

Article details: 2020-0012		
Title: The experiences of Indigenous peoples with cancer in Saskatchewan: a patient-oriented qualitative study using sharing circles		
Authors: Tracey Carr PhD, Lorna Arcand, Rose Roberts PhD, Jennifer Sedgewick MA, Anum Ali MBBS, Gary Groot MD PhD		
Reviewer 1: Carla Ginn, University of Calgary, Faculty of Nursing		
Reviewer comments	Author response	
1. Would be ideal to include participants as co-authors if able (in particular the Ca survivor and/or circle keeper mentioned in the manuscript).	Rose Roberts, circle-keeper, and Lorna Arcand, cancer survivor who was the patient partner for the project are both co-authors.	Already under Author contributions
2. There is some incongruency in using a cross-sectional design with qualitative methods, and no details regarding this cross-sectional design are provided.	We did not see this practice as incongruent. Here we reference another article that uses a cross-sectional design with qualitative methods. 13. Ekanayake S, Ahmad F, McKenzie K. Qualitative cross-sectional study of the perceived causes of depression in South Asian origin women in Toronto. BMJ open. 2012 Jan 1;2(1):e000641	#2 Reference #13
3. It would also have been ideal if participants were involved in data analysis and there was member-checking/integrated KT during each phase of analysis.	Yes, we agree participant involvement in these steps would have been ideal. Aside from the PDF, this project was unfunded, which made it necessary to find funds for honoraria/mileage and the meal. Unfortunately, to compensate participants for further contributions to the study was not feasible.	Did not add to text of article
4. There is no research question.	We rephased the first sentence of the second introductory paragraph to more explicitly reflect our research question: Building upon our literature derived theory of shared decision-making for Indigenous patients¹³ which found that trust and world view	#1

	play a significant role in how Indigenous patients interact with the health care system, we engaged an Indigenous cancer survivor to partner in our research.	
5. Participant quotes are very insightful, but more are needed in order to fully understand participant perspectives.	We have moved our table into quotes boxes and have added extra quotes.	Uploaded separately
6. The lack of current knowledge in the field could be emphasized in the introduction and in the discussion.	In the introduction we added: Much of what is currently known about Canadian Indigenous cancer patients' experiences is limited to epidemiological studies⁷ or focused on spirituality.^{11,12}	#1
7. The discussion is lacking a comparison of the current literature particularly in relation to patient-oriented research.	We acknowledge in the summary: Although other studies have explored Indigenous patients with cancer experiences, this study is the first to use patient-oriented research approach to gather data in a culturally appropriate way. We hope this is not a lofty statement – it is, to the best of our knowledge, the only POR of its kind.	#6
8. Inclusion of one researcher in the talking circle is a good strategy, but for a full patient-oriented research study, more involvement of participants throughout would be ideal.	We certainly agree with this point. For this study, we did not have the funds to support full engagement with patients throughout the research process. We relied on the perspectives of one patient for methodological input – protocols for method and data collection, and another patient for verification of our analysis. It's important to note that without patients leading this work, it would not have been possible.	Did not add to text of article
9. How will this research improve patient	Our premise here is that if	#6

