Decisions on cancer care by Indigenous peoples in Alberta and Saskatchewan: a narrative analysis

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ABSTRACT:

Introduction: The prevalence of cancer is increasing among Indigenous peoples in Canada. To enhance quality of life of those Indigenous people affected by cancer, their decision-making experiences must be understood. This article presents the findings of a qualitative study exploring the treatment decision-making practices among Indigenous peoples with cancer in rural and remote Alberta and Saskatchewan, Canada.

Methods: This study employed a qualitative narrative-based approach using the Indigenous research method of storytelling. Seventeen Indigenous participants (14 women, three men) with various forms of cancer were interviewed. Open-ended questions were used that were designed to understand participants’ decision-making processing regarding their cancer treatment.

Results: Keeping with Indigenous methodology, the interview transcripts were analysed by a narrative method, with the intent that the data would be presented in story format. Eight vignettes
relating to decision making were created: being strong for family; family support; strength and independence; denial and not wanting to know; fear-based decision making; finding the blessing; the spiritual journey; and traditional medicine and doctors. Participants were involved in validating the analysis to ensure that data were accurately interpreted.

Conclusion: The vignettes demonstrate the similarities and differences among Indigenous people with cancer from other countries. A primary feature is that family members play a central role in participants’ cancer treatment decisions. While some participants embraced and relied upon traditional medicines, others were supported by the providers of Western health care. A healthcare system that provides access to both traditional and Western medicine can be essential to culturally safe, high-quality cancer care for Indigenous peoples.

FULL ARTICLE:

Introduction

Yeah, you’re going to encounter people who walk in many different kind[s] of shoes and many different places and walks of life but there will be some, of course, similarities but probably you will see more differences than anything in how people react and respond to this sickness and disease.

(Research participant)

Indigenous peoples in Canada – First Nations, Métis and Inuit – have unique health needs, yet often encounter difficulty in the healthcare system. These disparities stem from the historical and ongoing effects of colonization that affect the determinants of health for Indigenous peoples. Regarding cancer, lack of prevention programs and equal access to cancer screening presents added challenges for Indigenous people. The contexts faced by Indigenous people with cancer have been examined through a patient, family member, healthcare provider and administrator lens. In Manitoba, a neighbouring province to Saskatchewan, Lavoie and colleagues called for a whole-system administrator lens. This article presents the findings of a qualitative study exploring the cancer decisions made by Indigenous participants in remote areas of Alberta and Saskatchewan, Canada.

Methods

The research team was guided by an Indigenous advisory group from the First Nations and Métis Health Services. This group works as a unit whose mandate is to ensure healthcare services are culturally safe for Indigenous peoples within the health region where the research took place. Members of the advisory group also had close ties with surrounding Indigenous communities. The lead investigator, who is non-Indigenous, spent considerable time with Indigenous Elders and Knowledge Keepers, receiving guidance on how to conduct the research in a culturally respectful and appropriate manner. In addition, the research team had both Indigenous and non-Indigenous members, as well as members with considerable experience in research with Indigenous peoples.

Participants and data collection

Seventeen Indigenous participants with cancer who were from rural and remote Alberta and Saskatchewan, Canada, participated in the study. Although all participants had lived on Indian Reserves, relatively remote tracts of land set aside under the Indian Act 1876 and treaty agreements in Canada, nine participants were currently residing in cities in Saskatchewan and Alberta when they were interviewed for the study. The remaining participants lived in remote communities with limited access to treatment such as surgery, chemotherapy or radiography. While the majority of participants held registered status as First Nation with Cree heritage, two participants were Métis, and two did not reveal their status.

Participants were recruited by an Indigenous person on the research team, who was also a cancer survivor and a well-known and well-respected member of several Indigenous communities and organizations. She contacted the participants and also followed up after the interviews. In addition, she attended sweat lodge ceremonies on behalf of the research program. Because she drew upon her social network to recruit, there were no particular exclusion criteria for recruitment. The ages of participants ranged from 45 to 67. There were three males and 14 females; types of cancer included colon, prostate, breast, ovarian, and lung; stages of cancer ranged from early diagnosis (stage 2) to terminal diagnosis; and length of time since diagnosis was from one to 20 years.

