


# “Breaking the Silence” to Improve Cancer Survivorship Care for First Nations Peoples: A Study Protocol for an Indigenous Knowledge Translation Strategy

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## Abstract

There is a significant knowledge-to-action gap in cancer survivorship care for First Nations (FN) communities. To date, many approaches to survivorship have not been culturally responsive or community-based. This study is using an Indigenous knowledge translation (KT) approach to mobilize community-based knowledge about cancer survivorship into health-care programs. Our team includes health-care providers and cancer survivors from an FN community in Canada and an urban hospital that delivers Cancer Care Ontario's Aboriginal Cancer Program. Together, we will study the knowledge-to-action process to inform future KT research with Indigenous peoples for improving health-care delivery and outcomes. The study will be conducted in settings where research relations and partnerships have been established through our parent study, *The National Picture Project*. The inclusion of community liaisons and the continued engagement of participants from our parent study will foster inclusiveness and far-reaching messaging. Knowledge about unique cancer survivorship needs co-created with FN people in the parent study will be mobilized to improve cancer follow-up care and to enhance quality of life. Findings will be used to plan a large-scale implementation study across Canada.

## Keywords

PAR, participatory action research, action research, arts-based methods, community-based research, photovoice

## What Is Already Known?

Advancements in cancer survivorship care show that holistic approaches tailored to specific needs can increase survival rates and enhance the quality of life for people with cancer. However, interventions predominantly target White, urban, middle-class people, and not much attention has been paid to the cancer survivorship needs of Indigenous people.

## What This Paper Adds?

The current study addresses the unique survivorship needs of indigenous peoples. Its overall goal is to improve cancer survivorship for First Nations (FN) people and to understand the process of translating knowledge into health-care practices and community-based programs with Indigenous people.

## Background

Cancer incidence rates among FN people are increasing faster than overall Canadian rates (Canadian Partnership Against

Cancer, 2009; Cancer Care Manitoba, 2008; Health Council of Canada, 2005). Late stage diagnosis, high rates of comorbidities, increased risk factors, and lack of survivorship supports are contributing to poor health outcomes and lower 5-year survival rates when compared to non-FN peoples (Cancer Care

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Manitoba, 2008; Kewayosh et al., 2015; Marrett & Chaudhry, 2003). Broad determinants of health, including poverty, geography, continued discrimination, and lack of access to basic health services, contribute to the unique cancer burden faced by FN peoples (Canadian Partnership Against Cancer, 2013; Tjepkema & Wilkins, 2011).

Advancements in cancer survivorship care have shown that a holistic approach, with long-term follow-up, regular monitoring for early detection, and interventions tailored to specific needs, can decrease cancer burden, increase survival rates, and enhance the well-being and quality of life (Poudrier & Thomas, 2009). Despite potential benefits, historical trauma from colonization, residential schools, and the spread of disease by European settlers has profoundly impacted FN peoples' willingness to engage with cancer survivorship interventions (Canadian Partnership Against Cancer, 2013; Gifford et al., 2014; Hammond et al., 2015; Poudrier & Thomas, 2009; Thomas et al., 2014, 2015). Our research shows that some FN peoples do not seek survivorship support for fear of being required to leave their communities or that cancer will attract illness and grief into their communities (Hammond et al., 2017). Likewise, a systematic review ( $N = 17$  studies) that analyzed Indigenous peoples' experiences of cancer survivorship services revealed that many have fatalistic attitudes toward cancer, with associated fears of cancer recurrence and community stigmatization (Cavanagh, Wakefield, McLoone, Garvey, & Cohn, 2016). Despite the awareness of the unique survivorship needs of Indigenous peoples, little has been done to address them and few supports exist that consider the intersections of culture, history, and marginalization.

