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Community directed assessment of pain in a northern Saskatchewan Cree community

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ABSTRACT
Indigenous Elder advisors in Pelican Narrows, a Cree community in Northern Saskatchewan, have indicated that Western pain scales may not be responsive tools for pain assessments within their community. This study employed a mixed methods research design that involved two phases. Phase one was the development of a pain scale in collaboration with an Elder and a Knowledge Keeper. Phase two was a pilot of the CDPS utilised during virtual physiotherapy sessions for chronic back pain. Twenty-seven participants completed the pre-physiotherapy treatment questionnaires, and 10 participants engaged in semi-structured interviews (9 community members; 1 healthcare provider). A weighted kappa analysis yielded k = 0.696, indicating a good agreement between the CDPS and Faces Pain Scale-Revised in terms of documenting participants' pain. Qualitative data from interviews with community members revealed three major themes: 1) Learnings Regarding Pain Scales, 2) Patient Centered Care; and 3) Strength-Based Solutions for Improving Pain Communication. Two themes were uncovered through conversations with the HCP: 1) Perspectives on CDPS and 2) Healthcare Provider Experiences Communicating about Pain. Moreover, a patient-centredcentred approach is important to ensure comprehensive pain assessments.

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Background/Introduction

Chronic musculoskeletal pain

Indigenous Peoples in Canada experience significant inequalities in health outcomes when compared to non-Indigenous Canadians. The prevalence of arthritis, rheumatism, back pain and other musculoskeletal conditions are higher in Indigenous Peoples than in non-Indigenous populations [1–3]. The prevalence of chronic musculoskeletal (MSK) pain conditions can be influenced by jeopardised social determinants of health, which for Indigenous Peoples, have been exacerbated by colonisation and government policies [4,5]. Additionally, healthcare access inequity further contributes to the impact of these conditions [6]. In Canada, people from rural and remote communities as well as Indigenous Peoples are 30% more likely to report chronic MSK conditions, like chronic back pain (CBP) [1]. Moreover, many Indigenous Peoples live with untreated or mistreated pain due to experiences with inequitable care and discrimination in the Canadian health system [7].

Conceptualization of pain

The conceptualisation of pain differs between Western ways of understanding and Indigenous ways of knowing. The western perspective on pain is primarily based on nociceptive, neuropathic, and nociplastic pain [8]; whereas, the Indigenous perspective on pain is viewed through a wholistic lens of the physical, mental, emotional and spiritual aspects of a person/community [9–11]. A study centred on pain, as perceived by Indigenous South Australian individuals, revealed additional factors such as: early childhood exposure to pain, history of trauma and injury, and apprehensions surrounding the risk of addiction can all impact pain perception [11]. A scoping review with a focus on physical pain within Indigenous Peoples was conducted in Canada in 2021 which reported a clear disconnect between Indigenous patients and western healthcare providers (HCPs) when communicating about pain [9].

Additionally, Jimenez et al. [12], reported in Canada and the United States, Indigenous populations underemphasise pain and disability, describing severe pain as "discomfort"

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and "ache" [12–14]. Yet, Indigenous populations are often perceived as exaggerating distress [12,15], which is a clear example of the systemic oppression Indigenous Peoples face in Canadian healthcare systems.

Pain assessment tools

The experience of pain for Indigenous Peoples may not be captured by current Western developed pain assessment tools [16,17]. Health disparities such as a lack of access to appropriate pain assessment tools and effective pain management strategies further increases Indigenous populations' risk of chronic pain [17]. Pelusi and Krebs [18], interviewed Indigenous cancer patients and survivors, and described this disconnect, revealing that many individuals were unable to use or understand Western pain scales and questionnaires. Additionally, there is a paucity of research on the responsiveness of numerical, image-based, and colour-based assessment tools within Indigenous populations. The numeric pain rating scale (NPRS) is a self-reporting tool that utilises a horizontal measure ranging from 0 (no pain) to 10 (worst pain possible) [19]. Indigenous Peoples communicate through oral narrative or storytelling; thus, describing pain in the form of a single number may be challenging [7]. NPRS has shown responsiveness in measuring pain intensity [20]; however, the ethnicity of participants within many studies were white/European-descent or not specified; therefore, the efficacy of NPRS among Indigenous individuals should not be assumed [21,22,23]. Image-based pain assessment tools often utilise scales with faces because they are easy and quick to administer [24]. Faces Pain Scale – Revised (FPS-R), for example, is a scale with six facial expressions depicting the experience of "no pain" to "worst pain possible" [25]. Facial expression scales can range from 6 to 11 facial expressions, and they have been validated with children and adults from different cultural groups (Caucasian, African American, Thai, and Lebanese) [24,26–29]. However, when used with Inuit adults from Alaska to assess pain, the FPS scale had limited success due to cultural differences in facial expressions [30]. Colour pain scales or colour analog scales (CAS) are often utilised in unison with other pain assessment tools, like a NPSR or FPS-R. Some CAS use colours with green representing no pain, yellow representing moderate pain, and red representing severe pain [31], while others display a red colour gradient from light red representing no pain to dark red representing severe pain [32]. The colours are often positioned in a linear format with corresponding numbers, facial expressions or words that describe pain. CAS have demonstrated reliability as self-reporting tools in the assessment of pain in children and adults [32–36]; however, limited studies have been done to test for the validity of CAS within Indigenous populations.

Furthermore, the Faces Pain Scale (FPS) is a well-established self-reporting pain assessment tool often used with children [25]. Bieri et al. [37], developed the FPS and established its reliability in self-reported pain for children. Hicks et al. [25], carried out three studies to revise the FPS and validate the Faces Pain Scale-Revised (FPS-R). FPS-R has shown to be reliable within a diverse demographic, from children, to adults, to older adults, and across cultures (Thailand, Portugal, and Spain) [25,38–40]. Moreover, the International Association for the Study of Pain lists FPS-R as one of their resources for conducting pain assessments [41]).

Different Indigenous communities may have unique needs, may exhibit different pain behaviours, and may speak different languages. Inuit people in Canada widen their eyes and raise their eyebrows to indicate agreement [24]. This expression is often mistaken with "no pain" on facial pain scales. Furthermore, there are Indigenous communities that do not have a conceptual recognition of numbers above 5 [42]; thus, a NPRS of 0 to 10 would not be an appropriate method of assessment. Moreover, a study conducted in Australia noted that Indigenous Peoples were "quiet about pain" they will "put a brave face [on]" due to reluctance to expose vulnerability [43]. This cultural difference should be taken into consideration when using pain assessment tools. Fenwick [42] reported Indigenous Peoples in Australia are often labelled as "stoic" by HCPs. Contributors to this label could be due to Indigenous Peoples' specific pain expressions and the use of vague descriptors to communicate about pain [12–14].

Indigenous Peoples have reported experiencing minimisation, invalidation, or disbelief of their lived pain experiences [9]. It is important that HCPs do not invalidate Indigenous patients' pain based on their own expectations as to how an individual should be presenting with pain. Labelling Indigenous Peoples as stoic may result in a lack of comprehensive pain assessments and under-treatment of pain. Moreover, systemic oppression should be considered as a factor contributing to Indigenous Peoples' hesitancy to share their lived pain experiences. Finally, with the vast number of cultural differences among Indigenous communities, it is important to not overgeneralise the needs of one community as the needs of all other communities.

Community concern about the Current way pain is assessed

Taking into account the differences in pain conceptualisation and the existence of reports of pain invalidation experienced by Indigenous Peoples, it raises the concerns: 1) there is a lack of understanding of chronic pain experienced by Indigenous Peoples, leading to a disconnect between HCP and patient when communicating about pain; 2) Western pain assessment tools are not developed with Indigenous Peoples; therefore, may not represent their experiences accurately or appropriately. To encourage better communication about pain we must collaborate with Indigenous communities to understand pain from their perspectives, and work in partnership with community members to co-develop a pain scale that could promote better exchange and understanding between HCPs and patients.

Researchers from the School of Rehabilitation Science at University of Saskatchewan are working in collaboration with the Northern Saskatchewan Cree community of Pelican Narrows on a project to enhance access to care for CBP in the community (led by BB and SL) (Lovo [44]. An Elder Advisory Group in Pelican Narrows advised that communication about pain in their community could be enhanced, and they recommended that a collaborative pain assessment tool be developed for their use. The objectives of this research are to: 1) to evaluate the validity, cultural responsiveness, relevance and patient experience of a community-led novel pain scale during a virtual team-based CBP intervention in a Cree community, and 2) to collect the community members' perspectives regarding the novel pain scale. This manuscript is derived from the Master's thesis of TZ, *"Building Bridges For Pain Communication And Management: Community-Led Insights From Cree And Dene/Métis Communities In Northern Saskatchewan"* [45].

Methodology

This project included two phases: 1) Phase one, collaboration with an Elder and a Knowledge Keeper from Pelican Narrows to co-develop the CDPS; and 2) Phase two, pilot of the pain scale in a virtual back pain clinic in Pelican Narrows, comparing CDPS to FPS-R, testing concurrent validity, and capturing community members' feedback. Faces Pain Scale-Revised was selected for the overarching CBP study, is commonly utilised in physical therapy clinical work, and there is prior evidence of use with other cultures. For this reason, it was utilised for comparison to the CDPS in the present study.

