual). Discussions emphasized the traditional role and need for grand-mothers to teach grand-children and youth about cultural ways, songs, language and how Elders stayed active and healthy through daily activities of hunting and gathering, and dancing and drumming in ceremony. Many Elders stressed the value of ceremony for staying connected to their community and how participating in ceremony is healing. One Elder shared a story about preparing her grand-child for their coming of age ceremony and in the process brought together a group of other family members and relatives who were also coming of age. And, because the spiritual practice of coming of age ceremony involved the whole family/community, the Elder’s fear about their personal health melted away. Another Elder explained how she felt her heart speeding up when at home which made her fearful of having another heart attack, and then decided to
start drumming which eventually calmed her down. The centrality of the drum for wellness appeared to be self-evident and all women described using the drum in ceremony or for personal medicine.

Women’s caregiver role & self-care needs

The stories that Indigenous women shared revealed how their (gendered) role as primary caregivers is a unique risk factor for their heart health. As one Elder put it: “women are caring for everyone else, but who cares for the caregivers?”

In the context of residential schools and racial discrimination, Indigenous women have the unique experience of two types of embodied fear: the fear of putting oneself first as a woman plus the fear of having one’s children taken away by social workers by putting oneself first: “you cannot show that you are not looking after your children.”

Other stories of heart problems being left undiagnosed or given inappropriate treatment showed how Indigenous women were often not listened to by medical professionals. Girls’ heart health may be given even less attention because heart problems are assumed to be an older person’s problem. The personal story of one participant who developed rheumatic fever at age 3 and experienced heart problems as a child that were ignored by adults, demonstrated the importance of listening to one’s body and to one’s children about what their bodies are telling them. One Elder reinforced the importance of Indigenous women’s self-care for CVD prevention by using the analogy of airplane safety rules of taking care of yourself first and then your children: “when you are okay, your children will be okay.”

Women’s caregiver role can also negatively impact on their self-care and wellbeing because of social isolation. One Elder described how she stopped visiting family and friends because of having to care for her ill spouse who used to do the driving. This was contrasted with a few stories describing how a daughter or grandson helped an Elder with self-care such as eating a better diet after cardiac surgery or being encouraged to take a ‘me-day’. Thus, staying connected to community and having a support system of friends and family were important factors to support Indigenous women’s heart health, because “family is so important to self-care.”

Drumming is a powerful cultural tool to engage people in reclaiming their life and power to be well.
PREVENTION CONVERSATIONS
(KNOWLEDGE & INFORMATION)
- Booklet of personal stories of prevention (survivors, elders)
- Fridge magnet about heart health
- Elders teaching grandchildren about local medicines & foods, traditional practices

SELF-CARE
- Encourage women to take a “me-day”
- Drumming to calm feelings of fear; singing & dancing
- Doing physical activities that are fun (e.g. Nature walks)
- Participating in ceremony

COMMUNITY CONNECTION & CULTURE AS INTERVENTION
- Health groups or group foraging events
- Ceremony & storytelling can remove fear (coming together is healing)
- Develop a food co-op for wild meats & plants (collective food resource)
- Cooking together as a family / community

CULTURAL SAFETY IN HEALTHCARE
- Indigenous wellness building; safe healing spaces for native women
- FN liaison/patient navigator + staff training in hospitals
- Aboriginal diet plan
- Patient nature walks
- Patients making their own drums pre- & post-surgery (first one is for giving away, second is to keep)
PRIORITIES FOR INFORMATION RESOURCES SPECIFIC TO INDIGENOUS WOMEN

Having a relevant and directly applicable educational resource online was a priority so that Elders and community members could easily access and share the information with their relatives and wider networks. This could be in the form of a YouTube channel or a series of videos that give short clips with first-person stories about Indigenous women’s heart health. Having different perspectives (e.g. Elder, husband, daughter, nephew, etc) for the stories that cover issues related to before, during and after a heart attack. One of the stories could be about what are the signs of a heart attack for an Indigenous woman and could be told from the perspective of a grandson seeing his grandmother prepare for the preserving of the salmon. Another topic of interest is having a pharmacist talk about medications for heart conditions and how to manage these.

The previous suggestion of fridge magnets was also endorsed as a tangible way to support Indigenous women’s heart health, but the advice given was to keep it very simple with limited information such as only the local emergency number with 1-2 key signs for families to know when to call for help.

PRIMARY AREAS FOR FUTURE STUDY

Elders were asked what they felt was the biggest knowledge need, or the question they most wanted to have answered, for their community. Many spoke about their diets and wanting to know what their ancestors ate, specifically how they ate according to the seasons and how communities can return to traditional food practices before contact. One Elder answered with the research question: ‘what are our diets?’ Elders had observed that in their urban-based communities that there is a lot of fast foods, sugar and junk food being consumed. So, a second key research question is ‘how can we make our diets healthier?’ As described by the Elders, there are storage constraints from living an urban environment that raise the practical question of ‘How do we make room for more vegetables and berries?’

