

BUILDING BRIDGES FOR PAIN COMMUNICATION AND MANAGEMENT:
COMMUNITY-LED INSIGHTS FROM CREE AND DENE/MÉTIS COMMUNITIES IN
NORTHERN SASKATCHEWAN

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Abstract

Background Indigenous Peoples in Canada experience a higher prevalence of chronic musculoskeletal (MSK) pain compared to non-Indigenous populations. However, effective communication and management of pain within Indigenous communities remain largely unexplored. This study aimed to collaborate with the Cree community of Pelican Narrows and the Dene/Métis community of La Loche, both located in northern Saskatchewan, to identify elements that would better promote culturally appropriate ways of pain communication and pain management.

Methods This thesis encompasses two studies. The first study focuses on the collaborative development of the Community Directed Pain Scale in partnership with a Cree Elder and a Knowledge Keeper in Pelican Narrows. The pain assessment tool was piloted and followed by semi-structured interviews to assess the scale's concurrent validity and gather recommendations for improving pain communication. The second study involves a comprehensive needs assessment conducted in partnership with the community of La Loche to identify the strengths and needs of the community in terms of pain communication and pain management.

Results: The Community Directed Pain Scale yielded comparable outcomes as the Faces Pain Scale-Revised, a well-established pain assessment tool. The needs assessments in La Loche revealed the impact the patient-provider relationship has on the effectiveness of pain communication. Recommendations were made from the members of both communities on ways to enhance rapport and improve pain communication.

Conclusions This research emphasized the significance of creating a safe environment for Indigenous community members to share their chronic MSK pain journeys. Through open and respectful conversations with community members in Pelican Narrows and La Loche, foundational elements such as patient-centered care, the provision of culturally responsive approaches, and the patient-provider relationship were identified as key to effective pain communication and management.

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I express my heartfelt appreciation to Dr. Stacey Lovo, my supervisor for this MSc project. Her exceptional mentorship, support, and invaluable guidance have been instrumental in shaping this research and my academic growth. I am truly fortunate to have had the opportunity to work under her guidance. I also extend sincere thanks to my committee members, Dr. Brenna Bath, Rachel Johnson, and Dr. Heather Foulds, for their commitment, expertise, and insightful feedback that influenced this research.

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Dedication

I am forever indebted to my parents for their extraordinary bravery, unwavering perseverance, sacrifices, and relentless dedication, which have been instrumental in shaping me as an individual. It is with profound appreciation that I dedicate this thesis to them. To my mom, the strongest person I know, thank you for everything. To my dad, I know you would be proud of the person I have become.

Self-Situating and Researcher Background

Ethnically, I am Chinese. I was born in China and immigrated to Canada when I was nine years old. I grew up in a rural Saskatchewan community with a population of 300. I completed my Bachelor of Science Honours degree in Physiology and Pharmacology at the University of Saskatchewan. Growing up with the influence of the Chinese culture, I learned to suppress my emotions, specifically I suppressed emotions towards pain. Stoicism was considered as a positive trait in Chinese culture (Tung & Li, 2015). Whenever I was hurt, I would fight back the urge to cry, as I felt crying was a sign of weakness. This perception was changed once I moved to Canada where I observed people openly expressing pain and encouraging pain to be discussed. As an individual who has immersed themselves within two different cultures, I can see the differences in pain perception and expression within these cultures. During my undergraduate degree, I worked as a research assistant focusing on increasing access to care for remote Indigenous communities in northern Saskatchewan. Through my role as a research assistant, I became more educated on Indigenous health, more specifically, ways to approach care in a culturally responsive manner. I completed my undergraduate honours project in collaboration with an Elder, a Knowledge Keeper, a nurse practitioner, and a physiotherapist where we co-developed a pain scale that may be more culturally responsive for the Elder's community. As a result of my research experience and my own lived experiences with understanding pain through different cultural lenses, I developed a passion to learn about pain from other cultural perspectives. This has led me to my research project for my thesis which acknowledges the historical and cultural context of Indigenous Peoples and explores pain from the perspectives of two Indigenous communities in northern Saskatchewan.

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List of Abbreviations

BC British Columbia

CAG Community Advisory Group

CAS Colour analog Scales

CBP Chronic Back Pain

CBPR Community-Based Participatory Research

CDPS Community Directed Pain Scale

CRA Community Research Assistant

FES Facial Expression Scales

FPS Faces Pain Scale

FPS-R Faces Pain Scale-Revised

HCPs Healthcare Providers

ID Interpretive Description

LBP Low Back Pain

MSK Musculoskeletal

NPRS Numeric Pain Rating Scale

SHA Saskatchewan Health Authority

TES Two-Eyed Seeing

Chapter 1: Introduction

Indigenous Peoples in Canada have the highest prevalence of chronic pain and poorer health outcomes when compared to the rest of the population (Kim, 2019; Meana et al., 2004). 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 (Mittinty et al., 2018). Untreated pain not only causes physical, emotional and social sufferings, but it is also linked to poor health conditions like cardiovascular diseases, diabetes and musculoskeletal diseases (Mittinty et al., 2018). It is important to acknowledge that the perceptions of pain and pain relief in Indigenous Peoples differ from that of non-Indigenous Peoples (Fenwick, 2006). The way individuals experience and express pain is heavily influenced by their cultural upbringing (Fenwick, 2006). Western based pain scales have a heavy focus on perceived intensity rather than a comprehensive evaluation and understanding of the pain experience (The Canadian Pain Task Force, 2019). There are various types of pain assessment tools; however, many of them may not be able to capture the complex experience of pain from the perspectives of Indigenous Peoples. Moreover, there is a vast gap in research regarding pain expression amongst Indigenous Peoples and culturally responsive pain assessments tools developed with Indigenous Peoples. Various groups of Indigenous Peoples exist in Canada, including First Nations, Métis and Inuit who all have distinct languages, culture, and beliefs. We recognize Indigenous worldviews and lived experiences are unique to each cultural group; therefore, it is important to work in collaboration with different Indigenous communities in order to understand their unique pain experiences, and to develop pain assessment tools that are specific to each community's preferences while incorporating key elements that help to communicate pain.

This chapter will outline the paucity in research on pain experiences Indigenous communities and relevant issues surrounding differences in pain perception between Indigenous and Western ways of knowing. It will describe the prevalence of chronic musculoskeletal (MSK) pain within Indigenous populations, pain disparities experienced by marginalized populations, and the unique pain management techniques and experiences within different Indigenous communities. This chapter will also outline the research objectives, methods, and significance.

The thesis comprises two individual manuscripts presented in chapters 2 and 3, respectively. Chapter 2 (manuscript 1) is a collaborative effort with a Cree Elder and Knowledge Keeper in northern Saskatchewan to develop a pain assessment tool tailored to their community

members' needs. It documents community members' experiences utilizing the novel pain assessment tool to communicate about pain, as well as healthcare providers' perspectives on the new pain scale. Chapter 3 (manuscript 2) is a needs assessment conducted in a Dene/Métis community in northern Saskatchewan to identify their strengths and needs regarding chronic MSK pain management techniques. Finally, Chapter 4 will present a comprehensive discussion and conclusion for the entire thesis.

1.1 The Importance of Context

When examining the lived pain experiences of Indigenous Peoples, it is essential to contextualize it within a colonial framework and understand the profound resiliency and strength Indigenous Peoples exhibited to persevere within an environment filled with oppressive laws and policies. It is important to recognize that the ongoing impacts of centuries of oppression continue to affect the wellbeing of Indigenous Peoples today. Historical policies, including the Indian Act, residential schools, the sixties scoop, the sterilization of Indigenous women, experiments on Indigenous children, and the confinement of Indigenous Peoples to reserves have had profound and detrimental impacts on Indigenous ways of living, knowledge systems, spiritual practices, and educational systems (Allan & Smylie, 2015; Hassen et al., 2021). These policies not only disrupted the wellbeing of Indigenous Peoples, but also contributed to the establishment of a society rooted in white privilege (Allan & Smylie, 2015). Understanding the impacts of colonial policies allows enhanced comprehension of the social determinants of health that contribute to poorer health outcomes experienced by contemporary Indigenous Peoples in comparison to non-Indigenous Peoples (Allan & Smylie, 2015; Harfield et al., 2018). Taking into account the colonial context is essential in dispelling the misconception that poorer health outcomes among Indigenous Peoples are solely attributed to biological predispositions (Allan & Smylie, 2015). By acknowledging the resilience, language, and cultural practices that have been maintained and revitalized despite the ongoing impacts of colonization, a more comprehensive understanding can be gained on the health disparities experienced by Indigenous Peoples.

Reading and Wien (2009) suggested there are three dimensions that can influence health and health outcomes, they are: the proximal, the intermediate and the distal determinants of health. The proximal determinants of health include employment, income, housing, access to care and education which have a direct and wholistic influence on the health of an individual

(Reading & Wien, 2009). Proximal determinants of health originate from things like community infrastructure, cultural continuity and the healthcare system which are considered as intermediate determinants of health (Reading & Wien, 2009). Lastly, the distal determinants of health consist of colonialism, racism, self-determination and social exclusion (Reading & Wien, 2009). The three dimensions are interrelated; not only do Indigenous Peoples continue to experience the effects of colonization, but colonial policies and discrimination have also impacted aspects of employment, income, access to care and health outcomes (Reading & Wien, 2009).

Residential schools, colonization, intergenerational trauma and racism are key factors in Indigenous Peoples' health and wellness (Truth and Reconciliation Commission of Canada, 2015). In Canada, residential schools began in the 17th century with the last one closing in 1996 (Degagné, 2007). The residential school system attempted to systematically strip away Indigenous Peoples' cultural identities (Truth and Reconciliation Commission of Canada, 2015). The children were taken from their homes at an early age and grew up in an environment filled with fear, confusion and loneliness (Truth and Reconciliation Commission of Canada, 2015). The system's goals were to sever the influence parents had on their children, instill in the children values, beliefs and ways of the Western society and assimilate the children into the Western world (Degagné, 2007). Many children died due to the impacts of malnutrition, diseases and abuse (Truth and Reconciliation Commission of Canada, 2015). The effects of cultural and language loss, physical abuse, sexual abuse and emotional abuse are not only experienced by those who attended residential schools, but also effect the descendants of those who attended through intergenerational trauma (Truth and Reconciliation Commission of Canada, 2015). Moreover, social, cultural and economic marginalization as a result of oppressive government policies, such as residential schools, has had a severe impact on Indigenous Peoples' overall health and wellbeing. Indigenous Peoples not only endure physical pain, but they are also affected by emotional, mental and spiritual sufferings due to the effects of colonization and ongoing systemic racism in Canada.

1.2 Pain: Definition and Conceptualization

Pain is a personal experience that exists universally often described as a complex and aversive sensory and emotional experience (International Association for the Study of Pain, 1979). The concept of pain is a well-researched phenomenon; however, there is a paucity of

research in pain expression, pain perception, pain communication, and pain management within Indigenous Populations in Canada. A scoping review with a focus on physical pain within Indigenous Peoples was conducted in Canada of 2021 which reported a clear disconnect when communicating about pain between Indigenous patients and western healthcare providers (Bailey et al., 2023). Moreover, the review reported a lack of research in relation to pain assessment tools within Indigenous Peoples (Bailey et al., 2023). The conceptualization of pain differs from Western ways of understanding and Indigenous ways of knowing. Western perspective on pain is primarily based on nociceptive, neuropathic, and nociplastic pain (Fitzcharles et al., 2021); whereas, Indigenous perspective of pain is viewed through a wholistic lens of the physical, mental, emotional and spiritual aspects a person and/or community (Bailey et al., 2023; Latimer et al., 2012). Indigenous Peoples' overall wellbeing is influenced by balancing those four factors (Graham & Martin, 2016; Graham & Stamler, 2010). The balance of the physical encompasses securing employment, a home, sufficient foods, and to manage chronic health conditions (Graham & Martin, 2016). The mental needs involve self-discipline, abstinence from drugs and alcohol, and a positive attitude (Graham & Martin, 2016; Graham & Stamler, 2010). The emotional needs manifested through limitation of stressors and the relationship with oneself, family, community, and the environment (Graham & Martin, 2016; Graham & Stamler, 2010). Their overall wellness is also dependent on spiritual beliefs and cultural practices through participation in sweat lodges, powwows, hunting and traditional medicine (Graham & Martin, 2016). Therefore, the experience of pain could have implications to the harmony of these four values; consequently, impacting the overall wellbeing of Indigenous Peoples.

1.2.1 Biopsychosocial Model of Pain

Pain is often viewed as a biomedical model where it fails to include the whole person and their experience of pain (Gatchel et al., 2007). The biopsychosocial model helps to describe the multidimensional complexity of pain as it takes into consideration how the nociceptive signals are filtered through a person's genetic composition, history, current psychological status, sociocultural influences, and socioeconomic standing (Gatchel et al., 2007). Psychosocial factors involve aspects of emotion and cognition. Emotion is the immediate reaction to the nociceptive signals; cognition attaches meaning to the emotion (Gatchel et al., 2007). The meaning that is attached can further influence a person's emotions which could amplify the experience of pain

(Gatchel et al., 2007). Indigenous Peoples have different values, worldviews, and histories when compared with people of Western Cultures (Hickey, 2020); thus, it is important to keep the biopsychosocial model in mind when assessing, diagnosing, and treating pain.

1.3 Chronic Musculoskeletal Pain

1.3.1 Epidemiology

Musculoskeletal pain is one of the top contributors to disability worldwide (Blyth et al., 2019; El-Tallawy et al., 2021). The Global Burden of Disease reported 1.3 billion cases of MSK disorders in 2017 (Safiri et al., 2021) and the prevalence of MSK in Canada for all ages was 27.8% (Kopeck et al., 2019). Pain that persists for longer than three months is labeled as chronic pain (Crofford, 2015). Globally, the prevalence of chronic MSK pain ranges from 11.4-60.0% (Cimmino et al., 2011), acting as the second largest contributor to years of life lived in less than ideal health (Vos et al., 2012). The Global Burden of Disease defined MSK disorders as five main conditions: rheumatoid arthritis (RA), osteoarthritis (OA), low back pain (LBP), neck pain, gout, and other MSK disorders (Kyu et al., 2018); however, it is important to acknowledge that MSK disorders involve more than what is listed above. They also include pain or injuries to the bones, muscles, joints, tendons, ligaments, nerves, and cartilage (Liu et al., 2022). The majority of the population will have experienced MSK pain or injuries throughout their lives (El-Tallawy et al., 2021). Age is a top risk factor to consider when it comes to MSK pain, as it is more likely to affect older people than younger individuals (El-Tallawy et al., 2021). However, MSK conditions are not limited by age as they can affect children and adolescents (El-Tallawy et al., 2021). Additional factors that contribute to the risk of MSK disorders include smoking, lower health literacy, physically demanding occupations, sedentary lifestyles, anxiety, depression, and sleeping disorders, (El-Tallawy et al., 2021; Liu et al., 2022).

1.3.2 Chronic Musculoskeletal Pain in the Indigenous Population

There is a paucity in knowledge of the prevalence of MSK pain in Indigenous Peoples within Canada. Studies in the United States and Australia inform our knowledge on the prevalence of chronic MSK pain and conditions within the Indigenous population in those countries. When compared to the general population, the prevalence of LBP is higher amongst the Indigenous population in Australia, the United States, and Canada; 1.1 times, 0.32 times, and

0.30 times greater respectively (Bath et al., 2014; Jimenez et al., 2011; Lin et al., 2020). Higher rates of osteoarthritis are also reported amongst Indigenous Peoples in Canada and Australia when compared to the non-Indigenous populations, 2 times and 1.2-1.5 times greater respectively (Barnabe et al., 2015; Lin et al., 2020). Moreover, incidences of rheumatoid arthritis are higher in Indigenous populations in Canada and Australia than the non-Indigenous populations, 1-2 times and 2-3 times greater respectively (Barnabe et al., 2017; Lin et al., 2020). With high rates of MSK disorders, the incidence of chronic pain will also be more frequent in these countries amongst the Indigenous Peoples when compared to the non-Indigenous populations (Lin et al., 2020). Indigenous Peoples may experience MSK conditions in diverse ways that differ from non-Indigenous populations due to cultural experiences and the influence of language in lived experience.

The Indigenous population in Canada possesses remarkable strengths, yet they continue to experience significant inequalities in health outcomes when compared to non-Indigenous Canadians. While social determinates of health play a role in the prevalence of chronic MSK pain conditions, health care access inequity is also another factor. Rural populations have diminished continuity of care, access to care, access to health resources and challenges in access to specialist care (Karunanayake et al., 2015; Sibley & Weiner, 2011). Reduced access to healthcare in rural populations is one of the factors leading to higher mortality and morbidity rates in rural regions when compared to urban centers (Karunanayake et al., 2015). Rural communities in Saskatchewan are home to a significant proportion (46.2%) of the Indigenous population (Statistics Canada, 2017). In addition to lack of access to care for Indigenous Peoples residing in rural communities, they also experience inequitable health with negative health outcomes as a result of being overlooked and met with discrimination, leaving them with untreated or mistreated pain (Latimer et al., 2014). This means many Indigenous Peoples are likely suffering with unmanaged pain.

1.3.3 Guidelines for the Management of Musculoskeletal Pain

The Canadian best practice guidelines, recommended by the National Pain Center (NPC, 2017), encourages optimizing non-pharmacological therapy over prescribing opioids for non-opioid users (Traeger et al., 2017). However, Belzak and Halverson (2018) from the Public Health Agency of Canada reported, in Alberta in 2013-2017, Indigenous Peoples were twice as

likely to be dispensed an opioid (codeine, tramadol, oxycodone, morphine, hydromorphone, hydrocodone, and fentanyl) than non-Indigenous individuals. Moreover, Indigenous Peoples were five times more likely to experience an opioid-related overdose and three times more likely to die from an opioid-related overdose (Belzak and Halverson, 2018). Factors that may affect the high level of opioid prescription within the Indigenous population are the limited access to health resources and the challenges with continuity of care (Webster, 2013). Webster (2013) reported northern Indigenous communities in Ontario are often located in remote regions where “fly in” physicians visit at scheduled times. Within these communities, many Indigenous Peoples who are dependent on opioids trace their dependency to the “fly in” physicians who work for Health Canada on short-term contracts (Webster 2013). The lack of continuous care leads to weak foundational relationships between physician and patient and the lack of alternative resources to pain management may generate a trend of extensive opioid prescribing (Webster 2013).

The Canadian Agency for Drugs and Technologies in Health has stated, “Canada is in the midst of an opioid crisis.”(CADTH, 2018); therefore, it is important to follow best practice guidelines to reduce the number of opioid prescriptions. In order to manage pain appropriately and effectively, it is important to first properly identify, categorize and understand the experience of pain.

1.4 Experiences of Racism in the Healthcare System and the Impacts it has on the Indigenous Population

In Canada, Indigenous Peoples experience higher rates of pain, and pain related disability than non-Indigenous people (Meana et al., 2004). Primary reasons for seeking healthcare include the management of chronic pain (Jimenez et al., 2011; Latimer et al., 2014; Meana et al., 2004). However, Indigenous Peoples’ pain is often dismissed by health providers due to biases and racist treatment in the health system including the assumption of drug seeking behaviours (Jimenez et al., 2011). In a 2020 Canadian report conducted by Turpel-Lafond in British Columbia (BC), it was revealed there is a widespread Indigenous-specific racism in the healthcare system. In BC, only 16% of surveyed Indigenous participants stated they have never faced discrimination when accessing healthcare (Turpel-Lafond, 2020). Moreover, 35% of surveyed healthcare professionals in BC reported they have witnessed discrimination and racism towards Indigenous patients and families in the healthcare setting (Turpel-Lafond, 2020).

Indigenous Peoples have persevered through a long history of racism and discrimination which have become rooted within the Canadian healthcare system, impacting how HCPs and patients engage with each other (Breault et al., 2021; Roach et al., 2023). Racism can manifest through implicit biases, discriminatory actions, or a lack of consideration towards individuals based on their racial differences (Phillips-Beck et al., 2020). Indigenous patients frequently report encountering feelings of judgment and shame when accessing healthcare services (Boyer & Bartlett, 2017; Breault et al., 2021). As a result of a fear of discrimination and judgment, Indigenous patients may refrain from accessing healthcare unless absolutely necessary (Turpel-Lafond, 2020). The cumulative effect of adverse encounters while seeking healthcare can result in feelings of insecurity and disconnection from the healthcare system as a whole (Boyer & Bartlett, 2017; Breault et al., 2021). This may lead to a lack of preventive healthcare and an increase in chronic conditions. Moreover, the healthcare system promotes systematic approaches to health and wellness that do not respect Indigenous ways of knowing resulting in further negative associations with accessing healthcare.

In rural areas, healthcare services within Indigenous communities tend to be more under-resourced and with fewer numbers of HCPs than white communities (Breault et al., 2021). The insufficient number of HCPs can lead to a lack of continuity of care which not only impacts the quality of care patients receive, but it also makes it more challenging to establish meaningful patient-provider relationships (Breault et al., 2021).

1.5 Pain Expression and Pain Communication

Effective pain communication between HCPs and patients is crucial for the delivery of quality care (Haverfield et al., 2018). Pain expression is subjective and can vary among individuals, with culture playing an important role in pain communication and behavior (Fenwick, 2006; Peacock & Patel, 2008). However, research on pain expression and communication within Indigenous communities in Canada is limited; thus, this discussion draws from studies on Australian Aboriginal and Torres Strait Islander Peoples. Culturally unique pain behaviors have been observed in Indigenous Australians, including underreporting of pain, stoicism, and reluctance to report pain (Arthur & Rolan, 2019; Strong et al., 2015). These behaviors are influenced by various factors, such as cultural beliefs and values, which may impact pain expression and communication differently. For instance, Arthur and Rolan (2019)

noted that Indigenous Australians may attribute different causes to their pain than what HCPs typically recognize, such as breaking Aboriginal laws or taboos. Additionally, the relationship between patients and HCPs can directly affect pain expression and communication. A lack of established trust in this relationship may negatively impact a patient's willingness to express pain (Haverfield et al., 2018). Strong et al., (2015) reported patients who experienced not being listened to by HCPs perceived a lack of established trust; therefore, felt reluctant to express their pain. Moreover, patients may feel hesitant to report pain or express their concerns if they have experienced negative stereotypes or judgment from HCPs in the past (Haverfield et al., 2018; Strong et al., 2015). This highlights the complex nature of pain expression and communication, which can be influenced by multiple factors such as culture, patient-provider relationships, and previous experiences with healthcare.

1.6 Different Indigenous Cultures and Overgeneralization

There is heterogeneity in the way of life between Indigenous communities like the Cree, Dene, and Métis. Within Saskatchewan, Cree communities reside from the North to the South, proudly practicing different cultures based on their region (McLeod, n.d.). There are differences in dialect and cultural practices, for example the Sun Dance ceremony which is only practiced in the southern regions (McLeod, n.d.). Like Cree communities, Dene communities are also spread across Canada. In the past, the Dene lived freely and followed the migration patterns of animals (Hay, n.d.). Today, in Saskatchewan, they reside in the North and South, speaking various dialects (Hay, n.d.). In terms of cultural practices, the traditional tea dance is performed during social gatherings, drums made out of caribou hide are still popular and the northern regions still perform the hand game (Hay, n.d.). Likewise, in Saskatchewan, the Métis reside across the province and are also one of its founding people (Cariou, n.d.). Being Métis is not only about having a mixed ancestry of Indigenous and European, it is also about making the conscious decision, as a community, to identify as a distinct nation (Royal Canadian Geographical Society, 2018). The Métis Nation possesses a unique culture as they have blended Indigenous and European ways into one, practicing Catholicism as well as cultural traditions, like the Red River Jig, beadwork decorations and distinctive language (Royal Canadian Geographical Society, 2018). In the past, the Métis were the most multilingual people in Canada, and they developed their own language known as Michif as well as variations like French Michif, Northern Michif

and Michif-Cree (Royal Canadian Geographical Society, 2018). In Saskatchewan, Métis communities in the northwest speak Michif with high Cree content when compared to southern Métis communities (Cariou, n.d.).

Although the Cree, Dene and Métis have distinct languages and cultural practices, they all share some similarities in worldview (Little Bear, 2000). They focus on a balance between the physical, mental, emotional, and spiritual (Little Bear, 2000). They have a collectivist mindset and a wholistic perspective to life and wellness (Little Bear, 2000). Moreover, nature is deeply respected, and they uphold principles of sharing and giving away (Little Bear, 2000). They believe that understanding one's place in life is essential for survival (Little Bear, 2000). Furthermore, they have strong relationships amongst individuals, families, extended families and communities (Little Bear, 2000).

While the Cree, Dene, and Métis Nations all share a common history of colonialism, they have distinct origins, languages, and traditions. Differences in culture, geographical locations, and language can impact social determinants that influence their health outcomes (Adelson, 2005; Allan & Smylie, 2015). Working collaboratively with different Indigenous communities will prevent the risk of overgeneralization when it comes to effective methods of chronic MSK pain management and pain communication.

1.7 Research Objectives and Overview of Methods

Pain assessment and management from Indigenous perspectives are underexplored in Canada, with limited research on the experience of pain, and culturally responsive pain scales for Indigenous populations. Moreover, pain experiences, expressions, and communication can differ amongst people, specifically, amongst people of different cultures; consequently, it is essential to understand these experiences to inform the development of a culturally responsive pain assessment tool and to understand the needs for pain management within two northern Saskatchewan Indigenous communities. This study aims to address this knowledge gap by examining the pain experience and barriers in effective pain communication, assessment, and management within a Cree and a Dene/Métis community.

1.7.1 Research Objectives of Thesis

This thesis has the following objectives and will address the following research questions:

1. Objective: To evaluate the validity, cultural responsiveness, relevance, and patient experience of a community-led novel pain scale among members with chronic back pain in a Cree community (manuscript 1).