Interpretive Description with analytic procedures of thematic analysis, informed by Community-Based Participatory Research and Two-Eyed Seeing will be utilised throughout this project [46–48]. Interpretive Description recognises realities are socially constructed with elements of the human experience [49]. This methodology was in keeping with our goal of having actionable outcomes to inform the co-development of a culturally responsive pain assessment tool which may allow improved communication about chronic MSK pain between clinicians and community members [49]. Community-Based Participatory Research ensures a collaborative partnership where researchers and community members will be treated as equals [50]. It allowed community members to lead and identify community strengths, needs, and desired health outcomes [50]. Two-Eyed Seeing is a research guide for Indigenous inquiries that combines knowledge of both Western and Indigenous worldviews [51]. Two-Eyed Seeing was the overarching framework allowing the outcome of this project to integrate the strengths of Indigenous and Western ways of knowing while prioritising Indigenous knowledge and experience.

Setting

Pelican Narrows is a community in Northern Saskatchewan, Canada that is a part of the Peter Ballantyne Cree Nation. In 2016, the combined population of Pelican Narrows was 1942 individuals [52].

Ethics process and community engagement prior to data collection

This study was carried out within a larger research project (Study A) associated with the School of Rehabilitation Science at the University of Saskatchewan that is evaluating the impact of virtual physical therapy on CBP in the Pelican Narrows community. The larger study received ethics approval from the University of Saskatchewan Biomedical Ethics Board. An amendment to Study A was submitted for the present pain scale research and the amendment was approved by the Biomedical Ethics Board; protocol number BIO-1435.

Due to previous engagements with Pelican Narrows, longstanding relationships within the community were established. In Pelican Narrows, the research team consisted of nursing staff who participated as community research assistants (CRAs), a community advisory group (CAG) of Elders, community members with chronic MSK conditions and health providers. The CAG has offered guidance and approval of the project and they have been actively engaged at every step to ensure the project was community-directed, incorporated Cree First Nation worldviews, and followed community practices/protocols.

Procedures

Phase 1: development of CDPS

Phase one followed a collaborative approach where the research team worked alongside a Cree Elder and a Knowledge Keeper to develop the CDPS (Figure 1 outlines the process of the two research phases). The primary investigator of the overarching CBP study had worked since 2015 with the Pelican Narrows community and an Elders' advisory group, and had developed a longstanding relationship with the Elder and Knowledge Keeper. The Cree Elder had originally identified the absence of a pain scale that was responsive to the needs of her community in discussion with the research team early in relationship building. The Knowledge Keeper provided translation whenever needed, to ensure Elders could participate in the Cree-TH dialect. We followed traditional protocol for the community, including offering tobacco and gifts to the Elder and Knowledge Keeper for their wisdom and knowledge sharing. Between November 2020 and April 2021, the Elder shared her knowledge with the research team through open discussions which included a nurse practitioner (who worked in Pelican Narrows), a research student, and the principal investigator (a physical therapist). The Elder shared teachings and community histories with the experience of pain and described how pain can be misunderstood for Cree community members.

An interview was conducted with an Elder via Zoom (due to COVID-19). The Elder's granddaughter facilitated the technology in the Zoom meeting and was also provided gifts to thank her for facilitating and sharing her knowledge of technology. The discussion included: 1) introduction of elements used in current pain scales: NPRS, FPS, and CAS, 2) discussion regarding relevancy of pain scale elements for community, 3) Elder storytelling about pain experiences, and 4) suggestions and discussions of possible revisions to improve cultural responsiveness of the pain scales.

Phase 2: piloting of CDPS

Phase two utilised a mixed methods approach where the quantitative data allowed assessment of validity and complemented the qualitative data which allowed for an in-depth understanding of the participant experiences with the new pain scale, as they were interpreted together. Quantitative data in the form of demographic information and pain scale utilisation pre-physical therapy assessment was collected for FPS-R as well as CDPS. Qualitative data in the form of semi-structure interviews were conducted after virtual programming was completed (assessment and follow up or three to four virtual physical therapy treatments). Purposive sampling was utilised to ensure participants had lived experiences with CBP and lived in the community. Participants were recruited through posters in the Angelique Canada Health Center, as well as through recommendations from physicians and nurse practitioners who provided research team contact information to their patients. The lead author and the PI for the overarching CBP study are English speaking. Community research team members are both Cree and English speaking. Interviews were conducted in English, and all participants were provided the option of Cree translation for interviews.

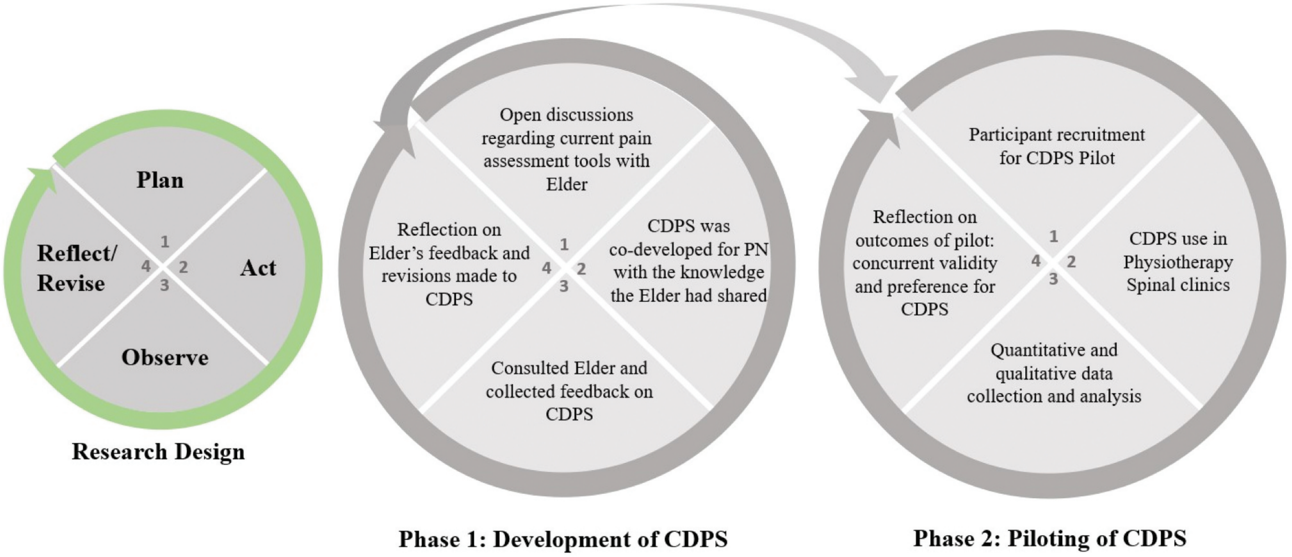

Figure 1. Pelican Narrows research process depicting the two separate phases of the project.

Phase 2: Quantitative Data Collection Procedures

The gathering of quantitative data included the utilisation of the CDPS and FPS-R pre-physiotherapy treatment during Study A, a virtual physical therapy intervention study. The inclusion criteria were: 18 years of age or older, from Pelican Narrows or surrounding communities (members of the Peter Ballantyne Cree Nation), and experiencing CBP (pain that has persisted for three months or longer). The only exclusion criteria was if a person was unable to consent to participate. Translation was provided as needed to ensure this would not be a reason for exclusion. Consents were reviewed in English by research team members together with participants, and a Cree speaking translator was available for any patient that may have preferred translation. Twenty-seven participants completed the pre-physiotherapy treatment questionnaire which included the utilisation of CDPS and FPS-R and a demographic form. Sixteen participants were female and eleven were male with overall average age of 49.7 years (Appendix A, Table 1 outlines demographics). Twenty-seven participants was the entire total of all participants within the back pain clinic who had agreed to participate in the pain scale substudy.

Phase 2: Qualitative Data Collection Procedures

As the piloting of the CDPS was a sub-study within study A, participants within Study A were recruited to participate in one-on-one semi-structured interviews to share perspectives regarding the CDPS. In addition, HCPs who were involved with Study A were invited to share their experiences with communicating about pain with patients, and their perspectives on CDPS. The semi-structured interview questions were developed in collaboration with the Indigenous scholars on the research team. (Appendix B).

Ten individuals were interviewed; nine community members and one HCP (a physical therapist). Of the nine community members, six were female, three were male with an overall average age of 45.2 years (Appendix C outlines demographics of interviewed participants). Participants were interviewed until we achieved saturation of qualitative themes. In June 2022, the research team travelled to the community and hosted a lunch at the local health clinic for community members and HCPs. Some interviews were conducted in-person. Additional interviews were conducted virtually using Zoom or remote presence technology. Interviews were conducted by the lead author and the principal investigator was present for some initial interviews to ensure process and community relationship building.

Interviews were audio recorded dependent on participants' comfort level. One individual was not comfortable with being audio recorded; therefore, the interviewer took detailed notes during the interview. Cree Elders who participated in semi-structured interviews received an offering of tobacco for their knowledge. We offered honorariums to all community members and Elders for their participation.

Transcription of recorded interviews occurred through the Canadian Hub for Applied and Social Research at University of Saskatchewan. The interviewer kept field notes and journals to document reflections, questions and critiques during data collection to aid in decision making during data analysis.

