

Ceremony, Respect, and Understanding: Storytelling as Method for Indigenous Patient Experience Measurement to Inform Culturally Safe Care

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Article Info

Keywords

Storytelling
Story-Based Approaches
Indigenous Patient Experience
Indigenous Health Research
Patient Experience Metrics
Health Services

Abstract

Globally, it is essential that Indigenous-specific patient healthcare experience metrics are developed, to ensure that the distinct experiences of Indigenous Peoples in healthcare are captured appropriately. In this study, we sought to understand Indigenous Elders' perspectives on storytelling as a way to measure and respond to Indigenous patients' healthcare experiences. This study is led by a team of Indigenous and non-Indigenous researchers committed to using culturally safe approaches throughout all stages of research. Four individual interviews were conducted with Indigenous Elders who serve patients in the healthcare system in Vancouver, British Columbia, Canada, and thematic and narrative analyses were used to identify themes pertaining to the use of storytelling in the Elders' work, and as an approach to measuring Indigenous patients' experiences. Four BC First Nations Elders participated in one-on-one in-depth interviews between March and August 2023. Elders shared that an important element of storytelling is the ability to centre positive conversation to help with a patients' healing journey. Storytelling, which represents a traditional practice of knowledge translation for many First Nations, Métis, and Inuit communities, was found to connect Indigenous Peoples to cultural teachings and supports, which allowed for the building and strengthening of relationships between patients, families, and healthcare providers. Findings illustrate that storytelling is an important and effective strategy for measuring and responding to Indigenous patients' healthcare experiences. Study results support the use of storytelling as a method for measuring Indigenous patients' healthcare experiences, and future research should focus on understanding community perspectives and logistics of implementing a storytelling-based, Indigenous-specific patient experience measurement tool.

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<https://doi.org/10.32799/ijih.v21i1.45607>

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Introduction

Globally, Indigenous Peoples continue to experience poorer quality of healthcare in comparison to non-Indigenous populations, contributing to known differences in health outcomes (Marrone, 2007). The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) requires “equal access to the highest standards of physical and mental healthcare,” requiring signatory states to take the appropriate measures to implement necessary improvements to achieve this goal (United Nations, 2007). Despite these commitments, there is a lack of understanding and no culturally safe approach to effectively measuring Indigenous Peoples’ healthcare experiences. This hampers the ability to enact meaningful change to ensure equitable and appropriate access to healthcare services.

In Canada, which is a signatory state to the UNDRIP, there are continued gaps in healthcare access, programming, and culturally safe care that require attention in order to improve the health and well-being of Indigenous Peoples (Adelson, 2005; Browne et al., 2016; Greenwood et al., 2018; Pilarinos et al., 2023), including First Nations, Métis, and Inuit Peoples (Government of Canada, 2009). This can be seen in British Columbia (BC), Canada—the province that this study was situated within—where a government commissioned report (Turpel-Lafond, 2020) identified rampant levels of anti-Indigenous racism across the public healthcare system, leading to significant harm and contributing to already high levels of distrust in the healthcare system. As such, to address anti-Indigenous racism and discrimination within healthcare, the report highlighted the need to understand, measure, and respond to Indigenous patients’ experiences in healthcare in a culturally safe and Indigenous-specific way. To do this requires equity-oriented, culturally safe metrics that are developed by and for Indigenous Peoples (Browne et al., 2016; Turpel-Lafond, 2020).