outcomes?	researchers better understand how Indigenous patients experience trust and perceive world view, these understandings can be translated to clinicians who will be able to improve patient outcomes.	
10. Differences between urban/rural/on-reserve responses would have provided another perspective.	This is a very good point. Our research group is currently undergoing this work – an assessment of Indigenous cancer patient support needs throughout Saskatchewan. For our study, with a relatively small number of participants these differences were difficult to observe.	#6
Reviewer 2: Carolyn Canfield, University of British Columbia, Faculty of Medicine		
Reviewer comments	Author response	
<p>1. Do the researchers provide a clear description of how they engaged patients in their research? This research designed to learn more about patient and caregiver experiences engaged the informed expertise of the research team's patient partner from start to finish: choosing the methodology, guiding its detailed design, situating the session, recruiting participants, and leading the information sharing. All of this was done by assigning remarkable respect and independence to the patient partner's distinct approach through the chosen culturally appropriate methods and actions. Would it be helpful to describe a limitation to the study as the unknown differences that might be introduced to the collected data if a different skilled Indigenous patient partner with Sharing Circle knowledge were to have led the session?</p> <p>o Were patients engaged in various phases of the project? (e.g., Were patients involved in identification of priorities for what should be studied, in how the research should be done, in analyzing or making sense of the data or in disseminating the findings?)</p> <p>Yes, remarkably strong in most facets. Data interpretation was verified by a second patient partner. No discussion of dissemination of findings was given, but the implication is that</p>	<p>We very much appreciate the perspective of the patient reviewer and are pleased to know that we were on the right track!</p> <p>We added: We also recognize that the perspectives of only these two patient researchers may have directed our findings in a particular manner that a different patient researcher may not.</p>	#6

<p>this study is still preliminary, so the findings relate primarily to guiding next steps in this research.</p> <p>o Did patients contribute meaningfully to the research (rather than just as a participant, or as a token member of the research team)? Consider the diagram below for examples of how patients can make meaningful contributions to research.</p> <p>Yes, entirely so.</p>		
<p>2. Do the researchers describe how the engagement of patient partners added (or did not add) value to the results or outcomes of the study?</p> <p>This seems precisely the objective of the manuscript.</p>	Thank you	
<p>3. Do the researchers describe any challenges with engaging patients in the study?</p> <p>Yes, clearly the research team accepted the initial challenge of relinquishing the usual degree of methodological control and assignment of shared task responsibility. The patient partner in fact took on the conduct of primary information gathering. The research team recognized the tension between more closely guiding the data gathering, as compared with this more open and organic process of revealing experiences and perspectives through a Sharing Circle.</p>	Thank you	
<p>4. Does the article include lessons learned from using a patient-oriented approach to research, so that others can learn from their experience?</p> <p>Yes, the conduct of the research is described in sufficiently detail as to guide other research teams interested in adopting authentic and respectful Indigenous inquiry methods that are led by Indigenous patient partners. Lessons from this initial study are limited, as the research team indicates that sufficient trust has been built and interest cultivated that more in-depth research is anticipated with the same participants, as building on this initial trial as a foundation.</p>	Thank you	
<p>5. In your opinion are the outcomes of the research ones that will make a real difference to patients, their families and their providers?</p> <p>The manuscript illuminates new approaches to understanding Indigenous patient and caregiver perspectives and concerns, and places them in a helpful broader cultural context. This is a distinctive model for co-design and co-</p>	Thank you	

<p>production, as well as new knowledge about the Indigenous patient experience. The success of this small project strongly suggests the methodology's considerable potential for developing greater Indigenous access to care and more supportive experiences. It is very encouraging to see the research team and participants' shared intention of building on these first steps that have established sufficient trust to continue into more deeply held understandings on what better cancer care might look like for Indigenous patients and caregivers and how to learn more in a truly patient-centric way.</p>		
<p>Reviewer 3: Sumeet Sodhi-Helou, Dignitas International</p>		
<p>Reviewer comments</p>	<p>Author response</p>	
<p>1. Introduction/background information is inadequate: it should include some summary or commentary on previous knowledge/literature/studies in this area/context and place this study within it.</p>	<p>We added this summary sentence. Much of what is currently known about Canadian Indigenous cancer patients' experiences is limited to epidemiological studies⁷ or focused on spirituality.^{11,12} While we recognize this literature can be discussed more fully, we wanted to keep within the word requirements and focus more on what this POR study can add.</p>	<p>#1</p>
<p>2. Rationale for explaining why study was completed: this section could be expanded either by literature/knowledge review above, or further clarification of context. Need more information on why trust and world view were prioritized compared to other alternatives.</p>	<p>We modified the second paragraph of introduction: Building upon our literature derived theory of shared decision-making for Indigenous patients¹³ which found that trust and world view play a significant role in how Indigenous patients interact with the health care system, we engaged an Indigenous cancer survivor to partner in our research. As a test of our theory, we asked patients and families how trust</p>	<p>#1</p>