Analysis

Phase 1 analysis

Using teachings offered by the Elder, we made revisions to elements of current pain scales to be more in keeping with her teachings. Two variations of the CDPS were created based on the Elder's teachings. Of the two pain scales presented to the Elder, she chose one that she felt could be most beneficial to her fellow community members.

Phase 2 quantitative data analysis: Cohen's Kappa

Twenty-seven participants completed demographic questionnaires and use of pain scales (Appendix A outlines demographics). Pain scale utilisation was completed by either circling or "X" marking the number, facial expression, colour, and/or scale that best matched participants' pain. Each participant response was considered as one response for a total of 27. Participants' pain ratings from the two different pain assessment tools were analysed using SPSS software for agreement. The agreement of the pain scales was measured using Weighted Cohen's Kappa [53].

Phase 2 qualitative data analysis: thematic analysis

Qualitative data was thematically analysed using a qualitative coding software, NVivo [54]. Thematic analysis began with familiarisation of the transcripts and proceeded with coding, initially within each transcript, then across transcripts. The preliminary codes were further analysed and grouped into emerging themes. Discussion occurred frequently between the researcher and principal investigator, who was experienced in qualitative analysis, to maintain reliability. The HCP transcript was analysed separately from community members' transcripts to allow for possible emergence of differing themes.

Findings

Phase 1 findings

Elements of different pain scales (numerical, facial expressions, and colours) were discussed with the Elder. Our findings included:

Numeric Pain Rating Scale (0–10)

The Elder instructed that numerical scales ranging from 0 (no pain) to 10 (worst pain possible), may not be beneficial pain assessment tools for the community members because they may not quantify their pain. The nurse practitioner indicated that the numbers were helpful to practitioners because they translate pain from an Indigenous individual's viewpoint into something that western practitioners can understand and document.

Faces pain scale

The Elder advised that four faces expressing varying degrees of pain would be sufficient and felt that six or more was too many. She indicated that facial expressions used in FPS and other facial pain scales may not be relevant for her community. She described that when in pain, the community members are more likely to be quiet; therefore, facial pain scales demonstrating the last facial expression as someone screaming in pain (with an open mouth) may not accurately represent individuals in her community.

Colour analog scale

Colours may carry different meanings for Cree individuals of this community. Before any CAS were shown to the Elder, the Elder was asked to share what colours they associated with increasing pain. The Elder stated: yellow (represents no pain), orange, red (represents the anger and emotion that comes with pain), and blue (represents maximum pain). The Elder explained that she associated blue with the most pain because it represented bruising and paleness, when a person is very unwell.

Community directed pain scale

After discussions with the Elder, different aspects of each scale were combined to create two revised pain scales for review by the Elder (Figure 2). Figure 2(a)'s facial expressions are formed with black outlines while Figure 2(b)'s facial expressions are formed with colours that match the colour scale suggested by the Elder. There are only four facial expressions indicating an increase in pain from the left to right. The last facial expression has a closed mouth to indicate silence as guided by the Elder. The colours used reflect what the Elder had guided to represent an increase in pain. Lastly, a numerical aspect was incorporated within the revised pain assessment tool to facilitate translation from an Indigenous individual's viewpoint into something that a Western practitioner can quantify. The Elder defined the Cree words that would describe different amounts of pain in the scale, and a Knowledge Keeper with linguistic expertise in the Cree Th- dialect provided the translations. Both Figures 2(a,b) were presented to the Elder, from which she informed Figure 2(b) as the most suitable scale; therefore, it was utilised during phase two.

Phase 2 quantitative findings

Twenty-seven participants ($n = 27$) completed pre-physiotherapy treatment questionnaires describing their pain using both the FPS-R and the CDPS. A Weighted Cohen's Kappa yielded a value of 0.696 ($k = 0.696$) indicating "good" agreement between the scales, with P-Value = <0.001.

Further analysis revealed participants utilised different elements within the pain assessment tools. Within the use of the FPS-R, 27/27 participants used the numerical features on the pain scale either by circling or X marking the number that represented their pain. Within the use of the CDPS, 4/27 participants utilised the horizontal colour scale by circling or X marking the location which represented their pain; 1/27 participants used the facial expressions and the numerical together by circling the face and number that best represented their pain; 1/27 participants used the colour scale and the numerical value in unison by circling the colour and number that described their pain; and the remaining participants (21/27) used the numerical elements of the pain scale to communicate their pain.

Nine individuals participated in follow-up semi-structured interviews where they shared further detail on what elements they used to comprehend the self-reporting tools. When using the FPS-R, 9/9 participants either circled or "X" marked a numerical element to describe their pain; however, only two participants indicated they solely used the numerical element to understand the pain scale (Figures 3 and 4). When using the CDPS, 7/9 participants either circled or "X" marked a numerical element to describe their pain; however, only 1/9 participant said they solely looked at the numerical element to comprehend the pain scale (Figures 3 and 4).

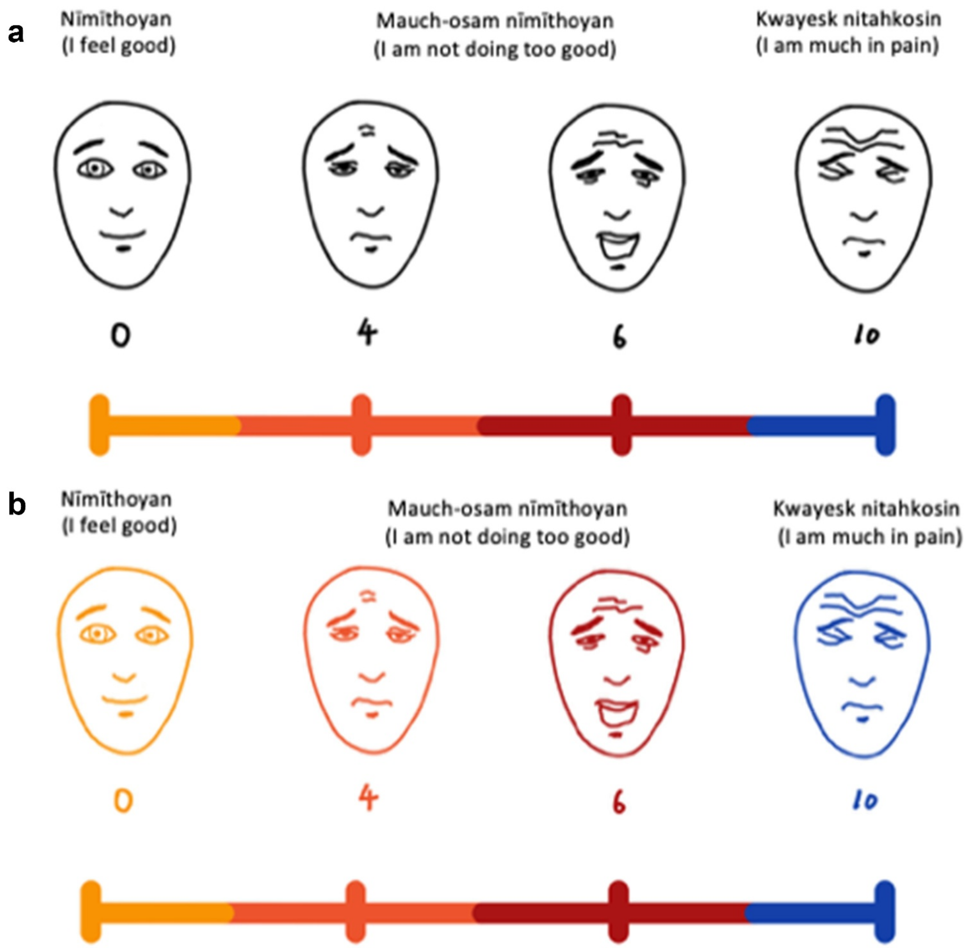

Figure 2. a&b community directed pain scale a & b.

These pain scales were generated by combining three pain scales elements (numerical component, facial expressions component, and chromatic component) and the Elder's suggested revisions. Descriptions of pain level are included in English and Cree.

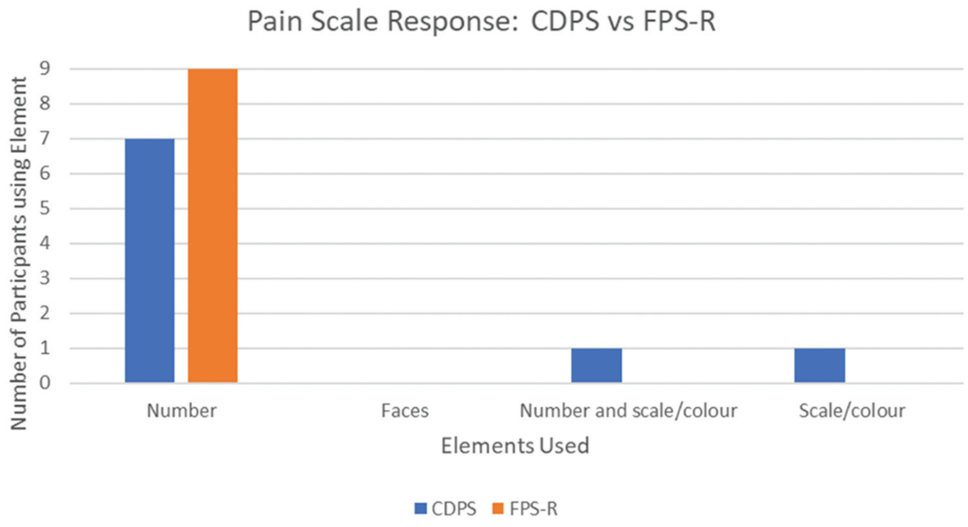

Figure 3. Pain scale response: CDPS vs FPS-R.