Ongoing measurement of patient experience is critical in order to continue to be accountable to address Indigenous-specific racism in our healthcare systems. Across Canada, patients' experiences are primarily collected through questionnaires that capture large sets of standardized data (Beattie et al., 2015). For example, the Canadian Patient Experiences Survey of Inpatient Care (CPES-IC) is a patient experience metric administered across Canada, including in BC, but it does not include any specific measure of Indigenous Peoples' healthcare experiences. Existing tools are unable to capture the nuanced experiences of Indigenous patients, as they were not designed with the involvement of Indigenous Peoples. There is a need to centre Indigenous voices using methods that uplift their unique experiences in the healthcare system. In BC, the Office of Patient Centred Measurements began measuring Indigenous experiences in healthcare in 2020, but primarily uses survey-based data collection that may not capture the distinct experiences of Indigenous patients (Morgan et al., 2021). If Indigenous voices are not represented in survey data, we will be unable to address anti-Indigenous racism and improve Indigenous patient experiences in the healthcare system. Therefore, it is essential to have Indigenous voices leading how Indigenous patient experiences are measured. Although there are no Indigenous-specific measures, three Canadian-specific frameworks have been created, including the National Collaborating Centre for Indigenous Health's (NCCIH) Framework for Indigenous Cultural Safety Measurement, the Canadian Institute for Health Information's (CIHI) Report on Measuring Cultural Safety in Health Systems, and the Indigenous Health Care Quality Framework from Ongomiizwin Indigenous Institute of Health and Healing and the George & Fay Yee Centre for Health Care Innovation (Canadian Institute for Health Information, 2021; Indigenous Health Research Team, 2022; Indigenous Healthcare Quality Leads et al., 2022; Johnson & Sutherland, 2022). These frameworks highlight the importance of cultural safety in care and the need for evaluating culturally safe practices, including the right to practice traditional healing, the right to self-determination, and access to healthcare services without discrimination (Johnson & Sutherland, 2022). In this article, we seek to explore how storytelling can be applied directly to patient experience metrics.

The process of patient experience evaluation in BC ensures that surveyors have Indigenous cultural safety and humility training prior to asking questions in the field. There is also an effort to recruit Indigenous surveyors to increase diversity within the provincial surveyor team. However, gaps remain in our ability to implement evaluation strategies in culturally appropriate and relevant ways. Given the limited capacity of survey and questionnaire-based data on patient experience to encompass Indigenous Ways of Knowing (Smith, 2021), there is a need to look towards Indigenous methodologies to understand how to align Indigenous patient experience evaluation with culturally significant strategies. Within the existing patient-centered measurement process, there are opportunities to include qualitative responses (narrative); however, the current process lacks the cultural context that storytelling can have, as articulated within this article. We sought to explore how Indigenous storytelling can enrich and capture the complexities of Indigenous patient experiences in BC healthcare systems through teachings from our Knowledge Keepers, and to propose additional resources in the field of patient experience to improve Indigenous-specific patient experience measurement.

Storytelling is a method of Indigenous methodology that has been used to learn, share, and reflect within Indigenous communities and Indigenous-led research (Smith, 2021). More specifically, storytelling offers an opportunity to share one's personal experiences in a way that is rooted in Indigenous Ways of Knowing and Being. Storytelling can be distinguished from qualitative research methods, as it is rooted in Indigenous epistemologies as a way to connect people beyond individual experience. One story can be representative of many stories; when we hear from an individual, we can expand the core of what is shared to others who have a similar world view or personal history. Hence, employing a storytelling method can create a safe space for rich conversations that present

valuable insights into Indigenous patients' healthcare experiences, and expand upon and deepen our understandings of Indigenous experiences. More specifically, researchers can use stories—inclusive of context and background, emotions, and perspective—without the need to fragment the data or lose the valuable insight of someone's entire experience when accessing healthcare (Barnhardt & Kawagley, 2008; Kovach, 2021; Smith, 2021). Indigenous truth telling through story is essential as we move forward on our journey of transforming health systems to adequately address anti-Indigenous racism and equity gaps.

Learning from Elders who are already engaged in providing supports to patients within healthcare settings may offer unique insight into how to employ storytelling as an approach to measuring Indigenous patients' healthcare experiences. Elders play a critical role within the healthcare system in BC, where their teachings are informing culturally safe care through both advising leadership and providing direct care to patients (Allen et al., 2020; Hadjipavlou et al., 2018; Kennedy et al., 2022). Embedding Elders into care systems strengthens patient connections to their cultural identity and builds further trust with patients, which has been shown to facilitate improved reception and retention in healthcare settings (Hadjipavlou et al., 2018). Hence, understanding how Elders use storytelling can provide insight into how to understand, measure, and respond to Indigenous Peoples' healthcare experiences. Through engaging with Indigenous Elders, we sought to understand the importance of storytelling within Indigenous communities and how this could be applied in patient experience evaluation to address anti-Indigenous racism and improve access to culturally safe care. The purpose of the present study was to explore and gather insight into Indigenous Elders' knowledge and perceptions of storytelling within the context of patient experience measurement, and to propose potential uses of storytelling to deepen the measurement and understanding of Indigenous patients' experiences to inform health system change.