	<p>and world view impact their journey. By understanding the role of trust and worldview, our objective was to provide insight into appropriate supports for Indigenous patients and families in detail.</p>	
<p>3. Research question and methods are appropriate, however a few suggestions/questions:</p> <p>a) May want to consider gender neutral pronouns when referring to the patient researcher to further help with anonymity/confidentiality.</p> <p>b) Recruitment section: need to clarify "those who had cancer" - had they completed treatment, were people with remission or cure included, etc. This section could be revised to be more clear on inclusion/exclusion criteria.</p> <p>c) Protocol/Data collection: clarify the role of the circle-keeper and context - was this also a study participant or a research team member?</p> <p>d) Patient orientated research: this section lacks clarity. Is the cancer survivor also the patient researcher? Please consider revising/repositioning/reframing for clarity.</p>	<p>a) Added gender neutral pronouns (they/their)</p> <p>b) Added this text under recruitment section: Eligibility for inclusion was connection to the patient researcher and past or ongoing cancer treatment or family member of a cancer patient or survivor.</p> <p>c) The circle-keeper was a member of the research team. This is clarified in the Protocol section.</p> <p>d) We clarified by stating clearly that the cancer survivor and the patient researcher are the same: The Indigenous cancer survivor, who served as the patient researcher on the project, was connected to the research team by a member of the provincial First Nations and Métis Health Service (FNMHS).</p>	<p># 2-3</p>
<p>4. Analysis: not clear if the 1st and 5th author also were the ones deducing the preliminary themes or they just did the coding afterwards?</p>	<p>Rewriting of this section was as follows: The fifth author did the searching for key concepts, read and reread, and highlighted sections. These processes were then verified by the first author. These highlighted sections were then reread</p>	<p>#3</p>

	and organized in a chart format to ensure the themes matched the narratives by the fifth author.	
5. Results: Tables 3 and 4 may be better represented as inline text to help with presenting the results a more organized way and for the reader to understand what is presented. Figure 1 is excellent.	We have taken away tables and have turned them into 2 quotations boxes and have added extra quotations from participants as another reviewer suggested. We decided to do this to keep within the word limit.	Uploaded separately
6. Interpretation/brief summary of the main results: the paragraph below doesn't provide any summary of the main results. Consider revising/reframing.	This section, which was not results focused, was moved to "lessons learned from patient involvement": A Sharing Circle offered a culturally safe environment for Indigenous patients to share their cancer journey experiences.²⁵ The Sharing Circle was made possible by the patient researcher who recruited community members with lived cancer experiences who were willing to share their stories. They also suggested the study setting and ensured the Protocols were followed for the gathering. Five sentences were added to the summary to provide greater explanation.	#6
7. Results: what else did the participants report aside from trust and worldview? Were there any unintended/unanticipated results? Assuming the sharing circle was not run by asking leading questions, it may be pertinent to summarize other themes that emerged. If not relevant, please explain why not relevant.	Many participants did mention fear regarding diagnosis and treatment. But considering this was a group of cancer patients, survivors and family members, fear was not a particularly unanticipated finding. Therefore, we did not highlight it.	Did not add to text of article

<p>8. Need to place study rationale, results and findings in the context of the literature - this has not been done by the authors, and limits the publish-ability, contextualization and generalizability of the study. Majority of the literature review is regarding methodology.</p>	<p>Added to rationale: Much of what is currently known about Canadian Indigenous cancer patients' experiences is limited to epidemiological studies⁷ or focused on spirituality.^{11,12}</p> <p>Building upon our literature derived theory of shared decision-making for Indigenous patients¹³ which found that trust and world view play a significant role in how Indigenous patients interact with the health care system we engaged and with the direction of an Indigenous cancer survivor, to partner in our research.</p>	<p>#1</p>
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