



**A Patient-oriented study of Indigenous Peoples’
Experiences of Cancer in Saskatchewan: A Qualitative
Narrative Analysis using Sharing Circles**

Journal:	<i>CMAJ Open</i>
Manuscript ID	CMAJOpen-2020-0012
Manuscript Type:	Qualitative
Date Submitted by the Author:	23-Jan-2020
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More Detailed Keywords:	
Keywords:	Aboriginal health, Oncology, Patient Oriented Research, Community medicine
Abstract:	<p>Background: Indigenous Peoples’ experiences of cancer tend to be affected, in part, by historical and ongoing effects of colonization. We used a combination of qualitative and Indigenous research methodology to understand shared decision making of Indigenous patients and families with cancer.</p> <p>Method: Qualitative data were collected from Indigenous patients with cancer and their families using Indigenous method of Sharing Circle. Our patient researcher orientated the question, and was involved in identifying the method (i.e., sharing circles), recruiting participants through snowballing contacts and social media. Keeping with Indigenous methodology, the interview transcripts were analyzed using a narrative method.</p> <p>Results: A narrative analysis revealed two meta-themes, Trust and World view, comprised of eight sub-themes. Trust involved subthemes of: Mistrust with diagnosis, Protection of Indigenous medicine, Physician expertise with treatment recommendations and Mistrust of western treatment after cancer treatment. Worldview included subthemes of: Best of both worlds, Spiritual beliefs, Required to be strong for family,</p>

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	<p>and the Importance of knowing Indigenous Survivors.</p> <p>Interpretation: Patients interactions and engagement with cancer were influenced by personal and historical experiences of those who had undergone previous cancer treatments. Due to the nature of the sharing circle method simply attaining views regarding trust and worldview was difficult. Allowing patients to freely discuss their cancer journey identified other key influencing factors in decision making. Our research will assist health care providers to better understand how trust and world view are important parts of Indigenous health care.</p>

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COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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Title: A Patient-oriented study of Indigenous Peoples' Experiences of Cancer in Saskatchewan: A Qualitative Narrative Analysis using Sharing Circles

Introduction:

Indigenous Peoples (First Nations, Métis, and Inuit) in Canada are diagnosed with common cancers at a higher rate,¹⁻⁵ are more likely to receive later stage diagnoses,⁶ and have lower survival rates^{7,8} relative to non-Indigenous Canadians. These disparities stem from the historical and ongoing effects of colonization that impact the determinants of health for Indigenous people⁹⁻¹¹ and the lack of prevention programs and equal access to cancer screening.^{12,13} In light of these disparities, we examined opportunities that empower patients in their cancer journey and moments that disengage Indigenous patients from accessing health care.

Building upon our theory of shared decision-making for Indigenous patients¹⁴ and the direction of an Indigenous cancer survivor, we chose to examine how trust and world view impact the journey of Indigenous patients with cancer and their families. To learn about these experiences, we chose a research method informed by a traditional Indigenous practice for governance, healing, and storytelling: Sharing Circles.^{15,16} Our objective was to offer a framework to health care providers regarding culturally appropriate patient-oriented decision-making and to explore recommendations for appropriate supports for Indigenous patients and families' in dealing with cancer.

Methods

Study design

A cross-sectional study design was used with qualitative data gathering methods. We used a practice suitable to an Indigenous population, Sharing Circles, conducted under the guidance of our patient researcher.

Setting

The study was held at the Wanuskewin Heritage National Park, a living reminder of the sacred relationship between the land and Indigenous People.¹⁷ Chosen by our patient researcher, this location was intended to provide participants with a culturally relevant environment to assist in reducing power imbalance between researchers and participants.

Recruitment

Participants were recruited by our patient researcher. A cancer survivor herself and a well-known, respected member of several Indigenous communities and organizations, she contacted several participants from various locations. In addition to drawing upon her social network, she played a pivotal role in the Sharing Circle itself. All participants were those who had cancer, were going through cancer treatments, or were family members of patients undergoing cancer treatment and who self-identified as being Indigenous. Patients and family members received \$100 CAD for their participation.