The elements the nine community members (who were interviewed) either circled or X marked when using the pain scales.

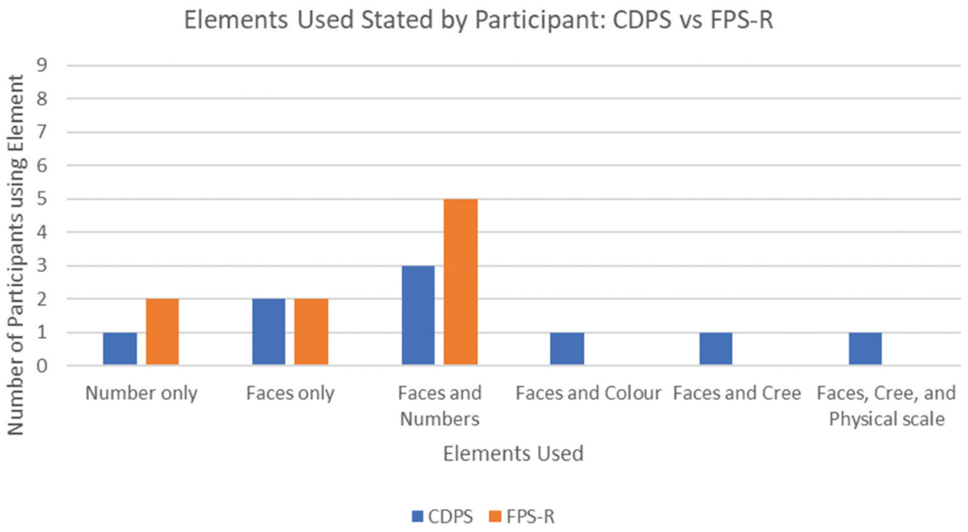

Figure 4. Elements used stated by participants: CDPS vs FPS-R.

The elements the nine community members (who were interviewed) were actually looking at on the pain scales to understand the self-reporting tool.

Phase 2 qualitative findings from community members

Qualitative findings from community members yielded three major themes each with subthemes and some sub-subthemes: 1) Learnings Regarding Pain Scales, 2) Patient Centered Care; and 3) Strength-Based Solutions for Improving Pain Communication. Figure 5 outlines the themes.

Major theme 1: learnings regarding pain scales

Community members revealed there were differing communication preferences when speaking about pain and differing pain scale preferences. The subthemes were as follows: 1) Communication Preferences, 2) Elements Participants Liked about the CDPS, and 3) Elements Participants Liked about the FPS-R. The complete list of quotes from community members is outlined in Appendix D.

Communication Preferences. Community members' communication about their pain through pain scales (CDPS and FPS-R) revealed elements which were meaningful. Some participants focused on the facial expressions in unison with another element. One participant shared, "I look at the face and then the number". While some solely looked at facial expressions, and some solely used numbers.

CDPS. Participants utilising the CDPS often looked at facial expressions in unison with another element with few solely using the numerical or the facial expressions to understand the pain scales (Figures 3 and 4).

FPS-R. When participants used FPS-R, many relied exclusively on facial expressions to utilise the pain scale (Figures 3 and 4). One participant shared the meanings of the facial expressions:

> Like the faces on number ten … so angry, and faces on number eight it's just like you're stressed out, and the faces on number six you're worried, [the faces on] number four you don't know what to do, and [the faces on] number two and number zero you're doing okay.

A few participants utilised the scale by looking at facial expressions in unison with numbers. While only a couple of participants preferred numbers exclusively to use the pain scale.

In addition, there were alternative preferences when it came to pain communication. Two community members preferred to express their pain experiences through storytelling than use of pain assessment tools. Although both participants did describe their experiences using the pain scales, they were both focused on explaining their experiences through stories. For example, when asked to describe their pain, both participants shared their pain experiences from beginning to end which described how they were injured, how long they have been experiencing pain, the way they feel pain and how the pain has affected their lives in terms of functional aspects of daily living.

Elements Participants liked about the CDPS. Out of the nine participants who were interviewed, four expressed a preference for the CDPS over the FPS-R (see Appendix C for participant demographics for pain scale preferences). The reasons for their

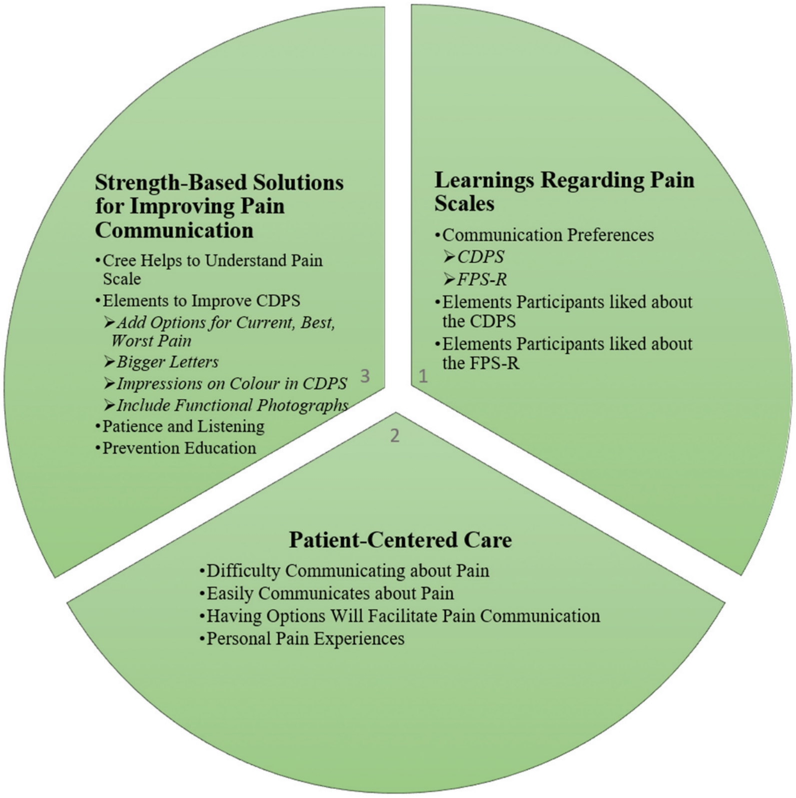

Figure 5. Pelican Narrows community members themes outline.
The three major themes with its subthemes and sub-subthemes outlined.

preference were diverse. One individual stated that they like CDPS more than FPS-R because there were too many facial expressions to pick from on the FPS-R. Another individual preferred CDPS because they were able to identify changes overtime on facial expressions. In addition, one participant liked CDPS because, "It's simple. And you could tell which colour in between, like half and half with the colours where they meet". Moreover, one participant enjoyed the CDPS and stated, "Because this one has colour in it and the faces have meaning to it … that's how I feel the pain, like number 6 in the face".

Elements Participants liked about the FPS-R. Five participants choose the FPS-R over CDPS (see Appendix C for participant demographics). Two individuals preferred FPS-R because it included more facial expressions to choose from. One stated, "it has more faces and you can tell how high it goes … The more faces you make, the more pain you are in". In addition, two other participants preferred FPS-R over CDPS because FPS-R asked about worst pain, best pain, and current pain while CDPS only asked about current pain. One participant appreciated those questions because they allowed the opportunity to capture changes in pain. Lastly, one individual liked FPS-R because he preferred numbers, and FPR-R presented more visible number options when compared to CDPS.

Major theme 2: patient-centered care

The second theme that emerged from conversations with community members indicated the importance of patient-centred care. The subthemes within major theme 2 include: 1) Difficulty Communicating about Pain, 2) Easily Communicates about Pain, 3) Having Options Will Facilitate Pain Communication, and 4) Personal Pain Experiences. The complete list of quotes from community members is outlined in Appendix D.

Difficulty Communicating about Pain. Three out of nine participants expressed having trouble communicating their pain in a way that accurately conveyed it. For example, when asked if participants had trouble with describing their pain and how they are feeling, one participant responded, "Yeah, like I have a hard time with words sometimes". Another person stated it was hard for them to find the right words to describe their pain and it is not due to language barriers, as they stated their English was good, but rather, it was just hard for them to find the words.

Easily Communicates about Pain. Six out of nine participants expressed having no trouble with communicating about pain. For example, one participant said, "Yeah, it's easy. I don't mind describing it because it will help the doctors or nurses more to see what they have to do, or what I have to do".

Having Options Will Facilitate Pain Communication. Many people expressed the importance of inclusion and suggested offering different options of pain scales for people to use to allow for effective communication about pain. One participant stated, "Everybody's different, some of them might like pictures or numbers. If you see some other patients someday, they might like this or this, hey?" Another participant stated, "We have to look at the other people too" talking about pain scale elements that were meaningful. In addition, one person showed their value of patient centred care by suggesting the addition of colour elements to the FPS-R as it might be beneficial for other people, " … maybe if it had a colour in here too, it would be a lot better for other people". Other individuals expressed the importance of considering the options available for Elders, with one participant stating, "I guess it will be different for others because if it's an Elder maybe the community one [the CDPS] will be better for them. Like if they just point at the colour and the facial".

