

Summary Report

Atlantic Indigenous Mentorship Network Kausattumi Grants Program, 2022-2023

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Courage, compassion and connection, and the journey to healing: Exploring cancer pre diagnosis for Nunatsiavut Inuit

Description of Research

Purpose: The current project sought to address a lack of patient-oriented research that evaluates the cancer care experience of Inuit peoples in Nunatsiavut, Labrador. The Nunatsiavut Government identified the pre-diagnosis cancer journey for Inuit patients, families, and health care providers as a research priority. This thesis explores the challenges in the pre-diagnosis cancer journey for Inuit in Nunatsiavut and recommendations to improve their pre-diagnosis journey.

Objectives: The research question guiding the study was: What challenges and solutions will cancer patients and survivors identify to improve the cancer care experience of Nunatsiavut cancer patients? The objective of this study was to identify key challenges in the pre-diagnosis journey of cancer patients living in Nunatsiavut and to develop and implement a plan to maximize use of tools and/or resources to make their experience more seamless. Improvements in the coordination of care during the pre-diagnosis cancer journey and enhancements to information sharing will advance the patient care priority area.

Research Setting and Context: The majority of Inuit in Canada live in Inuit Nunangat, which is the arctic homeland consisting of four Northern regions. One of these regions is Nunatsiavut, Labrador. The remote region of Labrador has been the home of Indigenous peoples for centuries. There are three main Indigenous groups in Labrador: the Nunatsiavut Inuit, the NunatuKavut Inuit, and the Innu. The Inuit of Nunatsiavut primarily live in Nain, Makkovik, Rigolet, Hopedale, and Postville, Labrador and are represented by the Nunatsiavut Government. The Nunatsiavut Government identified the journey one must undergo to receive a diagnosis of cancer in Labrador as a research priority. For the purpose of this thesis, project findings were focused on Nunatsiavut communities.

My relationship to the research: I am an Inuk who currently lives in St. John's, Newfoundland and Labrador. My family's roots are within the Nunatsiavut regions of Labrador. My education and research background piqued my interest in wanting to work to overcome existing barriers in healthcare and to improve the well-being of individuals of this province. Also, I had known about the poor healthcare experiences my family members who currently live in Labrador had endured. I wanted to transition to my key interest of working on health issues related to

Indigenous health in my province. I learned of Dr. Shea's extensive research background on health services for Indigenous communities, as well her long-term and strong relationships with Indigenous communities. After connecting with her, she offered me the opportunity to be involved with a few Indigenous focused projects, and after mentioning the current one, I jumped at the opportunity. In my role as a Master's student, I analyzed data and summarized findings, and completed a thesis focused on this project.

Methodology and Research Methods: I used a theoretical framework that drew on several theoretical and methodological frameworks including a decolonizing methodology, patient-oriented research, and community-based participatory research (CBPR). These approaches have been used in prior research involving Indigenous groups, and they were deemed culturally appropriate by the project Steering Committee members. The current study used a qualitative design to investigate the pre-diagnosis journey for Indigenous cancer patients from Nunatsiavut. Data was collected through a series of sharing circles and interviews conducted in Nunatsiavut.

Timeline: My thesis was submitted to the School of Graduate Studies at Memorial University of Newfoundland in the summer of 2023. I plan to submit an article or two to be published based on the completed research by August 2024.

Research Outcomes

This project was Indigenous-led and involved a partnership with Memorial University. Thirty-two participants took part in the study. Sharing circles and interviews were completed to engage cancer patients, survivors, family members, and healthcare workers to explore the challenges and opportunities in the cancer journey for Nunatsiavut community members.

Six core themes emerged from the discussions:

1. Access and Supports. Access and Supports included discussion around healthcare service and provider access, as well as the availability of resources related to cancer, and knowledge of the pre-diagnosis journey.
2. Prolonged Investigation. This theme was used to describe conversations on the length of time and the amount of effort that it took to receive a diagnosis of cancer.

3. Travel. The Travel theme was used to describe conversations related to the method of transportation and the distance required to commute to medical appointments. Also, this theme covered reflections on participant experiences associated with these commutes.
4. Communication. Communication was used to describe experiences of verbal and non-verbal interactions with healthcare providers, as well as their comprehension of language used by healthcare providers.
5. Fear and Anxiety. Fear and Anxiety was used to describe instances where patients spoke about their fear or anxiety for experiences related specifically to the pre-diagnosis journey (i.e., fear of traveling alone to receive a scan).
6. Being your own Health Advocate. Being your own health advocate was used to describe participant experiences where they advocated for themselves in the healthcare setting, or when they encouraged others to advocate for themselves.

The results demonstrated that the most important themes to target improvements in the patient experience are ‘access and supports’, and ‘prolonged investigation’. Individuals from all five communities discussed topics that fell under these themes. Outcomes of this research included recommendations to improve the pre-diagnosis journey such as: 1) Cultural Safety training; 2) Education and Resources on Cancer; 3) Increased awareness of Navigation Services; 4) Enhanced Mental Health Services; and 5) Support Groups.

Knowledge Sharing

- In September 2023 a one-day gathering was held in Happy Valley-Goose Bay with several community liaisons, representatives from the Indigenous groups, and Steering Committee members. At the gathering the results from the current project were presented and a roundtable discussion followed. Feedback was provided from all attendees, and they affirmed findings were an accurate representation of their community perspectives.
- Poster Presentation – Research Day, Faculty of Medicine, Memorial University March 24, 2023
- PowerPoint Presentation – Community Health Research Methods, Fall 2021

Completed Project Deliverables

- Thesis submitted to the School of Graduate Studies in the Summer of 2023.

Forthcoming Project Deliverables

- Publish an article or two based on the completed research.
- Present at an Indigenous Health or Cancer Conference

Activities Outside of Your Research

- Volunteer as President of the MUN Medical Graduate Student Society
- Research Assistant – Centre for Rural Health Studies, Department of Family Medicine, MUN
- Patient Partner: Surgeon – An Emergency Department Surge Management Platform, Centre for Rural Health Studies, MUN
- Ambassador Committee Member and Advanced Medical First Responder with St. John Ambulance
- Volunteer Soccer Coach with the Conception Bay South Soccer Association
- Graduate Studies Advisory Committee Member

Future Research Plans

My short-term research plan includes publishing a paper on the current project and to present this research at a conference. I hope that our research findings can be shared to larger audiences and to health care workers and leaders within the province of Newfoundland and Labrador. My long-term research goals are to continue doing research throughout the MD program at Dalhousie University, and into my career on topics of Indigenous health and health inequities. My aim is that the research I am doing will have a positive impact on the health of others.