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A Qualitative Investigation into Aboriginal Children and Youth's Expression of Pain: What's the Story?

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Abstract:	Background: Aboriginal children and youth have the highest rates of pain-related conditions yet there is little research on how this population expresses their pain or how and if it is successfully treated. Methods: We conducted a qualitative ethnographic study over an eight-month time period. Participants (n=114) shared their perspectives on how children and youth express their pain and how others interpret it. We held focus group conversations sessions with children and youth (n=76), parents (n=12) teachers (n=7) Elders (6) and health clinicians (13). Results: Themes regarding pain expression such as stoic and hiding behavior emerged from all groups, storytelling and descriptive language such as similes were the verbal expressions of pain, and a high degree of self-management practices were employed. Participants reported feeling unheard, stereotyped and discriminated against when they sought pain care. This resulted in either avoidance of seeking further care, perceptions of racism or repeat visits for unsuccessful previous treatment. Participants voiced concerns regarding the utility of the numerical rating and faces pain scales to meaningfully convey their pain. Interpretation: Culturally relevant assessment techniques are essential to identifying and reducing children and youth pain experiences. Aboriginal peoples have unique cultural and historical experiences that may influence the conceptualization and thus expression of pain. This may have a profound impact on how well health clinicians assess and treat the pain effectively. Without culturally appropriate assessment mechanisms this population of children will persist with untreated pain and impair their ability to grow, learn and develop into healthy adults.

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Background

INTRODUCTION

Aboriginal people's health, development and survival may be compromised by our ability as clinicians to provide relevant culturally safe pain care. One in five Canadians ages 12-44 years (3.6 million people) experience chronic pain and the incidence is highest in Aboriginal households and those with low educational attainment (Statistics Canada, Canadian Community Health Survey, 2012). While Canada ranks 3rd out of 177 countries in the Human Development Index, if only Canada's First Nations communities are considered, the ranking slips to an appalling 68th place (Canadian UNICEF Committee, 2009). In a recent comprehensive review of 28 studies examining the epidemiology and management of pain among US, Alaskan and Canadian Aboriginal peoples only five included children and/or adolescents, and only one took place in Canada (Jimenez, Garroute, Kundu, Morales & Buchwald, 2011). Results indicate that there are higher reported rates of dental pain (Leake, Jozzy, & Uswak, 2008), juvenile rheumatoid arthritis (JRA) pain (Mauldin, Cameron, Jeanotte, Solomon, & Jarvis, 2004), headaches (Rhee, 2000), injury (First Nations Regional Health Survey, 2003) and musculoskeletal and chest pain (Buchwald, 2005) in Aboriginal children and adolescents; yet less likely to be treated for it (Leake, Jozzy & Uswak, 2008; Maudlin, Cameron, Jeanotte, Solomon & Jarvis, 2004; and Rhee, 2000). Van der Woerd, Dixon, McDiarmid, Chittenden and Murphy (2005) report that 45% of 1700 British Columbia youth report missing school and other activities due to pain.

Much of what is known about pain care is derived from study in western settings and acculturation tests of the findings are rarely provided (Finley, Kristjánsdóttir, &

Forgeron, 2009). The ability to accurately assess pain in Aboriginal children and youth is viewed as the first step toward culturally safe care. The purpose of this study was to understand how Aboriginal Mi'kmaq children and youth express pain, and how others interpret it.

Methods

Design

This qualitative investigation used a community-based participatory action methodology. This consisted of ethnographic techniques (Roper, & Shapira, 2000) including interviews and focus groups (conversation sessions). Community members were involved in identifying the main research questions, the planning, data collection and analysis of the study data.

The protocol received approval by the IWK Health Centre Research Ethics Board and a regional Mi'kmaq Ethics Committee, Cape Breton University (CBU). The Mi'kmaq Ethics Committee at CBU was appointed by the Sante' Mawio'mi (Grand Council) to establish a set of principles protecting the cultural knowledge of the Mi'kmaq people.

Setting and Sample

The study was conducted in a large Mi'kmaq community of 3310 people (Statistics Canada, 2011) located 500 kilometers from the region's tertiary pediatric health centre. A collaborative relationship between the clinical researchers, the health directorate, and members of the Mi'kmaq community was established. A convenience sample using a purposive method (by school grade and adult group) was used to gather the perspectives of 114 Mi'kmaq community members. A community liaison and health nurse facilitated the interview and group sessions along with the principal investigator (Latimer) and co-investigator (Inglis).

