Author’s response to reviews

Title: “If You Understand You Cope Better with It”: The Role of Education in Building Palliative Care Capacity in Four First Nations Communities in Canada

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Author’s response to reviews:

The authors would like to thank Reviewer 2 for the useful comments. Each of the reviewer’s comments is addressed below. Please note that the line numbers referenced in the responses below are the line items that were inserted by the authors in the Word document (the larger line numbers next to the PDF generated ones in the submission)

Reviewer Comment 1. Page 4/58 Line 10 - "Indigenous" I am not an expert in researching these populations. Nonetheless, it appears as if "Indigenous" does not need to be capitalized. If you feel it is appropriate, please be consistent.

Author Response: Explanation: In Canada it is customary to capitalize the word Indigenous as a sign of respect. The word Indigenous is consistently capitalized throughout the article.

Reviewer Comment 2. Page 9 Lines 14-34 - I am neither a Canadian nor do I consider myself an Indigenous person. While the statements in these lines may actually be true and reflect feelings in these communities, it does not seem to be the thrust of your study. Perhaps this can be
condensed or perhaps you could just begin with "[Today] many First Nations communities in Canada..

Author Response: Rationale: In Canada, acknowledging the history of colonization, and the devastating impact it had on First Nations people is a national priority and provides important background and context to understanding this research. The Truth and Reconciliation Commission (2015) gave all Canadians a call to action that includes acknowledging the history of residential schools and advancing the process of reconciliation (nctr.ca/reports/php). These acknowledgments respect our First Nations community partners and the five authors of this article who are Indigenous people. A new reference to the Truth and Reconciliation Commission has been added (Background section, Page 8, Line 13) to the paper to provide background.

Reviewer Comment 3. Page 9/58 Lines 46-49 -"Westernized, medicalized approach" - I question whether the institutionalized approach is truly 'Western' or more appropriately 'industrialized' or some other adjective. I live in a 'Western' country which is industrialized. We are also actively seeking to provide palliative care to patients in their homes, surrounded by caring friends and family, supported by cultural institutions.

Author Response: Revised sentence: … it moves away from the medicalized approach of industrialized nations, often known as Western medicine.

We have incorporated reference to industrialized nations in this sentence (Background section, Page 8, Line 19) as requested, but also included the term Western medicine as a common term used to describe this approach. Western medicine is the terminology used to describe the health care system in a recent scoping review of palliative care for Indigenous peoples (Cajax et al; reference #52). In other cross-cultural health literature, the term Western medicine is commonly used to describe a scientific, deductive approach to health and the human body. This contrasts with a more holistic, integrative and inductive approach as used in countries such as Asia.

Reviewer Comment 4. Page 10 Line 4 - If this is "research", what is the question? What is the thesis? It almost seems more of a report of a process.

Author Response: Revision: This paper reports on research conducted as part of the larger participatory action research (PAR) project, specifically, the process of assessing and addressing palliative care education needs. Other publications have been referenced that report on the other aspects of the research.
This current research focus has been clarified in the Background section (Research Context subsection) on Page 9 by:

i) the addition of the subheading “Research Context: The Improving End-of-Life Care in First Nations Communities Project” (line 1-2)

ii) the addition of participatory action research to the overall goal statement (Line 4)

iii) specifying that the overall project is the research project, with this paper reporting on the data related to assessing and addressing palliative care education needs (Lines 15-17).

As a methodology, PAR is not guided by a thesis statement or research question. The goal and principles of PAR are described in the methodology section of this paper.

Reviewer Comment 5. I assume that most readers of this journal are not expert in work with Indigenous peoples. Perhaps explaining some terms could help us all better understand your particularly exciting line of research. For example, you might explain "stages of language revitalization".

Author Response: Sentence revised to improve clarity: “Retention of traditional language within the communities, an indicator of maintaining cultural tradition, ranged from retention rates over 50% to communities currently undertaking language revitalization (e.g. language emersion programs in the schools to promote and preserve their traditional languages).” Methods section, Page 10, Lines 20-23.

Reviewer Comment 6. Page 12/58 Lines 46-49 How did you assure that the translator was qualified and that he/she was accurately translating?

Author Response: These Indigenous community leaders are competent in the local language and are trusted by community members to report accurately. This sentence has been added to Methods section (Phase 1) Page 12, Lines 1-2. Note to reviewer. Accuracy of the data was never an issue raised. Integrity of all research data was monitored by the First Nations advisory committee (local Indigenous people) throughout the research.

Reviewer Comment 7. Page 13/58 Line 19 "Westernized concept" - perhaps one could just note that the concept of palliative care is unfamiliar to First Nations people, which is, in fact, the reason for education. How does the origin of the unfamiliar fact bear on the need for education? Might one suspect you are saying "Indigenous is good. Western is bad."?
Author Response: We have changed “Westernized” to “a medical concept unfamiliar to …” (Methods -Surveys section, Page 12, Line 13).