Research Questions:

- a. Is the Community Directed Pain Scale valid, culturally relevant and preferred by the community members?
- b. How does the novel pain scale compare to a validated pain scale, the Faces Pain Scale-Revised (FPS-R)?

2. Objective: To collect the community members' perspectives regarding the novel pain scale (manuscript 1).

Research Questions:

- a. From the perspective of a northern Saskatchewan Cree community, what elements of the novel pain scale are favorable and what elements can be improved?

3. Objective: Transferring knowledge learned through collaboration with the Cree community to build new relationships with a Métis/Dene community to gain better insight in understanding chronic MSK pain management needs in that community (manuscript 2).

Research Questions:

1. From the perspective of a northern Saskatchewan Métis and Dene community, what are the needs, preferences, strengths, and limitations in the management of chronic MSK pain in community?
2. What are the similarities and differences in the experiences of chronic MSK pain from the perspectives of a Cree community and a Métis and Dene community?

1.7.2 Philosophical Perspective

The research followed an interpretivist paradigm which assumes there are multiple socially constructed realities that are influenced by individual values, cultures, and beliefs (Creswell & Poth, 2018). Interpretative research is an inductive paradigm that seeks to identify patterns, form theories and it asks the questions “how” and “why” (Putnam & Banghart, 2017). Moreover, it attempts to understand people’s subjective experiences with a certain phenomenon (Given, 2008) instead of objectively explaining the experience. Interpretivists understand subjective meanings are not standardized. They believe the meanings are constructed through

interactions one has with others and are heavily influenced by historical/cultural norms (Creswell & Poth, 2018). In addition, interpretivists work in partnership with participants to ensure their voices are heard by accurately portraying the interpretations and context (Putnam & Banghart, 2017). For this project, interpretive paradigm allows for a better understanding of chronic MSK pain experiences, pain communication, and experiences with using pain assessment tools from the perspectives of Indigenous communities.

1.7.3 Community Directed Assessment of Pain in a Northern Saskatchewan Cree Community

A community-directed pain assessment tool (the Community Directed Pain Scale or CDPS) was developed alongside a Cree Elder and Knowledge Keeper to better facilitate communication of pain between HCPs and patients in the Cree community of Pelican Narrows. The CDPS was piloted within a virtual back pain clinic to assess its concurrent validity and capture community members' feedbacks. Twenty-seven individuals with chronic back pain from Pelican Narrows utilized the pain assessment tool. Ten individuals participated in semi-structured interviews (nine community members and one HCP). Community members shared stories of their lived pain experiences, pain expression, and experiences using the CDPS. The HCP shared their perspective on pain assessments and the CDPS. Transcripts from the interviews were used during thematic analysis.

1.7.4 Understanding Needs for Chronic Musculoskeletal Pain Management in a Northern Dene and Métis Community: A Community Based Needs Assessment

A community needs assessment was conducted in La Loche, a Dene/Métis community, to identify the community's strengths and needs when it comes to the management of chronic MSK pain. Thirteen individuals (eight community members and five HCPs) participated in semi-structured interviews to share their perspectives regarding pain expression, lived pain experiences, and the community's needs when it comes to pain management. Transcripts from the interviews were used during thematic analysis.

1.8 Relevance and Implications

Through this research, Indigenous Peoples in the two communities will have the opportunity to self-identify and define effective ways to facilitate pain communication, identify important aspects to include in pain assessment tools, and identify effective pain management strategies and recommendations. A culturally responsive pain scale was created in partnership with a Cree Elder and Knowledge Keeper that can improve communication between patients and clinicians, potentially leading to more accurate assessments, tailored treatments, and improved pain management outcomes. In addition, a second study provided valuable insights into the unique perspectives and needs of a Métis/Dene community in the management of chronic MSK pain. The findings of this research have the potential to inform future partnerships with Indigenous communities and contribute to a better understanding of the lived experiences of chronic MSK pain from a Cree and Métis/Dene perspective.

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Chapter 2: Community Directed Assessment of Pain in a Northern Saskatchewan Cree Community

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This manuscript has been reformatted from the original version for inclusion in the thesis. The manuscript is not yet submitted for publication. The target journal for this manuscript is the Journal of Circumpolar Health. Tayah Zhang is the lead author of this manuscript. Tayah led and completed the ethics submission and data collection. She was the first reviewer for qualitative and quantitative data analysis and collaborated with the research team for additional data analysis. She drafted and completed the edits for this manuscript.

2.1 Abstract

Background: Pain assessment tools are used by health practitioners to quantify patients' pain. There are several forms of pain scales (numerical, facial expression-based and color-based); however, 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.

Objectives: This study aimed to: (1) co-develop a Community Directed Pain Scale (CDPS) in collaboration with an Elder and a Knowledge Keeper from Pelican Narrows; and (2) pilot the CDPS during virtual physiotherapy sessions for chronic back pain (CBP) in community and capture community members' voices regarding their experiences with pain communication and pain scale utilization.

Methods: This study employed a mixed method research design that involved 2 phases. Phase 1 was the development of the pain scale with a Cree Elder and Knowledge Keeper. Qualitative data such as interviews, storytelling, and observations were gathered. Phase 2 was a pilot of the CDPS during virtual physiotherapy sessions for CBP. Participants completed pre-physiotherapy treatment questionnaires which included the utilization of the CDPS and Faces Pain Scale-Revised (FPS-R) and engaged in semi-structured interviews to express their perspectives regarding the pain scale. Twenty-seven participants completed the questionnaires and 10 participants were interviewed (9 community members; 1 healthcare provider). Quantitative data was analyzed using SPSS to assess for agreement and qualitative data was analyzed using thematic analysis with NVIVO software.

Results and Conclusions: A weighted kappa analysis yielded $k=0.696$ indicating a good agreement between the CDPS and FPS-R 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. Community engagement is an effective approach in developing a pain assessment tool that fits the needs of the members of Pelican Narrows. Moreover, a patient-centered approach is important to offer comprehensive pain assessments.

Keywords: Pain Assessment Tools, Chronic Back Pain, Indigenous Perspectives, Cree, Community-Engaged Research, Culturally Responsive Care

Acknowledgements: The authors wish to acknowledge Elder Rose Dorian and Knowledge Keeper Sally Sewap for sharing their knowledge. The authors are also grateful to the community members of Pelican Narrows and Peter Ballantyne Cree Nation for their warm hospitality and willingness to share their stories. Lastly, the authors appreciate the scholarship support provided by the Health Science Graduate Scholarship—University of Saskatchewan and Canada Graduate Scholarship Master's Program.

2.2 Background/Introduction

2.2.1 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 (Bath et al., 2014; First Nations Information Governance Centre, 2018; Ng et al., 2010). The prevalence of chronic MSK pain conditions can be influenced by jeopardized social determinants of health, which have been exacerbated by colonization and government policies (Adelson, 2005; Kim, 2019). Additionally, healthcare access inequity further contributes to the impact of these conditions (Greenwood & de Leeuw, 2012). In Canada, people from rural and remote communities as well as Indigenous Peoples are 30% more likely to report chronic MSK conditions, like CBP (Bath et al., 2014). Moreover, many Indigenous Peoples live with untreated

or mistreated pain due to experiences with inequitable care and discrimination in the Canadian health system (Latimer et al., 2014).

2.2.2 Conceptualization of Pain

Pain is universal, it transcends cultural barriers; however, the way an individual expresses pain is influenced by their cultural upbringing (Fenwick, 2006). It would be inappropriate to assume all individuals experience culture in a similar way. Moreover, it would be inappropriate to assume pain is experienced or expressed in similar ways across cultures.

In 2011, Jimenez et al., conducted a literature review which identified factors that may influence pain assessment and pain management for the Indigenous populations in the United States and Canada. They reported Indigenous populations underemphasize pain and disability, describing severe pain as “discomfort” and “ache” (Jimenez et al., 2011; Kramer et al., 2002a, 2002b). Yet, Indigenous populations are often perceived as exaggerating distress (Jimenez et al., 2011; Miner et al., 2006). This is an example of the systemic oppression Indigenous Peoples face and outlines a clear disconnect between Indigenous Peoples and Western healthcare providers when it comes to communication about pain.

This raises the issues: 1) there is a lack of understanding of pain experienced by Indigenous Peoples, leading to a disconnect between healthcare provider 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 address these issues and 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 healthcare providers and patients.

2.2.3 Pain Assessment Tools

In Canada, there is significant lack of literature regarding the use of pain measurement tools in Indigenous populations (Bailey et al., 2023). The disconnect between pain expression in Indigenous Peoples and the ability for western pain assessment tools to appropriately capture pain expression is highlighted in Pelusi and Kreb’s (2005) interview with Indigenous cancer patients and survivors which revealed that many individuals were unable to use or understand Western pain scales and questionnaires. There is a paucity of research on the responsiveness of

numerical, image-based and colour-based assessment tools within the Indigenous population. The numeric pain rating scale (NPRS) is a self-reporting tool that utilizes a horizontal measure ranging from 0 (no pain) to 10 (worst pain possible). Indigenous Peoples communicate through oral narrative or storytelling; thus, describing pain in the form of a single number may be challenging (Latimer et al., 2014). NPRS has shown responsiveness in measuring pain intensity (Childs et al., 2005); however, the ethnicity of participants within many studies were Caucasian or not specified; therefore, the efficacy of NPRS among Indigenous individuals should not be assumed (Jensen et al., 1999; Young et al., 2019; Mintken et al., 2009). Image-based pain assessment tools often utilize scales with faces because they are easy and quick to administer (Ellis et al., 2011). 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” (Hicks et al., 2001). Facial expression scales (FES) can range from six to eleven facial expressions. FES have been validated with children and adults from different cultural groups (Caucasian, African American, Thai, and Lebanese) (Ellis et al., 2011; Luffy & Grove, 2003; Newman et al., 2005; Wong & Baker, 1988; Zahr et al., 2006). However, when used with Inuit adults from Alaska to assess pain, the scale had limited success due to cultural differences in facial expressions (DeCourtney et al., 2003). Colour pain scales or colour analog scales (CAS) are often utilized in unison with other pain assessment tools, like a NPRS or FPS-R. Some CAS use colours with green representing no pain, yellow representing moderate pain, and red representing severe pain (Zale et al., 2015), while others display a red colour gradient from light red representing no pain to dark red representing severe pain (Bulloch et al., 2009). The colours are often positioned in a linear format with corresponding numbers, facial expressions or words that describe pain. CAS has shown its reliability as a self-reporting tool in the assessment of pain in children and adults (Bulloch et al., 2009; McConahay et al., 2007; McConahay et al., 2006; Bahreini et al., 2015; Scherder and Bouma, 2000); however, limited studies have been done to test for the validity of CAS within Indigenous populations.

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 (Ellis et al., 2011). 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 (Fenwick, 2006); 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 are “quiet about pain” they will “put a brave face [on]” due to reluctance to expose vulnerability (Lin et al., 2018). This cultural difference should be taken into consideration when using any forms of pain assessment tools. Fenwick (2006) reported Indigenous Peoples in Australia are often labelled as “stoic” by healthcare providers. Contributors to this label could be due to Indigenous Peoples’ low physical pain expressions and the use of vague descriptors to communicate about pain (Jimenez et al., 2011; Kramer et al., 2002a, 2002b).

Indigenous Peoples have reported experiencing minimization, invalidation, or disbelief of their lived pain experiences (Bailey et al., 2023). It is important that HCPs do not invalidate Indigenous patients’ pain just because the report of the lived pain experiences does not match the HCPs’ expectations as to how an individual should be presenting with pain. Labeling Indigenous Peoples as stoic may result in a lack of comprehensive pain assessments and under-treatment of pain. Moreover, in addition to culture as a factor influencing pain expression, systemic oppression also needs to 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 overgeneralize the needs of one community as the needs of all other communities.

2.2.4 Faces Pain Scale-Revised

Faces Pain Scale (FPS) is a well-established self-reporting pain assessment tool often used with children (Hicks et al., 2001). Bieri et al., (1990) developed the FPS and established its reliability in self reported pain for children. Hicks et al., (2001) 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) (Atisook et al., 2021; Ferreira-Valente et al., 2011; Hicks et al., 2001; Miró et al., 2005). Moreover, the International Association for the Study of Pain lists FPS-R as one of their resources for conducting pain assessments (International Association for the Study of Pain, n.d.).

2.2.5 Community Concern about the Current Way Pain is Assessed

Researchers from the School of Rehabilitation Science at University of Saskatchewan is working in collaboration with the Northern Saskatchewan Cree community of Pelican Narrows

on a project to enhance access to care for chronic lower back pain in the community (led by BB and SL) (Grona et al., 2018). An Elder Advisory Group in Pelican Narrows advised that the present way patients are asked about pain is not useful for their community 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 chronic back-pain intervention in a Cree community, and 2) to collect the community members' perspectives regarding the novel pain scale.

2.3 Methodology

This project included two phases: 1) Phase 1, collaboration with an Elder and a Knowledge Keeper from Pelican Narrows to co-develop the Community Directed Pain Scale (CDPS); and 2) Phase 2, pilot of the pain scale in a virtual back pain clinic in Pelican Narrows, comparing CDPS to Faces Pain Scale-Revised, testing concurrent validity, and capturing community members' feedback.

Interpretive Description (ID) with analytic procedures of thematic analysis, informed by Community-Based Participatory Research (CBPR) and Two-Eyed Seeing (TES) will be utilized throughout this project (Martin, 2012; Thorne et al., 1997; Wallerstein & Duran, 2006). Two-eyed seeing ensures the project incorporates the strength of both Indigenous and Western ways of knowing while prioritizing Indigenous knowledge.

2.3.1 Interpretive Description

Interpretive Description is a qualitative approach that seeks to learn about experiences with health and illness from a wholistic and interpretive perspective (Thorne et al., 1997). Interpretive Description is based in an interpretive paradigm that recognizes human experiences are complex issues that are constructed through interactions between the physical, the biological and the psychosocial (Thompson Burdine et al., 2021). It is a widely used method in nursing as it explores complex experiences and produces actionable outcomes (Thompson Burdine et al., 2021). It can also be used across all health professions when the aims of the project are to understand subjective experience, to identify themes and patterns of a population and to apply the knowledge into real world applications (Thompson Burdine et al., 2021). Not only does ID encourage evidence based research, but it also allows the voices of the participants to be heard

while presenting transparent procedures that can generate knowledge to inform better clinical practice (Thompson Burdine et al., 2021). Interpretive Description follows the generic qualitative research process where data are collected in the form of interviews, field notes/researcher journaling and observations followed by analysis of data in the form of coding (Thompson Burdine et al., 2021). Thematic analysis was used to identify patterns and themes from a ‘bottom-up’ manner where the construction of codes were generated from raw data and the construction of themes from codes (Castleberry & Nolen, 2018). Ultimately, major themes were constructed to help the researchers understand the phenomenon from the participants’ subjective experiences (Thompson Burdine et al., 2021). This methodology was in keeping with our goal of having actionable outcomes to inform the development of a culturally responsive pain assessment tool which may allow improved communication about chronic MSK pain between clinicians and community members.

2.3.2 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 (Government of Canada, 2017).

2.3.3 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 delivering virtual physiotherapy to address CBP. 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 community are 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.

2.3.4 Procedures

2.3.4.1 Phase 1: Development of CDPS

Phase 1 followed a collaborative approach in which the research team worked alongside a Cree Elder and a Knowledge Keeper to develop the CDPS (Figure 2.1 outlines the process of the two research phases). We followed traditional protocol and offered tobacco and gifting to the Elder and Knowledge Keeper as a respectful way of asking for guidance 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 physiotherapist). The Elder shared teachings and community histories with the experience of pain and described how pain can be misunderstood for Cree community members. Three elements of common pain assessment tools were discussed: NPRS, FPS, and CAS (Figures 2.2, 2.3, 2.4, 2.5).

An interview was conducted with an Elder via Zoom (due to COVID-19). The Elder's granddaughter facilitated the technology in the Zoom meeting. The discussion consisted of: 1) introduction of elements used in current pain scales: NPRS, FPS, and CAS (Fig 2.2-2.5), 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.

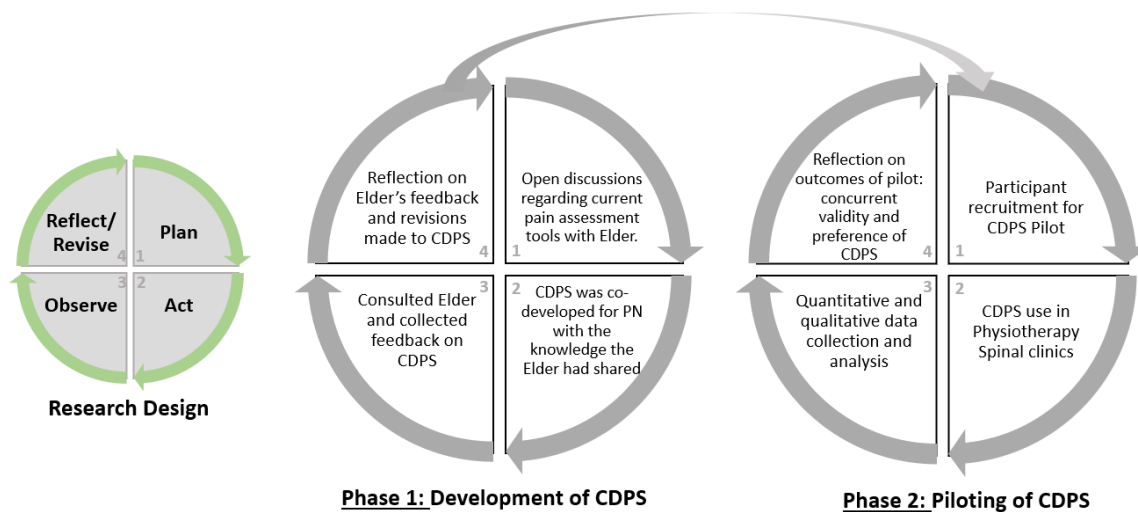


Figure 2.1 Pelican Narrows Research Process Research process depicting the two separate phases of the project.

2.3.4.2 Phase 2: Piloting of CDPS

Phase 2 utilized a mixed methods approach where the quantitative data complements the qualitative data as they are interpreted together. Quantitative data in the form of pain scale utilization pre-physiotherapy treatment 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.

2.3.4.2.1 Phase 2: Quantitative Data Collection Procedures. The gathering of quantitative data included the utilization of the CDPS and FPS-R pre-physiotherapy treatment during Study A, a virtual physiotherapy 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 3 months or longer). Twenty-seven participants completed the pre-physiotherapy treatment questionnaire (Appendix A) which included the utilization of CDPS and FPS-R and a demographic form.

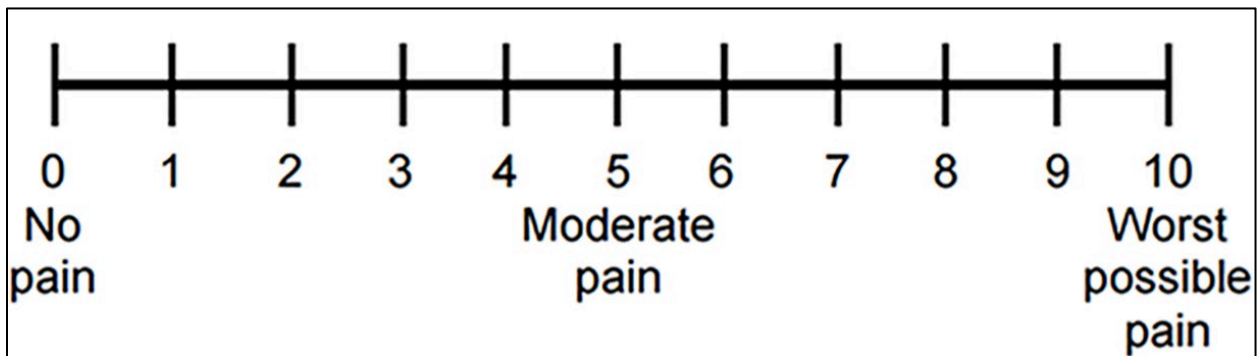


Figure 2.2 Numeric Pain Rating Scale An example of a Numeric Pain Rating Scale (Almarzouki et al., 2017)

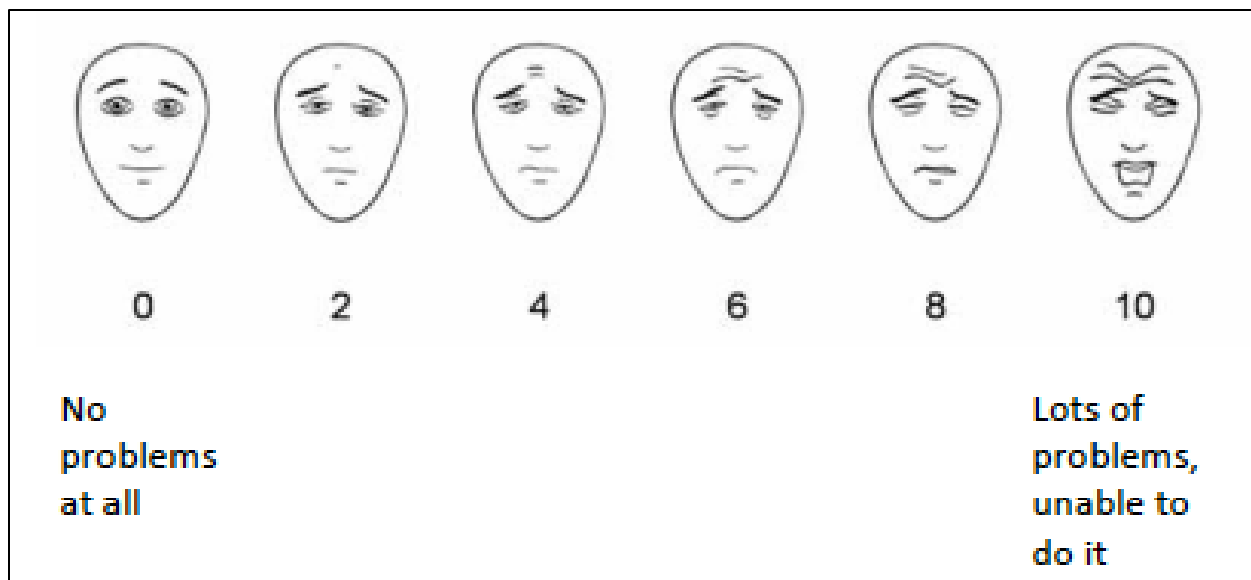


Figure 2.3 Faces Pain Scale-Revised An example Faces Pain Scale. (Faces Pain Scale – Revised, ©2001, International Association for the Study of Pain)

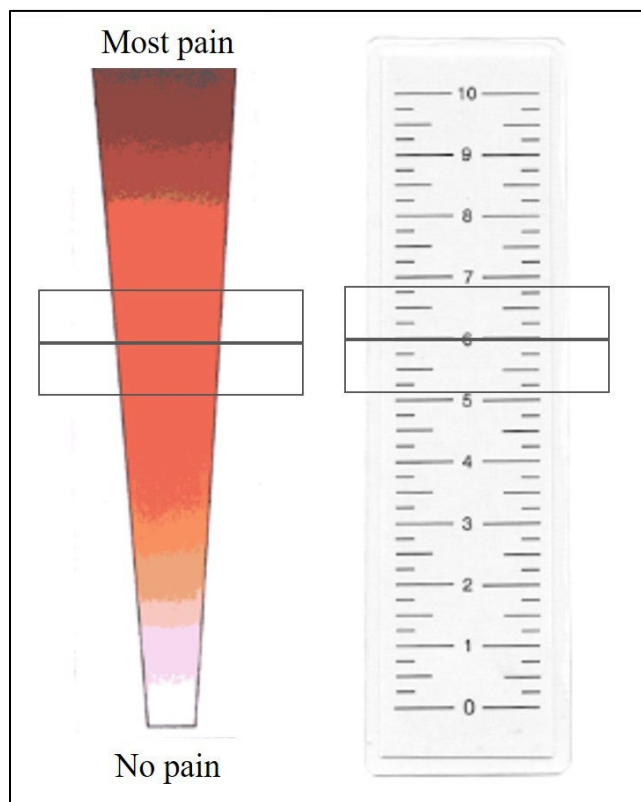


Figure 2.4 Colour Analog Scale An example of the Colour Analog Scale. (McGrath et al., 1996)

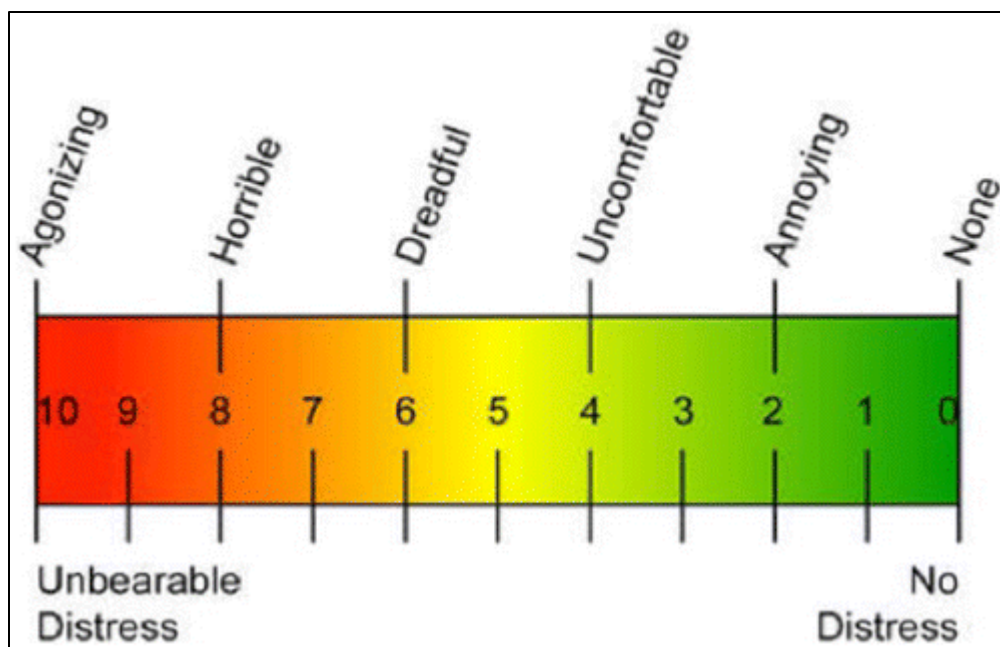


Figure 2.5 Another Colour Analog Scale An example of the Colour Analog Scale. (Zale et al., 2015)

2.3.4.2.2 Phase 2: Qualitative Data Collection Procedures. As the piloting of the CDPS is 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 pain communication with patients and their perspectives on CDPS. The creation and revisions of semi-structured interview questions were guided by Indigenous scholars on our team (Appendix B).