Protocol

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3 The gathering began with a meal provided by the researchers and hosted by the Heritage
4 Park kitchen staff. After the meal, the researchers explained the study and facilitated signed
5 informed consent. Our research was conducted according to customs of a Sharing Circle.^{16,}
6 ¹⁸⁻²⁰ Prior to data collection, an Elder was offered tobacco by the researchers on behalf of
7 the project and responded with a prayer in the Cree language. The Elder did not participate
8 in the Circle; rather, the Circle was opened by the circle-keeper who offered Smudging to
9 the participants. The Indigenous patient researcher started the Sharing Circle by sharing her
10 cancer journey. Next, a small stone was passed in a clockwise manner and whomever held
11 the stone shared whatever they felt comfortable sharing until every participant, including
12 the researcher, shared a single time. As part of her postdoctoral training, the principal
13 researcher (first author) was invited into the Circle by the participants, and she was the
14 final member of the circle to share. As an evaluator of health support programs for
15 Indigenous Peoples,²¹ the researcher had participated in many healing Sharing Circles. She
16 had also taken part in ceremonies with the circle-keeper. Afterwards, participants were
17 debriefed by the Indigenous patient researcher from our research team. The Sharing Circle
18 lasted for approximately two hours.
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22 **Data Collection**

23 The circle-keeper led the data collection phase and ensured the relevant customs of the
24 communities were observed. Because of the nature of the Sharing Circle methodology, the
25 circle-keeper guided participants to freely share their cancer experiences without pre-scripted
26 questions. Because of the familiar cultural aspects of the methodology, it was not necessary to
27 provide participants with detailed instructions regarding the structure and protocol of the Sharing
28 Circle. Stories were collected via auditory recordings for verbatim transcription.
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31 **Patient Orientated Research**

32 The Indigenous cancer survivor was connected to the research team by a member of the
33 provincial First Nations and Métis Health Service (FNMHS). Acting as a cultural
34 consultant on an earlier interview study with Indigenous patients with cancer,¹⁴ the patient
35 was instrumental to several research phases: formulating the research question guided by
36 her experiences, informing the research method (i.e., the Sharing Circle), participant
37 recruitment through her social networks, and research dissemination. She also filled the
38 role of patient researcher through influencing our Sharing Circle methodology, navigating
39 the identification of participants' cultural background, and leading the cultural Protocols of
40 a Sharing Circle. Alongside our circle-keeper, she facilitated the Sharing Circle Protocols
41 established within the community. As she was the first participant commencing the Sharing
42 Circle and the topic of discussion, she initiated the tone of the circle. To ensure the validity
43 of our analysis of the transcript data, a second cancer survivor who had not participated in
44 the Circle verified our analysis.
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48 **Ethics Approval:** The study received ethics approval from the University of Saskatchewan's
49 Behavioral Research Ethics Board.
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51 **Analysis**

52 In alignment with Indigenous methodology,^{16,17-20} we chose to conduct a thematic narrative
53 analysis to understand the role of trust and world view on shared decision-making of
54 Indigenous patients with lived cancer experiences. After audio-recording, the data were
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sent to a transcription service, the Social Sciences Research Laboratories (SSRL) at the University of Saskatchewan. The analysis was conducted in several phases. First, taking a deductive approach, we searched the transcripts for references to the key concepts of trust and world view. The transcripts were read and reread, and sections were highlighted to identify preliminary themes. These highlighted sections were then reread and organized in a chart format to ensure the themes matched the narratives. The first author and the fifth author coded the data. Based on keywords from the participant quotes, sub-themes and, finally, meta-themes were developed. An example of this phase of the analysis is included in Table 1.

Table 1: Example of Transcript Analysis

In the final analysis, there were 8 tables of grouped sub-themes which were collated into the 2 meta-themes. Because of our deductive analytical approach, we reached saturation once we found adequate representation of trust and world view in the data.²² The meta-themes and sub-themes will be described fully in the results section below.

Results

Participant Characteristics

The participant characteristics are summarized in Table 2. All participants self-identified as either First Nations or Métis. The majority were female (86%); most of the patients' stages of cancer ranged from early diagnosis (Stage 2) to terminal diagnosis. The length of time since diagnosis was one year to 20 years, with most of the participants having a diagnosis within 5 years. Half of the participants were from urban areas and the remainder lived on reserves or in smaller towns.

Table 2: Summary of Participant Characteristics (N=14)

Key Themes

Each of the 2 meta-themes comprised 4 sub-themes. The meta-themes were also interconnected. The participant quotes that reflect each sub-theme appear in the corresponding meta-theme table (Table 3 and Table 4). Sub-themes from meta-theme also overlapped.

