



Research Report

Needs Assessment by Service Providers for Indigenous Cancer Supports in Saskatchewan

Dr. Gary Groot
June 2020





1.0 Introduction

In spring of 2017, a research team which included Indigenous patients with cancer, researchers, clinicians, policy makers and Principal Applicant, Dr. Gary Groot, received funding from the Saskatchewan Health Research Foundation and the Saskatchewan Centre for Patient Oriented Research to conduct a needs assessment. The aim of the multi-method study, *Sâkipakâwin: Assessing the Support Needs for Saskatchewan Indigenous Cancer Patients and their Families*, was to assess the support needs, both formal and informal, for Indigenous peoples' cancer care as they journey through the health care system. Formal supports were defined as within the framework of organized, paid, professional work, while informal supports were considered as outside the context of organized, paid, professional work. Our ultimate aim was to propose novel patient and family centered interventions that can address those needs.

This study included a four-phase approach:

- 1) Gathering patient, family and service provider perspectives,
- 2) An environmental scan, including key informant interviews,
- 3) A survey of First Nations and Métis communities, and
- 4) Community feedback.

As part of the first phase of the assessment, this report provides a brief description of the perspectives of twenty Saskatchewan cancer care providers. All participants provided inpatient cancer care in three healthcare facilities in Saskatchewan—the Community Oncology Program of Saskatchewan-Prince Albert (PA-COPS), Allan Blair Cancer Centre (ABCC) in Regina, and the Saskatoon Cancer Centre (SCC).



2.0 Study Purpose

The purpose of the main study was to address the following objectives:

- a) To determine how Indigenous people in Saskatchewan understand cancer,
- b) To identify the current status of Indigenous cancer care support in the province,
- c) To detect Indigenous cancer care service gaps,
- d) To assess the cultural responsiveness of cancer services,
- e) To determine how the Saskatchewan Cancer Agency (SCA) and other cancer service providers are working with Indigenous communities, and
- f) To establish cancer service priorities of Indigenous people and communities.

Once these needs-based interventions are implemented and evaluated, the long-term impacts of this research will be an improvement in the quality of cancer care for Indigenous people in this province as well as the provision of seamless patient care. The purpose of this report is to share the results of the service provider interviews with the Saskatchewan Cancer Agency.

2.1 Method

With assistance from the Director of Clinical Research at the Saskatchewan Cancer Agency, two researchers from Dr. Groot's team facilitated the group interviews at two of the three locations—ABCC and SCC. Connections were made to the PA-COPS by one of the study's Patient/Family Advisors to conduct the final group interview.

Cancer care providers such as nurses, social workers, nutritionists, administrators, and patient navigators were invited to participate and signed consent forms. The discussions were guided in a semi-structured manner (see Appendix for interview guide), providing freedom for the participants to respond and ensuring everyone had an opportunity to speak.

Interviews were audiotaped and then transcribed by University of Saskatchewan Social Sciences Research Laboratories. The interviews took 60 to 90 minutes. The transcripts were analyzed using content analysis.

3.0 Findings

First, we asked participants how they identify their clients as Indigenous. Their responses were:

- Patient's self-identification – identify themselves as Indigenous
 - Patient provides their treaty number or travel clinic flag in medical chart
 - Provider asking directly – intention is for cost coverage
 - "Personal observation" – assumption based on appearance, the last name or address
-

3.1 Perceptions of Existing Formal and Informal Supports

Formal Supports

Patient Navigators

- Available to both Indigenous and non-Indigenous cancer patients
- Helps the patient navigate the treatment process as well as provides emotional support
- Assists in answering non-medical questions, may set-up appointment at cancer clinic, lodging, and support person if any
- Guide the patient through admitting to a cancer unit

Non-Insured Health Benefits Program

- Available to First Nations

Palliative Care

Informal Supports

Culturally-relevant Health Supports

- Eagle Moon Health Office (Regina): Healing lodge guided by knowledge keepers; offers consultants and safe space for traditional healing or spirituality

Community Support

- Family
- Elders

Transportation

- Medical transportation to get to appointments (depending on community)



3.2 Perceptions of Challenges & Barriers

1. Communication/logistics

- Inadequate communication and logistical supports such as phone, internet, telehealth
- Medical literacy, language barriers, and understanding of cancer
- Transportation and lodging – coverage of certain expenses and coordination of care for travel, medical taxis not ideal for many patients
- Inconsistency between patient and health care provider information
- Call center issues - difficult to communicate time constraints for appointments, if appointments get missed, patient wait time is lengthened
- Lack of communication between oncologists and northern GPs – with continuous rotations of doctors. In northern facilities – difficult to maintain continuity of care