Lack of awareness and knowledge of culturally safe practices affects practitioners' abilities to implement cancer survivorship strategies and supports that effectively address Indigenous peoples' distinct needs and strengths. Advancements in cancer survivorship care have shown that holistic approaches, with long-term follow-up, regular monitoring for early detection, and interventions tailored to specific needs, can increase survival rates and enhance the quality of life for people with cancer (Canadian Partnership Against Cancer, 2013). However, interventions predominantly target White, urban, middle-class people, and not much attention has been paid to the cancer survivorship needs of Indigenous people, who continue to endure poorer health from a long legacy of marginalization within North America. Historical trauma from colonization, residential schools, and the spread of disease by European settlers has profoundly impacted Indigenous peoples' willingness to engage with cancer survivorship interventions (Canadian Partnership Against Cancer, 2013; Poudrier & Thomas, 2009; Thomas et al., 2015). Metaphorically referred to as "falling through the cracks" (Poudrier & Thomas, 2009), little has been done to address the unique survivorship needs of Indigenous peoples, and few supports have considered the intersections of culture, history, and marginalization.

This study builds on two foundational studies, which used arts-based methods (photography, storytelling, journaling), that documented cancer survivorship needs of Indigenous people

(Canadian Institute for Health Research, 2013) across Canada (Gifford et al., 2014; Hammond et al., 2015; Poudrier & Thomas, 2009; Thomas et al., 2015). Findings highlight the profound failures of health services to recognize the distinct ethnic, cultural, and sociohistorical positioning of FN peoples. Results revealed that stigmatization and fear of disclosing cancer to family and friends may prevent FN peoples from engaging with health-care providers or community members about survivorship, including follow-up for reoccurrence and culturally appropriate psychosocial support (Hammond et al., 2017; Poudrier & Thomas, 2009). FN people require culturally safe approaches to cancer survivorship that are tailored to their distinct cultural needs, strengths, and resilience, including the integration of FN spirituality, traditional medicines, family involvement, and connections to FN cancer survivors, while recognizing the ongoing impact of colonization (Cheifetz et al., 2014; Hammond et al., 2015; Hammond, Thomas, & Gifford, 2015).

### Foundational Studies

This study builds on two previous studies: visualizing breast cancer study (VBC), a pilot study conducted in Saskatchewan (Brooks, Poudrier, & Thomas, 2008; Poudrier & Thomas, 2009; Thomas-MacLean, Poudrier, & Brooks, 2008), and the National Picture Project (NPP), a national study on FN and Métis people's experiences with cancer (Hammond et al., 2015; Thomas et al., 2014, 2015).

**VBC pilot study.** This program of research began with the VBC study, a photovoice pilot in which 12 FN and Métis women were asked to describe their experiences with cancer and survivorship through different mediums that included interviews, focus groups, and photography (Brooks et al., 2008; Thomas-MacLean et al., 2008; Thomas et al., 2015). Providing participants with the first opportunity to voice their experiences, VBC identified a research gap in the social and cultural location of cancer survivorship for FN and Métis women. This research highlighted (a) the impact of marginalization (e.g., geography, racism, class) on cancer survivors' experiences; (b) cultural taboos of cancer discussions; and (c) the importance of identity, spirituality, and culture (Brooks et al., 2008; Thomas-MacLean et al., 2008; Thomas et al., 2015).

**NPP.** The NPP was a multisite study which aimed to describe the cancer and care needs of FN and Métis people on a national scale. A 3-year arts-based study, the NPP utilized a participatory approach through sharing sessions, journaling, photography, and interviews. A total of 87 patients and caregivers from 5 communities across Canada shared their stories of cancer and survivorship. Findings highlighted the systemic failures of health-care services to recognize the distinct ethnic, cultural, and sociohistorical needs of FN and Métis people. Moreover, stigmatization, fear of disclosing cancer, and culturally insensitive health-care approaches prevented Indigenous people from receiving survivorship care including follow-up and regular

monitoring for early detection and interventions for enhancing quality of life (Brooks et al., 2008; The First Nations Information Governance Centre, 2013; Smylie, Martin et al., 2004; Thomas-MacLean et al., 2008). With the input of an advisory group, and feedback from participating communities on a poster of key themes, we created a video that documented cancer survivorship experiences. Key themes were (a) the impact of cancer and navigating health-care; (b) spirituality and ceremony; (c) the land, nature, and traditional healing; (d) sharing and creating; and (e) finding strength together.

