Author’s response to reviews

Title: Providing culturally safe cancer survivorship care with Indigenous communities: study protocol for an integrated knowledge translation study

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Author’s response to reviews:

Reviewer #1:

Response

Thank you for your supportive comments.

The first study has a focus on the process of translating Indigenous knowledge into cancer survivorship supports to make them more culturally relevant and safe for Mohawk First Nations people. Working in collaboration, we co-developed cancer survivorship supports that incorporate First Nations knowledge with western knowledge, and the study is evaluating the acceptability of the strategies and the feasibility of implementing them, and the process of western researchers working together with First Nations health providers to develop cancer survivorship strategies that are culturally relevant and safe.

The third study is working with different populations (Inuit and Algonquin First Nations), and is specifically looking at how nurses can implement cancer survivorship supports in rural and remote communities. In the third study we are not co-developing the strategies (as with the second study), rather the focus is on what nurses can do to support implementation of strategies. The strategies being explored are from a systematic review of cancer survivorship strategies.

These studies compliment each other by looking at different aspects of cancer survivorship for Indigenous people – co-developing and adapting survivorship strategies to be culturally relevant and safe; and implementation of cancer survivorship strategies. They also involve distinct
Indigenous Groups, which have their own cultural practices and knowledge towards health. The studies fit in the program of research as they have the same overall goal to improve health care for Indigenous people with cancer (i.e.: cancer survivorship).

The determinants of cancer mortality have been attributed to the historical impacts of colonization that that decreased Indigenous People’s access to health care and negatively effect their social determinants of health. This has been emphasized in the background section.

In the second study, we are co-developing the cancer survivorship strategies in partnership with First Nation’s health care leaders, Elders, cancer survivors and community members and evaluating the process of developing the strategies to support culturally safe cancer survivorship. We have clarified this in the text.

The first objective in the third study is based on a synthesis of the literature to find out survivorship strategies have been utilized by Indigenous people and the types of collaboration that are described in the implementation of the cancer survivorship strategies. We have clarified that the first objective in the third study is a systematic review addressing both the types of survivorship strategies described in the research literature that have been utilized by Indigenous People, and the characteristics of collaboration during implementation of the identified cancer survivorship strategies with Indigenous communities. We have clarified in the first objective that this is a synthesis of the published research literature.

We understand why this is confusing. To clarify, the study is a participatory because it involves research participants (i.e. Indigenous people) in all stages of the study.

We have clarified in the text that the design is descriptive using multiple methods - that include: review of the literature, focus groups, interviews, process log.

The review is a systematic review but is not examining the effectiveness of interventions. We have provided a reference for this type of systematic review. Rather we are synthesizing quantitative, qualitative and mixed-methods results and since the majority of research is descriptive, we will conduct a narrative synthesis to analyze the results.

Thank you for pointing out the need for clarity. The interviews will be conducted with a convenient sample of nurses, nursing aids and other healthcare providers and we have added this into the text.

For research question #2, we will conduct a descriptive analysis to understand barriers and facilitators to implementation so that the implementation strategies can be tailored to the barriers
and facilitators for the best chance of successful implementation. This is consistent with the theoretical underpinnings of the knowledge to action cycle in knowledge translation, and this has been added to the text with references.

Thank you again for identifying the need for clarity. Indeed we are field testing the feasibility and acceptability of the implementation strategies and the perceived influence of the strategies on healing. We have clarified this in the text and have added more clarity around the sample.

The description of the 'process log' has been moved up to the methods section for RQ3 and more clarity has been provided about what will be recorded in the process log.

Reviewer #2:

Response

Thank you for your comments.

We have elaborated on the limitations with cancer data for Indigenous populations in Canada in the background – to read:

Although cancer databases in Canada do not have identifiers for race or ethnicity (5), evidence is accumulating that cancer incidence rates for Indigenous people are increasing faster and cancer survival is worse (6, 7). For example, a recent report to understand cancer prevalence in First Nations people in Ontario has shown that colorectal cancer increased six and seven percent respectively for male and female First Nations people whereas the incidence stayed the same or decreased for non-Indigenous people (5).

We have expanded on the collaboration in the text under “Setting & Collaboration” (page 5), describing how our approach is guided by theoretical underpinnings of integrated knowledge translation and Indigenous knowledge translation.

This has already been considered and included in our literature search strategy, which is included in the appendix.
A comprehensive list of terms was selected by our health services librarian to represent all indigenous groups in North and South America (including Hawaii), Greenland, Australia, New Zealand, and Papua New Guinea. These areas were chosen since they have a context similar to Canada.

We are considering all published literature and have not included the grey literature at this time, but will consider this for the discussion of the review and future work.

We have added in a paragraph under ‘analysis’ to describe this important steps in the data analysis:

We will involve our Indigenous partners in all stages of the analysis, holding regular group meetings to facilitate accurate interpretation of data and iteratively co-develop themes that reflect culturally relevant community beliefs. Trustworthiness of findings will be sought through prolonged engagement with community partners and collaboratively analyzing data. Researchers will explicitly reveal their predispositions and maintain an audit trail and codebook to ensure transparency and dependability of the analytical process.

Thank you for pointing out this need for clarity. The health care providers from the community and will be involved in developing the implementation plan to deliver the survivorship strategy. We have clarified this in the text as follows:

Based on our previous work, we plan to recruit a purposeful sample of five health providers from each community to implement the cancer survivorship strategies, including nurses, traditional healers and Elders (total n=10). To be included, health care providers will have experience working with Indigenous cancer survivors in the community. Together with the research team, the health care providers will determine the methods to implement the chosen cancer survivorship strategies, tailoring their implementation methods to the barriers and supports identified (research question #2) and the context of the community.

As this is an established and funded protocol, we have chosen not to include a logic model although will consider the use of one in the future.