Ten individuals were interviewed; 9 community members and 1 HCP (a physiotherapist). 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.

2.3.5 Analysis

2.3.5.1 Phase 1 Analysis

Using teachings offered by the Elder, we made revisions to elements of current pain scales to meet the needs of the community. 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 community.

2.3.5.2 Phase 2 Quantitative Data Analysis: Cohen's Kappa

Twenty-seven participants completed quantitative data analysis components (Appendix C outlines demographics). Participants' pain ratings from the two different pain assessment tools were analyzed using SPSS software for agreement. The agreement of the pain scales was measured using Weighted Cohen's Kappa (Ranganathan et al., 2017). Kappa compares category ratings (in this case pain classifications) by independent evaluators (in this case two different pain scales) and accounts for agreement. A Weighted Kappa assesses ordinal data and takes into account the degree of agreement (Brenner & Kliebisch, 1996). Ordinal ratings that are close to one another are weighed less than ordinal ratings that are far apart (Brenner & Kliebisch, 1996). The classification of Bertilson et al. (2006) was utilized for this study: <0=no agreement better than chance, 0-0.2=poor, 0.21-0.40=slight, 0.41-0.60=moderate, 0.61-0.80=good and 0.81-1.0=excellent. A high level of agreement would indicate one scale for measuring pain could be substituted by the other scale, offering an indirect way of evaluating concurrent validity (Adams et al., 2014).

2.3.5.3 Phase 2 Qualitative Data Analysis: Thematic Analysis

Qualitative data was thematically analyzed using a qualitative coding software, NVivo (NVivo, 2018). Thematic analysis began with familiarization of the transcripts. The researcher

read over each transcript and during subsequent readings, made notes of general themes, patterns, and important ideas. These were subsequently transformed into codes, initially within each transcript, then across transcripts. The preliminary codes were further analyzed and grouped into emerging themes. Codes and themes were organized into a hierarchy of major themes and within each there were subthemes and some sub-subthemes. Preliminary codes, themes, and subthemes were discussed frequently between the researcher and principal investigator, who was experienced in qualitative analysis, to maintain reliability. These discussions often led to restructuring redundant codes and re-organization of codes and refinement of themes. The HCP transcript was analyzed separately from community members' transcripts to allow for possible emergence of differing themes.

2.4 Findings

2.4.1 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 or understand the purpose of the numbers. The nurse practitioner stated 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

FPS utilizes facial expressions that depict the experience of increase in pain. 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's 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). Blue was considered the most pain because the Elder stated it represented bruising and paleness, when a person is very unwell.

Community Directed Pain Scale

After open discussions with the Elder, different aspects of each scale were combined to create two revised pain scales for review by the Elder (Figure 2.6). Figure 2.6A's facial expressions are formed with black outlines while Figure 2.6B's facial expressions are formed with colours that match the color 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 Figure 2.6A and 2.6B were presented to the Elder, from which she informed Figure 2.6B as the most suitable scale; therefore, it was utilized during phase 2.

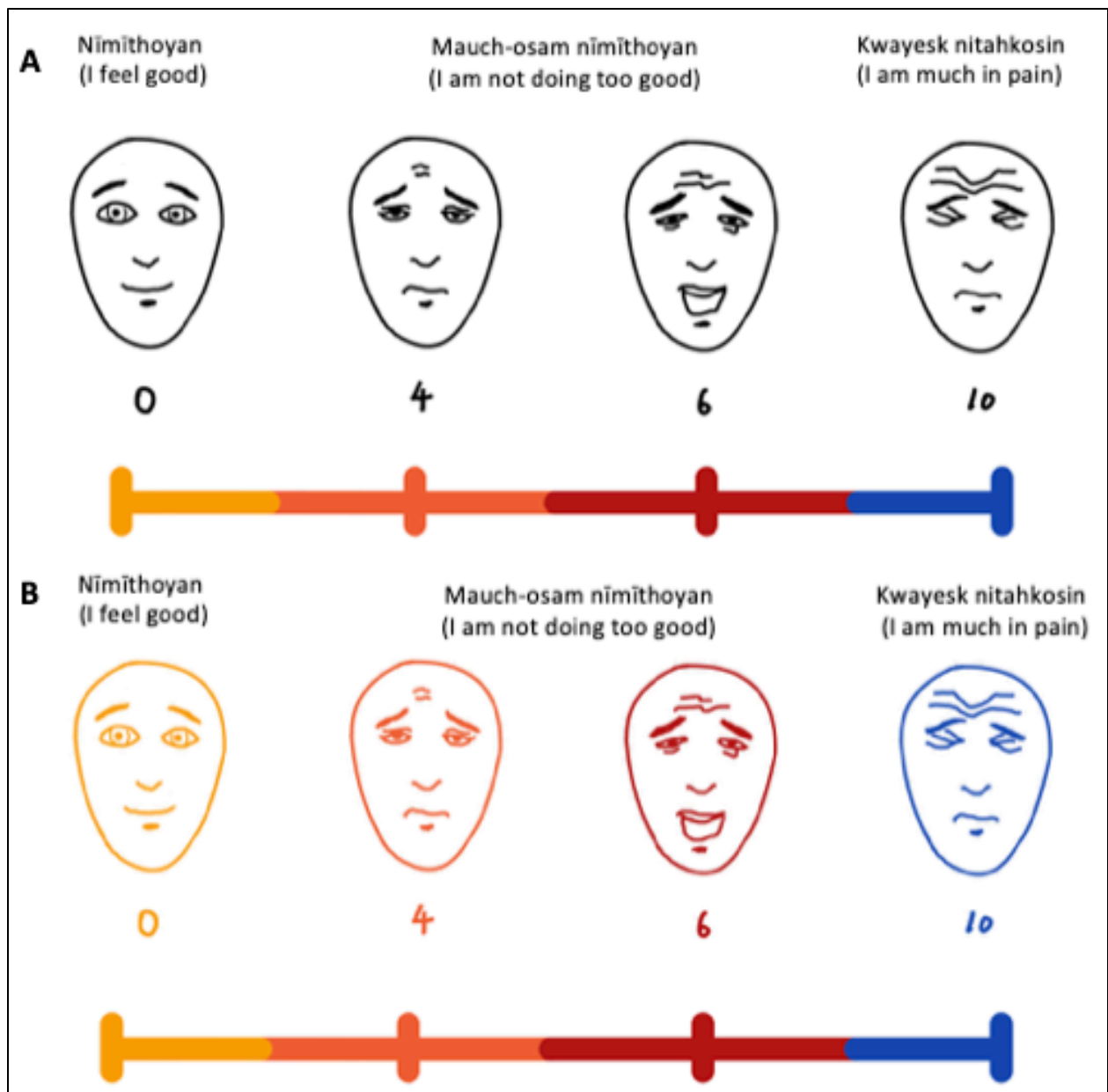


Figure 2.6 A&B Community Directed Pain Scale A & B.

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.

2.4.2 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 with P-Value = <0.001.

Further analysis of pain scale use revealed participants utilized different elements within the pain assessment tool. Within 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 CDPS, 4/27 participants utilized 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 color 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 semi-structured interviews where they shared the 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 solely used the numerical element to understand the pain scale (Figure 2.7 and Figure 2.8). When using the CDPS, 7/9 participants either circled or "X" marked a numerical element to describe their pain; however, only 1/9 participant solely looked at the numerical element to comprehend the pain scale (Figure 2.7 and Figure 2.8).

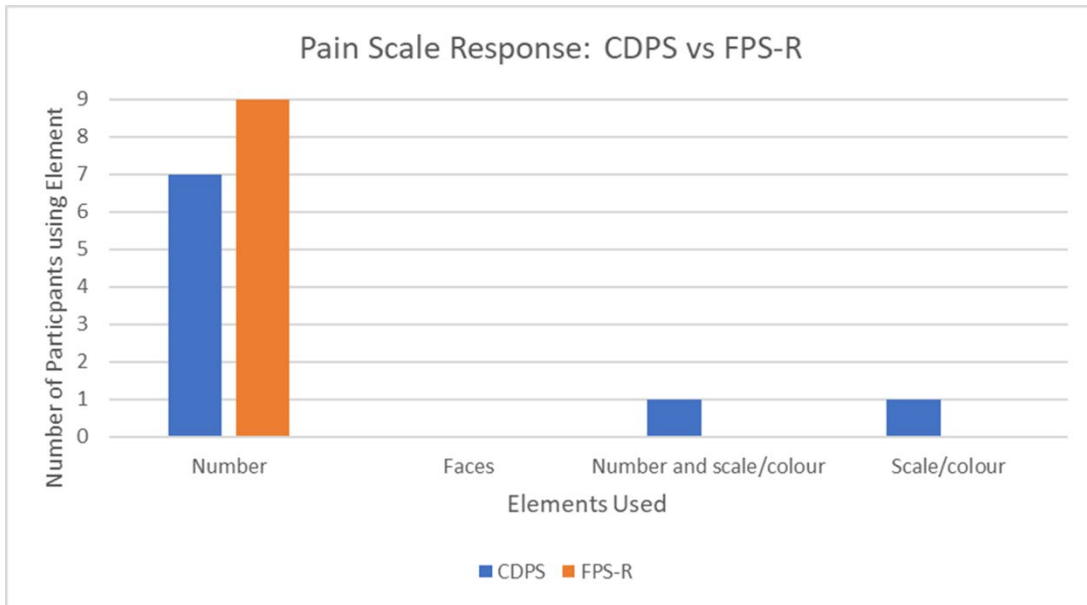


Figure 2.7 Pain Scale Response: CDPS vs FPS-R

The elements the 9 community members (who were interviewed) either circled or X marked when using the pain scales.

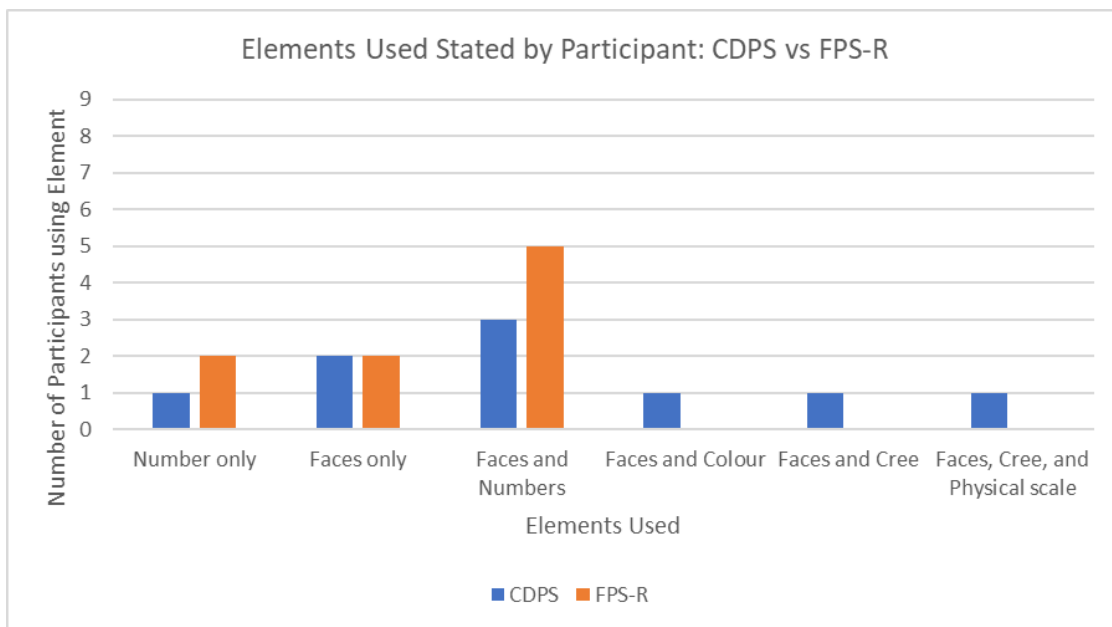


Figure 2.8 Elements Used Stated by Participants: CDPS vs FPS-R

The elements the 9 community members (who were interviewed) were actually looking at on the pain scales to understand the self-reporting tool.

2.4.3 Phase 2 Qualitative Findings 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 2.9 outlines the themes.

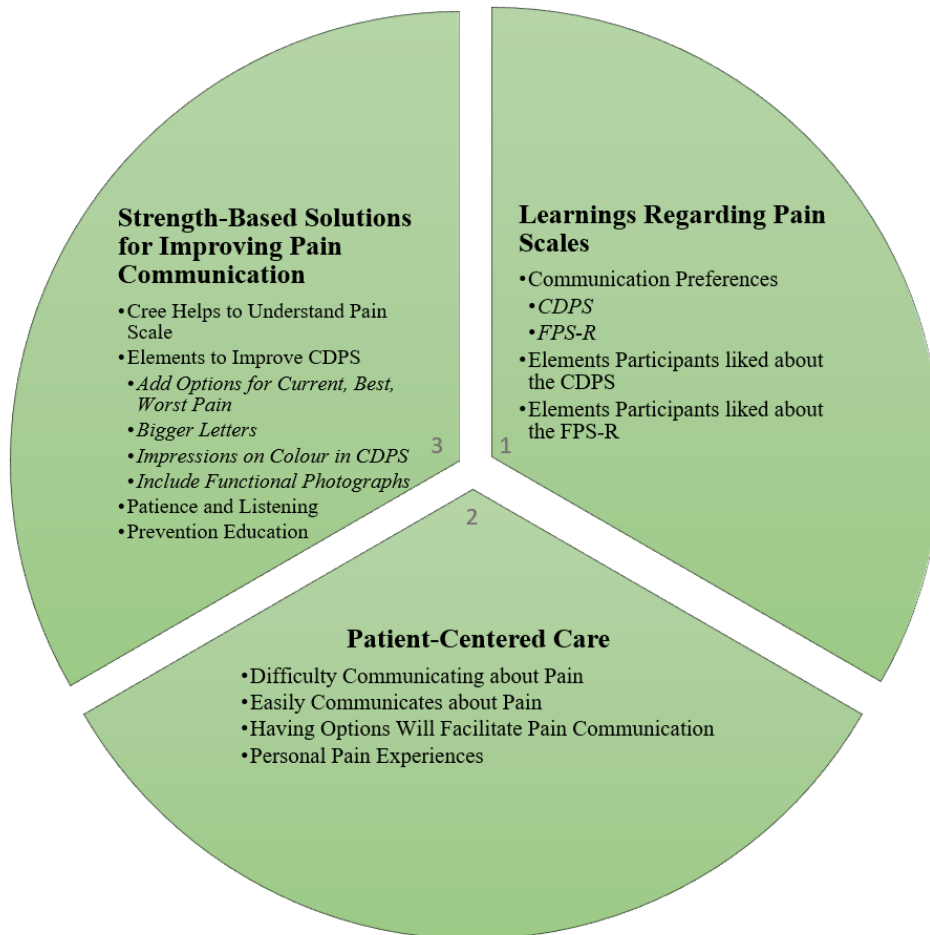


Figure 2.9 Pelican Narrows Community Members Themes Outline

The 3 major themes with its subthemes and sub-subthemes outlined.

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 are 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, while some solely looked at facial expressions, and some solely used numbers.

CDPS. Facial expressions in unison with another element were used by 7/9 participants. Four of the seven participants looked at facial expressions along with numbers. Moreover, one community member stated they were looking at facial expressions and colours. In addition, one participant used both facial expressions and Cree descriptors to understand and use the pain scale. Lastly, one participant used facial expressions and the physical linear scale that is presented within the tool.

The numerical element was preferred over any other element by one participant.

The facial expression element was preferred by one community member.

FPS-R. When participants used FPS-R, 3/9 utilized the scale by looking at facial expressions in unison with numbers.

A total of 4/9 participants relied exclusively on facial expressions to utilize the pain scale. One participant stated that the facial expressions helped with pain scale utilization, they explained that the facial expressions carried different meanings with the face for ten as anger, face for eight as stress, face for six as worry, and face for four as uncertainty, face for two and zero as doing okay.

A total of 2/9 participants preferred numbers only 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 participant who were interviewed, four expressed a preference for the CDPS over the FPS-R (see Appendix E for participant demographics). The reasons for their 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. 5/9 participants choose the FPS-R over CDPS (see Appendix D 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. FPS-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 an importance on delivering care that is patient-centered. 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. 3/9 participants expressed having trouble communicating their pain in a way that accurately conveys 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. There are participants who are comfortable with and easily describe their pain experiences. 6/9 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 centered 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.” Another individual expressed the importance of being inclusive and having different elemental pain scale options available for Elders, “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.” Another person valued inclusion and person specific care, they stated, “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. 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 Scale. 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. For example, one participant said, “Yeah, and maybe add more faces, add more numbers.” 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. Both participants expressed, “Well, I think, you know, bigger lettering.” And “Yeah, maybe if the font was enlarged bigger at the top.”

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 colors 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 during discussions indicated some members of the community have experienced a sense of being unheard when accessing healthcare. Participants explained elements that healthcare providers 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. Like sometimes Dr. [deidentified] rushes 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 [healthcare providers] 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, they stated, “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.” 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.

2.4.4 Phase 2 Qualitative Results Healthcare Provider

Qualitative findings from the healthcare provider yielded 2 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 2.10 outlines the themes.

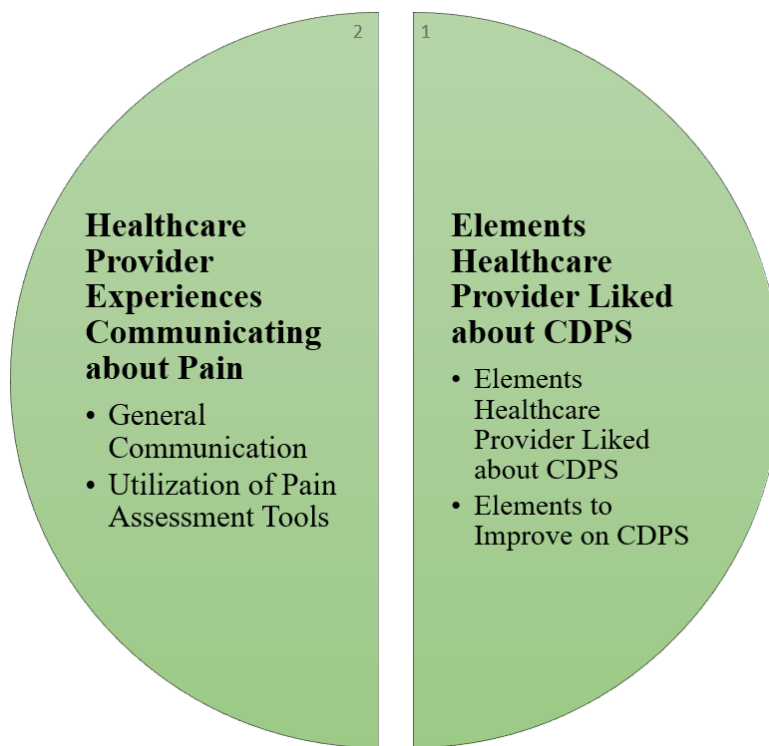


Figure 2.10 Pelican Narrows Healthcare Provider Themes Outline
The 2 major themes with its subthemes outlined.

Major Theme 1: Perspectives on CDPS

Discussions with a healthcare provider who was involved in the virtual assessments captured a physiotherapist'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 are 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 D.

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) utilization of pain assessment tools. The complete list of quotes from community members is outlined in Appendix D.

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 utilized 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.

2.5 Discussion

Through collaborative efforts with the community members of Pelican Narrows, a CDPS was developed and piloted. The CDPS yielded comparable outcomes to the FPS-R with a Weighted Kappa value of 0.696, establishing its concurrent validity. Conversations with participants revealed that they utilized the pain assessment tools in unique ways that were meaningful to each individual. They expressed the importance of having options available to accommodate individuals' different preferences when it comes to pain expression using self-reporting tools.

The teachings from the Elder align with the limited research that is present (Fenwick 2006; Ellis et al. 2011), Indigenous populations may express pain differently than those of Western cultures; thus, Western pain scales may not effectively facilitate pain expressions. Fenwick (2006) found that some Indigenous communities in Australia don't have conceptual recognition of numbers above five. The Elder echoed the lack of quantification of pain, informing that the community of Pelican Narrows may not put a measure on pain and the

members may become more silent when they are in pain; thus, the NPRS may not be effective. However, we can see, a lot 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, numbers may help Western health practitioners to understand pain from an Indigenous individual's perspective. Moreover, it was learned that most facial pain scales not only have too many facial expressions, but 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., (2023) 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; two studies involved Inuit communities in Nunavut (Bailey et al., 2023; Ellis et al., 2011; Latimer et al., 2014, 2020). To our understanding, we are the first to work alongside a Cree community in Saskatchewan to discuss pain measures and pain assessment tools. 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 include: 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, 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 focus on facial expressions along with another element to utilize 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. It's been well-established that each Indigenous community may have differing worldviews and pain experiences (Lin et al. 2018; Ellis et al. 2011; Fenwick 2006). 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 overgeneralized to all Indigenous Peoples. Rather, it should be utilized as steppingstone in future research to 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-centered care.

Results indicated it is crucial to establish a safe healthcare encounter 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., (2018) 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 encompasses subthemes such as *prevention education* and fostering a patient centered approach through *patience and listening*. These recommendations align 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' (Canadian Pain Task Force, 2021). In addition, the Canadian Patients Safety Institute highlighted patients' preference for HCPs who prioritize active listening and strive to understand patients' unique experiences as it facilitates positive relationships and a safe environment (Emanuel et al., 2011). The Canadian Patients Safety Institute's emphasized concepts further support 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-centered 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., (2014) with Mi'kmaq children which aimed to understand pain expressions and pain management. The study revealed participants accounts of feeling unheard, the importance of trust building, the value of storytelling as a means of pain communication, and the advantages of a patient-centered and family centered approach to care. The findings of this study, along with the studies of the Canadian Pain Task Force (2021) and Latimer et al., (2014), 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.

Latimer (2018) observed stoicism during sharing circles with two different First Nations groups in Canada (Mi'kmaq and Wolastoq). Jimenez et al., (2011) and Kramer et al., (2002a, 2002b) reported Indigenous Peoples within Canada and the United States underemphasized pain and described severe pain with vague descriptor such as, "discomfort" and "ache". Fenwick and Stevens (2004) found Indigenous Peoples in Australia also suppressed pain behaviours and were silent when in pain. In this study, we found that most of the nine community members who participated in interviews were comfortable with 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 possible that having local community members as HCPs facilitates a higher level of trust which creates a safe environment for patients to communicate.

This comfort level of participants with expressing pain may not be generalizable to health facilities in remote communities which are not managed by the community and First Nation governance structure.

Moreover, two themes were identified through conversations with a HCP: 1) Perspectives on CDPS and 2) Healthcare Provider Experiences Communicating about Pain. The HCP's themes complement the community members' themes and emphasize 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., (2011) revised a facial pain scale to enhance its cultural relevance for the Inuit community of Pangnirtung, Nunavut. Their findings align with this study, highlighting the importance of utilizing 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 first few studies dedicated to constructing a culturally responsive pain assessment tool for an Indigenous community in Canada. This study not only demonstrated a pain scale developed with an Elder and a Knowledge Keeper, but also piloted the pain scale to document its concurrent validity. The pilot also allowed community members' voices to be heard with 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.

2.5.1 Limitations

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 focused on adults. Further analysis of the CDPS with a larger population is needed to determine its efficacy and sensitivity. Incorporating the CDPS into "pain tool kits", such as the Chronic Pain Pathway resource document could be a valuable future application (Opioid Stewardship Program, 2022). The Chronic Pain Pathway is a pilot program within the

Saskatchewan Health Authority aimed to provide guidance to patients and HCPs in preventing, assessing, and managing chronic pain (Opioid Stewardship Program, 2022). Currently, the resource document utilizes the FPS-R as a self-reporting tool for pain assessments (Opioid Stewardship Program, 2022); therefore, the inclusion of the CDPS in the same document could offer a more culturally responsive option and provide additional resources for pain assessments. 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. Lastly, this project was community-driven and designed to meet the needs of Pelican Narrows, a remote Cree community. Therefore, it may limit its generalizability to other Indigenous communities. Nevertheless, 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.

2.6 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 utilized the pain scale in different ways that were meaningful to each individual. The elements used to comprehend the pain scale do not 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-centered 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 healthcare professionals.

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2.8 Disclosure Statement

The authors have no conflicts of interest to be declared.

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Transition from Chapter 2 to Chapter 3

Chapter 2 investigated meaningful elements of pain assessment tools within a Cree community and gathered knowledge on effective ways to improve communication regarding chronic MSK pain between HCPs and patients. This study determined that the CDPS was comparable in assessing pain as the well-established FPS-R. The CDPS was able to offer more elemental options for the community members to utilize which aided in the comprehensibility of the novel pain assessment tool. Community members also identified possible ways to improve pain communication and pain management through the idea of patient-centered care, patience and active listening. It is important to note that this study was conducted within a Cree community, and the findings may not be directly applicable to other Indigenous communities; therefore, Chapter 3 focuses on the partnership with a Dene/Métis community to identify their unique strengths and challenges in pain communication and pain management. This collaboration aims to address the final objective of the thesis: transferring knowledge learned through collaboration with the Cree community to build new relationships with a Métis/Dene community to gain better insight in understanding chronic MSK pain management needs in that community.