**Current study.** The overall goal of the current study is to improve cancer survivorship for FN people, and to understand the process of translating knowledge into health-care practices and community-based programs with Indigenous people. Specific objectives are to:

1. develop a holistic approach to cancer survivorship in health-care and community-based strategies;
2. implement the approach and strategies (developed in Objective 1) into health-care and community-based programs;
3. evaluate outcomes and experiences of this initiative, including the process of translating knowledge into health-care practices and community-based programs; and
4. develop and disseminate a model of Indigenous knowledge translation (KT) to improve health-care services.

These objectives will be achieved through our partnerships which are based on long-term collaboration with FN community members from the NPP study. Our team includes an FN community of approximately 12,000 people and an urban hospital that delivers Cancer Care Ontario's Aboriginal Cancer Program.

In keeping with our objectives and partnerships, we will use a participatory, mixed methods design guided by ethical principles and theoretical underpinnings of Indigenous KT (Canadian Institute for Health Research, 2013; Canadian Institutes of Health Research (CIHR) Institute of Aboriginal Peoples' Health, 2009). Indigenous KT offers different theoretical and epistemological paradigms to Western science-based KT (Government of Canada, 2015; Smylie, Kaplan-Myrth et al., 2004). As described by CIHR Institute of Aboriginal Peoples' Health, Indigenous KT is "sharing what we know about living a good life" and is strongly influenced by traditional Indigenous values (e.g., nature and spirituality in healing), practices (e.g., oral storytelling), and the historical impact of colonization, marginalization, and discrimination (CIHR Institute of Aboriginal Peoples' Health, 2009). An ethical requirement of Indigenous KT is community involvement, control, and support (CIHR Institute of Aboriginal Peoples' Health, 2009; The First Nations Information Governance Centre, 2013; Smylie, Martin et al., 2004). Culturally appropriate collaborative research with FN communities can result in improved health outcomes

(Smylie, Kaplan-Myrth et al., 2004), and offers new insights into the fields of KT and cancer research.

A fundamental underpinning of Indigenous KT is that FN peoples have a long and established history of translating their own knowledge into actions through oral traditions, experiences, engagement, and cross-cultural sharing. Using principles similar to participatory action research, Indigenous KT brings community stakeholders into full partnership with researchers; it utilizes culturally relevant channels of dissemination such as kinship networks, talking circles, stories, or moccasin telegraph (informal transmission via the "grapevine"). Participation by community leaders, chiefs, elders, and community members is key to translating messages (Smylie, Martin et al., 2004) in addition to employing multiple modes of communications to enhance KT and dissemination (CIHR Institute of Aboriginal Peoples' Health, 2009). Within Indigenous KT, research knowledge is examined in the context of policies, programs, and approaches that address the underlying determinants of Indigenous health, such as poverty, housing, access to health-care, discrimination, and historical trauma. The continued engagement with FN people in our parent study (Gifford et al., 2014; Thomas et al., 2015) has allowed us to establish partnerships and collaborations with community leaders, cancer survivors and family supports, health-care providers, and elders (referred to as "knowledge users") to plan, design, and conduct this study.

## Method

In collaboration with our knowledge users, methods are proposed in three sequential phases: (1) sharing and documenting through an advisory group retreat, focus groups, interviews, site visits, and reflective journaling; (2) video creation to document the KT process; and (3) video screening and facilitated community engagement to explore perceptions and satisfaction with the KT process.

### Phase I: Sharing and Documenting

In order to generate ideas to translate into health-care strategies and community-based programs, numerous community-based consultations have occurred and continue to occur. This included an advisory group retreat, and will include ongoing engagement with the community health department, as well as focus groups, interviews, and site visits.