Methods

Study Design

This study was conducted by an Indigenous-led research team consisting of both Indigenous and non-Indigenous health researchers. Using a Two-Eyed Seeing approach, which refers to the theoretical and methodological integration of Western and Indigenous Ways of Knowing in research (Bartlett et al., 2012), the research team conducted one-on-one interviews with Indigenous Elders to understand their perspectives on the use of storytelling in healthcare and to measure Indigenous patients' healthcare experiences. Two-Eyed Seeing is a term coined by Mi'kmaq Elder Albert Marshall, whose teachings come from the late Chief Charles Labrador of Acadia First Nation, as well the work of Elder Murdena Marshall with the Institute for Integrative Science and Health (Bartlett et al., 2012). It outlines the importance of upholding both Indigenous and Western epistemology in health research. All research activities took place on the traditional, ancestral, and occupied territories of the X̱m̱əθkwəy̱əm (Musqueam), Sḵwx̱wú7mesh (Squamish), and Səḻílwətaʔ (Tsleil-Waututh) Nations in what is colonially known as Vancouver, BC. Additionally, all team members were encouraged to reflect on their positionality and maintain notes and reflections, which later guided the analysis and interpretation of the findings. This research proposed to engage discussions with Elders on storytelling and the its importance in patient experience measurement, and was not conducted to gather any traditional knowledge of Indigenous Nations. Consistent with Indigenous-centred research principles (Smith, 2021), this knowledge sits with those whose ancestors have passed it down through generations and since time immemorial, and it is not to be shared for the purposes of research. This inquiry aimed only to focus specifically on gathering Elder input on how storytelling can

be amplified through Indigenous leadership, as a way to measure what matters in patient experience and to improve system accountability and systemic transformation and change.

Conceptual Framework

This research follows similar approaches to community-based participatory research (CBPR; Castleden et al., 2012), “yarning” (Bessarab & Ng’andu, 2010), and “the visiting way” (Gaudet, 2019), while also integrating foundational concepts in storytelling. CBPR is understood as a research method in which all research activities are shared between the researcher and the community involved (Castleden et al., 2012). While CBPR informs our work, storytelling methods are at the centre of this project. “Yarning” is a semi-structured interview that involves engagement of the researcher and participant in informal discussion (Bessarab & Ng’andu, 2010). “The visiting way” in research focuses on recentering relations in decolonizing research methods (Gaudet, 2019). This study implements these foundational research and interview frameworks to conceptualize a decolonial, story-based method for measuring and evaluating Indigenous patient experiences (Bessarab & Ng’andu, 2010; Castleden et al., 2012; Gaudet, 2019). These frameworks provide the foundation for our research procedures and study design.

Sampling and Study Procedures

Members of an Elders Circle brought together by the Vancouver regional health system to do work and provide leadership within the area of Indigenous patient experience were invited to participate in this study. Four Elders were recruited through convenience sampling with the support of the Elders Circle Coordinator and through the recommendation of the lead Elder of the circle. During recruitment, participants were invited to participate in a one-hour, one-on-one interview. The questions were shared with each Elder prior to the commencement of the interview, to allow them time to think through the prompts and to facilitate deeper conversation during the interview time. The interview guide was developed by the research team with guidance from Dr. Elder Roberta Price and under the leadership of co-authors Brittany Bingham and Andreas Pilarinos. Questions pertained to Elders’ perspectives on storytelling, and its use as a method to measure Indigenous patients’ healthcare experiences.

Once informed consent was obtained, co-authors Hannah Doyle and Andreas Pilarinos proceeded with the interviews. Each interview began with a land acknowledgement, followed by a round of introductions in which all participants, including research team members and the Elder, had the opportunity to introduce and situate themselves. The interview then proceeded, with questions from the interview guide posed to participants, and interviews were audio recorded and subsequently transcribed. Transcripts were then reviewed by Hannah Doyle prior to analysis for clarity and to remove any potential identifying information to protect participants’ confidentiality. Elders were provided with a \$250 honorarium for their time, in accordance with Elder honoraria policies and norms as defined by health system guidelines and local Indigenous community guidelines.