Chapter 3: Understanding Needs for Chronic Musculoskeletal Pain Management in a Northern Dene and Métis Community: A Community Based Needs Assessment

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This manuscript has been reformatted from the original version for inclusion in the thesis. The manuscript is not yet submitted for publication. The target journal for this manuscript is the Journal of Primary Care and Community Health. Tayah Zhang is the lead author of this manuscript. She contributed to the ethics submission, led, and completed participant recruitment and data collection. She was the first reviewer for qualitative data analysis and collaborated with the research team for additional qualitative analysis. She drafted and completed the edits for this manuscript.

3.1 Abstract

Background: Chronic musculoskeletal (MSK) pain disproportionately affects Indigenous Peoples, and rural/remote communities face significant barriers in accessing care. La Loche, a Dene/Métis community in northern Saskatchewan, has limited access to specialized chronic pain management services.

Objectives: The objective of the needs assessment was to gain insight into the community's priorities, strengths, and concerns regarding chronic MSK pain management. Community engagement and relationship building were essential to ensure cultural protocols were respected and community worldviews accurately represented.

Methods: A community-directed needs assessment was conducted in collaboration with local healthcare providers and community members. Open discussions were conducted in-person, over the phone, or via Zoom in a semi-structured format. Thirteen individuals were interviewed in total (8 community members and 5 healthcare professionals). NVIVO software was used to analyze qualitative data.

Results and conclusions: Interviews conducted with community members and healthcare providers were analyzed separately, and both yielded the same four major overarching themes: 1) Impact of Pain on Daily Living, 2) Barriers Limiting Access to Care and the Understanding of Pain between Healthcare Provider and Patient, 3) Systemic Oppression and Negative Experiences with Healthcare, and 4) Strength Based Solutions. Five recommendations were developed to promote culturally safe and patient-centered environments for pain communication:

1) Person-Centered and Community-Directed Care, 2) Clinic Model and Staffing Requirements, 3) Practitioner Education and Awareness, 4) Community Education and Awareness, and 5) Community Resources.

Keywords: Chronic Musculoskeletal Pain, Indigenous Perspectives, Métis, Dene, Needs Assessment, Pain Management

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3.2 Background/Introduction

3.2.1 Chronic Musculoskeletal Pain

Musculoskeletal (MSK) disorders are among the most prevalent diseases affecting 1.71 billion people worldwide (Liu et al., 2022; WHO Scientific Group on the Burden of Musculoskeletal Conditions at the Start of the New Millennium, 2003). Based on disability-adjusted life-years calculations in 2017, MSK disorders ranked fifth highest in terms of overall disease burden (Kyu et al., 2018; Liu et al., 2022).

The number of individuals living with chronic MSK pain is increasing (Kyu et al., 2018). Chronic MSK pain negatively impacts the quality of life, daily function, sleep quality, employment, social participation, life role fulfillments, and mental health of people with this condition (Cimmino et al., 2011; El-Tallawy et al., 2021).

3.2.2 Chronic Musculoskeletal Pain in Canada and among Indigenous Peoples

MSK disorders reported by Canadians in 2017 were as follows: 15.5% for low back pain, 7.5% for osteoarthritis, 3.5% for neck pain, 1.4% for gout, 0.35% for rheumatoid arthritis, and 6.9% for other MSK disorders (Kopec et al., 2019). Information on chronic MSK pain among Indigenous Peoples in Canada is sparse. The Canadian Pain Task Force (2019) reported Indigenous Peoples experience the highest prevalence of chronic pain in Canada and MSK conditions are commonly the reason for those chronic pains. Rates of low back pain, rheumatoid arthritis, osteoarthritis and other MSK conditions are higher in Indigenous Peoples in Canada

when compared to non-Indigenous populations (First Nations Information Governance Centre, 2018; Ng et al., 2010). Indigenous Peoples within rural locations in Canada have a 30% greater chance of experiencing chronic LBP than non-Indigenous individuals (Bath et al., 2014). In the face of the significant prevalence of chronic MSK pain, Indigenous Peoples continue to persevere despite the persistent disparities they face in pain management.

3.2.3 Pain Disparities

Chronic MSK pain involves social, psychological, financial and environmental factors which are all unique to each person's lived experiences (Ernstzen et al., 2017; The Canadian Pain Task Force, 2019). Due to the complexity of chronic MSK pain, comprehensive pain assessments by a multidisciplinary healthcare team is most appropriate and considered best practice (Ernstzen et al., 2017; The Canadian Pain Task Force, 2019). Chronic MSK pain management guidelines encourage minimal medication use by increasing preventative education and non-pharmacological approaches (El-Tallawy et al., 2021). A wholistic approach is recommended in the context of the patient's lived experiences, current lifestyle, preference, culture, and mental health (El-Tallawy et al., 2021; Ernstzen et al., 2017).

Despite established MSK pain management guides, many Indigenous Peoples still face inequitable pain management. Racialized healthcare experiences of Indigenous Peoples are rooted within Canadian history and must be reviewed in the context of the nation's colonial actions. Indigenous Peoples have fought for their identity and culture throughout oppressive and genocidal policies such as: residential schools, the Indian Act, the 60's scoop, and the sterilization of Indigenous women (Matheson et al., 2022). Indigenous Peoples across Canada are continually impacted by the long lasting harm of the historical traumas (Matheson et al., 2022).

Indigenous Peoples experience ongoing systemic racism and face the effects of culture and language loss. Systemic oppression resulted in inequitable social determinants of health such as poverty, food insecurity, lack of housing, loss of land, forced migration, lack of access to healthcare, low rates of employment, and lack of potable water which, in turn, result in health disparities (Matheson et al., 2022).

Mathur et al. (2022) suggested that pain disparities faced by racialized groups are direct results of injustices at the cultural, structural, and interpersonal levels. Racialized oppression shapes the lived pain experiences of minority patients and increases the risk of poor pain

outcomes (Mathur et al., 2022). Mathur et al. (2022) explains cultural injustice as inequalities that are built into language, society, values, and worldviews. Structural injustices involve inequalities built into governments and healthcare systems whose policies and practices exploit Indigenous People's right to vote, to receive education, to receive equal opportunities, to obtain housing, to secure employment, and to access equitable healthcare (Mathur et al., 2022). These factors impact an individual's pain outcomes and lead to pain disparities.

Explicit biases, implicit biases and discrimination are considered interpersonal injustice amplify the degree of pain physically, emotionally, psychologically, and spiritually (Mathur et al., 2022). Implicit and explicit biases towards Indigenous Peoples in Canada is well documented and discussed on social media and provincial reports in British Columbia (BC), Alberta (AB), and Ontario (Allan & Smylie, 2015; Roach et al., 2023; Turpel-Lafond, 2020). Implicit biases lead to discrimination experienced by Indigenous patients such as “abusive interactions, denial of service, inappropriate pain management, ignoring or shunning” (Turpel-Lafond, 2020). In a 2020 review of anti-Indigenous racism in BC and revealed only 16% of the Indigenous participants surveyed (n=2790) had not experienced discrimination or stereotyping when accessing healthcare (Turpel-Lafond, 2020). More than one third of the total surveyed healthcare providers (HCPs) (n=5440) reported witnessing discriminatory acts towards Indigenous patients and families (Turpel-Lafond, 2020). Widespread stereotyping of Indigenous Peoples as “drug seekers, frequent flyers, and less capable” within the healthcare system was identified (Turpel-Lafond, 2020).

Pain is interrelated with discrimination, trauma, social marginalization, invalidation of the pain experience, mental health, and healthcare inequities (Wallace et al., 2021). Persistent negative experiences of injustices, racism, discrimination, and poor healthcare will compromise an individual's views on healthcare which can lead to avoidance of care and lack of preventative care and education (Turpel-Lafound, 2020).

3.2.4 The Importance of Needs Assessments

Although it is important to understand the literature surrounding MSK pain and pain disparities experienced by Indigenous Peoples, it is also vital to not presume each Indigenous community experiences similar challenges, as every community possesses unique cultures, histories, and identities. A community needs assessment is a beneficial way to understand a community's strengths and concerns around MSK pain management. It can lead to community

identified health outcomes and an increase in the awareness of the needs, views, and preferences of community members to ensure future interventions are tailored to the community (Bhawra et al., 2022). To ensure meaningful relationships with community members, continuous community engagement that prioritizes the community voices is required (Cyril et al., 2015).

A needs assessment helps identify ways current policies, services, barriers to access, and health resources within community can be improved to benefit residents and their pain experiences. Partnership with community members prioritized their involvement in the research process to ensure relevant and practical future interventions. The aim of this needs assessment was to listen to community members' and HCP's stories in order to understand the community's current efforts in chronic MSK pain management and to capture community-identify recommendations that would be suitable for the community.

3.3 Methods

3.3.1 Framework

Interpretive Description (ID) with analytic procedures of thematic analysis, informed by Community-Based Participatory Research (CBPR) and Two-Eyed Seeing (TES) was utilized throughout this needs assessment to ensure the project was culturally relevant and community-led (Holkup et al., 2004; Martin, 2012; Thorne et al., 1997; Wallerstein & Duran, 2006). Interpretive Description recognizes realities are socially constructed with elements of the human experience (Thompson Burdine et al., 2021). This methodology was in keeping with our goal of having actionable outcomes to inform the development of future interventions for chronic MSK pain management (Thompson Burdine et al., 2021).

Community-Based Participatory Research ensures a collaborative partnership where researchers and community members will be treated as equals (Holkup et al., 2004). It allowed for community members to lead and identify community strengths, needs, and desired health outcomes (Holkup et al., 2004). Two-Eyed Seeing is a research guide for Indigenous inquiries that combines knowledge of both Western and Indigenous worldviews (Peltier, 2018). 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 prioritizing Indigenous knowledge and experience. This project facilitated a collaborative discussion *with* a Dene/Métis community about chronic MSK pain and pain management in hopes of improving future healthcare

experience and health outcomes. Indigenous scholars and community members were involved through all stages to ensure Indigenous worldviews were prioritized.

3.3.2 Setting

La Loche is a village located in northern Saskatchewan with a population of 2514 in 2021 (Statistics Canada, 2022). In the 2021 census, the community of La Loche comprised of 94.2% Indigenous residents (Statistics Canada, 2022). 35.7% of the population are Métis and 56.3% of the population are First Nations (specifically Dene) (Statistics Canada, 2022). In the same census, 51.7% of community members mostly speak Dene at home and 36.5% of members speak English (Statistics Canada, 2022). The Saskatchewan Health Authority (SHA) and Northern Medical Services oversee healthcare services offered within La Loche and surrounding communities (estimated to be around 4000 individuals) (Government of Saskatchewan, 2001). Due to the community's remote nature and distance from urban centers, access to specialized chronic MSK pain management services are reduced.

We worked in partnership with the community members and local HCPs to understand the strengths, concerns, and priorities of La Loche in terms of chronic MSK pain management. Community members' voices provided insights on culture, language, strength and needs of the community, and ensured worldviews and protocols were respected.

3.3.3 Ethics

Ethics approval of this project was received through the University of Saskatchewan Ethics Board (Beh ID 3016), a La Loche review, and a Saskatchewan Health Authority operational approval. All members of the research team completed the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, 2nd Edition* tutorial for research involving participants.

3.3.4 Community Engagement Procedure

The research team's initial focus was on fostering a meaningful relationship with the community of La Loche. Team members had previous relationships and worked to establish connections with Elders and local HCPs. A local Dene-speaking community research assistant (CRA) was hired. The CRA played a vital role in ensuring community protocols and culture were respected. The CRA also provided education on the importance of language in promoting

health, wellness, and trust. We were committed to ensure traditions and protocols of La Loche were followed; therefore, we made an effort to seek out guidance from Elders and provided tobacco (Dene participants) or gifted food and jams (Métis participants). To ensure the community members felt safe and respected, the CRA played a critical role as a translator for those who wished to participate in Dene.

3.3.5 Recruitment and Data Collection Procedure

Recruitment posters were shared to the community over Facebook, following the local CRA's recommendations. Individuals 18 years of age or older, from La Loche or surrounding communities, and experiencing chronic MSK pain (pain that has persisted for three months or more) were invited to share their experiences. Participants were provided honoraria, and Elders were offered tobacco or jam in addition to honoraria for their knowledge sharing. In addition, HCPs who work with individuals living with chronic MSK pain were invited to participate and share their perspectives. Nurses and physicians were contacted for participation; however, were not available.

Members of the research team visited the community twice in the summer of 2022 for community engagement, relationship building, and to conduct semi-structured interviews. Virtual semi-structured interviews were also conducted using Zoom or a phone call. Interviews were led by the first author and facilitated by the CRA in Dene. Indigenous scholars on our team (VM and JS) provided guidance in the creation and further revisions of the semi-structured interview guide (Appendix G and Appendix H). The interviews were audio recorded with the participants' consent and transcribed at the Canadian Hub for Applied and Social Research (University of Saskatchewan). A total of 13 individuals were interviewed: 8 community members and 5 HCPs.

3.3.6 Analysis

Transcripts were thematically analyzed using NVivo, a qualitative analysis software (NVivo, 2018). The process involved initial familiarization of the transcripts, followed by further readings focused on identification of recurring patterns and ideas within each transcript. Patterns and ideas across transcripts were then identified which developed the preliminary codes that were subsequently categorized into emerging themes. A hierarchy was established, with major

themes emerging from subthemes and sub-subthemes. The researcher and principal investigator engaged in regular discussions to ensure reliability throughout the analysis process. Indigenous scholars (VM and JS) were part of the transcript analysis to ensure TES procedures. Discussions facilitated the identification of redundant codes and restructuring, as well as organization of codes into detailed subthemes. To enable the identification of potentially differing themes, the HCPs' transcripts were analyzed separately from those of community members.

3.4 Findings

3.4.1 Community Members Themes

Qualitative findings from community members yielded four major themes each with subthemes and sub-subthemes: 1) Impact of Pain on Daily Living, 2) Barriers Limiting Access to Care and the Understanding of Pain between Healthcare Provider and Patient, 3) Systemic Oppression and Negative Experiences with Healthcare, and 4) Strength-Based Solutions. Community members' demographic information can be found in Appendix I. Figure 3.1 outlines the themes.

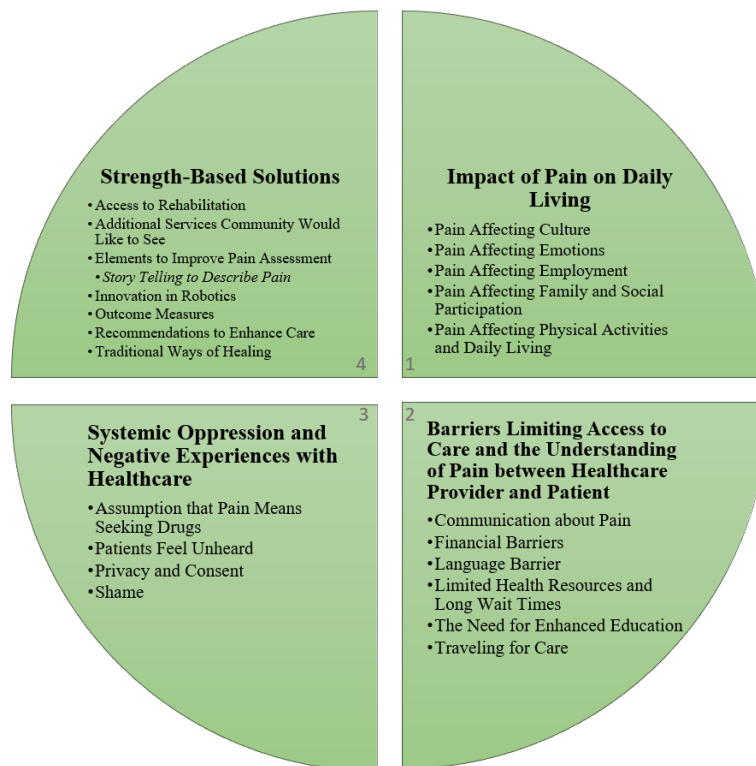


Figure 3.1 La Loche Community Members Themes Outline
The 4 major themes with its subthemes and sub-subthemes outlined.

Major Theme 1: Impact of Pain on Daily Living

Community members shared how MSK pain can affect multiple aspects of their livelihood from impacting culture, to negatively affecting emotions, employment, family relations, social participation, and directly limiting physical activities and function. The subthemes were as follows: 1) Pain Affecting Culture, 2) Pain Affecting Emotions, 3) Pain Affecting Employment, 4) Pain Affecting Family and Social Participation, and 5) Pain Affecting Physical Activities and Daily Function. The complete list of quotes from community members is outlined in Appendix J.

Pain Affecting Culture. Community members expressed MSK pain has limited their ability to practice their own culture and traditional way of living including participant in ceremony, hunting, and fishing. One participant shared, “There's these sweat lodges that we do, and I can no longer participate because of the pain that I feel with the heat. I can no longer go to traditional dances anymore. I can't participate in traditional community activities. I can't do a lot of things.” Another participant expressed, “I probably couldn't dance Powwow and I can't even kneel down if my knee is sore. So, it's hard for me to even get into a smudge or anything like that.”

Pain Affecting Emotions. Participants expressed feeling exhausted and frustrated living with constant pain. One participant expressed, “I get real bad anxiety and I feel like I can't do stuff right now. I'm just really depressed.” Another participant stated, “It has made me not want to be around people so much because I do get irritated.”

Pain Affecting Employment. When speaking about pain experiences, participants expressed that pain has negatively impacted their employment status. For example, one participant shared, “For me, pain has just totally destroyed my life. Cause I was working [extracted for privacy], and it got to the point where I couldn't work on pain meds... And because of my pain, I'm unemployed... My wage lost, everything.”

Pain Affecting Family and Social Participation. Participants reported that their pain has influenced their family responsibilities and social participation. Specifically, they shared that pain has acted as a barrier when it comes to engagement in social environments. A participant reported:

Some days it's tough and other days, it's fine but I find myself that I don't try to get involve in things cause I'm afraid to make it sore. I don't wanna kneel on it to aggravate it

more, so I just kinda don't bother... I have limited mobility. I find that I don't even like to have company because you can't really visit or nothing.

Pain Affecting Physical Activities and Daily Living. Community members expressed challenges with sleeping, household and outdoor chores, walking, lifting, bending, and appetite. One participant stated:

Yeah, I can't stand for a long time or I go walking around and stuff and I start feeling like I'm going to fall over. I don't know how to — or I can't lift anything too heavy anymore... It's even hard sleeping at night. My legs have to be a certain way and yeah, I can't do too much. Or even eating and stuff like that.

Major Theme 2: Barriers Limiting Access to Care and the Understanding of Pain between Healthcare Provider and Patient

The second theme that emerged described factors which challenged communication about pain between HCPs and patients. The subthemes included: 1) Communication about Pain, 2) Financial Barriers, 3) Language Barriers, 4) Limited Health Resources and Long Wait Times, 5) The Need for Enhanced Education, and 6) Traveling for Care. The complete list of quotes from community members is outlined in Appendix J.

Communication about Pain. Participants revealed a preference for describing their pain verbally along with motions to indicate the location of the affected area. Some community members shared they had never used a pain scale before during pain assessments with HCPs. Of those who had utilized a pain scale, the majority had only utilized the numerical pain rating scale and had utilized a visual skeleton to aid in communication. A participant said:

They'd give me a pain scale which said which level is where and all that stuff. They'd sit there with a human skeleton and whatever, They'd draw circles where your pain was and everything. That was Dr. [deidentified], they'd tell you, 'Point it out on a pain scale'... on the skeleton drawing you could say 'well my left arm is sore. From yesterday till today the worst pain is seven.'

Financial Barriers. A participant articulated the financial challenges they face in accessing healthcare, noting that although they have healthcare coverage, taking time off work to see a physician is not financially feasible because they have to prioritize work over their health in order to make ends meet.

Language Barrier. Community members shared experiencing challenges when communicating with HCPs who do not speak Dene. Two individuals participated within one interview and spoke about the significance of the Dene language in understanding the culture and social norms of the community. They said:

P1: Like, the Dene language, our language, the majority of the language is all facial expressions. Like, one word could mean a lot with different expressions, facial expressions. If you're gonna come and work in La Loche, maybe you should take some course on Aboriginal- La Loche people, just how the Dene people are. Then they'll have an idea "oh this guy's not drunk, he's speaking his language, he's speaking Dene to me. He's not talking gibberish." If there's a new doctor coming into town, they should arrange for a community tour or something to invite them into the community, talk to people, not hear it from somebody.... If you come to a three-year-old in La Loche, you talk to them in English, they won't understand what you're saying.... But if you talk to them in Dene, the three-year-olds would talk...in their native language, where they learn English in school as their second language.

Limited Health Resources and Long Wait Times. Participants expressed the remote nature of La Loche leads to a lack of health services and physician availability which in turn affects the wait times. One participant described, "When you phone in the morning, they open at nine, right? But at five to nine, it's busy and at ten after, it's all booked up. I find it very hard to get an appointment." Participants shared that the current physicians working within community were locum physicians and expressed concerns with a lack of continuity of care.

The Need for Enhanced Education. Community members emphasized the importance of clear and effective communication between patients and HCPs to ensure informed decision-making. One participant shared:

When you go to a hospital here, you just tell them how you feel or what's hurting you. They don't even check you. They are say[ing], 'just say take Advil or Tylenol'...I stopped going to the hospital, because they don't do nothing. They tell me to take Tylenol...They don't wanna explain much.

Participants identified a need for enhanced awareness of available health services in community and enhanced health literacy. A few community members were not aware of all the services and tools that are available at the local health centre, like physiotherapy, the remote

presence robot which can enhance service access, and the Opioid Antagonist Treatment (OAT) program. One participant shared feeling frustrated and stigmatized when speaking about the OAT program, they said, “Because there's no community awareness on the methadone program, so people see you and think you're a hardcore drug addict.”

Traveling for Care. Community members expressed a preference for seeking healthcare services in alternative communities and urban centers due to past negative experiences in the community. Community members shared, “Yeah, I usually go to Battleford to get- better treatment.” Two participants during one interview said:

I used to go see the doctor in Saskatoon that we see had been assigned but if not, I would go to St. Paul's or University. Even though I was a Native, I communicated good with the doctors. A lot of them were interested in my Native culture background and everything. And we'd sit there for an hour or two or whatever and the doctor would jump up "I've got more patients, I forgot!" Not here, you know? They just- you're not even allowed to warm up the seat a little bit. You stand there and you leave. I mean' it's not that bad but it feels that bad. You go into the doctor's office and you have to sit there, wait for 45 minutes, no music, nothing.

Major Theme 3: Systemic Oppression and Negative Experiences with Healthcare

The third theme highlights the ongoing systemic oppression that Dene/Métis community members have faced within the healthcare system. The subthemes include, 1) Assumption that Pain Means Seeking Drugs, 2) Patients Feel Unheard, 3) Privacy and Consent, and 4) Shame. The complete list of quotes from community members is outlined in Appendix J.

Assumption that Pain Means Seeking Drugs. Participants shared that HCPs often had preconceived notions that they were drug-seeking individuals despite expressing their desire for their pain to be treated seriously and requesting additional assessments to address their pain. One participant said:

They make me feel like I'm going there for pills, which I'm not even a pill-popper at all. They just make me feel like I'm there to get drugs, but I'm not. I really want x-rays done and stuff. They don't take it seriously.

Two participants shared during one interview, that they must manage their pain in order to practice their culture and sustain their livelihood. They conveyed that their pain is severely

debilitating, to the extent that it mentally exhausting. Their primary goal is pain management; however, when they seek care at the local health clinic, they are faced with stigmatization and presumptions that they are seeking medication.

Patients Feel Unheard. Community members also emphasized the importance of recognizing that people express pain in unique and varied ways. They cautioned against making assumption or judgements based on appearances. Two participants echoed similar experiences. They provided an example:

You know, when you go to see the doctor at the hospital for whatever reason, the doctor and the nurse themselves say ‘okay this is wrong with you, that's what's wrong with you.’ They don't listen to the patient, they decide what is wrong with the patient. Like I said, they decide for you. They don't listen to what you're there for, they decide for you...They don't acknowledge you. If only the doctors would listen to the people like us, maybe our lives would be different today.

Privacy and Consent. Participants shared their concerns regarding privacy and informed consent particularly in relation to the OAT program. They reported feeling stigmatized and two patients even reported experiencing a lack of privacy that impacted their social lives within community:

P1: Like the pharmacy, we said, there's no privacy. So the methadone is given to us right in front of everybody. And the people there on street drugs get their methadone, they sell it. And then they come and harass us that thy need people to buy it off us.

P2: Cause it's not given to us discreetly. If he was to give it to us discreetly, nobody would know we even get those meds. But instead he just does it out in the open so when those people, those whatever, they sell theirs, their short, they'll bother us to see if they can buy it off of us.... There's a few times we had to call the police on people that were bothering us.

Participants also shared their experience with lack of informed consent. They said:

There's one day where we went to the pharmacy, we got to the pharmacy and we walked in, there was a doctor and a couple other people from Saskatchewan Health Authority standing there...We were forced to sign something that we did not agree to. And we were forced to sign it because we were walking out sick. The doctor forced us to do that.

Because I was trying to read the fine print and everything, he kept trying to pull it away

from me. So finally I had a pen, steel pen, I hit him on the finger as hard as I could. I told him I'm a slow reader. I did tell him three times I'm a slow reader...

Shame. Community members conveyed that they experienced a sense of shame when accessing healthcare for pain management. They said:

P1: How do they treat us at the pharmacy when we're on Methadone? It's 40 below, it doesn't matter if the wind is whistling, snow blowing, we're standing outside. People are coming and going at the pharmacy but if you're on methadone, you stay outside like a dog until you're called in.

