Relationship Building with Indigenous Patients and Elders through Sharing Circles to Inform our Exploration of Cancer Survivors' Barriers to Care

Final Project Report 2024



RESEARCH TO ADVANCE CANCER HEALTH EQUITY

University of Manitoba

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INTRODUCTION

Cancer is a growing concern among Indigenous Peoples in Canada.* Over the past several decades, we have seen concerning health inequities: rising incidence of some cancers that are stable or declining among non-Indigenous Canadians, patterns in which Indigenous Peoples are diagnosed with advanced cancers that could have been detected through routine screening practices, and higher cancer-related mortality rates [1-7]. Existing research has primarily focused on environmental or 'lifestyle' factors (such as smoking, nutrition), and socioeconomic factors (such as poverty), with little consideration of systemic and structural factors (such as colonialism, racism, political and economic structures) [8-10]. Moreover, research to date has privileged Western ways of knowing and deficit-based understandings of these inequities, with little consideration of Indigenous strengths, knowledges or perspectives.

BACKGROUND

In response to the Truth and Reconciliation Commission of Canada's appeals for research to be done with Indigenous Peoples [11], as a team of Indigenous and non-Indigenous researchers and healthcare providers, we wanted to work collaboratively with Indigenous Peoples diagnosed with cancer to better understand the reasons for these inequities and develop meaningful strategies to address them. As a first step, we sought to build culturally respectful relationships with Indigenous Elders and Knowledge Keepers (referred to as 'Elders'), cancer survivors, and their family and support persons to inform research priorities and develop a foundation for the co-design of future research projects.

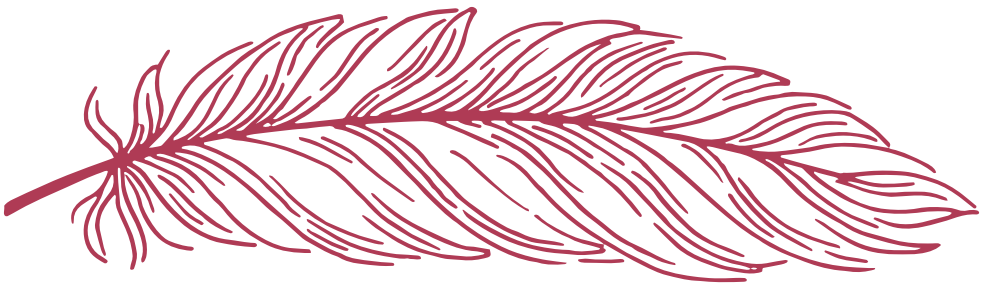
**In Canada, the term Indigenous Peoples is used to refer to three distinct groups: First Nations, Metis, and Inuit.*

OBJECTIVES

The objectives of our one-year engagement project were:

1. **To build culturally respectful relationships with Indigenous Elders and cancer survivors to partner with in future research studies.**

2. **To identify research priorities regarding access to cancer treatment and/or services among Indigenous Peoples.**



METHODS

Sharing circles can create a culturally safe environment that honors Indigenous perspectives and worldviews, and have been used for centuries among many Indigenous cultures [12-14]. Led by Indigenous Elders who function as spiritual leaders or guides, sharing circles provide a safe space to allow Indigenous participants to share their story of their personal journey with cancer, centering their unique experience/perspective/voice.

Through our professional and relational networks, we invited people who self-identified as Indigenous and had experiences of cancer or with the cancer care system (either themselves, or had supported a family member, community member, or friend). Over a fourteen month period, we planned and held four Elder-Led sharing circles in addition to a closing feast. Our initial sharing circle was held in person, and three additional circles were held virtually to accommodate people who were not geographically close, and/or who preferred a virtual circle while completing cancer treatment to lessen close contact with others. Some story sharers joined all four circles, and others chose to join only one circle.

All story sharers were invited to join a closing feast, where we shared a meal together. During the feast, themes from the four circles were shared back with story sharers, and Elder Mabel Horton led a time of reflection and sharing on these themes and next steps.



L-R: Florence Keeper, Wanda Phillips-Beck, Elder Mabel Horton,
Tara Horrill, Bobbie Hornan, Brenda Longclaws

WHAT WE HEARD

First Nations Understandings of Cancer

In First Nations languages, cancer is described as a bug or parasite that finds its way in, and attacks physical, mental, spiritual wellbeing. Story sharers described cancer as a spiritual experience, with cancer attacking how we think and feel. Story sharers talked about how cancer can be triggered by stress, unresolved grief, or negative emotions manifesting in the body. Story sharers also shared their perspectives on cancer being caused by changes in the environment, and how peoples' ways of life have been disrupted as a result of colonization and colonial policies. This includes the impacts of hydro dams and environmental degradation, water contamination, displacement from traditional lands, and changes in diet away from traditional land-based diets (fish and berries, for example). Story sharers also noted that in their younger years, they do not remember people in their communities either being diagnosed with or dying of cancer, but something has changed, and now their own friends and family are dying of cancer much more often.