Data Analysis

Once individual interviews concluded, thematic analysis was conducted by Hannah Doyle. This involved the development of an initial, overarching codebook, which was then refined through additional coding. Narrative analysis was employed to develop a nuanced understanding of Elders’ perspectives and experiences involving employing storytelling within healthcare settings. The additional analysis reinforced and strengthened the themes, and ensured that the knowledge shared

from the Elders maintained contextual significance. Specifically, themes pertaining to the uses of storytelling in Elders' work with patients and the Elders' perspectives on the applications of storytelling in healthcare were identified within the analysis, as well as how these ideas could be applied for patient experience evaluation.

Ethics Statement

Ethical approval for this study was received from the University of British Columbia Behavioural Research Ethics Board (H22-03433) and the Vancouver Coastal Health Research Institute.

Results

Interviews were conducted with four Elders who were recruited from the Elders Circle program and who had supported patients accessing healthcare. A majority of participants self-identified as women. All Elders were from BC First Nations communities and had experience employing storytelling in their personal lives and work supporting patients. Thematic analysis identified the importance of storytelling in building and strengthening relationships between Indigenous patients and clinicians, educating clinicians on Indigenous patient experiences, and engaging cultural practices in patient care and evaluation.

Significance of Storytelling Within Indigenous Communities

All Elders discussed the historical and cultural significance of storytelling to their respective and other Indigenous Communities. As one Elder shared, "*storytelling is a way [communities] preserve oral history,*" which demonstrates the importance of storytelling to protecting Indigenous Ways of Knowing, Being, and Doing. Elders discussed how the knowledge shared with them had been passed on "*since time immemorial*" from previous Elders, further emphasizing the significance of storytelling to teaching, learning, and well-being within Indigenous communities. The Elders shared that storytelling in patient experience evaluation presents an opportunity to engage cultural processes and promote further opportunities for healing and growth for Indigenous patients:

You hear all about who they are, where they come from and their experiences, you know, and some of them some of them come up with self-healing methods in an environment like that, because they feel comfortable...So by listening to [patients'] stories and knowing where they come from, that's really important. It shows that you care. It also helps with your healing. Knowing that somebody's listening to them.

This can also be seen through one Elder's recollection of storytelling in their upbringing, where the relevance and relatedness of stories supported their learning as a Knowledge Keeper:

It was always stories. If you asked the question, you were given a story, not "here's the answer." You had to think about it, work it out, go away. When you think you had it, then you go back to that Elder and they would discuss with you whether you got it or not. And if you didn't, they'd send you away and you had to go and think about it more...So for me, that was how I was taught. That's how I learn the fastest. Because I can remember the stories. I remember where I was. I remember who was there. Because that's how they taught me; by telling the story over and over and over it becomes relevant. It becomes about somebody you know or about yourself, or about when [the Elders] were young, to make it real to you. I think it was because I could see

it in my mind what they were talking about, what the story was about, and so it elicits an emotional response as well. Not just mental, but an emotional response, and then there was always the spiritual aspect of it, but having that emotional response, I think, is the best way to anchor for Indigenous Peoples.

Furthermore, the Elder described how storytelling continues to be used to share and transfer knowledge from generation to generation. As they explained, *“it’s how everybody in [their] family learned. It’s how [they] talk to their grandkids and [their] own kids, [they] would tell stories.”* Hence, it is evident that storytelling serves as a meaningful and important component of Indigenous communities’ knowledge sharing and cultural preservation, but that it also serves a purpose in improving trust in and safety within the healthcare system.

Benefits of Storytelling in Strengthening Relationships

Elders described the role of storytelling in establishing strong and positive relationships between patients and their healthcare providers. More specifically, Elders discussed how storytelling can be used as an opportunity for sharing with clinicians, creating a safe care environment, and advocating for patients. This includes understanding that storytelling is relational and an opportunity to gain insight into a patient’s life, circumstances, support networks, and other aspects of their health and well-being that are relevant to their care. More importantly, storytelling offers an opportunity for *“listening with respect and without judgement, [signalling that clinicians] are taking the time to get to know their patient.”*

Elders recognized patients’ desire to be heard, understood, and supported while accessing healthcare, further emphasizing the role of storytelling in creating a safe care environment. By listening to patients *“with a good heart and an open mind,”* one Elder explained that employing storytelling in their work was empowering for Indigenous patients. Feeling open to sharing and listening to the needs of patients contributes to cultural safety and increases patients’ openness to discussing their health concerns. As one Elder mentioned:

I really feel that it’s so very, very important for us to listen to [patients’] experiences, and often through a story, because it could make it more relaxed for them to tell and maybe be more open and trusting to actually share their journey. And no matter how hard it is to hear, I feel it’s important for us to take that time, have patience, have kindness and respect to listen to their experiences through their ways of telling us, which is often like telling a story.