Major Theme 4: Strength-Based Solutions

The final theme highlighted the recommendations provided by community members for enhancing pain management, improving pain communication, and advancing community healthcare services. In addition, participants suggested a possible outcome indicator that could be observed to determine level of improvement within community from future interventions. The subthemes were: 1) Access to Rehabilitation, 2) Additional Services Community would Like to See, 3) Elements to Improve Pain Assessment, 4) Innovation in Robotics, 5) Outcome Measures, 6) Recommendations to Enhance Care, and 7) Traditional Ways of Healing. The complete list of quotes from community members is outlined in Appendix J.

Access to Rehabilitation. Several community members shared that engaging in physical exercises, visiting physiotherapists, and seeing chiropractors have provided relief of their chronic pain, indicating a need for accessible rehabilitation services within the community. One community member shared the importance of movement in his pain management (with the help of a translator),

He said that he basically just helps himself by doing the stretching at home and just walking around at home when he feels the pain. When he mentioned earlier that when he feels the pain, he does a little bit of stretching and walking to ease the pain.

Additional Services Community Would Like to See. Community members shared their insights on possible solutions that could help manage pain for the residents of La Loche. Among the ideas suggested were educational support groups that could improve health literacy and promote physical activity such as a walking group. Some community members proposed home visits from HCPs as a way to aid those with pain.

Elements to Improve Pain Assessment. Participants offered suggestions on how pain assessment tools could be improved to better facilitate pain communication within the community. One participant expressed their own experiences using a pain assessment tool that was meaningful. They shared:

Well, when the doctor showed me all those, the skeleton and the pain scale with the one to nine to ten which would be the worst and one was the least, worst and stuff like that. That was good. Really simple to follow... Like, the Dene language, our language, the majority of the language is all facial expressions. Like, one word could mean a lot with different expressions, facial expressions.

Story Telling to Describe Pain. Participants often recounted their pain journeys, beginning with the initial onset of pain, through to the cause of their injury and its impact on daily activities. By allowing adequate time and being attentive, participants shared valuable insights into their pain experiences.

Innovation in Robotics. Community members suggested increasing the utilization of the remote presence robot in community. Many voiced the possible benefits of having a telehealth program within community to eliminate travel and increase availability of services in community. One participant said, “Yeah, it’s better if they start using it [the remote presence robot] on the people instead of hiding or tucked away someplace. Should bring it out and start using it on people.”

Participants identified potential obstacles that could arise from using the remote presence robot, including language barriers and technological difficulties. They recommended addressing these challenges by having a nurse or translator present during consultations using the remote presence robot.

Outcome Measures. Community members identified potential assessment indicators to evaluate the effectiveness of future pain management interventions within community. These included reduced wait times at the health clinic, decreased travel time for accessing healthcare, regular follow-ups with patients, and conducting surveys.

Recommendations to Enhance Care. Community members provided valuable insights on how HCPs can establish trust and promote a safe environment to facilitate meaningful conversations during pain assessments. They highlighted the importance practicing patience, and actively listening to the patient. One participant shared (conversation facilitated by a translator):

He's saying that when you go to the clinic, you sit there for more than three or four hours. He's also saying that when a person goes to the clinic, obviously, they're hurt. They should be examined more and be taken into real consideration instead of saying, 'Oh, you're not really hurt. You don't look really sick. I'll just give you Tylenol. Go home.'

Traditional Ways of Healing. Participants expressed the significance of incorporating cultural practices into the healing process, including the use of traditional medicine. One participant shared, "Rat root, I use that." Another participant said, "Well, drinking teas and also got rubs that were made out of natural products."

3.4.2 Healthcare Provider Themes

During discussions with five HCPs, several major themes emerged with subthemes and sub-subthemes. The major themes reflect similar ideas identified by community members. These major themes included: 1) The Impact of Pain on Daily Living, 2) Barriers Limiting Access to Care and the Understanding of Pain between Healthcare Provider and Patient, 3) Systemic Oppression and Negative Experiences with Healthcare, and 4) Strength-Based Solutions. Figure 3.2 outlines the themes.

Major Theme 1: The Impact of Pain on Daily Living

Healthcare professionals provided insights into the impact of chronic MSK pain on the community members of La Loche. They shared insights on culture, emotions, employment, physical activities and daily living, and social participation. The complete list of quotes from HCPs is outlined in Appendix K.

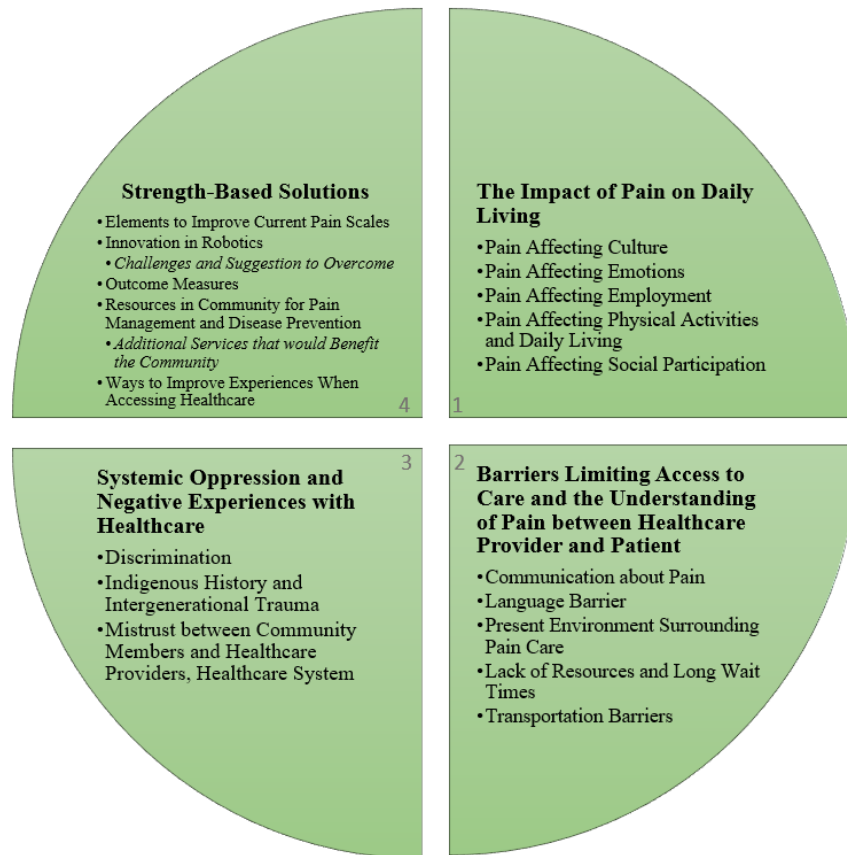


Figure 3.2 La Loche Healthcare Providers Themes Outline
 The 4 major themes with its subthemes and sub-subthemes outlined.

Pain Affecting Culture. Healthcare providers expressed pain has limited patients’ ability to practice their culture and traditional way of living from picking berries, hunting, and participation in spiritual activities. One HCP shared, “Participating in cultural or spiritual activities is affected because these individuals are not really going out into the community.” Another HCP noted that social activities may have cultural significance, but they acknowledged a lack of understanding of what qualifies as a cultural practice.

Pain Affecting Emotions. Healthcare providers conveyed that chronic pain has profound effects on patients' emotional well-being, resulting in limitations on mobility and restricted participation in the community. They highlighted that lack of social participation can lead to adverse emotional effects. They said:

These individuals have isolated themselves and it’s affecting them daily. Not leaving the home much, unless they need to. Their lives are definitely affected and they're not really

living because they're trying to stay in their comfort zone most of the time. These individuals are not really going out into the community.

Pain Affecting Employment. Healthcare professionals shared that individuals living with pain may face challenges with employment and may need to make career adjustments to manage their pain effectively. They said, “Sometimes it'll take a patient out of employment forever sometimes it might require a change in employment.”

Pain Affecting Physical Activities and Daily Living. Community members living with pain encounter barriers in their daily lives, including mobility challenges like walking. A HCP shared:

All of them are unable to do certain things in their lives that they would really like to be able to do. There are lots of conversations about them wanting to get back to doing this or this is causing me trouble now I can't do this thing anymore.

Pain Affecting Social Participation. Healthcare providers shared that community members have communicated experiencing social isolation as a result of limited mobility due to chronic pain. One individual expressed, “These individuals are not really going out into the community. It's difficult for them. If you're not going anywhere and you're not seeing much of anybody, then you're just basically keeping to yourself and your family.”

Major Theme 2: Barriers Limiting Access to Care and the Understanding of Pain between Healthcare Provider and Patient

Healthcare professionals highlighted that language differences could impact effective communication. They identified environmental factors such as lack of continuity of care, long wait times, and the high prevalence of chronic pain in the community that affect pain management strategies. They provided valuable insights on the various factors that could potentially impact patients' access to care and the patient-provider relationship. The subthemes are: 1) Communication about Pain, 2) Language Barrier, and 3) Present Environment Surrounding Pain Care, 4) Lack of Resources and Long Wait Times, and 5) Transportation Barriers. The complete list of quotes from HCPs is outlined in Appendix K.

Communication about Pain. Healthcare providers shared their experience with communication about pain management in the community, noting that traditional pain scales may not always be effective and identified that patients may prefer to communicate about their

pain experiences through storytelling. Providers noted a potential disconnect in the understanding of pain between themselves and community members. A HCP shared:

I'm just using mostly the visual analogue scale and with that one, sometimes I feel it doesn't trend. Maybe it's just because they haven't heard it before, or maybe it's because it's not geared to that population. It doesn't always seem to make sense right off the bat.

Language Barrier. Healthcare providers noted that effective pain communication requires attention to language differences. Specifically, community members of La Loche often speak Dene as their first language, while many HCPs primarily speak English. These linguistic differences can present a significant barrier to effective pain management. One HCP did not initially perceive language as a barrier; however, they were able to identify that many Elders in community often speak Dene as their first language which can pose as a challenge when communicating. This HCP expressed the importance of having auditory formats of Dene to facilitate communication. They shared:

We do utilize our community outreach education worker to help translate as much as possible, but I would definitely say out of all the communities within our northwest region that where we're going to see most language barriers for sure is in La Loche. It's interesting because when we have resources that are in the Dene language most individuals don't know how to read the Dene language, they just speak it. So, any resource really needs to be quite visual with pictures or audible we did get – I've seen resources in my previous position that were made in the Dene language, and no one could read them.

Present Environment Surrounding Pain Care. Healthcare providers highlighted potential challenges in pain management, including lack of continuity of care, extended wait times for appointments, and lack of access to care. One individual shared:

[MSK pain] can be anywhere in the body but probably the most common areas are our low back, shoulders, knees, those would probably be the top 3 areas...there's really zero consistency with who patients see at a primary care physician level.... 9/10 the person they're seeing on follow-up is different doctor than they saw last time and that definitely doesn't lead to ideal management when it comes to medications, ordering diagnostics, or following up on those... Some consistency at the primary care level in terms of care providers would be really helpful but that's a much bigger systemic problem.

Lack of Resources and Long Wait Times. Healthcare providers expressed concerns with the wait time and wait lists in La Loche. They also provided insights on resources that could benefit the community, such as cognitive-behavioral therapy (CBT) for pain management and an increase in staffing levels. A HCP shared:

I think too, there's a long waitlist and if you're needing to see them more than once every two weeks because of their patient load. That could be difficult, we just don't have the capacity to be serving the people of La Loche sometimes as much as the community may need especially in relation to really anything in healthcare.

Another HCP stated an increase in capacity of the healthcare clinic may benefit the community members.

Transportation Barriers. Healthcare providers highlighted the challenge of transportation as a barrier to accessing healthcare for community members in La Loche. Given its remote location, the health clinic is the only facility available within a certain radius, which requires patients to secure transportation in order to attend appointments. Additionally, due to the size of the town, community members located within La Loche may also require transportation to access the clinic. Furthermore, the range of services available at the local clinic is limited, necessitating patients to travel to urban centers like Prince Albert or Saskatoon for healthcare. A HCP shared:

It is a larger town so it also could be a barrier to sometimes getting to the clinic maybe difficult if you don't have a vehicle or access to a vehicle or access to a ride that could be difficult because we don't have public transportation. [Additionally] I think specialists appointments sometimes those are - I think it can really be hard to get patients to a specialist appointment in the south even if you have coverage like you are Treaty or you are on social assistance...what if you have a bunch of children that need to be cared for? What if you don't have a partner like and then you need to go the city which can be considered really big and scary for a lot of people it's very traumatic.

Healthcare providers highlighted that due to the remote location of La Loche travel expenses may be a limiting factor for some community members in accessing care. A HCP shared their personal experiences regarding traveling for healthcare and the financial burden it can impose. They stated,

We have to travel down south six and a half to seven-hour drive to Saskatoon to see a specialist. Those of us who are paying on our own, it's a lot of money, a lot of our time, hotels and meals...

Major Theme 3: Systemic Oppression and Negative Experiences with Healthcare

Healthcare providers identified discrimination and systemic oppression within the healthcare system. They emphasized the impact of intergenerational trauma and current discrimination on the establishment of trust and rapport between HCPs and Indigenous patients. Subthemes identified included: 1) Discrimination, 2) Indigenous History and Intergenerational Trauma, 3) Mistrust between Community Members and Healthcare Providers, Healthcare System. The complete list of quotes from HCPs is outlined in Appendix K.

Discrimination. Healthcare providers noted the negative effects of stereotypical views that are often directed towards community members, such as the perception of individuals as "drug-seeking". They said:

I feel like the doctors' notes that I've looked at feel like these people are just always seeking medication. Which makes sense, if you're in pain all the time you should be seeking out ways to manage your pain. I don't think that the practitioners are accusing these people of being drug seeking. I do feel there's a bit of tension there. People are asking for help and the medical system isn't able to provide it for whatever reason; whether there just isn't another drug that would help; we've tried all the options and unfortunately there just isn't something, or; whether the revolving door practitioners that visit La Loche just breaks down that continuity of care...

Indigenous History and Intergenerational Trauma. Healthcare providers shared their knowledge of impacts of colonization that can affect the experiences of chronic pain including, involvement of the church, forced sterilization and birth control, intergenerational trauma, and the mistrust of systemic institutions. One HCP said:

There're also mothers who maybe have a history with substance abuse but perhaps they're actually really working on themselves. And so, for their entire pregnancy [they] want to change their lives and... their children are still taken away from them when they deliver. And that is scarring...and you now have a population of people who believe that the health authorities is ripping families apart...inadvertently.

Mistrust between Community Members and Healthcare Providers, Healthcare System. Healthcare professionals recognized the systemic oppression experienced by the community has led to hesitancy in trusting the healthcare system. They noted that establishing rapport with community members can take time, but it is essential to foster trust and ensure respectful care. A HCP voiced concerns about how the lack of continuity of care could impede their efforts to build meaningful relationships with community members. They shared:

Any kind of care when it's that broken and inconsistent with who's providing it, you're not building a relationship with a care provider and establishing trust and rapport and as a provider getting familiar with that patient and their story and the patient not having to retell the exact same story every time they go in and see someone new.

Another HCP shared their observations of community members who choose to seek healthcare outside of La Loche, noting that the community members experience a sense of mistrust towards the local healthcare center.

Major Theme 4: Strength-Based Solutions

Discussions with HCPs revealed several suggestions for improving healthcare in La Loche including, how current pain scales could be enhanced, and the potential use of remote presence robots to improve access to care. They identified relevant outcome measures to monitor the effectiveness of interventions, and outlined key resources that could improve pain management and disease prevention. Additionally, they suggested strategies for enhancing the patient experience when accessing healthcare. The complete list of quotes from HCPs is outlined in Appendix K.

Elements to Improve Current Pain Scales. Healthcare professionals discussed adaptations to current pain scales to better facilitate pain communication, and considering the language barrier that heavily impacts pain assessment in La Loche. They suggested utilizing more visual pain assessment tools with auditory formats of Dene descriptors and exploring ways to work around language barriers to better serve the community. One HCP said:

Yah, I think that the visual analogue scale is too abstract...Having something that's a little bit more concrete, and then I'm noticing some more of that storytelling and whatever descriptions of pain...maybe having something that allows the people to select something a bit more concrete, a word or face or something like that would help. Then with the

language barriers too, I don't feel like I'm always explaining well, so having something that would help me translate certain extensive pain to other languages, to Métis to Dene, Cree, whatever people are speaking, I think that could be helpful too.

Innovation in Robotics. Healthcare providers expressed enthusiasm for the potential of utilizing the remote presence robot in the healthcare center, which could lead to more timely care, expanded services, and reduce the need for patients to travel unnecessarily to access healthcare services. They shared:

...when you're dealing with MSK issues where there's a lot of value in in person assessment, in person treatment, that's always best case scenario. But when it's a lengthy wait for those type of services and you can cut that wait time drastically by doing things remotely in the meantime then that's going to lead to better outcomes and patient satisfaction and care.

Another HCP expressed the potential benefits of limiting travel for patients seeking healthcare services, stating, "like I said, it would be easier for them to come in contact with a doctor from South than travelling." Another HCP identified the potential enhancement of interdisciplinary care with use of the remote presence robot:

...you know we do have physios in the far northwest too who actually have some really good backgrounds in persistent pain...so I think that just partly through working with these populations for many years as well as different continued education pieces...linking up with other people, networking with other providers that have similar skill sets or even more advanced training in those areas certainly doesn't hurt.

Challenges and Suggestion to Overcome. Healthcare providers expressed concerns about patients showing up for their appointments over the robot, challenges associated with the use of technology, establishing a meaningful relationship over the robot, and overcoming the language barrier. They emphasized the importance of having a local [staff member] present at appointments alongside the remote presence robot to not only act as a translator, if necessary, but also to provide a more comfortable environment to facilitate conversations.

Outcome Measures. Healthcare providers recommended patient and HCP surveys to gain meaningful feedback and emphasized the importance of conducting surveys in-person to offer more community engagement and relationship building.

Resources in Community for Pain Management and Disease Prevention. Healthcare providers discussed current resources available in community for pain management and promotion of physical activities, including physiotherapy, mental health services, addiction services, and open gym nights at the local school gym.

Additional Services that would Benefit the Community. Healthcare professionals explored potential additional services that could benefit the community, including increasing the number of physiotherapy positions available, providing access to translation services, establishing support groups, offering walking programs, and implementing a telehealth program to enable access to specialists. One HCP expressed the following perspective:

I have quite a few patients that I've asked about walking and they're all afraid of the dogs in town, which is a legitimate concern. I would really love to see, I don't know what the school is doing, but a program where people could get out and do some activity within the gym. Cause walking is so great for you and it's so social, it's active, it's good for pain management... Just to have a safe space to do that and then it could build that social aspect as well.

Ways to Improve Experiences When Accessing Healthcare. Healthcare professionals emphasized the significance of providing culturally sensitive care, continuity of care, and respect for traditional healing practices. They recognized that trust is a crucial component of patient care. One HCP said, "I think that would increase the trust if it was a local doing that intermediate support yeah, I think that would be helpful. It takes a long time to build rapport in La Roche." Another HCP shared:

I guess one thing that would kind of stand out is understanding that there is lots of people that follow traditional medicine in the north and do different herbs for medicine, and not taking an overly westernized approach in kind of disregarding those traditional practices just because they don't have a bunch of [Randomized Control Trials] RCT behind them...I think it's important to be evidence-based practitioners while at the same time respecting the patients and their beliefs, and their traditions and their cultural practices. Additionally, HCPs shared that it would be beneficial to have a clear understanding of funding systems in order to help patients cover their travel costs to access healthcare.

3.5 Discussion

Indigenous populations in Canada have historically been impacted by colonialism, systemic oppression, cultural and structural injustices, and interpersonal injustices, leading to pain disparities. Unfortunately, chronic MSK pain disproportionately affects Indigenous Peoples in Canada. Our research collaboration with the northern Saskatchewan community of La Loche aimed to identify the community's pain management strengths and needs through a community needs assessment. Qualitative analysis of community member and HCP interviews revealed four important themes: 1) Impact of Pain on Daily Living, 2) Barriers Limiting Access to Care and the Understanding of Pain between Healthcare Provider and Patient, 3) Systemic Oppression and Negative Experiences with Healthcare, and 4) Strength Based Solutions.

The narratives shared by community members in La Loche were echoed by HCPs, highlighting a mutual understanding of the obstacles faced by individuals in terms of pain management and healthcare access. Community members voiced barriers in accessing and receiving equitable care, as well as impacts of chronic MSK pain on their daily functioning. They described the systemic oppression experienced within the healthcare system, including being stigmatized and unfairly labelled as “drug seekers” when seeking pain management. Community members identified barriers in pain communication and expressed a sense of being unheard by HCPs. Healthcare providers emphasized the importance of considering worldview differences and how those may influence the perception and communication of pain, particularly when engaging with Dene/Métis community members.

Healthcare providers demonstrated a general awareness of the challenges faced by Dene/Métis community members in accessing healthcare, while community members provided specific examples. The shared understanding between HCPs and community members regarding barriers to effective pain management underscored the significance of addressing these issues to enhance the quality of care provided. Despite this recognition, there appeared to be a lack of proactive measures in addressing the identified barriers.

The needs assessment revealed issues related to experiences of racism, lack of continuity of care, lack of access to services, financial barriers, inadequate pain assessments, insufficient information about care, extended wait times, suboptimal clinic models, language barriers, and travel difficulties. Access to healthcare is a recognized treaty right for First Nations Peoples in Canada. However, both community members and HCPs reported challenges in access to

healthcare due to complex governmental and organizational jurisdictions. Navigating through the paperwork to obtain healthcare and travel coverage for healthcare has been difficult. These findings align with previous research conducted by Reichert et al., (2023) in a First Nations community-directed needs assessment in Saskatchewan.

Racism against Indigenous Peoples is widespread within healthcare systems across Canada. The “In Plain Sight” report conducted in 2020 revealed the racism and discrimination experienced by Indigenous Peoples within the BC healthcare system. Historical and systemic racial biases in Canada have been entrenched within laws, policies, institutions, organizations, education, healthcare, the justice system, and societal values that perpetuate white privilege and create disparities for marginalized communities. La Loche community members, like many Indigenous Peoples in BC as detailed in the "In Plain Sight" report, have described experiencing negative stereotypes such as being labeled as "drug seeking," when accessing the healthcare center for pain management. Due to the stereotypes, Indigenous Peoples have negative experiences when accessing healthcare which can lead to serious harm or even death such as occurred with Joyce Echaquan and Brian Sinclair. Smith et al. (2007) noted that experiences of racism can negatively impact health through compounding negative experiences and ‘racial battle fatigue’ which can cause mental and physical exhaustion for individuals dealing with ongoing discrimination. Some La Loche community members have expressed hesitancy about accessing healthcare services at the local clinic, citing concerns about judgement and shame. This has led to individuals avoiding seeking medical help altogether or choosing to travel six or seven hours to urban centers for services. Consistent negative experiences and discrimination within the healthcare system can lead to mistrust and avoidance of accessing health services, as reported elsewhere in the literature (Turpel-Lafond, 2020). All of these compounding factors can influence an individual's perspective on accessing healthcare and can lead to an avoidance of healthcare services, resulting in a higher prevalence of chronic illnesses within community.

Community members have expressed the need for comprehensive pain assessments, thorough examinations, active listening to patients’ concerns, and delivery of patient informed care. They emphasized the importance of patience and listening to patients’ storytelling. Both community members and HCPs identified challenges with language barriers, travel barriers, long wait times, and an ineffective clinical model. They have called for improvements in appointment

booking, availability of translators to alleviate language barriers, and an increase in staff capacity to handle the high demand and long wait times.

There was some disparity in the awareness and understanding of healthcare challenges between HCPs and community members in La Loche, specifically in the area of negative healthcare experiences. While HCPs generally acknowledged the barriers faced by community members such as lengthy wait times and difficulties accessing non-emergent healthcare, they may not have fully grasped the adverse experiences that community members have encountered at the local healthcare center. In fact, some community members expressed preference for seeking care in urban centers and other communities. Community members have reported a lack of informed decision-making, and confusion regarding their diagnosis and treatment plans, as well as instances of feeling unheard, experiencing shame when seeking pain management, and having their consent violated. In contrast, HCPs recognized the existence of discrimination within the healthcare system, but the extent of its impact on individuals was not fully understood. Overall, while there are areas of agreement between HCPs and community members in acknowledging certain challenges, it is imperative for HCPs to deepen their understanding of the negative experiences shared by community members to effectively address barriers to delivering comprehensive pain management strategies and fostering trust within the community.

This needs assessment yielded five major recommendations for improvement of chronic MSK pain management within La Loche, they are as follows:

1) Patient-Centered and Community-Directed Care

Patient-centered and culturally responsive healthcare delivery in La Loche requires a tailored approach that considers the unique needs and experiences of each patient and the community. It is crucial for HCPs to actively listen to patients, understand their experiences, and foster trust through shared decision-making. The Royal College of Physicians and Surgeons of Canada emphasizes the importance of effective communication and patient-centered care through the canMEDS framework, which encourages HCPs to consider not only a patient's medical condition but also their family history, socioeconomic status, social issues, and other social determinants of health (Frank et al., 2015). A recent communities-directed needs assessment conducted in First Nations communities in Saskatchewan (Reichert et al., 2023) yielded similar findings highlighting the significance of a patient and community-centered approach in all aspects of healthcare delivery within the File Hills Qu'Appelle Tribal Council

communities. A community-directed approach, facilitated through the formation of a community advisory group, could enable more culturally relevant care and promote Indigenous ways of knowing. A community advisory group with local governance, Elders, and Knowledge Keepers could ensure the community members' voices are heard during healthcare center decision-making.

2) Clinic Model and Staffing Requirements

Due to the remote location, HCPs often do not reside in the community, creating challenges in providing continued care. Efforts should be made to recruit and retain local HCPs committed to long-term work within La Loche. Increasing staff capacity and expanding the primary care clinic would improve access and alleviate long wait times. Current appointment booking methods at the local clinic may require review to enhance accessibility to healthcare. Moreover, utilization of the RPR could offer enhanced specialized care for the community.