Procedure

Two semi-structured conversation sessions were held with each of the 5 community groups in the school, community center and Elder's homes. Sample questions are provided in Table 1. Data includes participant demographic, conversation sessions (individual and group) and study investigators field notes.

Data Collection and Analysis

The project resulted in 10 group conversation sessions, and 5 individual Elder sessions collected over eight months. The sessions with children, parents, teachers, and health professionals were primarily in English; they were audio taped, transcribed, and any Mi'kmaq included in the discussions was translated to English for coding purposes. The primarily Mi'kmaq conversations held with five Elders, (not audiotaped), were captured via detailed field observation notes immediately following the sessions. Open coding and thematic analysis was completed by the principal investigator, the community liaison and nurse research coordinator. Inter-rater reliability between the three coders was >90% for final themes. Data themes emerged under the established categories of pain expression, interpretation, and management. Credibility of the themes was gleaned iteratively from transcribed data, the field notes, and confirmed with the participants, community-based research team and Elder advisor. Triangulation of all types of data added to the rigour and trustworthiness of the results (Thorne, 2008).

Results

Of the 114 community participants in this study, 76 were children and youth. Demographic data were collected and the children and youth groups were: grades 1-6 (n = 39), grades 7-9 (n = 19) and grades 9-12 (n=18). The 38 adults were: teachers (n=7), health professionals (ex. physicians, nurses, psychologist, n=13), parents of young children (n=12), and Elders (n=6). One Elder chose to withdraw.

Pain Experiences

The most common experiences of pain were categorized as medical and non-medical issues. Medical pain included physical aches such as ear, dental, musculoskeletal, headaches, abdominal or procedure-related immunizations and venipuncture. Non-medical pain was the result of injuries from falls from bunkbeds, trees, bikes (regular bicycles, dirt) as well as fights, abuse, self-injury and sports-related injuries. Children self-reported the frequency they experienced common medical pain and if they missed school or if they self-medicated for pain (See Table 2).

Pain Expression: Non Verbal & Verbal

Participants from all groups most commonly reported that children and youth were stoic in their pain expression, and often hide their pain. Many participants conveyed the youths "tough it out" or "be brave". It was consistently reported that children and youth might not always cry, nor verbally express their pain to others. Some reported that children and youth display pain by swearing, shouting, becoming angry and laughing. Comments indicated that children and youth are socialized to be stoic by their parents, grandparents, aunts/uncles and this is consistent in the conceptualization and expression of pain across all groups (Box 1).

Adult participants commented that children/youth display non-verbal pain cues via their eyes, voice tone, gait and their general body movement but may avoid eye contact and shy away from questions. Verbal expressions of pain consisted of the word 'hurt' consistently in both English and Mi'kmaq and in response to our question "what does pain mean to you?" participants would reply "a feeling of hurt" or "it just hurts". Many derivatives of the Mi'kmaq word kesa'si (translated to mean "I'm hurting") were noted in the transcripts (See Table 3). Pain was also expressed by telling a story relating the elaborate event details that caused the hurt.

Aboriginal children and youth appear to be socialized to 'be brave' and this expectation seems set especially for boys. The youngest participants expressed their pain but as they got older (after grade 4-5) they described not wanting to show their pain so they would not be perceived weak.

Pain Interpretation

When participants did seek health care for pain-related issues, they described their experiences as frustrating, and there was a reoccurring theme among all community groups of 'not feeling listened to'. The majority of young participants 60% (n=32) wanted their mom or dad to speak for them. Participants said they convey their pain via stories and our data also suggest more descriptive language using similes is a common pain communication strategy (See Box 2). Participants perceived discrimination and said health professionals stereotype them with preexisting alcohol and drug problems even before the pain assessment. They often associated longer wait times for care as discrimination. These negative encounters led to subsequent delays in seeking future treatment, repeat trips for care because they did not feel heard the first time, and overwhelming feelings of frustration and even anger (See Box 3).

Both community and clinician participants indicated that gold standard measures such as the numerical rating and facial coding scales are not effective in efforts to convey or interpret pain (Box 4). Alternatively health clinicians offered the following advice in conducting pain assessment: show respect, allow more time to respond to questions, and listen to their stories. Some clinicians use the Mi'kmaq language to greet and to build trust. Box 5 contains sample of their responses.

Pain Management

Self-management was the most common strategy for community members in treating their pain and included both pharmacological and non-pharmacological techniques. Sixty-eight percent (n=53) of the young participants reported they regularly took pain medication. Yet in the group sessions the most common way the pain was managed was through non-pharmacological self-managed strategies such as distraction (video games, television), applying heat/cold, humour or traditional practices such as smudging (See Box 6). Smudging involves burning sweet grass or sage to clear air of negativity. A few children spoke of self-medicating with acetaminophen however not using a prescribed dose. Self-management was common as there was little trust in the primary care system and a sense of reluctance to seek treatment.