When asked how the Elders saw storytelling can be implemented as a patient experience tool, they shared the different processes by which we can share stories individually and collectively to strengthen all our relationships. The use of sharing circles was discussed, with one Elder sharing that *“[Sharing Circles] are the most ancient form of spirituality that we have.”* Sharing Circles are a positive, safe, and inclusive method for embracing storytelling and sharing common experiences. The Elders discussed the power of collective sharing and the deeper connections that are created in Sharing Circles:

We sit in a circle, and sometimes [patients] bring knitting, crocheting, beading while we’re talking. And all the conversation is so interesting. [The patients] talk about their experiences in residential school and how they made it through and their treatment from doctors and, you know, medical people. And by talking to each other they trust each other and they get to know each other and compare stories and a lot of knowledge came out of that circle.

Furthermore, Elders described the use of storytelling as a method for advocating on behalf of patients as well as educating healthcare providers. One Elder explained that *“sharing [patients’] experiences with others in the healthcare system [can help] better treat the patients or communities that [clinicians] serve...[while also] honoring [patients] on their journey.”* Elders discussed the intersections of sharing and telling stories as *“two of the steps to healing for patients when they talk to their healthcare provider,”* further emphasizing the importance of storytelling as a path for trust and relationship building between patients and healthcare providers. Hence, storytelling offers an opportunity for patients to share, but more importantly for healthcare providers to learn from patients.

Educating Clinicians on Patient Experience Through Storytelling

An important part of addressing the ongoing racism and discrimination that Indigenous Peoples experience in healthcare and changing the way that we evaluate Indigenous patient experiences is focusing on education for healthcare providers and hospital staff. Specifically, there is a need to focus on education in story-based approaches to care and provide teachings to providers on how Indigenous patients require unique supports. One Elder emphasized the *“need to change the thinking, perhaps in the teaching when they’re in school, to teach that model about storytelling because it’s a very universal way to heal.”* Elders emphasized the need for *“healthcare providers need to listen”* to patients’ stories and experiences, understand their position in the patient’s healthcare experience by prioritizing patient-centered care, and finally to learn Indigenous histories of the lands in which they are working upon.

As one Elder explained, storytelling provides meaningful insight into a patient’s health, well-being, and healing journey:

Because a lot of people, a lot of Indigenous People, have difficulty. And I know this because I’ve worked with thousands of them. Patients have difficulty in talking about self. But if you can get them storytelling, it will eventually weave back to them. And then you find out, but you have to take the time. You have to have the time build that relationship that I do want to listen. I do want to hear how you ended up having to come to see [a clinician] because it’s the last thing that most Indigenous People want is to have to go to the doctor. Like every single one of my Elders said, and I never want to go to the hospital because that’s where you go to die.

Elders also explained the importance of understanding patients’ holistic circumstances when working with them to find optimal treatments, and how hearing patient stories and feedback can offer greater insight into improving overall experiences for Indigenous patients. One of the Elders posed the important question, *“How can you prescribe medication if you don’t know what else is going on in my life?”* Healthcare providers must learn to centre the patient’s needs and build relationships as part of their treatment. They must see themselves as equal. Their patients are people, and by understanding their stories healthcare providers will be able to work with their patients to facilitate a meaningful and safe experience. One Elder explained how they centre the patient through ceremony in a way that is helpful for their healing:

We do a welcoming, we do a blessing from our Elders. We share in ceremony in a good way and we share introductions. Who’s who? It’s so important. And I feel that clinicians just want data and that they don’t really look at the whole person and don’t really look at the strengths of the person.

There is a need for healthcare providers to become more educated on navigating Indigenous patient experiences. During all of the interviews, Elders stressed the importance of culturally safe care and the need for healthcare providers to understand the unique determinants of Indigenous health. Colonial histories and ongoing racism shape relationship between Indigenous patients and the healthcare system. It is essential that all healthcare providers understand the history of Canada and their position and privilege in colonial systems. Indigenous Cultural Safety (ICS) training is a critical part of embracing storytelling as a method for understanding Indigenous patients in a culturally sensitive approach that does not cause further harm:

And I think one thing that I maintain, I've been seeing it for years, is that every single person—whether you're in the medical field or anything else—needs to take some kind of ICS that's approved by [Elders] because they're not all created equal. [Clinicians] need to take that training as a starting point to see us as human beings.