3) Practitioner Education and Awareness

Healthcare providers working in La Loche would benefit from education and experience in the community to ensure a deep understanding of community norms, the Dene and Métis languages and cultural needs, and the historical context that includes historical atrocities such as colonization, residential schools, intergenerational trauma, and the 60's scoop. It is crucial for HCPs to recognize and address racism, discrimination, and systemic oppression in the healthcare system. Integration of HCPs into the community can lead to a better understanding of community members' lived experiences and foster meaningful relationships. Seeking guidance from Elders and Knowledge Keepers would help HCPs gain insights into the community and its history. These recommendations were also identified by Reichert et al. (2023). It was recommended that HCPs should receive specialized training in trauma-informed care, chronic pain management strategies, and comprehensive pain assessments with proper physical examinations, which is well supported in the literature (Hawker, 2017). Chronic MSK requires a wholistic approach that considers the biopsychosocial model and recognizes that an individual's background, socioeconomic status, and cultural upbringing can impact their experience and expression of pain (Ermstzen et al., 2017). The above recommendations align with the objectives of The Canadian Pain Task Force, which advocates for increased awareness and education on chronic pain and emphasizes the importance of specialized training for pain management (Canadian Pain Task Force, 2021).

4) Community Education and Awareness

Community members in La Loche would benefit from access to information sessions on pain management techniques, injury prevention, physical exercise, strategies for supporting those who live with chronic pain, and lifestyle modifications. El-Tallawy et al. (2021) found that there is a lack of health advice and education provided to patients with MSK conditions in primary care settings, with only 20% of patients receiving such support. Information sessions on racism, discrimination, and empowerment can help community members identify and address biases to help them to advocate for themselves and others. It is also important to increase awareness of local resources, including physiotherapists, mental health support, and the remote presence robot to ensure community members can access resources without travel. Education and information sessions for the OAT program should be made available to the community to raise awareness of its benefits, goals, and functions, and to create a safe and supportive environment for program participants. This may help to eliminate negative stereotypes that may stem from misinformation about the program. Presently, University of Saskatchewan researchers are collaborating with La Loche community members and Dene/Métis language experts to create pain materials in Dene and Michif.

5) Community Resources

Creating a safe and accessible space for physical activities, such as a walking facility, would promote physical wellness and allow community members to engage in activities without concerns for safety. The formation of support groups for those living with chronic pain would offer social support and promote a sense of community and could provide a safe and inclusive environment for individuals to share their experiences and connect with others.

The recommendations made align with the goals of the Canadian Pain Task Force (2021) in the areas of “increase awareness, education, and specialized training in pain”, “improve access to timely, equitable, and patient-centred pain care”, and “ensure equitable approaches for populations disproportionately impacted by pain”. Furthermore, the recommendations also align with the Truth and Reconciliation Commission of Canada's Calls to Action, specifically numbers 22 and 23 (Truth and Reconciliation Commission of Canada, 2015). These calls emphasize the importance of working in collaboration with Elders and Knowledge Keepers within the healthcare setting, as well as providing education to HCPs on cultural sensitivity and competency (Truth and Reconciliation Commission of Canada, 2015). Through the implementation of these

recommendations, an environment that is inclusive and culturally responsive could be developed, enabling community members to become advocates for their health and providing them with the necessary tools to more effectively manage their pain.

3.5.1 Limitations

This needs assessment was conducted in close partnership with the community of La Loche and the resulting recommendations are specific to the Dene/Métis members of this unique community. As such, the findings of this project may have limited generalizability to other Indigenous communities. However, the collaborative approach and outcomes of this project may offer valuable insights for future research in similar contexts.

3.6 Conclusion

The needs assessment conducted in collaboration with the community of La Loche, a Dene/Métis community in Northern Saskatchewan, provided valuable insights into chronic MSK pain management. Through conversations with community members and HCPs, recommendations were made to improve communication and support for community members living with chronic MSK pain. The findings emphasized the importance of community engagement, cultural responsiveness, and anti-racism/anti-oppression practices to enhance chronic pain management in La Loche. The implementation of these recommendations would support an inclusive and culturally responsive environment, empowering community members to become advocates for their health and providing them with the necessary tools and support to effectively manage their pain. The successful implementation of these recommendations could also enhance the quality of healthcare services provided in La Loche.

3.7 Acknowledgments

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3.8 Disclosure Statement

The authors have no conflicts of interest to be declared.

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Chapter 4: Discussion/Conclusion

The goal of this thesis was to engage in collaborative research with a Cree and a Dene/Métis community in northern Saskatchewan to explore experiences with chronic MSK pain from their perspectives. The ability to gain insights into community-specific pain expression and pain management strategies could help to facilitate effective pain communication and promote culturally responsive approaches to pain management. This goal was achieved through the completion of two manuscripts. The first manuscript was a mixed-method study that involved the development of a community-directed pain assessment tool in collaboration with a Cree community. The tool was evaluated for its concurrent validity, and community members' voices were captured to identify areas for improvement in pain communication with healthcare providers. The second manuscript revealed a community needs assessment within a Dene/Métis community. The assessment captured community members' perspectives on pain communication and pain management, and identified elements that would contribute to more effective pain management strategies in the community.

The following research questions were addressed in this thesis:

1. a) Is the Community Directed Pain Scale valid, culturally relevant and preferred by the community (manuscript 1)?
b) How does the novel pain scale compare to a validated pain scale, the Faces Pain Scale-Revised (FPS-R) (manuscript 1)?
2. From the perspective of a northern Saskatchewan Cree community, what elements of the novel pain scale are favourable and what elements can be improved (manuscript 1)?
3. From the perspective of a northern Saskatchewan Métis and Dene community, what are the needs, preferences, strengths and limitations in the management of chronic MSK pain in community (manuscript 2)?
4. What are the similarities and differences in the experiences of chronic MSK pain from the perspectives of a Cree community and a Métis and Dene community?

A synopsis of the two manuscripts will be provided here. An overall discussion will integrate the findings of the manuscript into contribution to research, future research considerations and clinical and policy recommendations.

4.1 Synopsis of Manuscripts

4.1.1 Responsive Methods of Pain Assessment within a Norther Saskatchewan Cree Community

In the first manuscript, the research focused on understanding pain communication within Pelican Narrows, a Cree community, and exploring community members' experiences with chronic back pain. A Cree Elder guided the team in the development of the CDPS as a way to improve pain communication between HCPs and patients. The Elder's insights revealed several key findings: 1) community members may not quantify their pain, 2) individuals experiencing significant pain often remain silent and 3) colours may hold different meanings for Indigenous Peoples than non-Indigenous Peoples. To assess the concurrent validity of the CDPS, twenty-seven (n=27) participants utilized both the CDPS and FPS-R during pre-physiotherapy assessments. A Kappa analysis was conducted which yielded a value of 0.696, indicating the CDPS is comparable to the well-established FPS-R in assessing pain. Semi-structured interviews with nine community members further captured their feedback, revealing three themes: *1) Learnings Regarding Pain Scales, 2) Patient Centered Care; and 3) Strength-Based Solutions for Improving Pain Communication*. Two major themes arose from conversations with a HCP: *1) Perspectives on CDPS and 2) Healthcare Provider Experiences Communicating about Pain*.

The qualitative analysis captured community members' individual preferences for pain communication. Among the participants, four preferred the CDPS, while five preferred the FPS-R. Those who favored the FPS-R appreciated its greater number of facial expressions and the inclusion of questions about current pain, worst pain, and best pain. Some participants simply preferred expressing pain numerically, which are more of a focus on the FPS-R. On the other hand, those who preferred the CDPS highlighted its simplicity and found that the facial expressions and colors added more meaning to the self-reporting tool. Additionally, it was revealed that having more elemental options available for patients to utilize can better facilitate pain communication through self-reporting tools.

Overall, discussions with community members and healthcare providers emphasized the need for a patient-centered approach to pain communication. This approach goes beyond the use of self-reporting tools and requires health professionals to demonstrate patience and active listening. The research also underscored the value of storytelling within Indigenous culture and

the Cree community. Community members suggested improvements to the CDPS, including the addition of more questions about current, worst, and best pain, larger lettering, the inclusion of functional photographs, and the availability of auditory formats for the Cree descriptors.

This study was tailored to the community of Pelican Narrows; thus, the generalizability of the findings to other Indigenous communities remains uncertain. Consequently, a subsequent study was conducted to explore pain communication and pain management strategies within La Loche, a Dene/Métis community in northern Saskatchewan.

4.1.2 Understanding Needs for Chronic Musculoskeletal Pain Management in a Northern Dene and Métis Community: A Community Based Needs Assessment

Manuscript 2 (Chapter 3) explored the experiences of chronic MSK pain management within the Dene/Métis community of La Loche by capturing the voices of community members and HCPs. Thirteen individuals participated in semi-structured interviews (8 community members and 5 HCPs). Thematic analysis revealed four overarching themes through conversations with community members and HCPs: *1) Impact of Pain on Daily Living, 2) Barriers Limiting Access to Care and the Understanding of Pain between Healthcare Provider and Patient, 3) Systemic Oppression and Negative Experiences with Healthcare, and 4) Strength Based Solutions.*

The community of La Loche takes great pride in their culture and language, with many community members speaking Dene as their first language. The community places significant value on storytelling as a means of communication with HCPs. Through engagements with La Loche community members and healthcare professionals, specific needs unique to the community have been identified. These include improvements in the clinic model and staffing capabilities, the necessity for practitioner and community education, and an expansion of community resources to create a safer environment for pain communication and the delivery of effective pain management strategies.

4.2 Contribution to Research

There is a paucity in research regarding chronic MSK pain experiences, expression, and communication among Indigenous Peoples. The collaboration with Pelican Narrows (manuscript 1) allowed the development of the CDPS with a Cree Elder and Knowledge Keeper to promote

enhanced communication about pain between HCPs and patients. Further semi-structured interviews provided community members' feedback regarding their experiences utilizing the scale, and their recommendations for improving pain communication. The partnership with La Loche (manuscript 2) allowed for greater understanding of chronic MSK pain management from the perspectives of Dene/Métis Peoples and allowed identification of recommendations to enhance the management of chronic pain in a northern Dene/Métis community.

Due to differences in the research questions posed in the two communities, a direct comparison of the two communities is not feasible. To establish a connection between the findings from both communities, several approaches were employed. These included conducting observations, gathering in-depth knowledge regarding the healthcare centers within each community, gathering direct inquiries from participants in Pelican Narrows regarding pain assessments and pain communication as well as indirectly addressing the topic of pain assessment, and engaging in direct inquiries with participants from La Loche concerning pain assessment, communication, and management. Through these varied methods, a comprehensive understanding of the experiences in both communities was attained, facilitating connections to be made between research findings. It was discovered that chronic MSK pain has had a comparable impact on the daily lives and cultural practices of community members in Pelican Narrows and La Loche. Individuals from both communities expressed that living with chronic MSK pain has restricted their ability to engage in daily tasks, such as chores and sleeping. Furthermore, members from both communities highlighted limitations in practicing their cultural traditions and way of life. In Pelican Narrows, these limitations manifested in activities such as pulling boats, portaging, and collecting wood. Similarly, members of La Loche expressed limitations in activities like hunting, fishing, gathering wood, participating in sweat lodges, and dancing in Powwows.

It is essential to acknowledge the distinct needs within each community. By utilizing observations, knowledge of the health centers, and community members' experiences, it was discovered that the way healthcare centers are managed could have influences on patients' comfort levels. In the case of Pelican Narrows, the Angeliq Canada Health Center is a community-managed health center which allows a community-directed governance structure and many health professionals who reside locally. This may contribute to a favorable environment in which patients can build rapport and trust with healthcare professionals. However, the members

of the community of La Loche face challenges in receiving consistent healthcare from the same HCP, which can lead to barriers in establishing trust. The differences in the healthcare center model of both communities have unique implications for pain communication. For example, Pelican Narrows community members reported greater comfort in discussing their pain with HCPs and have prior experiences with pain assessment tools, whereas many La Loche community members expressed less favorable experiences when seeking care for pain management and many have not utilized self-reporting tools to describe their pain. Furthermore, many La Loche community member participants express feeling negatively stereotyped by HCPs and reported experiences of discrimination, highlighting the need for additional education on anti-racism within the healthcare clinic. In comparison, the Pelican Narrows community member participants rarely expressed negative experiences when communicating about pain with HCPs. This highlights the significance of the relationship between patients and HCPs and emphasizes how past experiences with the healthcare system can have a profound impact on future healthcare access and the comfort level of patients when it comes to communicating about pain. This is also a widely documented phenomenon (Turpel-Lafond, 2020).

It is important to recognize that the needs within La Loche differ from those of Pelican Narrows, as each community has its own unique experiences and resources related to healthcare. However, despite the differences in community experiences regarding pain management and communication, similar foundational elements were identified by community members and HCPs as being critical in promoting pain communication and pain management within both communities. The essential elements that have been identified include:

1. *Understanding the ways chronic MSK pain severely impacts a person's life.*

Participants in both communities shared their experiences of living with chronic MSK pain and the challenges it presents in various aspects of their lives, including cultural practices, daily functioning, social participation, emotional well-being, and mental health. These insights emphasized the importance of HCPs developing a comprehensive understanding of the distinct impacts of chronic MSK pain within each community, in the context of language and culture. This understanding enables HCPs to deliver care that is personalized, responsive, and culturally responsive to the specific needs of each community.

2. *A dedication to nurture meaningful and trusting relationships between patients and healthcare providers.* Pain communication and pain management requires trust between the HCP and patient. A positive relationship promotes a sense of safety and comfort, creating an atmosphere of openness where patients can engage in judgment-free discussions. To ensure appropriate and respectful relationship building for these projects, community engagement was prioritized. The research team visited both communities, introducing themselves to local HCPs and community members. Local community research assistants were critical to further relationship building. Collaborating with local HCPs and community research assistants, the research team successfully established meaningful connections with community members. Through established trust and a supportive environment, community members felt at ease sharing their personal experiences with pain. Chipidza et al., (2015) reported that an impaired patient-provider relationship can negatively impact the patient's health outcomes. Community members in both Pelican Narrows and La Loche emphasized the significance of the patient-provider relationship. La Loche participants expressed their hesitancy to access healthcare at the local health center due to past negative experiences with HCPs. Many community members expressed a sense of being unheard and overlooked by HCPs, attributing it to inadequate comprehensive assessments and referrals. Due to these negative experiences, community members would choose to travel long distances to access health services at other healthcare centers. Recognizing the importance of the patient-provider relationship and prioritizing the establishment of a meaningful connection with patients is essential to health outcomes.
3. *Patient-centered approach.* Lin et al., (2020) highlighted patient-centered care as a recommended approach for effective management of MSK pain. This approach involves recognizing and incorporating the unique needs, values, experiences, preferences, knowledge, and family dynamics of each patient, fostering shared decision-making. The importance of patient-centered care was emphasized by community members in Pelican Narrows and La Loche. Members of both communities emphasized the significance of acknowledging individual preferences and called on HCPs to consider these differences among patients. Moreover,

community members expressed the value of HCPs taking the time to actively listen to their stories and develop a comprehensive understanding of their lives. Patient-centered care extends beyond the physical examination and encompasses effective communication. Lin et al. (2020) emphasized that effective communication involves not only assessing the patient's pain through the examination but also engaging and empowering patients during the shared decision-making process. This communication, whether verbal or non-verbal, plays a crucial role in building trust within the patient-provider relationship. To further promote patient-centered care and community involvement, the establishment of community advisory committees within each community can be beneficial. These committees can facilitate patient-centered and community-directed care by considering cultural and local protocols and empowering the community to actively participate in the decision-making process regarding their own pain management strategies. Furthermore, the committee can provide educational and experiential opportunities to incoming HCPs to ensure they develop a thorough understanding of community protocols and practices.

4. *Education and training.* The quality of healthcare provided to Indigenous Peoples has been negatively impacted by racism, stereotypes, and biases. In La Loche, community members shared their experiences of being unfairly labeled as 'drug seekers' when accessing healthcare for pain management, which significantly erodes their trust in the healthcare system. A study conducted by Roach et al. (2023) among Alberta physicians revealed that 10-25% of them held explicit biases against Indigenous Peoples, while overall, physicians demonstrated moderate implicit anti-Indigenous biases. It is essential for every HCP to have a deep understanding of Indigenous history, the history of colonization, and how this affects social determinants of health, access to healthcare, and health outcomes. Education on Indigenous history is a vital aspect of the Truth and Reconciliation Calls to Action and should be prioritized. Furthermore, it is crucial for HCPs to engage in anti-racism courses to address the high prevalence of anti-Indigenous racism in Canada. Additionally, it is crucial for HCPs to receive cultural responsiveness education to develop an understanding of subtle communication cues and cultural protocols within the local context. Cultural and communication training can enable HCPs to integrate medical expertise with

- local and cultural approaches. These efforts are necessary to enhance the quality of healthcare provided to Indigenous Peoples and promote equitable and culturally responsive care.
5. *Patience and listening.* The findings in both communities highlight the importance of HCPs practicing patience and active listening when engaging with patients seeking pain management as many participants expressed feeling rushed and unheard. These findings have been reported in a previous global systematic review by Rocque and Leanza (2015) to capture patient-provider communication. This review revealed that patients often reported being rushed, inadequate listening, and a lack of opportunity to express all of their health concerns to HCPs (Rocque & Leanza, 2015). Such experiences were labeled as negative and were associated with potential negative outcomes, including mistrust, lower quality of care, overuse or underuse of health resources, and overall dissatisfaction (Rocque & Leanza, 2015). Consequently, HCPs should be mindful of their actions and strive to ensure that patients feel heard in order to promote effective communication and foster positive experiences.
 6. *Auditory formats of pain assessment tools in Cree and Dene.* In both Pelican Narrows and La Loche, English is often a second language for many community members. Both communities take pride in their languages, with Cree being important in Pelican Narrows and Dene and Michif being significant in La Loche. Community members have expressed that having auditory resources available in their first language would greatly facilitate their understanding of self-reporting tools used during pain assessments and contribute to improved pain communication overall.
 7. *Importance of storytelling.* Storytelling holds significant cultural value within Indigenous communities, and both Pelican Narrows and La Loche community members expressed their pain journeys through this traditional practice. Through storytelling, individuals not only shared the physical injuries they have experienced and the resulting limitations in their daily functions, but they also revealed the emotional impact of their pain. By sharing their stories, community members were able to articulate the actions, practices, and events that hold personal importance to them but are now hindered by their pain, affecting them emotionally and even spiritually. Healthcare providers should demonstrate cultural awareness and recognize

the significance of storytelling within the communities they serve. By actively and respectfully listening to these stories, HCPs can gain a deeper understanding of the lived experiences of community members. It is important to acknowledge that these stories may carry meanings and insights that extend beyond the physical aspects of pain. Addressing the broader dimensions of pain ensures the right step towards providing wholistic care.

8. *Increase in preventive education and health literacy.* Many individuals in both communities have attributed their chronic MSK pain to previous injuries that continue to cause them ongoing discomfort. Participants have expressed a desire to take preventive measures to minimize the initial injury and expressed interest in learning pain management strategies that they can implement at home. These findings highlight the current lack of preventive health education on pain management within both communities. Therefore, HCPs should engage in open discussions with patients and provide personalized strategies for effectively managing pain at home. By tailoring these strategies to the unique needs of each patient, they can practice more autonomy and have an active role in their own pain management journey.

4.3 General Limitations

It is important to acknowledge the limitations of this research. One notable limitation is the challenge of investing sufficient time to establish meaningful relationships with community members, particularly within a busy clinical environment. The open-ended discussions conducted in this study allowed participants to share their pain experiences without time constraints, creating a safe and open environment. However, replicating this approach in a busy clinical setting with time limitations and demanding schedules may present challenges.

Another limitation to consider is the development of the CDPS pain scales incorporated the input and feedback from one Elder in the community of Pelican Narrows and the Elder was older than the average age of the participants involved within the study. It is important to acknowledge that these findings from participants may not be representative of every individual's perspective in the community. Furthermore, the specificity of the CDPS to the unique needs of the Cree community of Pelican Narrows. While the CDPS demonstrated promising results in this study, its applicability to other Indigenous communities may have

limitations. Each Indigenous group possesses its own worldviews, teachings, and perspectives on health, underscoring the importance of avoiding overgeneralization of the foundational components essential for effective pain communication and management.

Additionally, it is crucial to note that the needs assessment conducted in the La Loche community is specific to their strengths, priorities, and barriers. It would be inappropriate to assume that these findings apply to all Indigenous communities. Each community has its own distinct needs and cultural practices, emphasizing the need for context-specific approaches in addressing pain communication and management.

Furthermore, due to the differences in the research questions posed in the two communities, a direct comparison of their experiences was not possible. While the analysis utilized a multifaceted approach to facilitate connections between the findings, it is important to acknowledge that it does not possess the same level of association as a direct comparison.

Despite these limitations, this research provides valuable insights into the experiences and perspectives of two Indigenous communities in northern Saskatchewan. It lays the groundwork for future research and interventions that can be tailored to meet the unique needs of each community while also promoting culturally responsive and community-led approaches to pain communication and management.

4.4 Future Research Recommendations

Future research endeavors should aim to investigate the long-term validity of the CDPS by conducting assessments that examine its sensitivity in detecting changes over an extended period. Future research should also aim to determine its applicability for use with acute pain. Additionally, it is important to introduce the CDPS to other Indigenous communities as a starting point for discussions on pain assessment tools. This approach can foster future collaborative partnerships with other Indigenous communities that face similar barriers in utilizing Western pain scales, enabling the development of self-reporting tools that are tailored to meet their specific needs.

Furthermore, future research should prioritize the co-development of interventions in partnership with Pelican Narrows and La Loche, with the goal of enhancing pain communication and management while taking into account the foundational elements identified in this thesis. It

is essential to actively seek community feedback on these interventions and remain open to adaptations based on their valuable input.

Moreover, future research endeavors should actively engage with other Indigenous communities to explore their unique strengths and needs concerning pain communication within their specific community contexts. By conducting collaborative, community-driven research, a more comprehensive understanding can be gained on effective pain communication strategies and allow the tailoring of interventions, promoting equitable and culturally responsive healthcare practices for all Indigenous communities.

4.5 Conclusion

Through collaborative partnerships with two distinct Indigenous communities in northern Saskatchewan, this research has demonstrated the importance of creating a culturally safe space for community members to share their chronic MSK pain journeys. By engaging in open and respectful conversations with community members in Pelican Narrows, a community-directed pain assessment tool, the CDPS, was developed and piloted. The CDPS yielded comparable outcomes to the well-established FPS-R. It provided community members with more community-led elemental options to utilize in the description of their pain. Valuable feedback from community members highlighted the need for auditory formats of the Cree descriptors, functional descriptors, and the inclusion of questions about current, worst, and best pain levels.

Furthermore, the conversations held with community members in La Loche reinforced the significance of patient-centered care expressed by Pelican Narrows participants and the challenges Indigenous Peoples face when accessing healthcare. The negative experiences shared by La Loche community members have contributed to a hesitancy in seeking healthcare services, underscoring the urgent need for improved healthcare experiences in this community. Notably, several participants in La Loche had never utilized a self-reporting tool during pain assessments, emphasizing the importance of addressing this gap in pain communication.

While Pelican Narrows and La Loche communities have unique experiences with chronic MSK pain, there are underlying similarities in the core components that should be addressed to create a safer environment for sharing lived pain experiences. By focusing on the foundational elements identified in this thesis, such as patient-centered care, the provision of culturally

responsive care, and the significance of the patient-provider relationship, steps can be taken towards promoting equitable healthcare for the northern Cree and Dene/Métis communities.

In conclusion, this research highlights the significance of collaborative partnerships and respectful dialogue in addressing the complexities of chronic MSK pain within Indigenous communities. By centering the voices and experiences of community members, interventions can be developed that meet the specific needs of each community. This work contributes to the ongoing efforts towards providing culturally appropriate and equitable chronic MSK pain management strategies for northern Indigenous communities, fostering improved pain communication, and ultimately enhancing the overall well-being and quality of life for community members.

4.6 References

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List of Appendices
Appendix A- Pre-Physiotherapy Assessment Questionnaire
Community Directed Pain Scale[†]

Participant #: _____

Using the Cree words, colours and/or faces please choose the face that most closely matches your pain right NOW.

Nimithoyan
(I feel good)



0

Mauch-osam nimithoyan
(I am not doing too good)



4



6

Kwayesk nitahkosin
(I am much in pain)



10



[†] Complete at first and follow-up visit

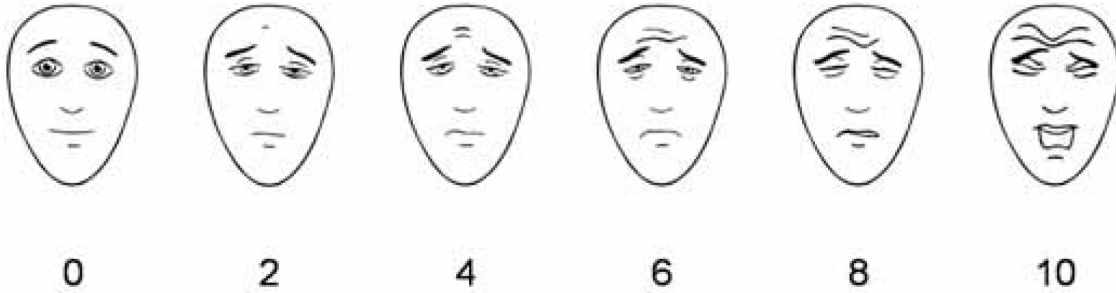
Faces Pain Scale—Revised†

Participant #: _____

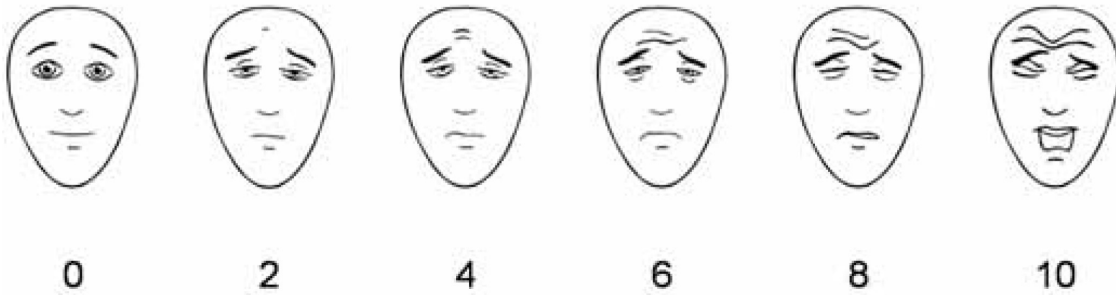
For the following questions, think about the amount of pain you have experienced in the PAST 24 HOURS ONLY.