Discussion

Pain exists in Aboriginal children/youth and may go undetected as a result of cultural influences on expression and inadequate clinician-based assessment. Pain interpretation may be more difficult as a result of miscommunication, and/or preconceived notions of western society's pain behaviours; and Aboriginal community members' stoicism, mistrust and subsequent delays in seeking treatment. Fenwick (2006) noted that Australian Aboriginal people display "stoicism" and silence when in pain in an effort to remain reserved and be respected in their culture. Australian indigenous people are reported to suppress pain behaviours and reluctant to discuss their pain experience with others (Honeyman & Jacobs, 2005). Furthermore, efforts to colonize Aboriginal people and specifically the residential school experience may explain the pain suppression behaviours. The notion of subjective pain behaviours seen as predominant in western culture (crying, restlessness, grimacing) may not be appropriate indicators of pain in Aboriginal children and youth.

In American Aboriginal pain studies, participants often reported pain only when severe, and used vague descriptions such as "ache" to express pain (Elliott, Johnson, Elliott, & Day, 1999; and Kramer, Harker, & Wong, 2002). In this study, while the researchers were asking about "pain" the respondents replied using words related to "hurt". On further exploration, there is not a translatable word for the English word 'pain' in the Mi'kmaq language, but there is for the word 'hurt' (kesa'si). While pain is a universal concept, language and cultural factors could affect clinician assessment. Mi'kmaq linguistic research (Inglis, 2002, 2004) has demonstrated that like other related Aboriginal languages such as Cree and Anishinaabe, Mi'kmaq is verb centered with most words either being verbs or, if nouns, derivatives from verbal stems. This would explain the use of the English verb 'to be hurt' instead of the noun 'pain'. For patients socialized within Mi'kmaq culture the linguistic concept of "pain" is not notionally interpreted as a state at one moment in time, thus the event causation story.

Historically, Aboriginal people have a strong oral history and values, beliefs and complex ideas are expressed by way of stories (Sinquin, 2009). The purpose of the storytelling according to Fixico (2003) is to draw the listener into the experience of the event allowing the listener, in this case the clinician, to come to their own conclusions concerning the degree of pain the child is suffering. Discourse patterns vary across cultures (Fixico, 2003; Chafe, 1980) and Mi'kmaq patients in pain do not often use English adjectival or adverbial phrases to quantify pain (Inglis, 2002, 2004). Participants indicated 'it hurts' but if clinicians pay attention to the details of "the story of pain causation" this is where the level of pain is expressed. This could explain why participants did 'not feel listened to' with respect to clinician / patient dialogues. Community-based clinicians suggest connecting on a cultural level by greeting in Mi'kmaq and then dedicate time to listen to patient's accounts of their pain experience.

Clinicians said Aboriginal children were shy, avoid eye contact (possibly out of respect) and want a parent/guardian to answer their pain questions while youth seek permission from their parents before they speak about their pain. Comparatively Australian indigenous family structure relies on relatives to report suffering and alterations in character or normal behavior of other family members to clinicians (Fenwick, 2006). A family centered approach likely increases culturally competent pain care.

Evidence suggests lower pain appraisal occurs for people of races different from the person assessing the pain (Drwecki, Moor, Ward & Prakachin, 2001) resulting in poorer treatment (Mills, Shofer, Boulis, Holena, & Abbuhl, 2010). Clinicians receive training to use numerical pain scales, although both the clinician and community participants in this study comment pain scales were of limited value. Fenwick (2006) also reports numerical pain scales may not be accurate when used in Australian Indigenous people. Similar poor pain evaluation was noted with the Wong-Baker Faces Pain Scale (WBFPS) (Wong, & Baker, 1988) and the Faces Pain Scale-Revised (FPS-R, Hicks et al. 2001), when assessing pain in the Northern Inuit culture and lead to the development of the North Pain Scale (Ellis et al., 2011). Further psychometric examination of pain scales in this population is warranted.

The finding of missing school due to pain is consistent with Van der Woerd et al (2005) report. The recurrent rates of ear, dental, muscle and injury pain consistent with the Canadian Pain Society (CPS, 2011) reports likely interferes with their ability to hear, eat, learn, and play: all fundamentally important to growth and development. According to the Conference Board of Canada, (2012), only 51% of Aboriginal people complete high school (compared to 88% of other Canadians), leading to question whether pain interferes with school-based achievement.