It is evident that education is one of the most important parts of embracing storytelling in healthcare environments. However, simply completing an ICS course is not enough. Healthcare providers must commit to honouring and respecting cultural and traditional practices and continue to prioritize Elders, Knowledge Keepers, and their patients as the experts on their own health. As one Elder explained, “*we're all at different levels of healing,*” but it is important to “*treat [patients] with respect, kindness, and don't stigmatize [Indigenous patients].*”

Storytelling as a Practice of Connecting Culture and Patient Care

When asked about their experiences using storytelling with Indigenous patients and its capabilities for increasing understanding, Elders emphasized the importance of working with patients in a good way through culturally safe practices like storytelling. Storytelling is “*very important for people, especially people working on their healing journey to help them through their experience.*” Elders focused on listening to stories and engaging in patient experiences to support them and help with healing in ways that Western medicine cannot. Ensuring that the patients feel heard and are comfortable sharing more about themselves is part of the Elders' work, as one Elder explained:

So by listening to [the patients'] stories and knowing where [the patients] come from, that's really important. It shows that [healthcare providers] care. It also helps with [the patients'] healing. Knowing that somebody's listening to them.

The Elders explained that storytelling is not only the patient sharing stories with them, but is also the Elders sharing personal stories and teachings with the patients. This reciprocal relationship in their work expands on patient-centered approaches in care and ensures that the patient feels supported and is having a positive experience. Elders use story to connect with the patient and to break down any potential barriers or concerns that the patients have. Through sharing their perspectives and experiences, Elders create a shared space of equality and respect and provide further opportunities for healing for the patient. As one Elder explained, connecting with patients through story has helped in various ways:

Sometimes [the patient] can't talk but I'll interact with them anyway and tell them stories—inspirational stories, personal stories on my life journey, and historical stories as well. And it takes your mind off of things. To open that part of the brain that has the imagination and to take [the patient's] mind off their pain or whatever they're going through and show them a way. An opportunity to healing.

Additionally, an important part of the Elders' work with patients is offering cultural and spiritual supports while in healthcare environments. Storytelling has been used in oral history and connects patients to traditional ways of sharing information, and "*further understanding of their culture and knowledge of traditions also helps with their healing.*" All the Elders referred to the importance of oral histories in many Indigenous cultures, to their work with their communities, and to ceremony. The Elders discussed the ways that storytelling is rooted in oral history and continues to connect Indigenous Peoples back to their traditions and their teachings. As one Elder shared:

When we bring ceremony into the picture, I really feel it changes peoples' attitudes and abilities to listen. **So welcome that through a ceremonial process and I really feel bringing ceremony creates respect, respect and perhaps through that respect better understanding.**

When asked about methods of sharing and understanding patient experiences, the Elders emphasized that surveys and data collection are not effective and that "*there've been so many surveys done with our people. So sometimes they get kind of surveyed out and they don't want to. They tune you out.*" The Elders brought up more relational and community-based approaches to sharing feedback through arts, music, ceremony, and digital approaches. The main theme that the Elders discussed was the use of qualitative approaches to patient experience evaluation that capture the nuances of individuals and collective experience:

Really, really advocating that, like qualitative is just as important as quantitative, and it seemed to me that the colonial system only looks at quantity versus quality. So being on that side with allies, standing up saying that qualitative research—which is stories and experiences—is just as valid or even more so than quantitative.

The underlying message that permeates the Elders' shared knowledge is that storytelling is the root of these qualitative research practices. While we look for new ways to engage patients, interact with healthcare professionals and systems, and implement improvements in patient experience, storytelling and patient sharing are at the centre. These changes will take time and will challenge colonial ideas and systems of health in Canada. Listening and learning from Elders will be critical in advancing culturally relevant and safe patient experience evaluation:

Much like the Hummingbird face in our Indigenous cultural safety wanting to put a forest fire out one drop at a time. You have got to be committed to doing the work even if you just start, it's going to take generations to unfold. But start somewhere.