Personal Pain Experiences. When discussing pain with community members, many shared their personal lived experiences with pain. Some individuals explained their pain journey, how they hurt themselves and how that pain has been affecting their daily living and culture. One individual expressed how their pain has been functionally and culturally limiting:

> Sometimes, I wish I never injured my back. It's not the same, hey? You can't do the things you used to do, like I said, like pulling a boat, the portages, getting wood from the bush and carrying like this or like this. I used to do that lots when I was younger, getting wood from the bushes, walking and carrying them like this on my shoulder, now I can't do that.

Another participant explained how they have been dealing with pain in their own way:

> Sometimes my lower back locks and I can't walk. I use a cane. Sometimes like today I only had to hold on to my mother's arm walking … [I] try to hide my pain and try always. I'm still in pain but I don't tell anyone. Sometimes, you know … just think about your pain for a moment and just try to forget about it … try sleeping 'cause if you're sleeping you're not in pain. If you can't sleep during the day just try your best not to think about the pain.

Major theme 3: strength-based solutions for improving pain communication

Discussions with community members revealed many strengths the community of Pelican Narrows possesses which should be taken into consideration when communicating about pain. The subthemes include: 1) Cree Helps to Understand Pain Scales, 2) Elements to Improve CDPS, 3) Patience and Listening, and 4) Prevention Education. The complete list of quotes from community members is outlined in Appendix D.

Cree Helps to Understand Pain Scales. Insights gathered from discussions with community members indicated the importance of having Cree within pain scales to facilitate understanding. More importantly, community members expressed the need to have Cree descriptors in an audio format. One participant said:

> Yeah, but for the Cree words they're gonna have to see if they know how to read the words in Cree … Yeah, it [having Cree descriptors in an audio format] would be helpful … like if you heard the audio and then it would help … But I need that audio [of the Cree descriptors] because … I don't really, I never really remember how to write and read. I did it when I was younger.

Elements to Improve CDPS. Feedback obtained through conversations with community members revealed improvements that could be made to CDPS for better pain communication such as the addition of more faces, numbers, and questions. Some participants also suggested the inclusion of additional elements, like weather to capture how weather can affect pain, thumbs up and thumbs down indicators, and having a binder to capture pain over a span of a week.

Add Options for Current, Best, Worst Pain. There were two participants who preferred the FPS over CDPS, the reason for enjoying the FPS was due to the way it asked about pain. FPS asked participants to describe their current pain, and pain when it is at the worst and best.

Bigger Letters. Perspectives shared by two community members indicated the need to increase the font size of the Cree descriptor on CDPS to aid in reading of the pain scale.

Impressions on Colour in CDPS. Opinions expressed by community members in conversations revealed a mixed preference for the colour element. Three community members expressed the colour element was not for them, but two believed it could be helpful for others, stating, "We have to look at the other people too".

Two participants found the colour element to be helpful during pain communication; however, they had different ideas where colours should be located to represent differing pain levels. For example, "Maybe you should put the blue on this one ['no pain'] and then go up and this [red] would be the last one". And another individual said, "Maybe switch up the red and blue".

Include Functional Photographs. One participant expressed the idea of including functional photographs to help people who might not be as vocal with pain expression to allow them to point to pictures showing certain actions that could lead to pain.

Patience and Listening. Knowledge shared by community members indicated some members of the community have experienced a feeling of being unheard when accessing healthcare. Participants explained that HCPs should take the time to listen to patients and not rushing during appointments. For example, one participant stated:

> Sometimes, they don't listen to me, they say "Oh, I'll give you this, I'll give you Tylenol, that'll help". Sometimes I feel rushed … and they see you really fast, that's it … they don't listen to you when you're talking …

When asked what would make this participant feel more comfortable to talk about pain, they replied, "Have them [HCPs] listen to you instead of cutting you off when you're trying to tell them something".

Prevention Education. Through conversations with community members, one individual explained the importance of having more injury prevention education for community members.

The participant explained their lack of awareness on the safe way to lift and carry heavy objects led to their initial back injury. From this participant's experiences, they felt a strong need to advocate for prevention education:

> Maybe you guys can tell other people – clinic workers, or wherever, every time [they] lift up a box or something, always to bend their knees … Prevention, so they won't hurt their backs or their legs. Even to the school students, that would be awesome, really important … so they won't injure their back like I did.

Phase 2 qualitative results healthcare provider

Qualitative findings from the HCP yielded two major themes each with subthemes and some sub-subthemes. The two major themes are: 1) Perspectives on CDPS and 2) Healthcare Provider Experiences Communicating about Pain. Figure 6 outlines the themes.

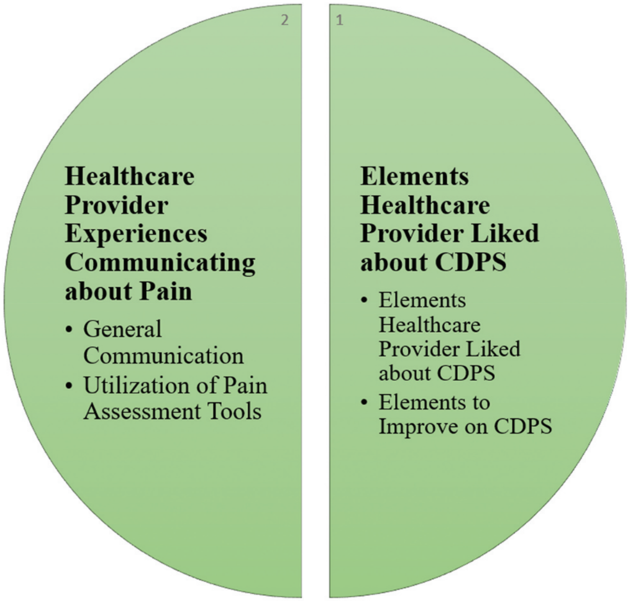

Figure 6. Pelican Narrows healthcare provider themes outline.
The two major themes with its subthemes outlined.

Major theme 1: perspectives on CDPS

Discussions with a HCP who was involved in the virtual assessments captured a physical therapist's perspective on elements in CDPS that could be beneficial for pain communication, and elements that could be improved. The subthemes within major theme 1 were as follows: 1) Elements Healthcare Provider Liked about CDPS and 2) Elements to Improve on CDPS. The complete list of quotes from the HCP is outlined in Appendix E.

Elements Healthcare Provider Liked about CDPS. Conversations regarding the CDPS captured the HCP's feedback in terms of the elements that they felt could be useful for pain communication with patients. The HCP believed the simplicity of the pain scale is a positive element and the non-traditional colours of the pain scale provides consideration for differing cultural perspectives. They felt the facial pain scale that is used depicts more realistic facial expressions as opposed to cartoonistic drawings, and the pain descriptors are not all about pain severity, but rather about feeling "good" or "not too good" which allows space for people to interpret. The provider stated:

> I like the wording. That it's not all about pain. To some that zero is no pain and I just feel good. That might even be in a little bit of pain. Right? The middle being not doing too good. It just allows space for people to have nuances and ranges. That was the other thing that stood out. Yes, this would be quite helpful.

Elements to Improve on CDPS. The HCP expressed that further direction on how to use the pain scale might be necessary for clearer understanding and directions on use of the pain scale with patients. For example,

> I have a choice of using the words, color, or faces. Maybe some further direction that you don't have to pick all three. You can actually pick one of them and that the colors aren't just a scale that I can just pick a color. I can say I'm feeling orange. Maybe just some clear direction that I can choose that. [And] … the other thing that might help is specific directions for the clinician of how to present this.

Major theme 2: healthcare provider experiences communicating about pain

Discussions with the HCP surrounding their experiences communicating about pain with patients revealed two subthemes: 1) General Communication and 2) Utilisation of Pain Assessment Tools. The complete list of quotes from community members is outlined in Appendix E.

General Communication. The HCP suggested ways to ensure better communication about pain with patients. They mentioned the importance of using common language to communicate about pain, being consistent with the language that is used throughout multiple treatments, and providing simple visuals when needed has offered meaningful ways to connect with patients.

Utilization of Pain Assessment Tools. Experiences revealed by the HCP suggested that general pain scales utilised to assess pain are the NPRS and the visual analog scale (VAS). Both require HCP expertise on how to effectively explain the scales to patients. The HCP expressed that the NPRS was more effective than VAS as VAS often required more explanation to understand. When asked how the medical community could improve pain scales, the HCP said:

> Make it simple. Anything else I'd say would be some other explanation of that, but we just need to focus on what matters. What matters is this pain changing factors. Whether that's getting better or getting worse or not changing … Not requiring a ton of explanation cause it would lose some of the experience. And then one that is not just simply explained, but then simply used throughout time and perspective, client understanding, and obviously, sensitive to change.