2. Socioeconomic

- Precarious finances - patients unable to pay up-front costs
- Inconsistent or confusing navigation of a complex funding system - funding structures between communities / bands
- Need to advocate certain FNHI coverage
- Companions not always covered
- Lack of Indigenous representation in staff, procedures and centers or unfamiliarity with the system
- Lack of streamlined healthcare accessibility or limited access to HCPs

3. Psychosocial

- Value system differences between patients and HCPs
- Concomitant traditional health practice difficulties from both sides (patients and HCPs)
- Recognizing spirituality
- Psychological / emotional Barriers
- Biomedical / disease processes
- Differences in “perception of illness”
- Lack of continuity of care between home community and treatment center

4. Sociopolitical

- Mistrust of government and services
- Misunderstanding/apathy/racism in the general population
- Predisposition to poor health from colonization and marginalization
- Navigating a complex, fragmented, multi-jurisdictional healthcare system

3.3 Recommendations for Indigenous Cancer Supports

Challenge/Barrier	Recommendations of Supports
Psychosocial	<ul style="list-style-type: none"> • Value system differences between patients and HCPs • Concomitant traditional health practice difficulties from patients and HCPs • Recognizing spirituality • Psychological/emotional Barriers • Biomedical/disease processes • Differences in "perception of illness" • Lack of continuity of care between home community and treatment center
Travel	<ul style="list-style-type: none"> • Indigenous safe lodges to address issues on travel and accommodation. This requires: <ul style="list-style-type: none"> -Respect of culture -Safe travel options from FN communities -Increase travel coverage allowance • Improved continuity of care
Health Care Support	<ul style="list-style-type: none"> • Hire First Nation/Metis representatives for workforce representation and to provide support/services. Currently, no one is employed by the SCA in this role • A role in advocacy, cultural connection and support; few "available", but very busy • More referrals to FN health services with greater capacity, prefer an SCA-specific service • Make patients aware that advocacy is available • More services available at home such as line care • Crash course for nurses on chemo/cancer education to reduce referrals back to treatment center • Consistent employees that are good advocates and can create ties to community • Need monitoring and accountability to notice patterns of healthcare use
Communication & Logistics	<ul style="list-style-type: none"> • Improve telehealth implementation • Translation of available written resources into prevalent languages (Cree, Dene) • Cancer center materials (e.g., pamphlets) into Indigenous languages • More than one "token Aboriginal" to support translation services • Improving Call Support • Simplify the referral of results
Community Care	<ul style="list-style-type: none"> • Incentives to ensure continuity of care in remote communities • Better procedures for transmitting care plans to home community • Continue to cover all supplements (e.g., Ensure) • Simplify the referral of results

4.0 Conclusion

Although there are formal and informal support that the province's health care system provides to cancer patients from cancer diagnosis to treatment, Indigenous peoples still encounter challenges to access cancer care support. The service provider participants identified some gaps and offered some insights to improve Indigenous cancer patient care.

This study offers a way to continue the conversation in addressing the challenges and connect with the proper solutions in providing the support that the Indigenous cancer patients and their families need. The results of the complete needs assessment will be available to each community for use in community planning.

Acknowledgements

This research report is a product by the Sâkipakâwin research team: Gary Groot, Tracey Carr, Terri Hansen-Gardiner, Sylvia Abonyi, Lorna Arcand, Eugene Arcand, Julie Stakiw, Gabe Lafond, Veronica McKinney, Ray Deobald, Tania Lafontaine, Raymond Laliberte, Corey Miller, Darren Okemaysim, and Bruna Bonavia-Fisher.

Appendix 1: Group Interview Questions

1. How do you know when your patient is Indigenous?
2. What formal supports exist in your workplace for Indigenous patients?
 - At the time of diagnosis?
 - During treatment?
 - What aftercare/follow-up services are available?
 - How effective or helpful are local formal supports?
3. What informal supports (e.g., Elders, homecare workers, lay-counsellors) exist in your workplace for Indigenous patients?
 - At the time of diagnosis?
 - During treatment?
 - What aftercare/follow-up services are available?
 - How effective or helpful are local informal supports?
4. From your point of view as (ask for person's position), what do you think your workplace needs regarding formal supports for Indigenous patients with cancer and their families?
 - Around the time of diagnosis?
 - During treatment?
 - What aftercare/follow-up formal supports are needed in your community?
5. From your point of view as (ask for person's position), what do you think your workplace needs regarding informal supports for Indigenous patients with cancer and their families?
 - Around the time of diagnosis?
 - During treatment?
 - What aftercare/follow-up informal supports are needed in communities?
6. From the formal support needs you have identified, which ones are the most important to improve Indigenous patient care and family experiences?
7. From the informal support needs you have identified, which ones are the most important to improve Indigenous patient care and family experiences?
8. When it comes to formal supports, what barriers or obstacles affect their usefulness?
9. When it comes to informal supports, what barriers or obstacles affect their usefulness?
10. Do you have anything else you'd like to add about the cancer care needs of Indigenous patients in your workplace?