Limitations

This study is limited, as the approaches may not be generalizable across healthcare authorities. We recognize the unique cultural and traditional knowledge of the Indigenous communities in which the health authorities are situated and the importance of avoiding pan-Indigenous perspectives. This paper is not proposing that researchers start collecting Indigenous stories, but rather that a thoughtful and intentional approach to amplifying Indigenous leadership is needed, and that employing storytelling as part of a method in this work in patient experience can help to avoid extractive storytelling processes and ensure ethical engagement with Indigenous patients. In this study, we did not collect information on the Indigenous groups or Nations that these Elders were members of, and we recognize that their implementation of storytelling reflects their unique experiences and education. The teachings from the Elders provides a strong foundation for storytelling

in patient experience and presents the applications of storytelling in healthcare; however, further engagement with community members and other community partners is necessary to validate and enhance the application of storytelling as a method for understanding and measuring Indigenous patient experiences.

Discussion

Our study has shown that storytelling is an important part of the Elders' practices and work with patients. This approach to patient experience evaluation presents opportunities for educating clinicians, creating a safe care environment, and advocating by and for patients through their unique experiences. Our results capture the importance of storytelling not only as ceremony but as a way of bringing ceremony into the act of measuring what really matters for Indigenous patients. This approach addresses the limited capacity of existing patient experience frameworks and evaluation tools to capture the nuanced experiences of Indigenous patients in the healthcare system. Addressing the limitations in current methods of data collection will assist in addressing the existing gaps in healthcare access, programming, and culturally safe care. We are honoured and grateful that these Knowledge Holders shared with us the importance of storytelling in how we measure patient experience moving forward to address anti-Indigenous racism and create culturally safe systems of care.

Alongside the experiences and knowledge shared by the Elders in this study, there is a growing body of research in the field of storytelling as a method of Indigenous methodology and in Indigenous health research. However, limited literature in health-related research and patient experience evaluation has focused specifically on the use of storytelling as a patient experience measurement tool (Chan, 2021; Fontaine et al., 2019; Iseke, 2013; Kovach, 2021; Smith, 2021). It was evident in the interviews with Elders that storytelling is not simply a method for connecting with patients and building relationships, but a culturally relevant form of ceremony that builds understanding and respect that can enrich patient experience measurement. These findings are consistent with the long-standing history of storytelling in many Indigenous cultural practices and teachings and its use since time immemorial by many Indigenous Communities (Emberley, 2014).

The Elders reported the importance of story to connect, learn, and understand ideas, especially when they work with Indigenous patients who are under physical, mental, and emotional stress. Although current patient experience metrics focus on specific areas of care, they are not always inclusive of Indigenous world views and lack the ability to adequately report and contextualize the nuanced experiences of Indigenous Peoples in the Canadian healthcare system. The cultural safety module in the BC Patient Centred Measurement does expand on specific areas of care to include human characteristics and human interactions indicative of a broader concept of "safety." However, these are reflected mainly in quantitative data; therefore, the argument of story as a significant method is vital. Our findings build off of previous literature that stresses the importance of prioritizing Indigenous voices in healthcare (Emberley, 2014) and combines it with the capabilities of storytelling to facilitate meaningful conversations, connect Indigenous patients to their culture, and build relationships (Castleden et al., 2012; Gaudet, 2019; Hadjipavlou et al., 2018). From our conversations with the Elders, we learned that storytelling is an important way for Indigenous patients to share what matters to them and feel that they are being heard. Through this work, we address the Truth and Reconciliation Commission's (2015) Calls to Action 19 and 22, which seek to identify and close gaps in health outcomes for Indigenous patients and to recognize the value of Indigenous healing practices in patient experience evaluation.

The findings from this study, alongside the growing literature on the healing properties of Indigenous storytelling, suggest that patient storytelling and sharing presents opportunities for healing in a good way (Friskie, 2020). An example of implementing a strategy for engaging with communities

through storytelling is the method articulated by Indigenous groups in Australia called “yarning.” Although it is known by various names, “yarning” is a conversation-based process that involves sharing stories that can be used to involve patients in their care, giving them autonomy over their health (Bessarab & Ng’andu, 2010). Through conversation, healthcare providers can engage with Indigenous patients in ways of sharing that embody Indigenous knowledge sharing practices. Through applications of similar approaches to “yarning” in the context of Coast Salish knowledge systems, we can begin to articulate a method for story-based approaches in patient experience research specifically for patient experience evaluation in BC.