Reviewer Comment: 8. Page 14/58 Line 21 "The focus groups and interviews audio-recorded. " I assume "were" is to be inserted between "interviews" and "audio-recorded".

Author Response: Thank you. This has been corrected (Page 13, Line 15).

Reviewer Comment: 9. Page 15/58 Line 4 - Should analysis be pleural, 'analyses'.

Author Response: Thank you. This has been corrected (Page 14, Line 8)

Reviewer Comment 10. Page 17/58 Line 53- Extra space?

Author Response: Thank you. This has been corrected (Page 17, Line 4)

Reviewer Comment: 11. Page 18/8 Line 34 - Acknowledging that Indigenous people have had disruption of their traditional intergenerational transmission of collective culture and traditions is important. One might argue whether colonization was the only culprit. Reeducation of the current community members is nonetheless still needed whatever the cause.

Author Response: The Truth and Reconciliation Commission of Canada (2015) has attributed the disruption of cultural transmission of knowledge to the impact of colonization.

The authors rationale to include the reference to colonization is that colonization provides the reader contextual information to interpret the data (the quote); the sentence about colonization has therefore been moved to immediately preceded the quote (Results Section, Educational Needs of First Nations Community, Community Members: Page 17, Line 22, Page 18 lines 1-2).

Reviewer Comment 12. Page 20/58 Lines 27-31 - While some institutions and hospitals may be understaffed or staffed with uncaring health care staff, care at home, whether through home-health, hospice, or just care by family and friends, can suffer from neglect and inattention. Not all health care providers are compassionate; not all family members are compassionate. Elder abuse perpetrated by family members does occur. The statement seems pejorative.
Author Response: We’re sorry the reviewer finds the statement pejorative.

The text in question is a direct quote from the participant. It is data based on their experience that must be honoured. However, we have shortened the quote to maintain the essence but removed some of the offending detail (Results Section, Educational Needs of First Nations Community, Internal Health Care Providers: Page 19, Lines 15-19).

Reviewer Comment 13. Page 22/58 - Line 14 What is "cultural safety"? "Cultural competency"?

Author Response: Cultural safety is an environment that is experienced as safe for people: where there is no assault, challenge, or denial of a person’s Indigenous identity, who they are or what they need. Cultural Competency is an individual’s ability (e.g. a medical practitioner) to understand, appreciate, and interact respectfully with Indigenous peoples and their cultural teachings and traditions. These definitions (and corresponding references) have been added to the Results Section: Educational Needs of Canada’s Health Care System, Page 21, Lines 9-13.

Reviewer Comment 14. Page 23/58 Lines 28-31 - Does this need a footnote?

Author Response: The authors cannot identify anything that needs a footnote on page 23; though we have added reference to the World Health Organization’s position that advocates that all people deserve quality palliative care (Discussion section, Page 22, line 19-21). This is the discussion section of the paper and thus allows for researchers’ perspective.

Reviewer Comment 15. Line 38: Westernized as above noted in #3

Author Response: Discussion Section we have changed “Western” to “medical” and (Page 23, line 23) “Westernized” to “concept in medicine” (Page 24, Line 10).

Reviewer Comment 16. Line 38“and”

Author Response: To improve clarity, the sentence has been changed from: “Palliative care is a medical concept and traditionally First Nations people do not medicalize death” to: “Palliative care is a medical concept unfamiliar to First Nations people because traditionally, First Nations people do not medicalize death” Discussion section, Page 23, Line 23 – Page 24, Line 1)
Reviewer Comment 17. Page 24, Line 41-43. “So am I to understand that a First Nations individual, operating either as an individual or as part of a group, could never conceive of or implement a culturally inappropriate program or process? This is truly remarkable and deserves more elaborate development. How do you explain this?”

Author Response: The statement made in the paper refers to the participants of the research being described, not to First Nations individuals in general. The PAR process undertaken in the research ensured the resources created were culturally appropriate. Development began with a detailed needs assessment of educational needs. The assessment was done by the First Nations people themselves. The identified needs were then systematically addressed by the First Nations community members (community leader, advisory committee as described in the methodology section) with support of the researchers. Educational resources were pilot tested, evaluated and revised iteratively, until the community members were satisfied that the resources met their needs in a culturally appropriate manner. Having the resources be culturally appropriate was a criterion of their development and this criteria was indicted in the methodology section. Using the PAR process described ensured that the resources were culturally appropriate when complete. The PAR process for developing the resources is described in the methodology section of the paper (see Methodology phase 3).