Meta-Theme: Trust

Table 3: Sub-themes of Trust with Participant Quotes

Trust or lack of trust with the health care system and its providers was an important aspect of participants' experiences during their cancer journey. While some participants described their accordance with "doctor knows best", others preferred a second opinion to confirm diagnosis. Western treatments were especially suspect when cancer recurred, prompting participants to look to alternative treatments. When a second patient partner reviewed our themes, she reported that based on her work as an Indigenous patient navigator that patients in the more remote areas of

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3 northern Saskatchewan tended to be absolute in their trust of physician expertise. Her refinement
4 of this meta-theme indicated the complexity of trust's role in decision-making.
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6 Some participants shared a strong protective sentiment over their own medicines. Traditional
7 healing practices tended to not be shared with health care providers because of previous
8 stigmatizations. Participants viewed these more traditional healing practices as requiring
9 protection from Western health care. Others refused to share as they perceived the threat of the
10 commercialization of the traditional medicine. In instances where doctors accepted that patients
11 will try traditional forms of healing, a better therapeutic alliance with physicians was formed and
12 trust increased. Most Indigenous patients initially had trust in the physician's treatment
13 recommendation, however, they often used traditional healing after the first round of cancer
14 treatments.
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18 **Meta-Theme: World View**

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20 Table 4: Sub-themes of World view with Participant Quotes
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24 Strong adherence to Indigenous world view encompassed beliefs in the healing power of
25 traditional ceremonies. Similarly, there were many participants who blended "both ways" –
26 belief in the western health care system and trust in traditional healing, including ceremonies and
27 medicine. Participants spoke both of the need to encourage Indigenous cancer patients to engage
28 in traditional healing practices and for the health care system to support traditional practices in
29 facilities.
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32 Family relationships were especially salient for the Sharing Circle participants. Many of the
33 participants described using inner strength fostered by their Indigenous identity to sustain
34 themselves and their families. They expressed, unequivocally, the requirement to continue to be
35 strong, despite cancer, to support their families and remain resilient. A final aspect of Indigenous
36 world view was the importance of community. Knowing Indigenous survivors was highly
37 appreciated and valuable throughout their cancer journey. One participant noted how comforting
38 it would have been to "see a brown face" at the cancer facility. It increased morale knowing there
39 were other Indigenous survivors, and many participants spoke of the therapeutic value of the
40 Circle itself.
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46 Connections between the meta-themes and sub-themes are shown in Figure 1.
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51 A final observation about the data was that the two meta-themes, trust and world view,
52 were connected in important ways. For example, when participants trusted that their use of
53 Indigenous medicine was not at risk, they embraced both Western and Indigenous
54 medicine. They were passionate in their defense of traditional medicines:
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3 ...we have to be careful of them [western health care providers], very careful.
4 Because we have to – we're of the generation that has to preserve that, those
5 medicines. And they are medicines. And we have to share these stigmas that go
6 with it.
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9 Another connection between trust and world view was articulated by this participant who
10 trust both western medical results and traditional ceremony:
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12 In finding out something about your genes, my dad's traditional. My dad, he
13 sweats, he has led a rough life but he chose to go back to his roots. So what I can
14 say with that finding out the genetics [of cancer diagnosis], I've been able to find
15 my traditional roots again.
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18 The intersections among the meta-themes reveal the complexity of the experiences of
19 Indigenous patients living with cancer.
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22 Interpretation:

23 24 25 **Brief summary of the main results of the study**

26
27 This study explored concepts of trust and world view in decision-making with Indigenous
28 patients undergoing cancer treatment. A Sharing Circle offered a culturally safe
29 environment for Indigenous patients to share their cancer journey experiences.²³ The
30 Sharing Circle was made possible by the patient researcher who recruited community
31 members with lived cancer experiences who were willing to share their stories. She also
32 suggested the study setting and ensured the Protocols were followed for the gathering.
33 During the Circle, participants reported experiences related to trust and mistrust of the
34 medical system and several manifestations of Indigenous world view. Trust appeared to be
35 connected to the participant's perception of the health care system's acceptance of
36 Indigenous world view.
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40 41 **Limitations of the study**