Storytelling approaches have been reported as culturally appropriate knowledge sharing methods used by many Indigenous Peoples since time immemorial. The Elders expressed their experiences through storytelling and how story has been a part of their lives since they were young and throughout their lives. Storytelling enriches patient experiences by capturing and acknowledging patient stories in a culturally safe way and seeks to give meaningful feedback to the systems of care working towards culturally safe care. This underscores the capacity of such approaches to generate important conversations and approaches to evaluating the healthcare that Indigenous patients receive. Although the functions of storytelling methods are relatively new within health research, it is essential to acknowledge and remember the elements of this research method that are rooted in Indigenous histories and knowledge sharing practices (Archibald, 2008).

Without adequate feedback systems that build upon the knowledge shared by individuals through storytelling, these approaches to patient experience evaluation cannot be successful. Listening to Indigenous patients, hearing their unique experiences, and providing spaces for healing are all important, but we cannot make meaningful changes to the systems that shape Indigenous patients’ experiences without finding ways to share these stories back with healthcare providers. The Elders expressed the importance of sharing stories from patients back with healthcare providers, and doing so in respectful ways that honour the patients. We cannot simply share these stories but must identify the determinants that impacted the individual level of care, alongside the determinants that shape the systems of oppression and ongoing anti-Indigenous racism that make it unsafe to access care (Fonseka et al., 2021; Warr et al., 2021).

The findings from this study have highlighted the applications of storytelling in patient experience evaluation as articulated by Elders, drawing from their teachings and their experiences in using storytelling with patients. Both researchers and healthcare providers can apply storytelling as a method in practice to uplift Indigenous patients through culturally safe approaches. For researchers, storytelling provides a method that can offer deeper insights into patient journeys, highlight systemic barriers, and generate culturally informed evidence to guide the improvement of Indigenous patient experiences. For healthcare providers, integrating storytelling into clinical practice can strengthen relationships, enhance cultural safety, and support care that is responsive to the lived experiences of Indigenous patients. Therefore, we recommend that storytelling be used to engage Indigenous patients to better understand their experiences, address anti-Indigenous racism in our healthcare system, and create systems of care that are culturally safe.

Conclusion

There is a need to focus on the methods that are currently used in evaluating patient experience, and how these models of data collection perpetuate Western research methods and may not be culturally sensitive for Indigenous Peoples. Our study prioritizes the teachings from Elders who use storytelling in their work with patients as a way to foster connections; understand the unique experience, feelings, and concerns of patients; and develop relationships beyond the healthcare setting. As highlighted by the results of this study, Elders have and continue to engage Indigenous

patients through storytelling approaches that allow for deeper understanding of each patient. In the development of harmonized Indigenous-specific patient experience measurement strategies, we must uphold Indigenous knowledge systems that emphasize ethical and respectful engagement, centre Indigenous patients, and allow for structural change to establish culturally safe spaces in healthcare. Moving forward, engagement with Indigenous Peoples of BC should be prioritized in developing an Indigenous-specific patient measurement tool, to ensure that is culturally safe, locally relevant, and prioritizes feedback towards improving Indigenous patients' access to healthcare services and the quality of care received.

Acknowledgements

We acknowledge the unceded, traditional territories of the *X̣m̄əθkwə́yəm* (Musqueam), *Sḵwx̣wú7mesh* (Squamish), and *Səl̓ílwətaʔ* (Tsleil-Waututh) Nations on whose land this research was conducted. We would like to acknowledge and extend our sincere gratitude and appreciation to each of the Elders that shared their knowledge and insights with us and for their overall support in conducting this study.

Tribute to Elder Doris Fox

We would like to dedicate this work to the memory of Elder Doris Fox, our powerful teacher, leader, and matriarch. Our lives and work have been profoundly shaped by the guidance of Elder Doris, who has been both a mentor and a source of endless inspiration to us all. Her wisdom transcends generations, offering timeless lessons in resilience, compassion, and the pursuit of knowledge. She has always led by example, teaching us the importance of hard work, integrity, and the strength to persevere through challenges. Her support has been a constant, she has nurtured our development with love and patience, and has inspired all of her students to reach their fullest potential. She has not only shaped our paths, but has also touched the lives of so many others leaving a lasting legacy of strength, kindness, and wisdom. We love you Elder Doris.

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