The time and place for the interview was negotiated between the participant and the interview team. One of the strong suggestions from an Elder was for the lead investigator to do the interviews himself. On some occasions, the lead author (a Woodland Cree
The following statement was used to focus the narrative creation: “narrative format to answer the research questions. The aim was to value participant voices in a relational, storied and understood ideas and relationships as valued equitably. Our guided by Indigenous methodologies. Indigenous methodologies cancer treatment decision-making vignettes represents an analysis narrative would not be appropriate. Rather, eight vignettes were to convey participants’ treatment decision-making experiences in a cohesive narrative. Collectively, the presentation of the cancer treatment decision-making vignettes represents an analysis guided by Indigenous methodologies. Indigenous methodologies understand ideas and relationships as valued equitably. Our aim was to value participant voices in a relational, storied and experiential way.

Each participant was sent a copy of their transcript for review. In addition, several interviewees attended a gathering where the meta-narratives were presented. This method was intended to encourage feedback to ensure that the researchers had not misinterpreted the data when creating the vignettes. Due to word limitations in most journals, not all the vignettes can be presented. The authors apologize to the participants for not being able to share all their words.

**Data analysis**

The data were sent to a transcription service and then analyzed by RR, who is Indigenous, in consultation with TC, who is non-Indigenous. The process of analysis was to read the transcripts once, read them again and highlight significant sections. The highlighted sections were reread to identify preliminary themes. A similar analysis was performed by RR in a study of the meaning of cancer among the Woodland Cree in Saskatchewan. This process elicited a list of 26 themes such as becoming more vigilant and aware of changes in body, doctors not taking appropriate action, family members with cancer.

The highlighted sections were then cut and pasted under the 26 themes; in some cases, the text was placed under more than one theme. On reading the data for a fourth time, eight meta-themes emerged: family; decisions; health care and cancer care; diagnosis and treatment; history and miscellaneous; personal effects, suggestions and wanting to help; worldview; and traditional healing. The next step was to bring the information together into a narrative format to answer the research questions.

The following statement was used to focus the narrative creation: “The story of your cancer and how you made decisions regarding your treatment”. Due to the variety of cancer types, gender differences and severity of illness, it was decided that one meta-narrative would not be appropriate. Rather, eight vignettes were created: being strong for family; family support; strength and independence; denial and not wanting to know; fear-based decision making; finding the blessing; the spiritual journey; and traditional medicine and doctors. The purpose of the vignettes was to convey participants’ treatment decision-making experiences into a cohesive narrative. Collectively, the presentation of the cancer treatment decision-making vignettes represents an analysis guided by Indigenous methodologies. Indigenous methodologies understand ideas and relationships as valued equitably. Our aim was to value participant voices in a relational, storied and experiential way.

**Ethics approval**

Ethical approval was granted by the University of Saskatchewan’s Behavioural Research Ethics Board (No. 16-123).

**Results**

Each participant had their own story and honouring their story was important in the methodology as well as from perspectives of Indigenous worldviews. One of the teachings among Indigenous Elders and Indigenous ways of knowing is that the interpretation of a story is up to the listener and/or reader. Thus, the vignettes will be presented without any preamble and comprise voices from multiple participants.

**Being strong for family**

I signed power of attorney over to my daughter already. But I woke up and one of the things that made me wake up was seeing the look on my son’s face when I signed the power of attorney over to my daughter. And I thought about it, and I phoned him the very next day and I said ‘listen, don’t you ever, ever let me take hope from you again. I will never, ever do that’.

He says ‘okay mom! I won’t’.

And so I realized that’s what’s pulling me through, is being strong for them.

One of the things that I always, always said was ‘my kids aren’t going to see me like this. I’m not going to let them know that I’m in pain. My kids won’t’.

I really withdrew from my family I thought, I’m going to die I need to prepare them. And I didn’t allow them to be part in helping take care of me at all. Which was a mistake, it was a huge mistake. So I tried to pretend for them that everything was fabulous. I did a lot of crying in the bathroom, [laughs] I – go take a bath and sit there and cry.

I can’t be that different from most other Indian women you know they don’t talk about it because you’re the strength in the home. You have to be. You don’t want your children to see you weak. Having cancer in our life and in our circles, you are fragile all of a sudden – without wanting to be.