Another primary area for future research concerned patient care. Specifically, a key question raised was how to educate clinicians so that they speak “using plain language” and in a way that is not condescending. A second key question on patient care is to know ‘what are the many and varied symptoms of a heart attack in Indigenous women?’ so that clinicians can be more aware and be better at making a diagnosis.

We give our thanks to the many Elders and Knowledge-Holders who supported our engagement work to ensure that any future collaborations move forward in a good and respectful way.
What We Learned at the Gatherings
KNOWLEDGE MOBILISATION / TRANSLATION

A submission will be made to the REACH award competition from the MSFHR to support one of two potential projects that our gatherings identified as priorities for immediate action on education and awareness.

Indigenous women’s heart health videos

This small knowledge translation project will involve the co-development and co-dissemination of a series of first-person videos on Indigenous women’s heart health. As identified by Elders during the stakeholder engagement process, the videos will comprise first-person stories of the signs and symptoms, management, prevention, family support, and other aspects of Indigenous women’s heart health. The project will require ongoing consultation with and involvement of local Elders and community members to develop the content of each story, and identify the appropriate story-teller to ensure the stories told offer a wide range of perspectives. This project will add to and expand on the video recently produced by the First Nations Health Authority, called ‘Silent Killer’ about Grand Chief Akile Ch’oh Edward John’s experience of a silent heart attack. We will use videographers at UBC’s Media Relations Department and draw on the marketing expertise of the Squamish Nation and the First Nations Health Authority to promote the educational videos through networks and APTN.

Cookbook of traditional & low-budget meals in urban settings

This small knowledge translation project will involve the co-creation and co-publication of a cookbook to support healthy, low-budget eating for Indigenous women and families in urban settings. The cookbook will provide traditional ingredients and food preparation, with urban-specific substitutes. We will gather recipes from existing resources (e.g. Indigenous toddler cookbook and FNHA recipe cards), add to these and include a split section on foods specific for women’s nutrition and health. This project will predominantly involve working with Elder Marr who has expertise and experience in developing low-budget, traditional meals for urban Indigenous community members. We will seek additional advice and consultation with other interested Elders and community members with knowledge of traditional food practices.
KNOWLEDGE CO-CREATING / BUILDING

A proposal for a Project Grant will be submitted to CIHR’s Institute of Indigenous Peoples’ Health (IIPH) to support one of two potential research collaborations that our gatherings identified as initial priority areas.

Measuring the diets of urban Indigenous communities

This research project will fill the gap in knowledge about what local urban Indigenous community members are eating. Past dietary surveys have not focused on diverse Indigenous communities living in the Vancouver area and the Squamish Nation was not included in the 2008-09 data collection in BC for the national on-reserve First Nations Food, Nutrition & Environment Study. We will partner with Elders in the Squamish Nation and in Vancouver’s downtown clinics to adapt existing food frequency questionnaires to the local urban context, and to include pictures of example food items in electronic form to reduce literacy barriers.

Feasibility study of a new land-based wellness program

This implementation science project seeks to co-create a heart health wellness program involving ‘foraging walks’. We will partner with Elders from the Squamish and Tsleil-Waututh Nations to obtain land-use permission from respective Councils and to co-develop a short-term program led by interested Elders for community members to learn about ancestral foods and harvest traditional medicines (as appropriate). These ‘foraging walks’ offer a holistic and culturally appropriate approach to CVD prevention by combining cultural food practices with the positive health benefits of physical activity and being in nature. The research element of this collaborative project will by the evaluation of feasibility through systematic measurement of whether the foraging walks are doable, acceptable and affordable.
University of British Columbia Indigenous Women’s Heart Health
LIST OF WEBSITES AND RESOURCES SHARED AT THE 2ND GATHERING
LEARNING ABOUT HEART DISEASE

Women
• https://www.heartandstroke.ca/groups/women
• https://www.heartandstroke.ca/women/risk-and-signs

Indigenous peoples

ASSESSING YOUR OWN RISK
• Heart & Stroke Foundation: https://ehealthra.heartandstroke.ca/questions#ga=2.7427506.1819006954.1544749585-1943827915.1544749585
• Diabetes Canada: http://guidelines.diabetes.ca/patient-resources/am-i-at-risk

PREVENTING POOR HEART HEALTH
• https://www.heartandstroke.ca/get-healthy
• https://www.diabetes.ca/diabetes-and-you/recipes
• https://www.nhs.uk/live-well/eat-well/20-tips-to-eat-well-for-less/

Tip: Buy frozen. Frozen fruit and vegetables are underrated. They come pre-chopped and ready to use, are just as good for you (try to avoid those with added salt, sugar or fat), and are often cheaper than fresh varieties. Frozen vegetables are picked at the peak of freshness and then frozen to seal in their nutrients.

ACCESSING SUPPORT AFTER A DIAGNOSIS
Home Support / Adult Day Services / Caregiver respite
• https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost
• http://www.fnha.ca/what-we-do/nursing-services/home-and-community-care
Vancouver Campus
2329 West Mall
Vancouver, BC Canada V6T 1Z4
Tel (Directory Assistance) 604 822 2211

Okanagan Campus
3333 University Way
Kelowna, BC Canada V1V 1V7
Tel 250 807 8000