

Summary Report

Atlantic Indigenous Mentorship Network Kausattumi Grants Program, 2021-2022
JENNIFER BENT, MASTER OF SCIENCE IN MEDICINE (COMMUNITY HEALTH)

Courage, Compassion, and Connection - The journey to healing: Exploring cancer pre-diagnosis for Indigenous peoples in Labrador

Description of Research

Cancer is the leading cause of death in Canada and the second leading cause of death worldwide. Previous research has highlighted that the rate of cancer is generally higher in non-Indigenous populations, however, recent findings have shown that the rate of cancer in Indigenous populations is increasing (Ahmed et al., 2015).

There are approximately 1.7 million individuals who identify as Indigenous in Canada (Statistics Canada, 2020). Various factors place Indigenous peoples at risk for developing poor health outcomes. Indigenous populations disproportionately experience poverty, poor living conditions, limited access to healthy foods, and low socio-economic status (Ahmed et al., 2015; Rahman et al., 2019). Individuals of lower socio-economic status experience greater incidence rates of cancer and lower survival rates following a cancer diagnosis.

Approximately 40% of all Indigenous peoples in Canada live on reserves, and about 14% live in remote regions (Statistics Canada, 2020). These regions report lower access to health care services compared to urban regions and may only be accessible by ship or airplane, making it more difficult to receive quality medical care, disease screening, and diagnosis (Cerigo et al., 2012). As a result, Indigenous peoples in Canadian provinces present with later-stage cancers at the time of diagnosis and are, therefore, more likely to die from cancer (Ahmed et al., 2015).

Disparities have been observed in cancer rates, stage of cancer when it is detected, and incidences of cancer between Indigenous and non-Indigenous populations in Canadian provinces (Ahmed et al., 2015). The Assembly of First Nations (2009) highlighted that in British Columbia, Indigenous women are diagnosed with breast cancer at later stages than non-Indigenous women. Elias et al. (2011) found that Indigenous peoples in Saskatchewan and Manitoba have poorer survival rates of breast cancer than non-Indigenous peoples. Additionally, the incidence of kidney and cervical cancer in these provinces is higher in Indigenous peoples. In this context Labradorians may also have similar health-care experiences to other Canadian Indigenous populations.

Approximately 30,000 people live in the remote region of Labrador and one third of residents identify as Indigenous (Alaghehbandan et al., 2010). Consistent with previous research, Indigenous communities in Labrador lack health care centres. Additionally, cancer patients from

Labrador lack cancer care services, therefore patients are often required to fly to Newfoundland to receive treatments and medical tests (Labrador-Grenfell Health, 2021). Also, Labrador hospitals can be difficult to reach due to poor road conditions, and weather, requiring individuals to be airlifted to the nearest hospital to receive medical assistance.

Despite the abundance of evidence highlighting that cancer is detected in later stages in Indigenous peoples, there is a lack of patient-oriented research that explicitly evaluates the cancer care experience of Indigenous peoples in Labrador. The objective of this study is to identify key challenges in the health care journey of Indigenous cancer patients living in Labrador and to develop and implement a plan to maximize use of instruments and/or resources to make their experience more seamless. That is, what challenges and solutions will cancer patients and survivors identify to improve the cancer care experience of Labrador's Indigenous cancer patients?

Procedure

The current study used a qualitative study design with culturally safe and appropriate research methods using sharing circles. According to Indigenous scholars, decolonizing research involves placing the voices of Indigenous peoples in the center of the research process (Datta, 2017). In a sharing circle all participants and the moderator are viewed as equal (Restoule, 2004); allowing for the discussion to be led by participants. Stories, experiences, information, and spirituality can be shared (Lavallée, 2009). Therefore, this method was deemed beneficial as it would allow for a deepened understanding of the experiences of Indigenous patients and survivors affected by cancer.

Following the identification of participants, the researchers and community contacts set dates in which sharing circles could be held in the community. Discussions were conducted in the English language, however, a translator was present and called upon if needed. Once a date was set, interviews were conducted by the Project Coordinator Kathy Michelin. They went over the consent process with participants and answered any questions. Interested participants provided written consent.

Participants took part in sharing circles and one-on-one interviews (if preferred) in their respective community that ranged between 10 minutes to an hour and a half. Sessions were audio recorded and transcribed by a Research Assistant from Memorial University. Participants were

invited to review transcripts and reports for accuracy. One sharing circle took place in each of the Labrador communities identified.

Kathy provided prompts to ensure the discussion was centered around cancer, such as, discuss your cancer experience, how you received a diagnosis of cancer, how long did it take after you started to experience your first symptoms of cancer did you receive a definite diagnosis of cancer, whether travel was required, and potential solutions that would make navigating the healthcare system simpler.