The faces show how much pain or discomfort someone is feeling. The face on the left shows no pain. Each face shows more and more pain and the last face shows the worst pain possible.

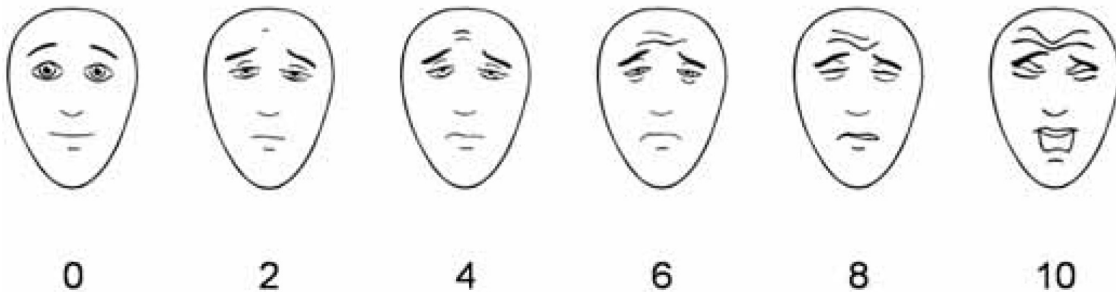
Current Pain: Point to the face that shows how bad your pain is **right NOW**



Worst Pain: Point to the face that shows how bad your pain was **at it's WORST?**



Least Pain: Point to the face that shows how bad your pain was **at it's BEST?**



† Complete at first and follow-up visit

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 colors 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 colors 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 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 D- Pelican Narrows Themes and Quotations from Semi-structured Interviews
with Community Members**

Table A2: Pelican Narrows Community Members Table of Quotes

1. Major Theme 1: Learnings Regarding Pain Scales

Subthemes	Sub-subtheme	Quotes
Communication Preferences	<i>CDPS</i>	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.
	<i>FPS-R</i>	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 much 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.
		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
	<i>Add Options for Current, Best, Worst Pain.</i>	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.*
	<i>Bigger Letters</i>	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.
	<i>Impressions on Colour in CDPS</i>	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.
	<i>Include Functional Photographs</i>	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.

<p>Patience and Listening</p>		<p>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.</p>
		<p>Have them [healthcare providers] listen to you instead of cutting you off when you're trying to tell them something.</p>
		<p>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.</p>
<p>Prevention Education</p>		<p>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.</p>

		<p>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.</p>
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* These quotations appear in more than 1 subtheme

Appendix E- Pelican Narrows Pain Scale Preference Demographic

Table A3: 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 F- Pelican Narrows Themes and Quotations from Semi-structured Interviews
with a Healthcare Provider**

Table A4: Pelican Narrows Healthcare Provider Table of Quotes

1. Major Theme 1: Perspectives on CDPS

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, 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 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		<p>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 visualization with modification for me, that has been the most impactful.</p>
Utilization of Pain Assessment Tools		<p>For pain scales in general, I've used both the NPRS, the Numerical Pain Ranging Scale. There's also the VAS, Visual Analog Scale.</p>
		<p>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.</p>

		<p>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.</p>
		<p>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.</p>

Appendix G- La Loche Community Participant Focus Group and Individual Interview Guide

Please note that these questions will be reviewed and further informed by our community partners... as they may have other suggested questions/modifications to questions

Preamble:

Hello, my/our name(s) is/ are X and my pronouns are (she/he/they), and we are part of the research team looking at your community's needs for chronic pain related to bones, joints and muscles. Chronic MSK pain includes pain from muscles, bones and joints that has been present for at least 3 months or longer. We are also interested in how the robot at the community health facility can be used to join chronic MSK experts from other locations with your community members to help in their chronic MSK care (virtual care).

Thank you for agreeing to talk to me/us about your experiences with having chronic MSK problems.

As you know from the consent form we just reviewed together, the information you provide will help us to better understand: 1) your experiences of living with chronic MSK pain; 2) what your unique preferences might be regarding the use of technology, specifically a remote robot technology, to support chronic MSK pain care; 3) what type of information would help to understand if using robot technology is helpful in the treatment of people with pain in your community.

This information you provide will help us to better understand how the health system can work better for you, for treating and living with bone, muscles or joint pain, which may also be relevant to other members in your community. What you share with us will help design and evaluate a process for using remote robot technology as well as in person care to treat pain in your community, with the hope of improving access to physical therapy and pharmacy services.

We hope this information will be used to develop further health services and supports to benefit the community.

This interview/ discussion should take approximately 30 minutes for one-on-one interviews, and up to 2 hours for group discussions.

I/ We will be recording our conversation today and the recording will then be typed up into a written script for analysis after the research project is completed. Are you ok with proceeding with the interview at this time?

Do you have any questions before we get started?

If no...

Let's get started...I/we am/ are turning on the recorder now.

1. **Tell me/ us a bit about your chronic MSK pain.** *(pause after this statement and wait for a response; and if needed, use the following bulleted list as probes to draw out information from the participant)*
 - a. How long have you experienced this problem or problems?
 - b. How has having pain affected your life?
 - i. Physical functioning (intense activities, moderate activities, dressing and bathing daily activities)?
 - ii. Social participation? i.e. activities with family, friends, community, work
 - iii. Emotional consequences?(feeling tense, depressed, having enough energy)
 - iv. Your ability to practice your culture and/or spiritual activities?
 - v. Other? (e.g. sleep)

2. **Can you describe to me your behaviour when you are in a lot of pain?** *(if needed, use following as probes)*
 - a. How do you communicate to others?
 - b. How do you handle daily tasks when you are in a lot of pain?

(Examples to describe if needed)

 - c. Get frustrated more easily, get quieter, cry, look for distractions, groan, go lay down, etc.

3. **Tell us what it is usually like to communicate with health providers about your pain.**
 - a. Do you find it difficult to talk about your pain or explain your pain?

4. **Is there anything that would make you more comfortable to talk about your pain?**
 - a. How does the environment effect how you feel?
 - b. Is there anything the health provider can do to make you feel more comfortable when talking about your pain?

5. **How have you described pain to health providers in the past?**
 - a. Verbally?
 - b. Demonstrated the location?
 - c. Used certain pain scales that required you to compare your pain to faces, colors or numbers?

6. **If you have used pain scales to talk about your pain to your health providers, how well do you feel they allowed you to communicate about your pain?** *(If needed, use probes)*
 - a. Challenges understanding language?
 - b. Challenges understanding of the meaning of the pain scales?
 - c. Cultural limitations?

7. **If you have used pain scales, what did you think about them?**

- 8. What would make pain scales better or easier for you to use to explain your pain?**
- 9. What types of supports/ services have you found helpful for management of your pain?**
- Health care services? (including physical therapy services...? Medications?)
 - Community supports?
 - Local/traditional cultural practices?
 - Others? (e.g. companion animals, other self-management strategies?)
- 10. Can you tell us about any challenges you have had in trying to access health care for your pain issues?**
- Travel?
 - Wait times?
 - Financial/ costs?
 - Cultural?
 - Comfort interacting with health care professionals?
 - Language or interpretation? (cultural languages, use of pronouns or reference to incorrect gender, etc).
 - Mobility accessibility?
 - Experiences with racism?
 - Other?
- 11. What types of services and/ or supports do you think would help to support you in better treating and managing your pain and overall abilities to do the things you want to do?**
- What considerations for new services and providers should be taken into account specifically regarding your language and culture, the culture and protocols in your community, that new providers should be mindful and aware of to ensure care provided is culturally appropriate and responsive to your needs and preferences?
- 12. Do you think that using technology like the (remote presence) robot might help people in the community access better care related to their pain?**
- Why or why not?
 - What might be some important ways to ensure that your culture and perspectives are respected and honored while using robot technology?
 - What do you see as potential challenges to using robot technology to treat pain problems in your community? (these could be anything including language or other cultural practices... as examples)
- 13. Do you think that linking community members, such as yourself, to physical therapists and pharmacists using remote technology and with the support of local health care providers would be helpful for people in the community with chronic pain problems?**

- a. Why or why not?
- b. If technology could be used to increase access to care (such as physical therapy and pharmacy care) to treat low back pain in communities such as yours, what do you think is needed to ensure that the process and interactions with health care providers are meaningful to you?

14. How would we know if this type of service were relevant and useful for people living with pain in your community?

- a. Do you have some ideas on what types of measures would help capture the usefulness of using robot technology to increase access to physical therapy and pharmacy care?
 - i. Participant experiences/ stories?
 - ii. Less pain? (Measuring pain levels?)
 - iii. Better quality of life? (Clarifying what types of activities you are now able to participate in, that you couldn't do before receiving physical therapy care via robot technology...?)
 - iv. Better movement/ mobility?
 - v. More able to participate in social/ community activities?
 - vi. Less use of prescription medicines?
 - vii. Less travel from the community?
 - viii. Others?

15. Is there anything else you would like to share with us about either your experiences with pain problems, health care access/ use or what type of new service using the robot or other supports in your community might be helpful?

Thanks so much for your time and your thoughts. Before we finish today, I would like to go back to the consent form briefly. Now that we have been through the interview and you know what you have shared with me, I just want to go back through the sections we checked off and see if you still consent in the same way as before we started. It's perfectly OK to change your mind on any of this. [At this point confirm all the check box decisions with the participant]

Appendix H- La Loche Health Provider/ Manager Interview Guide

Please note that these questions will be reviewed and further informed by our community partners... as they may have other suggested questions/modifications to questions.

Preamble:

Hello, my/our name(s) is/ are X, and my pronouns are (she/he/they) and we are part of the research team looking at community needs for chronic musculoskeletal (chronic MSK) pain management using the remote presence robot and health care teams.

Thank you for agreeing to talk to me/us about and share your guidance and experiences.

The information you provide will help us to better understand: 1) your observations of experiences of community members with chronic MSK pain; 2) what your preferences might be regarding the use of remote presence robot technology to support care; 3) what type of measures would be relevant to you and/ or the community to help understand if a new health service using remote presence robots and health care providers teams is useful.

This information you provide will help us to better understand what the community needs for chronic pain are and help design and evaluate a pilot intervention for people in the community with chronic MSK pain.

Our hope is that this information will be used to develop further health services and supports to benefit the community.

This interview/ discussion should take approximately 30 min - 1 hour.

I/ We will be recording our conversation today and the recording will then be typed up into a written script for analysis after the research project is completed. Are you ok with proceeding with the interview at this time?

Do you have any questions before we get started?

If no...

Let's get started...I/we am/ are turning on the recorder now.

- 1. Tell me/ us a bit about what you have observed regarding people who experience persistent chronic MSK pain?** *(pause after this statement and wait for a response; and if needed, use the following bulleted list as probes to draw out information from the participant)*
 - a. How has having chronic MSK pain affected the lives of people in your community?
 - i. Physical abilities?
 - ii. Social participation? i.e. activities with family, friends, community, work
 - iii. Emotional consequences?
 - iv. The ability to practice culture and/or spiritual activities?

v. Other?

2. **What Western pain scales have you traditionally used to assess Indigenous patients' pain? In your opinion, how effective has that process been in the past?**
3. **From your experiences, which types of pain scales were the most preferred by Indigenous patients when asked to share their pain experience?**
4. **Describe your experience communicating about pain with patients when using the Western pain scales.**
5. **In your opinion, is there anything we could do to improve pain scales?** (*Prompts if need*)
 - a. What did you like or didn't like about the scale?
 - b. What things do you think would make pain scales better for your patients?
6. **Do you have any additional concerns about your ability to understand pain from an Indigenous patients' perspective?**
7. **What types of supports/ services do you think would be helpful for management of chronic MSK pain?**
 - a. Health care services (including physical therapy services...? Pharmacy services? Medications?)
 - b. Community supports?
 - c. Local/traditional cultural practices?
 - d. Others? (e.g. companion animals)
8. **Can you tell us about any challenges people in the community have reported or experienced in trying to access health care for chronic MSK problems?**
 - a. Travel?
 - b. Wait times?
 - c. Financial/ costs?
 - d. Cultural?
 - e. Comfort interacting with health care professionals?
 - f. Language or interpretation? (cultural languages, use of pronouns or reference to incorrect gender, etc).
 - g. Mobility accessibility?
 - h. Experiences with racism?
 - i. Other?
9. **What types of services and/ or supports do you think would help to overcome these challenges?**
 - a. What are community supports and strengths in the community that would help to support people in the community with chronic MSK pain?

- b. What types of information, cultural understanding and communication is important for new providers to have and demonstrate, to ensure care is culturally responsive, appropriate and patient centered?
- 10. Do you think that using technology like the remote presence robot might help people in the community access better care for their pain problems?**
- a. Why or why not?
 - b. What do you see as potential challenges to using robot technology to treat musculoskeletal problems in this community? (these could be anything including language or other cultural practices... as examples)
- 11. Do you think that a new service linking local health care providers with remote health care providers like physical therapists and pharmacists would be helpful for people in the community with chronic pain problems?**
- a. Why or why not?
- 12. How would we know if a new type of service were relevant and useful for the community? What types of measurements would help capture this?**
- a. Participant experiences/ stories?
 - b. Less pain?
 - c. Better quality of life?
 - d. Better movement/ mobility?
 - e. More able to participate in social/ community activities?
 - f. Less use of prescription medicines?
 - g. Less travel from the community?
 - h. Others?
- 13. Is there anything else you would like to share with us about either your observations of people with back problems, health care access/ use or what type of new service using the robot might be helpful?**

Thanks so much for your time and your thoughts. Before we finish today, I would like to go back to the consent form briefly. Now that we have been through the interview and you know what you have shared with me, I just want to go back through the sections we checked off and see if you still consent in the same way as before we started. It's perfectly OK to change your mind on any of this. [At this point confirm all the check box decisions with the participant]

Appendix I- La Loche Community Member Demographic

Table A5: Participant Demographic Information La Loche

Variable	Participant Demographics (n=8)
Age	48.25 average 54 median
Gender	4 female 4 male

Appendix J- La Loche Themes and Quotations from Semi-structured Interviews with Community Members

Table A6: La Loche Community Members Table of Quotes

1. Major Theme 1: Impact of Pain on Daily Living

Subthemes	Sub-subtheme	Quotes
Pain Affecting Culture		There's these sweat lodges that we do, and I can no longer participate because of the pain that I feel with the heat. I can no longer go to traditional dances anymore. I can't participate in traditional community activities. I can't do a lot of things.
		I probably couldn't dance Powwow and I can't even kneel down if my knee is sore. So, it's hard for me to even get into a smudge or anything like that.
		Like I said, we use wood stove. We- I can't help him get wood, cut wood because I'm in the same pain as he is.
		For sure. I can't dance or anything. I would dance...
Pain Affecting Emotions		I get real bad anxiety and I feel like I can't do stuff right now. I'm just really depressed. Also, yeah, it's kind of hard.
		It has made me not want to be around people so much because I do get irritated. Just irritability.
		Well, it makes you kind of depressed cause you're always stuck at home, or you can't enjoy the activities you use to do, even walking, that simple.

Pain Affecting Employment		For me, pain has just totally destroyed my life. Cause I was working [extracted for privacy], and it got to the point where I couldn't work on pain meds... And because of my pain, I'm unemployed... My wage lost, everything.
Pain Affecting Family and Social Participation		I don't do a lot of stuff that, how people do, like bending over, sitting with kids. I can't do that eh. I can't sit long.
		I don't know how to — or I can't lift anything too heavy anymore. Bending, I notice too, just carrying my nieces on my back or something like that, whatever, doing tasks like that, will start affecting my back.
		Some days it's tough and other days, it's fine but I find myself that I don't try to get involve in things cause I'm afraid to make it sore. I don't wanna kneel on it to aggravate it more, so I just kinda don't bother... I have limited mobility. I find that I don't even like to have company because you can't really visit or nothing.
Pain Affecting Physical Activities and Daily Function		It does. It affects my breathing like the pain I have in my back causes my- it's so much pain that it gets hard to breathe when I sleep and when I wake up.
		I used to get up at six, seven o'clock in the morning and because the pain comes around in the morning when I'm sleeping, I have to get up. that's when the pain goes away.

		Yeah, I can't stand for a long time or I go walking around and stuff and I start feeling like I'm going to fall over. I don't know how to — or I can't lift anything too heavy anymore... It's even hard sleeping at night. My legs have to be a certain way and yeah, I can't do to much. Or even eating and stuff like that.
		Some days, it's hard for me to get into a shower. It's hard to do my house chores or anything. It varies. I can't walk on it. I have a hard time walking and I have to wear a tensor bandage.
		We have had to hire people a few times- we both had to hire people to do stuff for us around the house. He has to hire some guys to cut wood for us, and me because I cannot clean up or whatever, I have to hire a girl, some young girl to do my housework for me. That wasn't us, we were perfectly good people where we could just get up, 7 o'clock in the morning to go to work.. I used to get up at five o'clock in the morning cause I had to go to work at seven until seven in the evening, a 12 hour shift. I did that no problem, I can't do that now. There's no way I'm gonna get up at 5 o'clock in the morning, jump in the shower, get on the bus at 7 to get to the office to go to work and sit there all day till seven in the evening.

2. Major Theme 2: Barriers Limiting Access to Care and the Understanding of Pain between Healthcare Provider and Patient

Subthemes	Sub-subtheme	Quotes
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Communication about Pain		Yeah, I usually point to where it hurts.
		He'd give me a pain scale which said which level is where and all that stuff. He'd sit there with a human skeleton and whatever, he'd draw circles where your pain was and everything. That was Dr. [deidentified, 00:29:01], he'd tell you 'point it out on a pain scale'... on the skeleton drawing you could say 'well my left arm is sore. From yesterday till today the worst pain is seven.' Dr. [deidentified, 00:33:34], that was his tool. 'Oh my elbow is sore on a pain scale of seven.' Well then he knows he has to act on it, right?
Financial Barriers		Financial resources as in money, vehicle transportation, no support. I'm currently learning how to drive in the city. I'm treaty, so I think that would cover some medical things. Other than that, I get no support. I go to school and get the minimum wage of seven and that goes straight to my vehicle which needs parts and [it goes to rent]. So, there's no money left.
Language Barriers		Like a language barrier for sure in this community because a lot of Elders are Dene speakers so that might be a challenge for them to get their point across.

		<p>P1: Like, the Dene language, our language, the majority of the language is all facial expressions. Like, one word could mean a lot with different expressions, facial expressions. If you're gonna come and work in La Loche, maybe you should take some course on Aboriginal- La Loche people, just how the Dene people are, Then they'll have an idea "oh this guy's not drunk, he's speaking his language, he's speaking Dene to me. He's not talking gibberish." Stuff like that. If there's a new doctor coming into town, they should arrange for a community tour or something to invite them into the community, talk to people, not hear it from somebody.... If you come to a three year old in La Loche, you talk to them in English, they won't understand what you're saying.... But if you talk to them in Dene, the three year olds would talk...in their native language, where they learn English in school as their second language. That's how strong our language is, and there's communities, like Dene communities an hour away from all of us, kids don't even speak...Dene, teenagers don't even speak the language, they lost their language. I'm so proud to see people from La Loche talking that don't- the whole kindergarten talking Dene, and the teacher standing there, they don't understand what the kids are saying.</p>
<p>Limited Health Resources and Long Wait Times</p>		<p>We don't have a lot of doctors in our community. We only have like two or one. We only have a limited walk-in clinics so it's harder for them to see the doctor and get the help that they need. Let's say they're in pain, they'll be lucky to get in because there's only limited doctors and stuff like that.</p>
		<p>When you phone in the morning, they open at nine, right? But at five to nine, it's busy and at ten after, it's all booked up. I find it very hard to get an appointment.</p>

		<p>P2: If you went there to see a doctor or nurse, like what he said, unless there's more than six people or whatever, the doctor won't come in. They'll tell you "unless we have this many people we are not gonna call the doctor." I said "hello, what do you mean? I need the doctor to see this, and then they keep insisting that they're not gonna call the doctor unless there's six or more people." P1: Sometimes it gets to the point where we have to call relatives or friends to come into the clinic just to register their names so that the doctor can come. Now is that right?</p>
		<p>P1: These doctors in town here, they're not considered full time, they're considered locums, we can't sign the contracts, that's one of the main reasons what we can't get help from the doctors. Because they're not considered permanent, they're considered locums...P2: They're just transient doctors. P1: Totally, yeah. And you go see a different doctor and they say 'wow, you've seen a different doctor, I can't help you.</p>
The Need for Enhanced Education		<p>Because there's no community awareness on the methadone program, so people see you and think you're a hardcore drug addict.</p>
		<p>When you go to a hospital here, you just tell them how you feel or what's hurting you? They don't even check you. They are say[ing], "just say take Advil or Tylenol" Something like that. I stopped going to the hospital, because they don't do nothing. They tell me to take Tylenol. Just once, one Tylenol will do. They don't wanna explain much. They don't even explain how it hurts, where it hurts. Like there's a plate in my arm right now. They said they were gonna take it out. I went back there, they said we'll book you into...specialists...And then still nothing. I got nothing in the mail...</p>

		<p>At first, cause I was a cancer patient, I was put on some pump medication when I was in the hospital, I didn't know what it was, morphine? The doctor says, 'if you have pain, just press it.' So when I had pain I did that. I've never experimented with drugs in my life, ever. So when that thing got me smiling, happy and everything, I kinda thought 'maybe that's something I shouldn't- whatever.' Anyways, once I was discharged from the hospital I was given some pain meds and I was on pain meds for a while, but then the doctor just doesn't give it to you anymore because of some people, you know? It makes my life hard cause my pain is really bad and I don't have nothing to manage it with, so I just use Advil, Aleve, whatever works for the pain. So that's how my pain really affected me, it still does. If I was on my feet for two days, I gotta stay with my feet elevated for three days because my feet get so fat, my legs. I go to the doctor, they say 'your body's retaining water.' Well is there a treatment for it? Is there something wrong, why is it doing that? Nothing, they just tell you 'your body's retaining water.'</p>
<p>Traveling for Care</p>		<p>Yeah, I usually go to Battleford to get- better treatment.</p>
		<p>I usually go to a walk-in health clinic in P.A. or in Saskatoon.</p>

		<p>P2: Sometimes we just take our own vehicle and go down south if we can afford to see a doctor down south. That's what we do at times. P1: No, actually. I used to go see the doctor in Saskatoon that we see had been assigned but if not, I would go to St. Paul's or University. Even though I was a Native, I communicated good with the doctors. A lot of them were interested in my Native culture background and everything. And we'd sit there for an hour or two or whatever and the doctor would jump up "I've got more patients, I forgot!" Not here, you know? They just- you're not even allowed to warm up the seat a little bit. You stand there and you leave. I mean' it's not that bad but it feels that bad. You go into the doctor's office and you have to sit there, wait for 45 minutes, no music, nothing. All of a sudden the doctor comes in, wants to look at your previous chart, as soon as he does they say 'this is what's wrong, this is what's wrong, this is what's wrong' and they just send you out.</p>
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3. Major Theme 3: Systemic Oppression and Negative Experiences with Healthcare

Subthemes	Sub-subtheme	Quotes
<p>Assumption that Pain Means Seeking Drugs</p>		<p>First time I start seeing the doctor about my shoulder, I was asked if I could get, like 'What kind of medication do you want?' You want the Tylenol 3? That's what they asked me. The doctor should describe what pills I should get not what I want. I was asked one time. I didn't like that. I wasn't there for pills.</p>
		<p>They make me feel like I'm going there for pills, which I'm not even a pill-popper at all. They just make me feel like I'm there to get drugs, but I'm not. I really want x-rays done and stuff. They don't take it seriously. I tell them that my leg's affecting my whole body because I can feel the nerve from my leg to my back. I tell them that it hurts and some x-rays done on it or something, or I don't know. They just tell me that, 'No, it's fine. I'll be okay; nothing to worry about.'...</p>

		I don't bother going to the hospital here because my other doctor was in Saskatoon. I've been living here now for six years but I don't even go to the hospital....They kinda look down on you and treat you different and they say right out, 'You're just here for drugs,' so I don't even bother going there.
		P1: It's not just about getting people to talk while they're here, it's not just about getting high, we're trying to control our pain so we can sustain our livelihood, practice our culture. You can't do that when you're in pain, you can't even think about anything when you're in pain. If you go in and say you're in pain, you say you're looking for pain medication,- P2: They say that to you. 'You're just looking for pain meds.' And that's not right, that's very discriminative.
Patients Feel Unheard		Yes, health providers are not listening to [him], not to just him, he also say that to the people. Most people, when you go into the hospital, you just get sent home with Tylenol. It's not fair. ...They will still not take him seriously. He also just said that they won't do anything anyways even though we tell them where it hurts and all that...They just don't give out any other medications when you ask for help or they don't offer any other service besides getting seen, not getting fully examined, and offering Tylenol. That is it.
		The doctors, they just tell me that I'm fine. Yeah. They think like, just because I look healthy, that I'm okay. But I'm not. I usually go there and they tell me I'm healthy; they don't really look at me; they don't do anything.
		P2: You know, when you go to see the doctor at the hospital for whatever reason, the doctor and the nurse themselves say 'okay this is wrong with you, that's what's wrong with you.' They don't listen to the patient, they decide what is wrong with the patient. Like I said, they decide for you. They don't listen to what you're there for, they decide for you...They don't acknowledge you. If only the doctors would listen to the people like us, maybe our lives would be different today.