But I don’t have to rant and rave to my family and put this burden on my family. We understand our treatments and how we feel.

**Family support**

When it came to deciding on treatment I talked to family. I phoned my sister. And she says, ‘Well whatever you decide’.

I also spoke to one of my cousins and she said ‘this is your life. Always remember you have to be the one to want to do things. All of us we love you. We care about you. We’re here for you. We’ll support you any which way you want’. She said, ‘you have to make those choices yourself, we can’t make them for
you. You need to do that yourself.

My husband was real good support for me too. He was always there, like when we were at the doctor's office, he said, 'whatever she decides I'm behind her, what she wants to do'.

And he would always be the one who would just snap me out of where I was going. And we did a lot of back and forth stuff about, you know I'd read something, or I'd go to an appointment, and the only thing that I would remember is the negative stuff, you know? And then he would say, 'no that's not what she said, she said this, and she said this'. The only things that I heard were going to be negative, or I'd hear the word death – you know, the bad things. That's what I would pick up on and I would focus on those, right?

But I finished my treatments, they were very hard 'cause halfway through I just kind of gave up. I had mouth sores and I was – I had no energy and – everything that chemo does to people. I was convinced that this is the part where I'm dying – and I didn't want to go back anymore. I was like I'm done. But my kids and my husband kept – convinced me to – to do this.

But, it was the best choice I could have made.

**Strength and independence**

You have to speak up for yourself because nobody else is going to do it for you. You need to stand up for yourself. I started researching things. I made those decisions myself. What I wanted to do. How I wanted everything to go. I just told them.

I'm very outspoken, you know whatever I want to say, I say. Because I'm one of those crazy people that keep digging in until I'm comfortable with what I find.

When the doctor told me he wanted to operate on me right away. I said, 'no, you're going to check me good. You're going to check me for all those tests, because I want to know how far this cancer has gone, and how long I've had it'. He sent me for every test.

Treatment was a horrendous experience. After the first treatment I lost all my hair, that in itself was hard to deal with but what I did was I just shaved it all off. I wasn't going to watch it fall out because it was getting me depressed. I was just staying in this moment. I wasn't going to think about what's going to happen six months down the road. I wouldn't let my mind wander that far ahead. Right now I have to take care of myself and that was my thinking right through it.

With the chemotherapy I was told that if I got a cold or got sick or anything that I was supposed to move to the hospital right away and I just flatly refused. I did get sick but I just took care of myself at home.

I forced myself to eat. And when I started to feel nauseated I tried to not let it. I ignored it, because I thought if I don't eat I'm going to get weaker. I have to eat. I couldn't taste my food because all I tasted was that chemo in my mouth for how many days. So all the things I liked to eat I couldn't taste them but I forced myself to eat. I didn't let that chemo overtake my body and my mind. I know I have a real stubborn mindset, and it's good to use it in a positive way, because that will beat anything in your life. Another thing I started doing was I started to walk. My first little walk was maybe from here to the end of that wall. That was my first little walk and I just kept walking a little more. I remember after the second treatment, when I decided I was going to walk I said to myself 'if you want to get through this, you've got to build up your strength' so that's why I pushed myself to walk. I knew I had to keep my strength up to get through that chemotherapy. I had to. I just knew it.

After my sixth treatment – I was actually supposed to go for eight double treatments but the seventh treatment I refused. I just couldn't. I knew my body wasn't strong enough to take the seventh treatment so I just said no. I go see my doctor and I say 'I'm not taking it. I can't. I'm too weak. I can't right now'.

I mean at the end you just do what you have to do right? For me getting better had a lot to do with who I am. I want you to know that.

**Denial and not wanting to know**

I already kind of knew. I had a strong sense something was wrong, because my body the way it was acting. The way I knew was because your body normally talks to you, but I was trying to ignore it.

Yeah but you know, you don't want to think it's cancer. I mean I've been healthy pretty much all my life. I've been working and doing all kinds of things, travelling and I was just basically in denial at that part. I was sick – very sick.

When I got the diagnosis, my husband was with me. He broke down, and he was crying and there's me standing there because it hadn't hit me yet. He said, 'how can you just stand there? Judy that's so scary. You know?'

I said, 'maybe this hasn't sunk in yet'.