Discussion

Through longstanding relationships and working partnerships with an Elder and a Knowledge Keeper from the community of Pelican Narrows, a CDPS was co-developed and piloted. During this time, we met regularly through virtual means as a team, including a youth family member facilitating technology, since we could not travel to community during Covid-19. Protocols such as gifting and tobacco continued through mail to ensure the process proceeded in the right way. The CDPS yielded comparable outcomes to the FPS-R with a "good agreement" following Weighted Kappa analysis, establishing its concurrent validity. Conversations with participants revealed that they utilised the pain assessment tools in unique ways that were meaningful to each individual. They expressed the importance of having different options available to accommodate individuals' different preferences when it comes to pain expression using self-reporting tools.

The teachings from the Elder aligned with the limited research that is present [24,42] which indicates Indigenous populations may express pain differently than those of Western cultures; thus, Western pain scales may not effectively facilitate pain expressions. Fenwick [42] found that some Indigenous communities in Australia don't have conceptual recognition of numbers above five. The Cree Elder in the present study echoed the lack of quantification of pain, indicated that the community members of Pelican Narrows may not put a measure on pain, and that the members may become more silent when they are in pain; thus, the NPRS may not be effective. However, a number of individuals chose a number on the self-reporting tool to communicate their pain even though they were looking at multiple different components in addition to or outside of the numerical element. Additionally, we learned that numbers may help Western health practitioners to understand pain from an Indigenous individual's perspective. Moreover, we learned that existing facial pain scales that we demonstrated to the Elder may have too many facial expressions, the expressions may not all be universally expressed, and colours may carry different meanings for individuals of this community.

A scoping review done by Bailey et al. [9], looked at physical pain among Indigenous Peoples in Canada and yielded a total of four original research studies discussing pain measures and pain assessment tools. Two studies involved Mi'kmaq, and Wolastoq First Nation groups; and two studies involved Inuit communities in Nunavut [7,9,24,55]. To our understanding, we are the first to work alongside a Cree community in Saskatchewan to discuss pain measures and pain assessment tools that would be more relevant for communication in their community. The participants' use of the CDPS to express their pain had good agreement with the well-established FPS-R. This indicates the CDPS is a valid pain assessment tool capable of capturing patient's pain while offering more elemental options to choose from compared to the FPS-R. Unlike the FPS-R, the CDPS incorporates five elements rather than only two. The five elements included: Cree descriptors, numbers, facial expressions, colours, and a horizontal scale. The inclusion of these components has been shown to be beneficial in facilitating understanding of the pain scale. While 21/27 participants indicated their pain via the numerical component on the CDPS (either circling or "X" marking the number), 6/27 participants expressed their pain via another component (either circling or "X" marking colours, facial expressions or the physical scale). Although the majority of individuals chose a numerical element on the pain scale, one cannot assume that this is due to a preference of numbers over another component, as semi-structured interviews with nine participants revealed 88.9% (8/9) of them were looking at other elements either in addition to the numeral aspect or solely looking at another element in their use of the pain scale. Of the nine participants interviewed, 8/9 responded with a number yet seven of them were not solely looking at the numbers to understand the pain scale. The present study suggests that participants within Pelican Narrows often focused on facial expressions along with another element to utilise self-reporting pain scales. This observation is important to consider for future research and clinical practice. Incorporating multiple elements can potentially enhance the comprehensibility of pain assessment tools, specifically for the community of Pelican Narrows. Of the nine individuals, three females and two males preferred the FPS-R while three females and one male preferred the CDPS. Individuals that were interviewed had a median age of 44 years while the Elder who shared teachings regarding pain experiences was 74 years of age. Due to the gap in age, it is difficult to determine whether younger and older community members would perceive and communicate pain in the same way.

It's been well-established that each Indigenous community may have differing worldviews and pain experiences [24,42,43]. We understand there is uniqueness of each Indigenous community in terms of culture, protocols, and beliefs; therefore, the findings of this study should not be overgeneralised to all Indigenous Peoples. Rather, it should be utilised as steppingstone in future research to continue to investigate and understand the pain experiences of Indigenous Peoples across Canada.

Additionally, we also learned that other components within healthcare interactions need to be addressed in order to establish a safe environment that promotes better communication overall. Qualitative analysis of community participant interviews revealed three important themes: 1) Learnings Regarding Pain Scales, 2) Patient Centered Care, and 3) Strength-Based Solutions for Improving Pain Communication. The relationship among the three themes is important, as HCPs need to first understand the community's perspective regarding pain expression and individuals' lived pain experiences, while acknowledging and integrating the community's suggested ways for improving pain communication in order to truly provide patient-centred care.

Results indicated it is crucial to establish safe healthcare encounters to promote meaningful pain communication. Most participants shared their experiences through storytelling. Through the stories, answers to the questions of "where it hurts, when did it first begin, how did you hurt it, how has it been affecting your daily function and cultural practices" were expressed. This finding aligned with a research study conducted by Latimer et al. [56], which found that when First Nation youths were provided with a safe space, they were more willing to share a wholistic view of their pain experiences that not only outlined the physical impact, but it allowed them to address emotional pain, mental pain, and spiritual pain. Through patience and listening, HCPs can acquire a large amount of information regarding pain.

Community members provided suggestions for enhancing current pain communication strategies through a strength-based approach which included subthemes such as *prevention education* and fostering a patient centred approach through *patience and listening*. These recommendations aligned with two of the Canadian Pain Task Force's goals, "improve access to timely, equitable, and person-centered pain care" and "increase awareness, education and specialized training for pain" [57]. In addition, the Canadian patients Safety Institute highlighted patients' preferences for HCPs who prioritise active listening and strive to understand patients' unique experiences as it facilitates positive relationships and a safe environment [58] which further supports the pain communication recommendations suggested by community members.

Members of Pelican Narrows expressed pain communication will differ among the community members – aligning with the patient-centred care model – therefore having different options for pain scales, incorporating a variety of pain scale components, and practicing patience and listening can potentially aid in pain communication. This finding is consistent with a qualitative study conducted by Latimer et al. [7], with Mi'kmaq children which aimed to understand pain expressions and pain management. Latimer's study revealed participants felt unheard, valued trust building, storytelling as a means of pain communication, and the advantages of a patient-centred and family centred approach to care. The findings of our study, along with the studies of the Canadian Pain Task Force [57] and Latimer et al. [7], suggest the need to give patients the space for storytelling. To conduct a comprehensive pain assessment and allow patients the space for storytelling may take time, may take several visits, and may take a multidisciplinary team.

There is a gap in knowledge on pain beliefs from Indigenous perspectives [16]; however, silence when in pain was observed within many Indigenous Peoples in Canada, the United States, and Australia [12–14,56,59]. Latimer (2018) [56] observed hiding pain during sharing circles with two different First Nations groups in Canada (Mi'kmaq and Wolastoq). Jimenez et al. [12], and Kramer et al. [13,14], reported Indigenous Peoples within Canada and the United States underemphasised pain and described severe pain with vague descriptor such as, "discomfort" and "ache". Fenwick and Stevens [59] found Indigenous Peoples in Australia also suppressed pain behaviours and were silent when in pain. Further research in imperative to comprehend the cultural reasons underlying the silent response to pain, recognising the variability of beliefs across different Indigenous cultures. Nevertheless, Latimer et al. [7], suggests the reserved response to pain could be contextualised within the history of colonisation and mistrust with the healthcare system through learnt behaviours stemming from intergenerational trauma.

In this study, we found that most of the nine community members who participated in interviews were comfortable sharing their pain, with the exception of one individual who expressed that they will often hide their pain. It is important to note that in the community of Pelican Narrows, the Angelique Canada Health Centre is managed by the Peter Ballantyne Cree Nation Health Services with local community members as employees and health providers, with non-community member health professionals living in community for two weeks at a time also providing care. It is likely that local community member HCPs facilitate a higher level of trust which creates a safe environment for Indigenous patients to communicate. This comfort level of participants with expressing pain may not be generalisable to health facilities in remote communities which are not managed by the community and First Nation governance structure. Furthermore, the CDPS incorporates elements such as the Cree language and facial expressions that closely align with the experiences of pain among community members. The inclusion of culturally relevant elements likely facilitated increased trust and a safer environment for open communication about pain.

The HCP interview complemented the community members' themes and emphasised the critical aspects that must be taken into account to ensure effective pain communication, including the importance of using simple pain assessment tools and incorporating relatable and realistic facial expressions in pain scales to convey meaning and capture change in pain intensity. Ellis et al. [24] revised a facial pain scale to enhance its cultural relevance for the Inuit community of Pangnirtung, Nunavut. Their findings aligned with the present study, highlighting the importance of utilising simplistic pain assessment tools that capture facial expressions that hold cultural significance and resonate with community members.

To our knowledge, this research is the first study in Saskatchewan to develop a pain assessment tool in collaboration with a northern Cree community that is tailored to their needs. Moreover, it is one of the few studies dedicated to co-construction of a culturally responsive pain assessment tool with an Indigenous community in Canada. This study demonstrated a pain scale developed with an Elder and a Knowledge Keeper, and piloted the pain scale to document its concurrent validity. Community members provided ideas for enhancement of the tool. This preliminary study lays a solid foundation for future research in the domain of culturally responsive pain assessment tools while offering insights to HCPs on how to approach pain assessments, ensuring patients feel respected and safe.