Data Synthesis Methods

Audio recordings and transcriptions of sharing circles were reviewed independently several times by two Dr. Shea and myself. This allowed us to become familiar with the interview content and to assign preliminary codes to describe data content. A search for patterns and themes was then conducted across different interviews and similar text fragments were assigned codes. The frequency of codes between each sharing circle session was tracked and common themes relating to the Indigenous cancer patient experience were identified and combined to accurately depict data. The Primary Investigator (J. S.) reviewed and determined the final list of themes. I quantified the number of themes from each respective community. Dr. Shea then completed a final report that identified which themes made meaningful contributions to understanding what the data means. In September 2022, myself and Dr. Shea travelled to Labrador to connect with Kathy and the Indigenous partners to discuss the identified themes in an effort to reduce bias and ensure themes were accurate.

Research Outcomes

This study will pinpoint key problems and areas for improvement in the pre-diagnosis phase of a cancer journey for Indigenous peoples in Labrador and make it easier for governments, policy makers and health-care providers to step in and take action to address identified issues. It is expected that participants will discuss challenges related to cost, travel, wait-times, delay of diagnosis following first symptoms experienced, and poor coordination of care during the pre-diagnosis phase of their cancer journey. Further, it is expected that participants will provide suggestions on how to improve the pre-diagnosis phase of cancer to make navigating the healthcare system simpler. From this information, tools, resources, and cultural safety training sessions for health care professionals will be developed by the research team to support the patient experience and healthcare services in Labrador.

Knowledge Sharing

- In September of 2022, Dr. Jennifer Shea and I travelled to Happy Valley Goose-Bay to connect with community liaisons and gather feedback on the current study and knowledge translation tools that have been developed.
- A presentation was completed by Dr. Shea and Kathy Michelin and discussion took place regarding main findings from prior sharing circles.
- Feedback from community members was transcribed by myself (J.B) and major themes were discussed.
- Community members felt that our results to date were accurate.
- Resources and tools that were developed by the research team including infographics displaying health information and study findings, as well as maps depicting travel time and costs to arrive at hospitals, clinics and care centres throughout Labrador were discussed.
- Feedback from community members was noted and changes will be made to the tools created.

Completed Project Deliverables

- Ethics Proposal Approved (Summer 2021)
- Participant Recruitment (Winter 2021)
- Participant Information Session (Winter 2021)
- All Graded Masters Course Work: Introduction to Community Health 91, Epidemiology 90, Community Health Research Methods 87, Graduate Research Seminar (December 2021)
- Critical Theory in Health & Society -87, Advanced Qualitative Methods - 84, Disease and Injury Prevention – 89 (April 2022)
- Report writing (1/4 completed; February 2023)
- Trip to Happy Valley-Goose Bay to reconnect with community liaisons and participants regarding the project (September 2022)

Forthcoming Project Deliverables

- Data Analysis (Anticipated before January 2023)
- Report Writing and Defense Preparation (September 2022- August 2023)
- MSc Defense (Anticipated before August 2023)
- Submit Master's thesis for Publishing (Anticipated before September 2023)
- Trip to Labrador to report back to the community with findings and to receive feedback (Anticipated before January 2024)

Activities Outside of Your Research

- Awarded Gold Duke of Edinburgh Award (March 9th, 2022)
- Graduate Assistant - Centre for Rural Health Studies, Faculty of Medicine (Memorial University of Newfoundland; MUN) – 2021 to Present
- Presenter at NAPCRG's 50th Annual Meeting: 'Building a Learning Health Care Community (LHCC) in rural and remote areas to support research and healthcare' – November 18-22, 2022 in Phoenix, Arizona
- President of the MUN's Medical Graduate Student Society

- Founder of Strikers Star Development Program – Conception Bay South (CBS) Soccer Association
- Graduate Student Advisory Committee Member - Student Representative (2021-Present)
- Volunteer Research Assistant for MUN's Behavioral Medicine Laboratory
- Volunteer Advanced Medical First Responder with St. John Ambulance
- Volunteer Soccer Coach for the CBS Soccer Association
- Completed National Coaching Certification Program – Coaching Athletes with a Disability Training (May 25, 2022)

Future Research Plans

I aim to apply the skills I have learned from my Bachelor of Science Honours degree to the current project and submit a thesis as a part of the Master of Science in Medicine (Community Health) program. I want to connect with Indigenous peoples in Labrador and around the province and learn about the challenges they face with regards to their health care and well-being. From there, I want to be able to work with them to help improve their health care journey and eliminate existing barriers. Results from this project will be used to make changes and/or additions to resources as identified. Research will be shared with the community and stakeholders as it becomes available as well as other jurisdictions at various points of the project. We will also facilitate knowledge translation activities.

My academic goals include completing the Master of Science in Medicine (Community Health). I plan to use the knowledge I will gain through the courses offered in the Master of Science in Medicine (Community Health) and lessons learned from Dr. Jennifer Shea to continue conducting research on Indigenous health in the future. My long-term goal is to become a physician that also completes research on topics related to Indigenous Health.

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