<p>Privacy and Consent</p>		<p>P1: Like the pharmacy, we said, there's no privacy. So the methadone is given to us right in front of everybody...And the people there on street drugs get their methadone, they sell it. And then they come and harass us...to buy it off us. P2: Cause it's not given to us discreetly. If he was to give it to us discreetly, nobody would know we even get those meds. But instead he just does it out in the open so when those people, those whatever, they sell theirs, their short, they'll bother us to see if they can buy it off of us.... There's a few times we had to call the police on people that were bothering us.</p>
		<p>There's one day where we went to the pharmacy, we got to the pharmacy and we walked in, there was a doctor and a couple other people from Saskatchewan Health Authority standing there...We were forced to sign something that we did not agree to. And we were forced to sign it because we were walking out sick. The doctor forced us to do that. Because I was trying to read the fine print and everything, he kept trying to pull it away from me. So finally I had a pen, steel pen, I hit him on the finger as hard as I could. I told him I'm a slow reader. I did tell him three times I'm a slow reader...</p>
<p>Shame</p>		<p>P1: How do they treat us at the pharmacy when we're on Methadone?... It's 40 below, it doesn't matter if the wind is whistling, snow blowing, we're standing outside. People are coming and going at the pharmacy but if you're on methadone, you stay outside like a dog until you're called in. Then you're called in and you go to the pharmacy and get your medication, you can't say anything or look at anybody or touch anything, or you're considered a thief.</p>

4. Major Theme 4: Strength-Based Solutions

Subthemes	Sub-subtheme	Quotes
Access to Rehabilitation		He said that he basically just helps himself by doing the stretching at home and just walking around at home when he feels the pain. When he mentioned earlier that when he feels the pain, he do a little bit of stretching and walking to ease the pain.
		When I'm home [I do] a lot of physical work...To ease the pain...cause I'm always moving. Other than that, I just rub myself wherever it hurts to get the pain away. When I was in McMurray, Alberta, working, I used to go swimming there to keep the muscle moving. And all my muscles are moving. I swam for like an hour, every time I work up there it's two weeks, One week out. So, 13 days out of 14 days, I used to swim every day for an hour. That helped.
Additional Services Community would Like to See		Maybe where someone would come into the community and a group of people would participate in certain activities to help manage different sorts of problems.
		Maybe a walking facility like, just a little walk course or something. Ten minutes. People don't know how to work with time I guess I don't know. Some people like they've gotta work from nine to five. Ten minutes at a time [of walking], it helps..But they don't even like, they got nothing here, not even for a walk around the building or anywhere, right.
Elements to Improve Pain Assessment		Well when the doctor showed me all those, the skeleton and the pain scale with the one to nine to ten which would be the worst and one was the least worst and stuff like that, that was good. Really simple to follow... Like, the Dene language, our language, the majority of the language is all facial expressions. Like, one word could mean a lot with different expressions, facial expressions.

	<p><i>Story Telling to Describe Pain</i></p>	<p>Like my shoulder pain it's really painful, it comes around just for few seconds that's it. It comes around and it goes, big gaps in between hey? That's how it is for my shoulder, because I damaged my shoulder, when I was mining back in early 1990s. And it bothers me now. I've been seeing a doctor about it a few times and now for the last couple of months, I've been waiting to see a bone specialist, I think. That's what I'm waiting for right now.</p>
		<p>I don't know, my legs give out or a nerve — there's like nerve damage or something. My back hurts a lot. When I try and stand for long periods of time or I'm sitting a certain way — my hands, I can't do much with them either because they have arthritis; like really bad joint pain. Sometimes my body just feels inflamed... and it's sore to do daily things... My knee, I had fell one time on a cement pad and it shattered my knee cap. I went to try and get something done and stuff but had a harder in the North. My lower back, I had gotten into a car accident a while back and became unconscious, so, I didn't go in for a check up. But my quad accident shortly after that affected my back 'cause I about flew right off the quad. And my hands, I have — they're just dissociated or something on my fingers. It's hard to do certain tasks I've done every day.</p>

		<p>Okay yeah it seems lockup. All my shoulders, my elbows, everything. Like right from the knees. So, what I used to do, back in the day in the sports, I hit the boards in the back first, so there used to be a Saint-Paul Hospital in La Loche. It used to be on Saint-Martin or something—forgot the name—but, I hit the boards there. I laid in bed for 12 days without moving. It was bruised up or something. They could do nothing. So, I got up that problem from hockey, and then my collarbone was broken. And then I used to see a chiropractor every week. there used to be a chiropractor in La Loche, and then he left. And we had nothing. I stopped going there and I started doing what he showed me to do just by myself, tried to get the pain away and all that. And then I got hit by a vehicle. My forearm broke, just one bone. Everything locks up all over. But with operating on that doesn't help, everything my hands, my knees, my toes. It's always stiff. I do a little bit of stretching, a lot of walking. When I'm home a lot of physical work, I'm a mechanic and carpenter and all that. To ease the pain. Cause I'm always moving. Other than that, I just rub myself wherever it hurts to get the pain away.</p>
<p>Innovation in Robotics</p>		<p>Yeah, it's better if they start using it [the remote presence robot] on the people instead of hiding or tucked away someplace. Should bring it out and start using it on people.</p>

		<p>You know, people talk about it and I've seen it standing in the corner but I've never actually seen it work. I heard about one scenario where the doctors themselves were on the robot, they did a really good diagnostic on the person and the person survived....the person pulled through with help from the robot, the doctors down south. That would even be another option of seeing a pain specialist or whatever, to go to the doctor or sit in the office and look at the robot doctor... Well give it to a doctor down south who's willing to deal with pain management that are part of a survey like this. It'll save you the time and the finances of going south, you can do it right here at the clinic, if the doctor or the clinic took part and says 'okay Friday, we're gonna designate all the pain management, all the pain specialists to be on the robot to talk to the patients.'..Instead of, you're in pain, you're sitting in a medical taxi with 10 other people bouncing around, that's still an uncomfortable feeling. Whereas of you can talk to the doctor in the robot, go home and relax on the couch. And then the robot, you can get the pharmacist on board and talk with the doctor, you know?</p>
		<p>There would have to have somebody here that has patience to explain to us, this is how its gonna work. Stuff like that. I just can't be, for me I can't understand the robot. I can't even type on computer...</p>
Outcome Measures		<p>Maybe taking a survey with the members, ask them if it's helpful.</p>
		<p>They would have to do a review.</p>
		<p>The person receiving the care would also have to update their status if it's pain management or if it's working or not, right?</p>
		<p>It's better if they come back and check up on the patients to see how their experience was with the robot machine. Instead of just thinking that "Oh they use the robot that's good" and then let's just move on to another one. Instead check up on the patient again, to see where they're at.</p>

Recommendations to Enhance Care		He's saying that when you go to the clinic, you sit there for more than three or four hours. He's also saying that when a person goes to the clinic, obviously, they're hurt. They should be examined more and be taken into real consideration instead of saying, 'Oh, you're not really hurt. You don't look really sick. I'll just give you Tylenol. Go home.'
		Yeah. I like my doctor in P.A. and she's a young woman and she's really smart and she does really try to get to the bottom of everything; she'll check you for everything... She's more open with ex drug users. I have a lot of nerve damage probably from drug using. At least since I've been clean, I've been like noticing that I have nerve damage and stuff and she was really educated. She would educate you on it.
		P1: Unless somebody from the Saskatchewan Health Authority comes down here and disguises himself and sits there with a couple, with three, four Indians and sits there in a waiting room and then goes and sees what actually happens, is being said to the patient, like "you shut up and sit there. The doctor will come but if not, just sit there." I thought I talked to you, and if you say something, they'll call the cops on you. The cops will escort you out. P2: Yeah, it'll be different. The discrimination is too strong in that place.
		A doctor that understands the patient and take the time to listen to their patient instead of deciding on their own. 'No this is wrong with you, that's wrong with you.' A person knows their own body...you can talk to somebody that's knowledgeable and maybe somebody that's not afraid to try and speak the Dene language or whatever so you could feel comfortable talking to them.
Traditional Ways of Healing		Rat root, I use that.
		Well, drinking teas and also got rubs that were made out of natural products.

Appendix K- La Loche Themes and Quotations from Semi-structured Interviews with Healthcare Providers

Table A7: La Loche Healthcare Providers Table of Quotes

1. Major Theme 1: The Impact of Pain on Daily Living

Subthemes	Sub-subtheme	Quotes
Pain Affecting Culture		The things that would prevent people from doing would be most common recreational pursuits might be just like going for walks, berry picking...
		Participating in cultural or spiritual activities is affected because these individuals are not really going out into the community.
		A lot of it seems to be quite social as well like, 'I wish I could go quadding with my friends, but I can't. Because my chronic low back pain just can't handle that.' Or canoeing like, 'I can't sit in the canoe for that long.' I haven't heard as much on specific cultural things that people can't do, but those waters get muddied a little bit where I don't always know what's cultural and what's just an activity. Sometimes people will be like, 'I can't go hunting anymore,' and I don't know if that's a cultural tie to hunting that they're missing or whether they just liked that activity as a social outlet and it's not so much related to cultural practices.
Pain Affecting Emotions		These individuals have isolated themselves and it's affecting them daily. Not leaving the home much, unless they need to. Their lives are definitely affected and they're not really living because they're trying to stay in their comfort zone most of the time. These individuals are not really going out into the community. It's difficult for them.
Pain Affecting Employment		Sometimes it'll take a patient out of employment forever sometimes it might require a change in employment.

Pain Affecting Physical Activities and Daily Function		All of them are unable to do certain things in their lives that they would really like to be able to do. There are lots of conversations about them wanting to get back to doing this or this is causing me trouble now I can't do this thing anymore. Absolutely limiting.
Pain Affecting Social Participation		These individuals are not really going out into the community. It's difficult for them. If you're not going anywhere and you're not seeing much of anybody, then you're just basically keeping to yourself and your family.
		Going for walks and visiting people, limited in those kinds of regards. Absolutely. From my experience it's been more about missing out on time with friends and family, not having the energy for that, being able to go to those activities.

2. Major Theme 2: Barriers Limiting Access to Care and the Understanding of Pain between Healthcare Provider and Patient

Subthemes	Sub-subtheme	Quotes
Communication about Pain		I'm just using mostly the visual analogue scale and with that one, sometimes I feel it doesn't trend. Maybe it's just because they haven't heard it before, or maybe it's because it's not geared to that population. It doesn't always seem to make sense right off the bat.

	<p>The storytelling component is pretty big. I find that people's score really high in situations when I wouldn't necessarily consider, with how they're presenting, to match with that high of a scale. Sometimes it gets a little bit more accurate, or what I feel is accurate, what I feel matches up with their physical appearance and presentation in that regard. It's just really different, it's been taught to me differently then somebody who's First Nation living in a northern community. I feel that disconnect sometimes. Looking at somebody and they're saying they're a seven out of ten pain, and you look like a three to me, like there's clearly something different in how we're processing pain and understanding where that scale is, how to express it. I don't think I always do a great job of figuring out what the differences are. I'm trying. One of the things that I noticed is I'll ask for where somebody's pain is and I'm expecting a word or an indication of a more specific spot, but I'm getting quite general answers. Then when we dig into it deeper it turns out the pain is fairly specific. I think that's a difference in how I as a white person and potentially they as First Nations people conceptualize pain as well. I'm still trying to figure out what I think about that, what it means.</p>
<p>Language Barrier</p>	<p>Usually just [use] a verbal analogue scale, 0-10. [It's] medium effective. I think where it is ineffective is when you're dealing with Dene first language patients, and they don't really entirely comprehend the scale. Language would be the only thing that stands out to me as a bit of a barrier when understanding pain specific to the dene community.</p>

	<p>There are many people in La Loche who do not speak English or English is their second language. I actually didn't think that was a barrier, but it can make it very difficult especially our Elder population, a lot of them don't speak English. We do utilize our community outreach education worker to help translate as much as possible, but I would definitely say out of all the communities within our northwest region that where we're going to see most language barriers for sure is in La Loche. It's interesting because when we have resources that are in the Dene language most individuals don't know how to read the Dene language, they just speak it. So, any resource really needs to be quite visual with pictures or audible we did get – I've seen resources in my previous position that were made in the Dene language, and no one could read them.</p>
<p>Present Environment Surrounding Pain Care</p>	<p>It [MSK pain] can be anywhere in the body but probably the most common areas are our low back, shoulders, knees, those would probably be the top 3 areas. Yeah, probably higher rates as progress through the age frames. I guess another thing would be just from a primary care level and physician perspective, there's really zero consistency with who patients see at a primary care physician level... 9/10 the person they're seeing on follow-up is different doctor than they saw last time and that definitely doesn't lead to ideal management when it comes to medications, ordering diagnostics, or following up on those... Some consistency at the primary care level in terms of care providers would be really helpful but that's a much bigger systemic problem.</p>

		<p>I would say that it seems like there's quite a few people that seem to have these ongoing pain issues... 20 years' worth of pain...it's been a really long time. So far in my experience it's always been a really traumatic event that kicks off the whole cycle. It does sound like most people received some kind of medical intervention early on. Whether the revolving door practitioners that visit La Loche just breaks down that continuity of care. The people just see these one-off people coming and assume that they're drug seeking for whatever reason. They might assume that. When you're trying to get follow ups on things and it's a different person every time and they don't know what the last guy did. Sometimes referrals for imaging will get mixed up and somebody won't know that the next guy supposed to follow through on that.</p>
		<p>So, let's say they weren't trying to access physio directly, they were trying to access maybe their primary care provider and then moved to getting a referral for physio. So, if they were going that route, there is definitely a barrier to accessing non-emergent healthcare in La Loche so there's an unfortunate model at the clinic...now I believe they have it where everybody needs to call each morning, they do not book ahead, because there were problems with no shows...we have trouble booking morning appointments in La Loche, it's almost like it's the circadian rhythm in that community starts later in the day and so afternoon they're usually heavily booked. Whereas mornings are a lot of no shows there are a lot of people that aren't able to make it.</p>
		<p>For pain management people will come to the Health Center clinic or the emergency room...Booking an appointment at the clinic is very difficult. You have to show up in person or call in at 9:00am to see a physician. Spots are full by 9:10am.</p>
	Lack of Resources and Long Wait Times	<p>I think too, there's a long waitlist and if you're needing to see them more than once every two weeks because of their patient load. That could be difficult, we just don't have the capacity to be serving the people of La Loche sometimes as much as the community may need especially in relation to really anything in healthcare.</p>

	<p>It's this un-serviced, it would be nice if we could have more physios up there....</p>
	<p>Patients who are in chronic waitlists who have had back pain for example, 5 years, they're often not seen very quickly when we're not fully staffed such as right now and those people tend to wait sometimes very long periods before being seen. Someone who just had a knee replacement or stroke, they're going to be seen within a week or 2 whereas someone on that chronic waitlist depending on staffing levels, they could be over a year. I think on the mental health side there's always improvements that can be made there for regular mental health patients but also patients with persistent pain on the mental health side whether that's from a CBT [cognitive behavioural therapy] approach to managing pain which I think would be really helpful which isn't really available on offered in La Loche or very much of the northwest. On the behavioural therapy, I think that could be very useful for some patients but there's just little to none of it offered by mental health in the northwest to just managing various psychosocial issues in patients' lives which can predispose people to developing chronic and persistent pain.</p>
	<p>And the last thing I was going to say is it's again a capacity issue but like if our physiotherapist could be out in community more you know they're living in [extracted for privacy] so they're often involved in activities within the community promoting physical activity and what not in those communities but we don't have that in La Loche we just don't have that capacity.</p>

<p>Transportation Barriers</p>		<p>It is a larger town so it also could be a barrier to sometimes getting to the clinic maybe difficult if you don't have a vehicle or access to a vehicle or access to a ride that could be difficult because we don't have public transportation. [Additionally] I think specialists appointments sometimes those are - I think it can really be hard to get patients to a specialist appointment in the south even if you have coverage like you are Treaty or you are on social assistance if you do take the medical taxi you're generally not taking like what if you have a bunch of children that need to be cared for? What if you don't have a partner like and then you need to go the city which can be considered really big and scary for a lot of people it's very traumatic.</p>
		<p>Yah, travel is a hot mess. Medical taxi system right now is especially just not doing a good job. I'll book patients in and the taxi drivers will just decide not to work that day, and then my patients can't come whether they want to or not. That's tricky. Then coordinating that travel arrangement sometimes can be pretty frustrating or difficult. ...Sometimes the weather inhibits people from coming whether they have a ride or not.</p>
		<p>There are also a few neighboring communities outside of La Loche they're smaller but there are individuals that live there and that would be a financial barrier because that's a lot of gas to get to town but that would be the nearest place to receive that service. The physiotherapy services offered outside of La Loche are free to the public, but transportation can cost a lot for people.</p>
		<p>People that are on social assistance, they're able to get on taxis. Those that aren't on assistance or aren't Treaty, their trips aren't covered. People have more difficult time to get South if they're unemployed or employed but making, say minimum wage...As well as our seniors. We're talking about chronic pain, there's a lot of seniors with different illnesses or issues. They're not covered to go on a medical taxi so family, or they have to find a way down for their appointments for themselves.</p>

		We have to travel down south six and a half to seven-hour drive to Saskatoon to see a specialist. Those of us who are paying on our own, it's a lot of money, a lot of our time, hotels and meals...
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3. Major Theme 3: Systemic Oppression and Negative Experiences with Healthcare

Subthemes	Sub-subtheme	Quotes
Discrimination		I feel like the doctors' notes that I've looked at feel like these people are just always seeking medication. Which makes sense, if you're in pain all the time you should be seeking out ways to manage your pain. I don't think that the practitioners are accusing these people of being drug seeking. I do feel there's a bit of tension there. People are asking for help and the medical system isn't able to provide it for whatever reason; whether there just isn't another drug that would help; we've tried all the options and unfortunately there just isn't something, or; whether the revolving door practitioners that visit La Loche just breaks down that continuity of care... I had a couple interactions with people where they were just like, "I don't go to the doctors anymore. Period. If I can help it. Because they don't listen, they don't understand. They don't respect me. I came in and needed help and they just kicked me out.
		And I also think about I don't know this for sure, but you know what about the individuals who are in pain and perhaps do need medication for that pain but are really discriminated against because of their identity?
Indigenous History and Intergenerational Trauma		...you have a lot of health care professionals coming to the north and really unfairly treating the community.
		There're also mothers who maybe have a history with substance abuse but perhaps they're actually really working on themselves. And so, for their entire pregnancy [they] want to change their lives and... their children are still taken away from them when they deliver. And that is scarring...and you now have a population of people who believe that the health authorities is ripping families apart.... inadvertently.

<p>Mistrust between Community Members and Healthcare Providers, Healthcare System</p>		<p>Any kind of care when it's that broken and inconsistent with who's providing it, you're not building a relationship with a care provider and establishing trust and rapport and as a provider getting familiar with that patient and their story and the patient not having to retell the exact same story every time they go in and see someone new.</p>
		<p>..there is a huge mistrust between the community and the healthcare system... So, a lot of individuals who do have access or are a little bit more privileged will choose to access services such as physiotherapy in other urban centers and are willing to drive to receive those services.</p>
		<p>I feel like the few people that I've dealt with that have had these long-standing chronic pain issues, feel really disregarded by the health care system. I think there still is quite a bit of mistrust between the First Nations and health care relationship. I had a couple interactions with people where they were just like, 'I don't go to the doctors anymore...' Especially people with chronic pain. It's just so exhausting on its own, never mind to have to defend yourself and explain yourself over and over again.</p>

4. Major Theme 4: Strength-Based Solutions

Subthemes	Sub-subtheme	Quotes
Elements to Improve Current Pain Scales		<p>Yeah, I think that the visual analogue scale is too abstract. It's floating in the air, kind of concept. You can use the picture version, obviously, I don't ever have it out. I can do better with that, because I think that helps quite a bit. Having something that's a little bit more concrete, and then I'm noticing some more of that storytelling and whatever descriptions of pain. Everybody describes pain so differently so it's hard to have those words that go along with different levels of pain or different types of pain, but maybe having something that allows the people to select something a bit more concrete, a word or face or something like that would help. Then with the language barriers too, I don't feel like I'm always explaining well, so having something that would help me translate certain extensive pain to other languages, to Métis to Dene, Cree, whatever people are speaking, I think that could be helpful too. I'll get people saying, 'I don't really know how to say it or how to explain it.</p>
Innovation in Robotics		<p>Yeah, and again I don't think it's necessarily better care but more prompt care. I think that anytime you can work with someone face to face especially when you're dealing with MSK issues where there's a lot of value in in person assessment, in person treatment, that's always best case scenario. But when it's a lengthy wait for those type of services and you can cut that wait time drastically by doing things remotely in the meantime then that's going to lead to better outcomes and patient satisfaction and care.</p>
		<p>...like I said, it would be easier for them to come in contact with a doctor from South than travelling.</p>

		<p>...you know we do have physios in the far northwest too who actually have some really good backgrounds in persistent pain and extra graduate site classes in that area, so I think that just partly through working with these populations for many years as well as different continued education pieces...linking up with other people, networking with other providers that have similar skill sets or even more advanced training in those areas certainly doesn't hurt</p>
	<p><i>Challenges and Suggestion to Overcome</i></p>	<p>Getting patients for in person appointments is difficult, getting them in for telehealth could potentially be even more challenging so it would be good to have a good system of reminder phone calls setup, making sure it's extremely clear where they need to go; when they need to go, what they need to bring to that telehealth appointment. I mean the technology component itself I'm not too sure how complex that is but making sure that there's simple instructions, maybe a staff on hand to help with setting it up, making sure that the people who aren't as tech savvy you know Elders or non-Elders don't have much exposure to telehealth or technology they don't have any issues going in the room and being confused and not having things set up ahead of time.</p>
		<p>Yeah, I think one thing is not a fear of technology, but it can be difficult to develop rapport even in person but sometimes if you add technology in there like a robot or a screen and now it can be even more difficult to develop that rapport. I think it would be helpful if there was a local person there that they trusted as well. I'm just a little concerned about the rapport building piece.</p>

<p>Outcome Measures</p>		<p>Getting feedback from the people that are participating in those services would be the best place to start. But you would have to do it in person, any type of assessment measure that's involved with a community member has to be done with them face-to-face while they're already in your center; relying on email communications or mailouts, or even phone calls. I don't know that you would get the response volume or whatever that you would need. It would be much better to do it all in face-to-face interactions.</p>
<p>Resources in Community for Pain Management and Disease Prevention</p>		<p>I don't actually know. I know that I could do a better job of knowing some of those services. I know there's mental health and addiction services that people with chronic pain can certainly access. Then there's our physio services. There's the clinic in town and obviously a more emergency stuff, but beyond that I don't think I know about much about what kind of community programs are offered up there.</p>
		<p>We do have a physiotherapist that come in three times a week... Plus, we have... an occupational health therapist. So, we have those. Besides different programs- I know at the school, they have open gym nights or the weight room where people can actually go just to get exercise in.</p>
		<p>Individuals come in to see physicians seeking medications for pain management, while other Individuals come in to see physiotherapists for pain management where they are taught to do muscle exercises. There's nothing other than the two I mentioned. There are no facilities or a place for exercise equipment or people to go to.</p>
	<p><i>Additional Services that would Benefit the Community</i></p>	<p>I have quite a few patients that I've asked about walking and they're all afraid of the dogs in town, which is a legitimate concern. I would really love to see, I don't know what the school is doing, but a program where people could get out and do some activity within the gym. Cause walking is so great for you and it's so social, it's active, it's good for pain management... Just to have a safe space to do that and then it could build that social aspect as well.</p>

		We require a lot of Services. I believe people can benefit from having staff that can do translations, have more telehealth sessions or utilize the Robot for specialist examinations.
Ways to Improve Experiences When Accessing Healthcare		People are okay about bringing themselves to appointments though, and there's more funding out there than what I'm aware of. I think that could be something that, help me out anyhow, is understanding better the funding systems that would help people get travel. I know to contact specific travel coordinators but sometimes my patients will show up with forms to fill out and I have no idea what organization they're going to or what kind of reimbursement they're getting. If I had a better concept of that I could potentially be advocating for other arrangements for travel other than just this one medical taxi system that I know about. One thing that I didn't mention at all is that a lot of my chronic pain people have come through SGI as well, through that system. Navigating that has also been pretty tricky.
		I think that would increase the trust if it was a local doing that intermediate support yeah, I think that would be helpful. It takes a long time to build rapport in La Loche.

		<p>I think a lot of the services are there it's just the consistency... making sure there's not a different care provider each time, making sure that mental health services can provide things like CBT. I don't necessarily think there needs to be anything brand new in place but it's just kind of improving the existing supports and services that are already there. I think well I guess one thing that would kind of stand out is understanding that there is lots of people that follow traditional medicine in the north and do different herbs for medicine, and not taking an overly westernized approach in kind of disregarding those traditional practices just because they don't have a bunch of [Randomized Control Trials] RCT behind them. Sometimes we can think that western medicine is the only way and if there isn't an RCT supporting something then it is of no value whatsoever. I think it's important to be evidence-based practitioners while at the same time respecting the patients and their beliefs, and their traditions and their cultural practices. If someone wants to use some sort of herbal remedy or use bear grease on a sore back or shoulder, not to tell them that "don't do that" "there's no evidence behind that" and to say, 'If that's working for you, that's great. These are some other things we'll do so supplement that.'</p>
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