In terms of future research, suggestions were received from participants to enhance the CDPS and these modifications and discussions could be made in partnership with the Elder, Knowledge Keeper and community members, perhaps through sharing circle work, to continue to enhance the pain scale and prioritise community voices. As well, given the multi-modal nature of the CDPS that was developed in this project, comparison to the Disabled Veterans Pain Rating Scale [60] is another area for future work. Further analysis of the CDPS with a larger population is needed to determine its efficacy and sensitivity. Additional future research could assess the validity of the pain scale with children and the unique pain experience of Indigenous children. Moreover, long term follow-up using the CDPS to test the sensitivity of the pain scale to detect changes in pain over time could be explored.

Rigor and limitations

The qualitative rigour of this study was achieved through the adherence to criteria such as credibility, transferability, and dependability. Credibility was established by engaging in peer debriefing sessions, wherein the lead author and the PI frequently met during data analysis to discuss emergent themes. Moreover, the results and findings incorporated participants' verbatim expressions, safeguarding an accurate interpretation of their experiences. Transferability was addressed through contextualisation of the phenomenon within the demographic of Indigenous populations and with detailed descriptions of our collaboration with the Cree community. To establish dependability, the study's purpose, participant recruitment processes, interview methodologies, and analysis procedures were clearly expressed. This comprehensive depiction equips other researchers with the necessary insights to replicate the study. It is crucial to note, what was presented in this study may not be culturally responsive to another Indigenous community, which highlights the importance of adhering to traditional protocols guided by community members.

This study has some limitations. The development of the CDPS pain scales included the feedback from one Elder which may not be representative of every single member of the community of Pelican Narrows. In addition, the CDPS pain scale may have limitations with age as this study only included adults. Lastly, this project was community-driven and designed to meet the needs of Pelican Narrows, a remote Cree community. Therefore, it may limit its generalisability to other Indigenous communities. The process and outcomes of this study may provide valuable insights and learnings for future research and for communication about pain that is culturally responsive for Indigenous Peoples.

Conclusion

In summary, by working alongside a Cree Elder from the community, a CDPS was developed. Preliminary testing of the CDPS yielded comparable outcomes to the well-established FPS-R. Community members utilised the pain scale in different ways that were meaningful to each individual. The elements used to comprehend the pain scale did not necessarily reflect the elemental response given by participants. Community feedback regarding pain communication and the use of the CDPS revealed the importance of offering different elemental components within a pain scale to allow participants the space to make sense of the pain assessment tools. Moreover, a patient-centred care approach when discussing CBP pain is important to ensure a safe environment where patients feel they can tell their stories and be heard by HCPs.

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Appendix A: Pelican Narrows community member demographic for pre-physiotherapy questionnaires

Table A1. Participant demographic for pre-physiotherapy questionnaires.

Variable	Participant Demographics ($n = 27$)
Age	49.7 average 52 median
Gender	16 female 11 male

Appendix B: Pelican Narrows semi-structured interviews for patients and health providers

Oral Re-Consent:

☐ I have re-read and explained the information in the Consent Form to the participant, and the participant has given verbal re-consent to for the researcher team to use information provide in this interview.

________________________ ________________________ ____________

Name of Participant *Community Researcher Initials* *Date*

Preamble:

Hello, my name is X, and I am part of the research team looking at evaluating the community-directed pain scale that you used as part of the remote presence and chronic back pain project. Thank you for agreeing to talk to me about your experiences with the project.

As you know from the consent form we just reviewed together, the information you share today will help us evaluate the pain scale that was developed with an Elder and Knowledge Keeper and make improvements that may make it easier for Indigenous patients to communicate about their pain. You can decide not to answer certain questions, and you decided to stop the interview at any time.

The information you share will be combined with information shared by other community participants and health care providers involved in the project.

This discussion should take approximately 30 minutes to 1 hour.

Do you have any questions before we get started?

If no …

Let's get started … I am turning the recorder on now.

Patients

1. **Tell us what it is usually like to communicate with health providers about your pain.**

   Prompts: Do you find it difficult to talk about your pain or explain your pain?

2. **Is there anything that would make you more comfortable to talk about your pain?**

   Prompts: How does the environment effect how you feel? Is there anything the health provider can do to make you feel more comfortable when talking about your pain?

3. **Tell us about your experience filling out the faces pain scale** (interviewer should show them the 10 faces pain scale).

   Prompt: How well do you feel this scale helped you to communicate your pain?
   a. Challenges understanding of the expressions of the faces?
   b. Were the facial expressions similar to how you would express your pain?

4. **Tell us about your experience filling out the community-directed pain scale** (interviewer should show them the novel pain scale).

   Prompt: What did you find different about this scale compared to the 10 faces one?
   Prompt: How well do you feel this scale helped you to communicate your pain?
   a. Challenges understanding of the expressions of the faces?
   b. Were the facial expressions similar to how you would express your pain?
   c. Do the colours help you to identify and explain your pain?
   d. Do the Cree words help you to identify your pain?
   e. Were the numbers on the scale helpful to you? Did you use it?

5. **Which scale did you prefer using?**
   Follow up: **Why?**
6. **In your opinion, is there anything we could do to improve the new community-directed pain scale?**

   Prompt: What did you like or didn't like about the scale?
   Prompt: What things do you think would make pain scales better for you?

7. **Would you use the community-directed pain scale again for other health provider visits? Describe when you think this would be useful (other situations).**

8. **Is there anything else you would like to share with us about either your experiences with using pain scales or your experiences with pain?**

Providers

1. **What pain scales have you traditionally used to assess Indigenous patients' pain? In your opinion, how effective has that process been in the past?**

2. **From your experiences, which types of pain scales were the most preferred by Indigenous patients when asked to share their pain experience?**

3. **Describe your experience communicating about pain with patients using the community-directed pain scale.**

   Prompt: Was the scale easy to understand?
   Prompt: Were the colours useful?
   Prompt: Did the Cree language on the scale provide help or clarification?
   Prompt: Were the numbers on the scale used?
   Prompt: Were the facial expressions representative of how they would express pain?

4. **In your opinion, is there anything we could do to improve the new community-directed pain scale?**

   Prompt: What did you like or didn't like about the scale?
   Prompt: What things do you think would make pain scales better for your patients?

5. **Do you have any additional concerns about your ability to understand pain from an Indigenous patients' perspective?**

6. **Is there anything else you would like to share?**

Appendix C: Pelican Narrows pain scale preference demographic

Table C1. Participant demographic for pain scale preferences.

Variable	Preference for FPS-R	Preference for CDPS	Total Participants Interviewed ($n = 9$)
Age	46.80 average 47.00 median	43.25 average 41.50 median	45.20 average 44.00 median
Gender	3 female 2 male	3 females 1 male	6 female 3 male

Appendix D: Pelican Narrows themes and quotations from semi-structured interviews with community members

1. Major theme 1: learnings regarding pain scales.

Table D1. Pelican Narrows community members table of Quotes.

Subthemes	Sub-subtheme	Quotes
Communication Preferences	***CDPS***	I look at the face and then the number.
		The faces. Comparing it in between the score.
		It's easier on a scale from one to ten, hey? It's easier for me that way. If I really had a really sore back right now, but I would've been about nine, eight or nine.
	FPS-R	Well, that's what I'm looking at too at the same time; I'm looking at the face and the numbers. but if it's just a number, it's kind of hard to explain it, but when you see those faces and those numbers, like for instance, my pain right now is about here, number four.
		Like the faces on number ten … so angry, and faces on number eight it's just like you're stressed out, and the faces on number six you're worried, [the faces on] number four you don't know what to do, and [the faces on] number two and number zero you're doing okay.
		Yeah, easy. Well like, this is easy, like scale from one to ten to describe my pain? Yeah. Yeah, I can't – I like reading the Cree words, but like I said, to have an easier time on a one to ten scale.
Elements Participants liked about the CDPS		It's simple. And you could tell which colour in between, like half and half with the colours where they meet.
		Because this one has colour in it and the faces have meaning to it … .That's how I feel the pain, like number 6 in the face.
Elements Participants liked about the FPS-R		It has more faces and you can tell how high it goes. The more faces you make, the more pain you are in.
		Because it tells you the least pain and the worst pain and then the other one there. Yeah, the current, worst and least pain *
		Like, 'cause it tells you now then worse, when you're resting, you know. 'Cause it's, you have different patterns during the day.*

*These quotations appear in more than 1 theme.

2. Major Theme 2: Patient-Centered Care

Subthemes	Sub-subtheme	Quotes
Difficulty communicating about pain		Yeah, like I have a hard time with words sometimes.
		Some people, I don't know, maybe older people wouldn't understand how most pain they have when you ask them how much pain they have on a scale of one to ten, they might say five, in the middle, and they might say nine if it's really bad, and they might say two if it's not bad. Yeah.
Easily communicates about pain		I don't really mind, I don't mind because I just want to say how I feel about my back, hey? I don't mind. It's okay. Yeah, it's easier for me that way. Like I said, if some other person asks me, 'How's your pain', I'll just tell them, 'What's up, it's four right now', something like that, hey?
		Yeah, it's easy. I don't mind telling them how the pain is. I don't mind describing it because it will help the doctors or nurses more to see what they have to do, or what I have to do.
Having options will facilitate pain communication		Everybody's different, some of them might like pictures or numbers. If you see some other patients someday, they might like this or this, hey?
		We have to look at the other people too.
		… maybe if it had a colour in here too, it would be a lot better for other people.
		I guess it will be different for others because if it's an Elder maybe the community one [the CDPS] will be better for them. Like if they just point at the colour and the facial.
		I'm thinking of many Elders and other people in general that are not vocal enough and can maybe point at the pictures.
Personal pain experiences		Sometimes, I wish I never injured my back. It's not the same, hey? You can't do the things you used to do, like I said, like pulling a boat, the portages, getting wood from the bush and carrying like this or like this. I used to do that lots when I was younger, getting wood from the bushes, walking and carrying them like this on my shoulder, now I can't do that.
		My pain, was really uncomfortable. I couldn't even sleep well; I was awake at like 5–6 in the morning with backache. I had to switch sides, it was on my left or right, but I was more comfortable on my left. And cleaning up, it was from washing, wiping, sweeping off the floor and doing laundry that makes it, to carry the laundry upstairs, I've always had like steady pain on my back, my lower back.