The Advisory Group Retreat is largely composed of people who participated in our previous study, as well as members of the hospital delivering Ontario's Aboriginal Cancer Strategy. The Advisory Group members function as full members of the research team and consists of an Indigenous elder, an Indigenous traditional teacher, Indigenous cancer survivors, Indigenous family caregivers, Indigenous and non-Indigenous health-care providers, registered nurse-patient navigators, a student nurse, a postdoctoral fellow, and non-Indigenous university researchers. The purpose of the Advisory Group is to translate findings from our previous studies about FN'

survivorship needs into culturally appropriate health-care strategies, interventions, and community programs.

Engagement with the FN health department and Advisory Group will occur throughout the study. Focus groups and interviews with health-care providers and community members will be held to determine the best approaches and strategies to address cancer survivorship needs in the community.

Health-care approaches and community-based strategies will be implemented to address cancer survivorship needs. Strategies being considered include healing circles that provide ways to support healing and psychosocial support for cancer survivors and their families and caregivers (e.g., art activities such as sewing, beading, quilting, journaling, or traditional ceremonies); teachings of traditional practices and medicine facilitated by traditional healers, traditional teachers, and/or elders; leadership development and peer support (e.g., training with health-care providers to develop peer-led cancer support groups); as well as information provision on health-care system navigation and the provision of an Aboriginal nurse navigator.

Qualitative interviews and site visits will occur 3 months after implementation to understand (1) cancer survivors' perceptions of strategies and impact on well-being; (2) health-care providers' awareness, attitudes, and approaches toward survivorship needs; (3) health-care providers and community members' satisfaction with the KT process; and (4) facilitators and challenges along the way.

### **Phase II: Video Creation**

Based on directions from the Advisory Group, a video will be created on the KT process and/or the approaches and strategies to incorporate the survivorship needs into health-care and community supports. The video will be created using Indigenous consensus-building protocols such as sharing circles and talking feathers to come to "one heart, one mind" about the overarching message and most relevant content for the video. Existing materials from the parent study will be used to develop the video, including photos, posters, quotations, and an accompanying booklet of cancer survivors' stories and photos.

### **Phase III: Video Screening and Facilitated Community Engagement**

Two public community screenings of the video will occur: one in the FN community center and another in the hospital delivering the Aboriginal cancer strategy. Based on our previous study's sharing sessions, we anticipate approximately 30 people to attend each video screening (total  $n = 60$ ).

Question and answer discussions (i.e., focus groups) will be facilitated after the video is viewed to increase community awareness of cancer survivorship needs and elicit further ideas about how to address survivorship through health-care approaches, interventions, and community-based programs and services. The video and discussion questions will be made publicly available for health-care facilities, community organizations, and individuals to view and display as needed.

A Likert-type scale survey with open-ended questions will be administered at the end of the focus groups to understand the acceptability of the video and community screening process. In the survey, we will ask for contact information for people interested in participating in follow-up interviews. All data collection tools will be developed in partnership with the community Advisory Group; however, we anticipate topics related to cultural safety, addressing cancer stigma, holistic healing (including spirituality), and managing anxiety to be relevant. Consistent with ethical principles of FN research (Government of Canada, 2015), members of the Advisory Group will then work with other community leaders (i.e., chiefs and council members), community members, and health-care providers for three months to facilitate incorporating messages from the video into health-care and community care approaches and programs.

**Analysis.** Events will be audio-recorded with consent (e.g., retreat, focus groups, interviews). Audio recordings will be transcribed and qualitatively analyzed for descriptive themes. The focus groups and interviews will be analyzed for strategies and approaches to integrate knowledge of survivorship needs into health-care practices and community programs. Interviews during and following the screenings will be analyzed for: changes in awareness, attitudes, and behaviors of health-care practitioners; the development of organizational and community initiatives to address survivorship needs including follow-up and monitoring of recurrence; and self-care practices of cancer survivors.