When I had my biopsy I went in and my doctor said 'I want to put you in the hospital. Sign this release form' so I signed the release form. He said 'if what I find is cancer, you will wake up without a breast. But if it's not cancer, if it's a benign I will take a partial off but you will still have part of your breast'.

I did trust, I do trust the system. How can you not? Everybody is learning still about this cancer thing [laughs]. I have to trust the system.

I was encouraged to go to a cancer circle but I said 'no, I don't have time for that'. I thought 'well I don't really want to hear those stories'. I don't know if it's denial. I didn't want to hear those stories. I just didn't want to hear other people's suffering because I really didn't want to talk about my own suffering either.
They did so much to me that I just, you know, like sometimes I want to block it off.

Fear-based decision making

Well, it was also the fear. I think the fear comes from not knowing and not understanding, because I think a lot of First Nations people, when they hear, and that's what they see, right? A lot of people in our communities are – by the time they're diagnosed with breast cancer, lung cancer, ovarian cancer, colon cancer – they’re at stage four, and they're dead within three months. A lot of people don't want to know. If you don't know, then you’re okay. You know, people say after, when somebody has died, they'll say, 'I remember they complained about something in their back, or they complained about lots of pain, but they wouldn't go to the doctor'.

When I finally went to my doctor, I got referred to a surgeon right away. The surgeon called it aggressive and she wanted to deal with it with everything; surgery, chemotherapy and radiotherapy, and of course that's scaring me during the process. This is all fear, fear, fear, fear being added to everything.

I looked at the surgeon and I said, 'take both of them off'.

She said, 'are you sure?'

I said, 'yeah. Because you know what, I don't want it going to everything. I was scared to die. I was scared to lose control. And I was angry at some level, that I couldn't do anything about that, that I had no choice in that and – I felt a lot of anxiety around that time. And I thought about my wife and my children and, I thought about a lot of things like that, regrets, guilt.

But then I started asking myself questions, like why are you scared? Because I'm scared of this, I'm scared of that, I'm scared of leaving. I'm scared of being out of control and, so what's that doing for you? I asked myself that.

But I want to be able to see all the things a person, wants to see. You want to see your children grow up, you want to see your grandchildren healthy.

But the journey I’ve been has re-acquainted me more so with my spiritual dimension, my yearning and love for family and my land and my people and ... as terrible as it sounds this mets [metastatic] has made me a better person. I’ve become more compassionate, more sane [laughs].

My children are beautiful. The reason I say they are so beautiful is because I know I did everything right. They gone to school, they gotten educations, and they become these beautiful independent people. So I’m not afraid when I pass. That's right, it's inevitable. That's one of the most important things of this new journey I’ve realized, it’s just a new journey in my life. It's teaching me a heck of a lot.

Including my views on life. I love life. I love waking up in the morning and seeing sunshine and saying 'thank you God' because that's life. It's joy.

The spiritual journey

When the doctor gave me my diagnosis, he left me alone in that room for a while while I – I proceeded to have a huge argument with God and just angry and, you know, I want to see my grandchildren it's not fair my mom didn't get to see them and, fuck you – sorry for the 'F' word but that's how I felt I was just panicking.

It’s always been believing the spirituality, because that’s who we are, with our belief and our Creator and Mother Earth. But I knew I had to make time to talk to Creator, I couldn’t just expect him to be there when I needed ... So by going back to ceremony, I had to learn more of the ceremonies.

I did a lot of praying. I did a lot of talking to my body. I just said 'you know what, you do not belong in my body. You just stay the way you are. Don’t grow anymore until they can get to you' and I just meditate, and meditate, and meditate. I did a lot of meditating, I did a lot of praying, I did a lot of spiritual faith kind of stuff. I prayed a lot. I stayed in this moment.

Okay, so when they remove pieces of you, like in surgery, I asked if I can have my breast, and they said no. Like I have a lot of friends that have grown up very traditional as well, and like one in particular her dad had diabetes and had to have both of his legs amputated from the knee down. And they insisted, because that's the way they were raised – there's a belief that our spirits will wander, if we’re not wholly given
back to Mother Earth, right?

I didn’t know what I would do with it, I thought if I, put ‘em in a freezer or did something so that when I do leave this earth – they could just come with me but they said no. I asked, ‘What do you do with – what are you doing with them? You know do they just go in a heap? Do you throw them out? Like what do you do?’ But I – I never did get a good answer to that.