42 Although a Sharing Circle offers a culturally relevant and potentially more appropriate method
43 for Indigenous participants to share experiences, the protocol means limited influence over
44 specific topics that participants discuss. Specifically, once the Circle started, the researcher was
45 unable to focus participants' stories to concepts of interest. Retrospectively, we could have asked
46 our patient researcher (the first person to speak) to explicitly highlight how trust and world view
47 impacted her decision-making regarding her cancer journey. This may have prompted other
48 participants to share more exclusively about their experiences related to trust and world view.
49 However, the nature of the flowing discussions and unpredictability in patient's narratives is
50 common in Indigenous methodologies, meaning the interpretation is often up to the listener.²⁴ In
51 verifying our analysis with a second patient researcher, we endeavored to stay true to a patient
52 understanding of the data.
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Lessons learned from patient involvement

Sharing Circles cannot be conducted with Indigenous People without following traditional Protocols. A circle-keeper who knows how to properly facilitate a Sharing Circle is instrumental to this research methodology. Our patient partner's familiarity with conducting the Protocols allowed us to respect and follow these practices prior to, during, and after the gathering. When a second patient partner reviewed our initial analysis and both confirmed and offered refined explanations, we recognized the value of having multiple patients in various stages of the project. As researchers, we gained valuable experience in participating within a Sharing Circle. Collaborating in this gathering helped strengthen our ties with Indigenous communities. We are confident that this could lead to further dialogue in how to optimize Indigenous access to and experiences with health care.

Conclusion and future directions in the area of the study

Our experience with Sharing Circles was fruitful in providing understanding of Indigenous views on trust and world view in health care decision-making. We were also able to form meaningful connections with local Indigenous communities. With one of the researchers partaking in the circle, we hoped to reduce the power dynamics between researchers and patients. Future directions could involve having Indigenous patients identify key solutions surrounding health care barriers in accessing cancer care. The connections between trust and world view could be explored in future research, ideally with the same participants from this study as trust and familiarity will have already been established. By building relationships between researchers and Indigenous patients, we are well positioned to lead future research in this area. Through collaboration with patients we can work toward reducing disparities in cancer care.

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Table 1: Example of Transcript Analysis

Participant Quotes	Key words	Concept (sub-theme)	Final/Meta-Theme
<p>And, I did what I had to do because I didn't know what else there was to do. I figured the doctors, they're the experts they know what's best for me. And, I believed in them I trusted them. And I had a discussion with my mom and she asked me if I was going to do the treatment they had planned out. I said, "Yes." And, I felt it from her that she didn't agree with it she didn't want me to do the chemo. And like me, thinking, 'Mom these are professionals they know what they're doing. I'm just going to do what they want, what they think is best for me.'</p>	<p>And, I believed in them I trusted them.</p>	<p>Physician expertise with treatment recommendations</p>	<p>Trust</p>
<p>And I think that's all we can do and share whatever we can. It's always nice to be able to sit like this and share with people because I think it's an important thing. Sometimes you need to get the load off and it's – sometimes it gets to be a little much load.</p>	<p>Increasing morale</p>	<p>Importance of knowing Indigenous survivors</p>	<p>World View</p>
<p>– I feel like I was able to assure him that I believed I was going to be okay. Because somewhere I did believe I was going to be okay because I thought of people like Sandra that were survivors</p>			
<p>And I just remember being in such despair and just feeling hopeless. And then I just thought I had to – I just got strong about something and I just thought, 'Barb, there's survivors. There's survivors.' And that's when it hit me, this is not a death sentence. People have survived it. Then I got hope and then I just took off from there and, spoke to people</p>			
<p>Right from the start I told them (children) what was going on because I just felt like I needed them to know, and I just – they're really very, very supportive and my husband is really supportive in all of it too.</p>	<p>Support system helps improve cancer journey</p>		
<p>And I think that's all we can do and share whatever we can. It's always nice to be able to sit like this and share with people because I think it's an important thing. Sometimes you need to get the load off and it's – sometimes it gets to be a little much load.</p>			
<p>He got a lot of my anger and how I was screaming at that time. But I don't think he took it personally, he was very supportive. Like I said he always turned it into humor, which sometimes I'd [laughs] get even more mad but - ."My kids are supportive they're behind me 100% and they didn't want me to do the chemo either. So, that was good. We agreed on all that.</p>			
<p>And, through this journey I've had – I've got five children. So I've got lots of grandchildren and, now I'm on to the great grandchildren, and they're all so supportive and they've always, always been there beside me, beside their mother. Beside everybody that's been sick in my family, we're all always there.</p>			
<p>so I'm going through the journey, and you were talking today about family ...And she was upbeat and we were chatting and, she was the strength. I could feel her strength, and that's what really helped me support. I really felt that the support of</p>			