All qualitative data will be entered into the qualitative software program NVivo 10 to facilitate data management and analysis. Data will be analyzed for themes within settings (community and hospital delivering Ontario's Aboriginal Cancer Strategy) and collectively across all data. Survey ratings and open-ended questions from the video screening will be aggregated and analyzed descriptively. The process log will descriptively document the KT processes, and the research team's journal entries will be qualitatively analyzed for lessons learned to strengthen the Indigenous KT process.

**Rigor.** Analysis of the findings will abide by Munhall and Oiler-Boyd's (1993) qualitative criteria (e.g., credibility, patterning, saturation, and transferability). Rigor will be ensured with recording and reporting of the process by means of an audit trail. In addition, independent coding will occur by researchers. Theme development will be reviewed in team meetings with the Advisory Group.

## **Results**

Outcomes will be confirmed with study advisors, who will be offered an initial menu of choices that include: (1) integration of culturally responsive KT approaches and interventions into health-care practices and community programs to address survivorship needs (including preventative self-care, early detection, and psychosocial support); (2) cancer survivors'

engagement in KT survivorship interventions and perceptions of improvements with self-care; (3) health-care providers' and community members' awareness of FN distinct cancer survivorship needs; and (4) satisfaction with the Indigenous KT process including engagement, communication, KT delivery mechanisms, and suggestions for improvement. Outcomes #1–3 will be addressed through qualitative interviews and site visits with policy reviews, and Outcome #4 through Likert-type scale survey, qualitative interviews, debriefs with Advisory Group, research team's reflective journals, and discussions. A tool kit will be created from the study for engaging in Indigenous KT to improve health-care in FN communities in Canada.

### Ethical Considerations

Historically, research involving Indigenous people has been defined and carried out primarily by non-Indigenous researchers and has not generally reflected Indigenous world views or benefited Indigenous communities (Government of Canada, 2015). As a result, the apprehension and mistrust that Indigenous people have toward research present potential challenges and delays in this research process. Our strategies are grounded in the approaches outline in Chapter 9 of the *Tri-Council Policy Statement: Research Involving the First Nations, Inuit and Métis Peoples of Canada* (Government of Canada, 2015). Recognizing and respecting the importance of traditional cultural values, community engagement, and mutually respectful relationships, we will continue to take guidance from this policy and from the FN community partners that are collaborating on this research.

We have established relationships in the FN communities through our research over the past 3 years (Gifford et al., 2014; Thomas et al., 2015). The Advisory Group continues these relationships and maintains a community-based orientation in our research. Recognizing that community engagement is integral to ethical research with FN, we will conduct this research in full collaboration with our community partners and the Advisory Group, and will also maintain a regular presence in the community. In our previous study, this involved regular consultations with elders and chiefs, being interviewed on community radio, and participating in a community cancer walk. While it is difficult to predict how many engagement visits will occur, we anticipate at least one per month for the duration of the project. We are committed to following FN Principles of OCAP™ (ownership, control, access, and possession), which recognize that FN control the data collection processes in their communities and own, protect, and control how their information is used (The First Nations Information Governance Centre, 2013). We will continue to build trusting relationships to conduct this research and have allowed for sufficient time while balancing costs, in recognition that strong trusting relationships are integral to conducting ethical research with FN people.

### Discussion

Results will advance knowledge of conducting culturally appropriate Indigenous KT to mobilize and translate

knowledge of cancer survivorship needs into health-care practices, approaches, and community-based programs and services with FN people. Ultimately, this will lead to increased follow-up for screening and culturally appropriate psychosocial supports and services to improve health outcomes, cancer survival rates, and the quality of life for FN peoples in Canada. The Indigenous KT process developed from this work will be important for translating knowledge with other FN communities across the country in culturally responsive ways to improve health-care services, quality of life, and health outcomes.

### Authors' Note

Views expressed in the submitted article are the coauthors' and not an official position of the institution or funder.

### Declaration of Conflicting Interests

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