I know my life is in God’s hands, but I still want to take precautions to ensure that I live a long life. I made different health choices. I’ve been overweight. So I got healthy again, lost the weight, tried to do as much as I can, but I try not to dwell on it. When you experience your spirit, your holiness, your sacred-ness, your one-ness your, whatever it’s called, there’s no turning back. And you wake up. You wake up to what you’re capable of. And nothing in this world really has to change but you can.

So am I going to beat this? I don’t think so. You know, I’ve come to appreciate and accept death. Honestly, just having accepted it has settled my mind and emotions at the onset. Death is not an option, it’s inevitable.

**Traditional medicine and doctors**

I informed my oncologist straight up that I’m already on medication and he goes ‘what kind of medication are you on?’ and I told him I had my Elder who has doctor me and he asked for a sample of it, to see if it interfered with the drugs and the chemicals that they’re providing for me and I honestly told him I couldn’t and he was okay with that. Then he came back in two weeks with my chemotherapy review and he asked me again for a sample of it [laughter] and I refused. He was pretty adamant about it that he goes ‘I’ve just got to know what’s going to happen’.

I told him, ‘trust me. It’s going to work’.

Every time I went and got checked he’d tell me the tumor is shrinking. He’d say, ‘this is how much it’s shrunk already’. He’s kinda looking at me.

But I had to protect it. The validity in terms of me acquiring that knowledge is the understanding that I have to at least respect the Knowledge Keeper, his or her wishes and that I cannot share this, especially with the Western medicine. I was told by my Elders that I shouldn’t you know, really brag about what I’m taking.

I guess what I’m seeing here is two people operating in isolation but there’s one person in the middle that they’re both trying to help but there’s no connection, there’s no relationship.

I don’t expect a really close strong relationship to develop between patient and doctor but all I’m saying is that I shouldn’t have to feel guilty for taking my own medicine.

**Discussion**

This study explored the treatment decisions made among Indigenous peoples with cancer in rural and remote Alberta and Saskatchewan. The cancer-related decisions of individuals in this study were grounded in spirituality, family, and individual strength. At the same time, decision-making could be influenced by fear and denial. Individuals found blessings through their culture, which in turn impacted on their perspectives of health and healing. Cultural beliefs were not always recognized by the system. For example, a woman noted the importance of preserving the parts of her body post-surgery and the system’s inability to accommodate that. When the healthcare system was open to other forms of healing, Indigenous cancer experiences could be enriched.

While this study examined the treatment decisions made among Indigenous peoples with cancer in Alberta and Saskatchewan, the themes paralleled the experiences of Indigenous people with cancer in other Canadian jurisdictions and in other countries. How the healthcare system can support methods of traditional healing has been explored in some parts of Canada. In northern Ontario, Anishinaabe people with cancer and key informants with Indigenous and Western health perspectives described traditional medicine as essential to achieving health. This study found that an Indigenous realization of health (Minobinamadiziwin) was possible despite cancer diagnosis. When the two forms of healing, traditional and Western, were ‘braided’, the result was optimal health. A notable finding from our study was the decisions participants made regarding traditional medicines and doctors. Participants wanted access to both types of treatment – ones derived from their culture and Western medicine. In an Australian study, Indigenous patients with cancer have reported comparable treatment options. The women in Prior’s study emphasised the use of traditional medicine alongside Western medicine to not compromise their cultural value for holistic health.

The recognition of the crucial role of spirituality has also been recognized among Indigenous patients with cancer. As the harms of lack of cancer supports are documented, Indigenous designed survivorship programs are emerging. At the same time, the individuals in this study spoke of their strengths in facing cancer. The development of support programs could focus on identifying and encouraging these strengths.

Similar to our study, other research has found that family support is a key aspect of Indigenous cancer patient experience. Being strong for family has been described by both male and female Australian Indigenous cancer patients. For female Australian cancer patients, treatment decisions are often influenced by family considerations. The inextricable connection between family and culture was deeply comforting to Australian male cancer patients. The participants in our study remarked on family supporting any decision made by the patient – which also reflected the participants’ strength and independence.