(*Continued*)

(Continued).

Subthemes	Sub-subtheme	Quotes
		Yeah, because some days, before I started it [physiotherapy], there was like – every morning, I'd get up and have a sore back and my shoes, like sometimes I couldn't take – you put on your shoes like this, sometimes I'd be like … Like that, trying to reach my show. And ever since those exercises I started, I can go on boat rides, jump on a trampoline, no sore backs. I used to always have sore backs in south end.
		Sometimes my lower back locks and I can't walk. I use a cane. Sometimes like today I only had to hold on to my mother's arm walking … try to hide my pain and try always. I'm still in pain but I don't tell anyone. Sometimes, you know … just think about your pain for a moment and just try to forget about it … try sleeping 'cause if you're sleeping you're not in pain. If you can't sleep during the day just try your best not to think about the pain.

3. Major Theme 3: Strength-Based Solutions for Improving Pain Communication

Subthemes	Sub-subtheme	Quotes
Cree Helps to Understand Pain Scales		Translators, yeah. Some of the relatives that are here, they don't really like talking, but they'd rather talk to that person that'd explain everything because they're kind of shy because they don't really know how to say it in English, so it's better to have a translator.
		Yeah, but for the Cree words they're gonna have to see if they know how to read the words in Cree.Yeah, it [having Cree descriptors in an audio format] would be helpful like that because in reality, well I know they were supposed to come back to our own cultural, but actually it's really hard for people because there's no room for older people. And just too late. If you go to school. But it would be helpful, like if you heard the audio and then it would help. But I need that audio [of the Cree descriptors] because … I don't really, I never really remember how to write and read. I did it when I was younger.
		I can't seem to pronounce them [when reading the Cree descriptors].
Elements to Improve CDPS		Yeah, and maybe add more faces, add more numbers.
		The six faces will be better [than four faces] because some people say "well I feel like this" for just right now you'll feel like this one but before your pain changes like from a two to a six. 'Cause the longer that you sit down, well I find it that the longer you sit down the pain comes in faster.
		You can use the weather too at the same time. Yeah, because for me, for my pain, when the days the weather really is nice I'm in pain and I'm able to walk around and everything. But I'll just wake up with the pain in the back, but I'll still try to help myself out.
		Maybe a thumbs up or a thumbs down. [Thumbs up] as in feeling okay … thumbs down as in feeling not good.
		If you wanted to know about everyday pain, it would be good to have a little binder or something, for a least a week to see how your pain rate is
	Add Options for Current, Best, Worst Pain.	Because it tells you the least pain and the worst pain and then the other one there. Yeah, the current, worst and least pain.*
		Like, 'cause it tells you now then worse, when you're resting, you know. 'Cause it's, you have different patterns during the day.*
	Bigger Letters	Well, I think, you know, bigger lettering. Yeah, maybe if the font was enlarged bigger at the top.
		Yup. Yeah, maybe if the font was enlarged bigger at the top.
	Impressions on Colour in CDPS	Not really [about if the colour help with describing pain], but maybe some other people. We have to look at the other people too.
		Maybe you should put the blue on this one ['no pain'] and then go up and this [red] would be the last one
		Maybe switch up the red and blue.
	Include Functional Photographs	Maybe how, what do you call, a schedule like, say grocery, from cleaning, to shoes, to bed, like what is causing the pain. Or from not wearing proper shoe wear … I'm thinking of many elders and other people in general that are not vocal enough and can maybe point at the pictures … Yeah, if they're in pain doing the activity or like a visual schedule.
Patience and Listening		Sometimes, they don't listen to me, they say 'Oh, I'll give you this, I'll give you Tylenol, that'll help'. Sometimes I feel rushed. Like sometimes Dr. [deidentified] rushes and they sees you really fast, that's it. 'I understand, I understand, I understand that' like that, they don't give you – don't listen to you, what you have to say … Yeah, like they rush their patients, I find. They don't listen to you when you're talking to you, they'll cut you off and say this and that.

(*Continued*)

(Continued).

Subthemes	Sub-subtheme	Quotes
		Have them [healthcare providers] listen to you instead of cutting you off when you're trying to tell them something. But they don't really help. No. They don't really. Some of them do, the other ones just give me Tylenol. Some will give me [medications that will help with pain management]. It's kinda balanced.
Prevention Education		I hurt my back in '92, I think. Ever since then, that pain doesn't go away. It never goes away. That's why I don't do labour work anymore, because I can't, hey? If I do labour work, it'll hurt right away, it's going to make it worse. That's why I hardly do labour work now. Uh huh. I wish I was taught that when I was little, but I was never taught that. Like, this box here, if it goes on the floor, if you lift it up, you always have to bend your knees and go up slowly. Maybe you guys can tell other people – clinic workers, or wherever, every time I lift up a box or something, always to bend their knees … Prevention, so they won't hurt their backs or their legs. Even to the school students, that would be awesome, really important. Like I said, when you lift something, you always bend your knees and take it easy, and don't lift heavy objects. If you want to lift this thing, you probably need two guys to take it out, just take it easy, yeah? Things like that, just sort of get through it with people. Well, like I said, that you guys have [to teach] some of those kids, how to do this kind of stuff, like put them in walkers or they need to bend their knees. It's really painful once you have it. Like I said too before, to teach them young kids at school or even here at the clinic to come see you guys, so they won't injure their back like I did.

*These quotations appear in more than 1 subtheme.

Appendix E: Pelican Narrows themes and quotations from semi-structured interviews with a healthcare provider

1. Major theme 1: perspectives on CDPS.

Table E1. Pelican Narrows healthcare provider table of Quotes.

Subthemes	Subtheme	Quotes
Elements Healthcare Provider Liked about CDPS		First impression is there's only four choices which I like cause it's simple. It [the colours] not in the traditional sense of red being bad. Cause red isn't bad for some culture perspectives. My favourite thing about this is the facial expression. Only cause my concern with other tables, they have other facial expressions is it's almost too cartoony. It's tough to relate to. This, I can see a furrowed brow. All the way from a four to ten with different changes in the facial features that most humans would be able to connect with. I like the wording. That it's not all about pain. To some that zero is no pain and I just feel good. That might even be in a little bit of pain. Right? The middle being not doing too good. It just allows space for people to have nuances and ranges. That was the other thing that stood out. Yes, this would be quite helpful.
Elements to Improve on CDPS		I have a choice of using the words, colour, or faces. Maybe some further direction that you don't have to pick all three. You can actually pick one of them and that the colours aren't just a scale that I can just pick a colour. I can say I'm feeling orange. Maybe just some clear direction that I can choose that. And there might be a soft inquiry that comes with this but the other thing that might help is specific directions for the clinician of how to present this.

2. Major Theme 2: Healthcare Provider Experiences Communicating about Pain

Subthemes	Sub-Subtheme	Quotes
General Communication		That has been what I found has been the most helpful and beneficial is using very common, simple language. Is it pain or none? And all the way up to worst pain you can imagine. With the modifications being as I said, mild, medium, or a lot. Cause again, in the spirit of just the subjective perception that I then use consistently through the major of their treatment you can still gage a sense of improvement or not. Which with the pain scales, clinically, there's been increasing, decreasing, or not changing. However, we can capture that with simple wording and simple visualisation with modification for me, that has been the most impactful.
Utilization of Pain Assessment Tools		For pain scales in general, I've used both the NPRS, the Numerical Pain Ranging Scale. There's also the VAS, Visual Analog Scale. I would say that the NPRS I personally find more beneficial. That being said, beneficial only with the experience of how to explain the scale and script it so that it's understood and again, just leaving the space and the opportunity for there to be a knowledge of the understanding of the scale. That's the way I've found it effective. I have found [the VAS] less effective only because within the clinical setting, I'll say that everything's behind about time, I found the explanation required for the Visual Analog Scale truthly across ages and cultures has taken more time than using a different scale. Make [pain assessment tools] simple. Anything else I'd say would be some other explanation of that, but we just need to focus on what matters. What matters is this pain changing factors. Whether that's getting better or getting worse or not changing. Sometimes in tools, any clinical [inaudible, 00:06:20] community insight of the simplest reason. Any tool we use, it's gotta be simple. Not requiring a ton of explanation cause it would lose some of the experience. And then one that is not just simply explained but then simply used throughout time and perspective, client understanding, and obviously, sensitive to change.