WHAT WE HEARD

Access to Cancer Care & Barriers to Care

There are significant and persistent barriers to accessing care across the cancer continuum, including cancer screening, diagnosis, treatment, survivorship, palliative and end-of-life care.

Racism & Colonialism

At the root of inequities in access to cancer care are racism and colonialism. For example, the lack of cancer screening in First Nations communities stems from colonial federal policies related to health service provision. Moreover, the location of these communities in remote and isolated areas of Manitoba is itself a reflection of colonial and racist governmental policies.

Biomedical Model of Cancer & Cancer Care

A major barrier to accessing cancer care is the biomedical model of cancer and cancer care, in which cancer is seen as a biological and/or physiological disease, abstract from the whole person. This is problematic because cancer affects all parts of one's life, and is counter to Indigenous conceptions of health and cancer.

Use of Traditional Medicines

First Nations peoples are using traditional medicines more often, and there is a desire to use these alongside Western/biomedical cancer treatments. However, many are not using these until late in their cancer journey, and there are fears about telling healthcare providers about using traditional medicines. This prevents knowledge keepers and Elders from working with oncologists.

Lack of Indigenous-Specific Cancer Services in Manitoba

There are very few Indigenous-specific cancer services in Manitoba (i.e., services that are designed specifically by and for Indigenous peoples). There is a desire and a need for services that can include spiritual care, ceremony, and traditional medicines. Healthcare services generally, including cancer services, are delivered primarily in English, and rarely are able to accommodate people who do not speak English. As a result, people who do not speak English are excluded from care and care conversations.

Lack of Cancer-Specific Services in Indigenous Communities

Indigenous Peoples are often not able to access cancer-specific care in their own communities. Worse, their pain and other symptoms are not investigated, resulting in people diagnosed with cancer much later than they should be. There is also very little access to cancer screening services in most communities and people are not necessarily aware of what they should be doing in terms of cancer screening. In communities where cancer specific services do exist, people do not always know how to access them. Many people who live in Indigenous communities are required to travel, sometimes significant distances, to access cancer services, bringing many challenges with it.

WHAT WE HEARD

Perspectives on Future Research: Priorities for Research & Health Systems Innovations to Improve Access to and Experiences of Cancer Care

Across all four sharing circles, ideas and priorities for research were shared. These are summarized as:

1

Develop and implement Indigenous-specific cancer services in Manitoba, including:

- Indigenous cancer navigators
- Indigenous-specific cancer support groups and counselling
- Indigenous peer-support programs
- Traditional ceremonies and practices

2

Use storytelling to share the stories of Indigenous cancer survivors and/or Elders and Knowledge Keepers:

- Strengths-based with a focus on traditional knowledge and traditional medicines
- Focus on what makes people well and keeps people healthy
- Bring more awareness to Western healthcare providers and Indigenous cancer survivors

3

Improve cancer prevention education and cancer screening:

- Deliver educational programming in communities, by community members
- Leverage novel screening technologies that can be brought into community

4

Create a patient care advocate or navigator position in each First Nation community in Manitoba and ensure that these services are available in all five Indigenous languages in Manitoba.

5

Study the impact of colonization on cancer and cancer outcomes in First Nations communities, including the impacts of environmental and living conditions, and the impacts of loss and grief resulting from colonization.

CONCLUSION

In this one-year project, we aimed to build respectful relationships with Indigenous Elders and cancer survivors, and identify priorities for future research and collaboration. During our closing Feast, story sharers encouraged our team to continue building relationships with Elders, cancer survivors, community members, and Indigenous organizations with the goal of pursuing collaborative partnerships to co-lead future research projects. These story sharers also expressed a strong desire to share our work and describe our processes of engagement and relationships building more broadly – as an example of authentic relationship building and decolonizing research.

NEXT STEPS

1. Our research team will actively pursue building relationships towards the goal of a future co-led research project, addressing one or more of the research priorities identified.

2. Our research team and sharing circle story sharers will work together to share our processes of engagement and relationship building through academic publications, presentations, and public summaries for the public. These will be forthcoming, and freely available online through the REACHE website.



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Contact

REACHE Lab
Helen Glass Center for Nursing
89 Curry Place
Winnipeg, MB, R3T 2N2
204-480-1467

www.equityincancercare.com
reachelab@umanitoba.ca
@REACHElab
@reachelab

Academic Team

Tara Horrill, RN, PhD, Principal Investigator
Annette Schultz, RN, PhD
Kendra Rieger, RN, PhD
Marlyn Bennet, BA, MA, PhD
Lea Mutch, RN, MN
Gordon Buduhan, MD, MSc

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