Aligning with our theme of denial and not wanting to know, Newman and colleagues reported how one participant in their study ‘didn’t want to know the bad bits’ (p. 4). Such denial prohibited participants in another study from seeking health services because cancer was tantamount to a death sentence.
Once Indigenous patients seek treatment, fear might drive their decision-making processes. In our study, a participant told her surgeon ‘take both [my breasts] off’ to reduce her perceived risk of mortality. With the belief that cancer is equivalent to death, fear-based decisions could lead to discounting early symptoms and not initiating treatment after diagnosis.\(^2\)

Despite the fear and anxiety that permeates the experience of cancer, participants in our study found the blessing of family and daily life and transformed the fear into gratitude. Newman and colleagues\(^2\) found a similar theme with Indigenous men with cancer, who identified a main component to their experience as the blessing to be alive. A connected theme is the spiritual journey. Spirituality and culture are linked for many Indigenous cancer patients – for some, cancer diagnosis is associated with a spiritual curse\(^2\) and for others, spirituality offers a mechanism to cope with the disease.\(^2\)

The results of another Canadian study about First Nations experiences with cancer have documented the systemic challenges with diagnosis and treatment.\(^6\) In Manitoba, a neighbouring province to Saskatchewan, patients and families and service providers reported several challenges when accessing cancer care.\(^6\) For patients navigating the system, obtaining timely diagnoses, and logistical burdens were systemic issues. Patients also experienced difficulties with the logistics of travel and other income supports. They expressed a fear of dying while away from home and preferred connection to community to need for care. In the current study, fear also played a role in decision making, and family support was paramount for the cancer journey.

**Strengths and limitations**

This study considered the cancer journeys of a small number of Indigenous people in Alberta and Saskatchewan. Most participants were from one specific Indigenous background (First Nations – Cree heritage). Given the diversity of Indigenous groups in these two provinces and the small sample size, we acknowledge our findings are relatively limited. The study’s main strength was the capacity to interview participants through gaining trust. By working with an Indigenous advisory committee and an Indigenous cancer survivor, we were able to have in-depth conversations about personal cancer experiences. This lends to the authenticity of the findings.

**Implications for future research**

Our work with Indigenous patients with cancer can lead to a closer examination of decision making in the healthcare system. Some participants spoke about tensions between cultural beliefs and service provision. While this study could offer healthcare providers insights into how Indigenous patients with cancer make decisions, understanding how providers perceive Indigenous patients’ decision making could lead to better cancer care. Research into providers’ perspectives could facilitate interactions with Indigenous patients and establish system level support needs.

Another area of study would be an examination of Indigenous patients in remote and rural areas versus urban centres. Given greater availability of screening and treatment centres in urban centres, decision-making experiences of Indigenous patients could be different. In the present study, we also did not consider status differences between Métis and First Nations. Since these two Indigenous peoples have separate healthcare supports, future research could uncover the impacts of these differential supports on cancer care.

**Conclusion**

Within Indigenous world view, respectful research, analysis and interpretation of data are paramount. Indigenous protocols were followed as much as possible in conducting this research. A member of the research team attended sweat lodge ceremonies, requesting prayers and guidance. The participants understood the protocol of being offered tobacco as a form of reciprocity and acknowledgement.

Storytelling is an important method of teaching in Indigenous communities.\(^14\) The storyteller does not tell the audience what they are supposed to ‘learn’ from the story, rather it is up to the individual to decipher the intricacies within the story to find meaning for themselves. The participants had the opportunity to share their stories and how cancer has affected their lives and their families.

What the researchers learned from these stories can be lessons to enhance the supports for Indigenous people and their families along their cancer journeys. A primary feature of these narratives is that family members play a central role in participants’ cancer treatment decisions; some sought advice from family and received support for their own decision. Thus, supports for cancer patients could also include assistance for families. Vignettes of finding blessings and a focus on spirituality appeared interconnected with strength and independence. While some participants embraced and relied upon traditional medicines, others were supported by the providers of Western health care. A healthcare system that provides access to both traditional and Western medicine may be essential for culturally safe, high-quality cancer care for Indigenous peoples. Given the role of spirituality, ceremony and Elder guidance, the implementation of Indigenous world view into cancer care practice could be beneficial. Recognition of Indigenous world views by care providers and policy makers could be a next step to supporting Indigenous patients in Western systems.

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