Revision: The resources were all culturally appropriate because they were developed through PAR in First Nations communities by First Nations people, for use by First Nations people. (Discussion section: Practice and Policy Implications, Page 24, Lines 1-3)

Reviewer Comment 18: Line 7: Western

Author Response: Revision…the word western is removed.

Reviewer Comment 19. Page 25, lines 9-14: I am not sure I understand this. Who would you propose should choose about the care an individual receives at the end of life? Should the dying individual have no say in this discussion? His or her perspective might be construed as an individualistic framework, especially if he or she eschewed some or all of a First Nations group recommendations. Should he or she not be free to decide on how he or she would like to die? Please explain.

Author Response: The authors are not taking a position on this statement as implied by the reviewer in the comment. The authors are reporting on the literature pertaining to advance

Author Response: Thank you. One has been changed to a possessive pronoun (from ones to “one’s” (Page 24, Line 17).

Reviewer Comment 21. Page 25, Line 4: For the reader who is not well versed in care of indigenous peoples, the First Nations people in particular, one might explain how non-indigenous health care is unsafe. You might provide a substantiating reference as well.

Author Response: A definition of culturally safe care has been added Page 21 (see comment 13 above), and the reference added in this section as well (Page 25, Line 9).

Reviewer Comment 22. Page 26/58 Lines 9-41 - This portion assumes as fact that 'Western medicine' and its practitioners are self-righteous, condescending, insensitive, disrespectful and untrustworthy. As such it is more a polemic than a scientific report. I do not believe it either supports or refutes your methodology or your data. I would suggest it be removed.

Author Response: One of the roles of the Discussion is to suggest implications of the research findings for practice. The discussion makes no assumptions about practitioners as implied by the reviewer. Rather, based on the results of our research, we are endorsing a particular form of practice (cultural humility) as meeting the needs of First Nations people. Cultural humility as a practice concept is described and referenced.


Reviewer Comment 23. Page 26/58 Line 43 'for First Nations people'. Is not dying a cultural and spiritual life transition for 'ALL' people? Perhaps end-of-life care should be viewed through a social lens for 'ALL' people. Perhaps 'ALL' people should have culturally consonant care at the end of their lives by a team of compassionate health care providers who are expert in their craft.
Author Response: We agree with the reviewer that all people could benefit by having dying viewed through a social lens. However, this article specifically addresses the experience of First Nations people based on our research. We’ve clarified this by stating that “Our findings emphasize that dying is a cultural…. (Discussion Section, Page 26, Line 3).

Reviewer Comment 24. Page 26/58 Lines 46-53 - Perhaps allowing the individual, in conjunction with his or her family, to choose the location of his or her death, whether in a hospital, a hospice, an extended care facility, or in one's home would be preferable to insisting that the preferred place of death is in one's home. It appears that you might be imposing your Welanschauung on others. Your Table 5 states this well, "Understanding that the spiritual and cultural practices of individuals and families are highly individualized and health care providers should proactively ask what practices would offer comfort and support."

Author Response: We disagree with the reviewer that the assumption is being made that the preferred place of death is always in the home. In fact, the sentence reads … “to support end of life care at home where possible and desired”. (Page 26, Line 7).

Reviewer Comment 25. Page 28/58 Lines 43-46 - "development described in this research." seems to be an incomplete sentence. Please revise or delete.

Author Response: Thank you. This has been deleted.

Reviewer Comment: 26. Page 28/58 Line 58 through Page 29/58 Line 7 - "Specifically, on ... educational needs." seems to be an incomplete sentence. Please revise.

Author Response: To improve clarity, this sentence has been revised to: “Specifically the focus was on the educational components of the community assessments, and on the community-led initiatives (tools/resources) that were developed to address the identified educational needs.”(Page 28, Lines 9-11).

Reviewer Comment 27. Page 48/58 Line 17 "Fist" seems misspelled.

Author Response: Thank you. Fist has been corrected to First (Table 5, Page 49, last sentence).
Reviewer Comment: 28. Page 49/58 Lines 49-51 - Were all participants required to participate in the religious portions of the meetings?

Author Response: Participants were not required to participate in anything. Consistent with the principles of participatory action research, community members chose what experiences to participate in.

Reviewer Comment 29. Page 50/58 lines 7-9 - In some cultures and communities, individuals who may have lived lives not congruent with cultural or community beliefs might find some 'appropriate' apprehension anticipating their own death.

Author Response: This observation by the reviewer is not linked to any specific text in the article, or request for revision.

Reviewer Comment 30. Page 51/58 Line 40 - "culturally safe" see previous notes.

Author Response: A definition of cultural safety has been added on Page 21 (See comment 13 above), the corresponding reference [50] has been added to this section as well (Table 6, Page 52, Row 5).