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friendship is also very huge. The support of family is huge and I had that support from my children, to this day I do. But also the support of friends, So that was important so, I think that piece is really important is the support of friends. Because sometimes you don't have the family, or you're perceived as the strongest one in that family.			
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Confidential

Table 2: Summary of Participant Characteristics (N=14)

Characteristic		Frequency (%)
Sex	Male	2 (14)
	Female	12 (86)
Who attended	Patients	9 (64)
	Family members	5 (36)
Types of Cancer	Bladder	1 (7)
	Breast	4 (29)
	Cervical	1 (7)
	Colon	1 (7)
	Ovarian	1 (7)
	Uterine	1 (7)
Cancer Stage	Cancer free	6 (43)
	Living with Cancer	3 (21)
	Recurrence	2 (14)
	Family with cancer	5 (36)

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Table 3: Sub-themes of Trust with Participant Quotes

Sub-themes	Participant Quotes
Physician expertise with treatment recommendations	And, I did what I had to do because I didn't know what else there was to do. I figured the doctors, they're the experts they know what's best for me. And, I believed in them I trusted them. And I had a discussion with my mom and she asked me if I was going to do the treatment they had planned out. I said, "Yes." And, I felt it from her that she didn't agree with it she didn't want me to do the chemo. And like me, thinking, 'Mom these are professionals they know what they're doing. I'm just going to do what they want, what they think is best for me.'
Mistrust with diagnosis	So he sent me to do surgery right away. And I don't know I just have no idea why but I told him, "I want a second opinion. I don't want to just go into surgery and not know what's going on." So he sent me to [specialized tertiary centre] and the surgeon there because they had already scheduled my surgery and everything, but I told them no I want a second opinion. And so anyway the – he sent me to [specialized tertiary centre] and the doctor said, "Had they done that surgery there in [local hospital] it would've been the wrong one. So it's good that you asked for the second opinion
Mistrust western treatment after cancer recurrence	I said, "I want to live, I want to live. I want the best quality of life and I don't think chemo is quality of life." To have to go through the pain and everything, I wanted to give up halfway through my first bout of chemo...So when I was diagnosed a second time, it was – no I know I'm not doing chemo. No. Two years ago and it's back again, I'm going to try something else.
Protection of Indigenous medicine	Everything's getting better I'm getting healthier and stronger, and she asked – that's when she said, "Well what are you doing?" Yes I was doing the cannabis she knows, she knows I was drinking a lot of chaga tea and stuff like that. Eating healthy is the main thing, and, this lady that I've been seeing, she's helped me a lot too throughout my journey. And I believe that's why I'm still here today. And, I just tell the doctor I'm just doing the same thing. Only thing I'm going to share, because if I share anymore what are they going to do with it? Are they going to go after her? Are they going to ban the stuff that she uses? Take that from her? For helping us, anybody that she's helping

Table 4: Sub-themes of World view with Participant Quotes

Sub-themes	Participant Quotes
Best of both worlds	He was our way, and he was the white man's way. "The best of both ways", he said. It's the way I followed that, and he also said, "Do four ceremonies, sweat, dance, round dance, sun dance, use those as a support." And that's what we try to do today. We go to these ceremonies. It's amazing how it's helped us
Spiritual beliefs	These things that we believe in - an eagle feather can help a person in the hospital, just have it by the pillow or a bag of sweet grass, makes them feel good and stronger. So I try to share that
Required to be strong for family	"And I needed to be strong for my kids, I didn't have time to panic, but I was panicking. I'm strong. I'm a strong, beautiful indigenous woman with a strong voice, and I will use that voice to help all of us for our children and our grandchildren. Because, we need to be there for them. We need to set this foundation for them we need to show them and we need to lead the way"
Importance of knowing Indigenous survivors	So, I really like the story though about gathering of stories and, so that people have something to refer to. Our people know that there are avenues out there that are – people to help, there are things that exist that can help our people get through the – not only the physical, but the emotional trauma that impacts not only the person that has been afflicted with a cancer but the surrounding people in their support groups. I think that they're just as important. That was it.

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Connections between the meta-themes and sub-themes are shown in Figure 1.