A variety of pharmaceutical and non-pharmaceutical measures were used to manage pain and include conventional western medicine (physical or behavioral strategies) and cultural practices such as "smudging". Better pain assessment and treatment may occur if clinician knowledge reflects cultural experiences.

Finally, participants reported feeling as if their concerns were not heard by clinicians, and believed they experienced discrimination while trying to seek care; citing longer wait times in emergency departments and frustration when their pain was not treated. These negative encounters are consistent with the Health Council of Canada's (2012) *Empathy Dignity and Respect* report from interviews with Aboriginal people from across Canada regarding why First Nations people are reluctant to engage with the healthcare system.

Conclusion

Pain exists that can interfere with Aboriginal children/youth learning and development. Cultural beliefs and colonizing historical events may influence children's conceptualization and socialization to 'be brave' which may result in muted pain expression and delays in seeking treatment. They may distrust the public health system due to their own experiences or those of their family members. The Mi'kmaq Aboriginal language does not have a translatable word for 'pain' but does for the more encompassing word 'hurt' and this may resonate as a better assessment term to elicit their comfort level. In considering a culturally sensitive approach to pain care clinicians are encouraged to respect the oral traditions of Aboriginal people and consider less reliance on traditional numerical pain scales and the predominantly western opinion of objective pain behaviours. Additional research examining pain behaviours/expression and the utility of established pain scales in this population is warranted.

It is suggested that clinicians explore means to build trust and allow for additional time to assess pain via "storytelling" or word descriptions as well as a family centered approach to pain care. The Aboriginal population in Canada has the fastest growing demographic for all Canadian children (Statistic Canada, 2011), with high pain therefore there is an urgency to improve the encounter and experience of Aboriginal people.

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Table 1:

Sample semi-structured interview questions

English	Mi'kmaq
What does pain mean to you?	Talite'timo'q tan wen kesinukwat kisna jile'k?
What does pain look like? If you have had an earache or tooth ache, or muscle pain how would you describe or draw it?	Tan kesa'sik eksituawaqn kisna kipit, kisna ketaqasin, tali aknutmuis?"

Table 2:

Time 1 data for pain experiences in Aboriginal School Children

Pain Experience	n/N	%
Earache	44/78	56%
Muscle Ache	43/78	55%
Toothache	41/78	53%
Missed school due to pain	40/78	51%
Took pain medication regularly	53/78	68%

Table 3:

Mi’kmaq translation for derivatives of the word hurt

Mi’kmaq	English
Kesa’si	I’m hurting
Kesitesk	It hurts
Kesi’k	It hurts
Kejunkwun	Sore, aching
Yiya (**for younger children)	Ow, ouch

Box 1:

Participants’ comments demonstrating child’s stoic response

CA1: No, she just sat there. She just held it.

CA2: I said she don’t cry for nothing. They said oh don’t worry, all kids cry. I’m like no, she don’t cry for nothing. …when she’s in pain she won’t. But when they opened her finger only one eye was crying, I wanted to punch that nurse.

HCP1: A little girl…I guess she was abused growing up. She hid her pain.

HCP2: One little kid I work with his mom was really concerned because he wasn’t talking…responding at all. We sent him for hearing tests. They said the blockage in his ear was really bad. That’s why he is not speaking. But he didn’t feel the pain.

CA3: My daughter has chronic pain in her pelvic area. She is a competitive gymnast and refused to stop. Even her doctors told her not to do it. She would go somewhere in her head when she as doing it.

CA4: For my kid when she’s in pain she doesn’t complain. She tries to pretend she is fine, to avoid going to the doctor. I have to really read her body language because she does not want to go to the doctors. She’s so scared, so she pretends she’s fine.

Y1: I just won’t say anything to them, save it to myself.

HCP3:I think there is a tendency to wait too long. Like if a pain medication killed it the first day, second day, third day. All the while the tooth is getting more infected. There is a point where you can’t save it anymore. By the time they get to you it’s too late. I have people say they have been in pain off and on for two and three months.

Notes: Quotes are verbatim from individual interviews and conversation sessions.

CA: community adult; HCP: health care professional; Y: youth.

Box 2:

Perspectives of community members regarding communication of pain

CA1: We paint a picture

CA2: We're story tellers, describe in detail and then they don't believe us

CA3: Can't describe in words what we feel- it just hurts

CA4: feels like someone is stabbing me from the inside

CA5: feels like a heart attack

CA6: A lot of people get sent home and then they end up in Halifax because they didn't believe them over there.

CA7: Many don't know the proper terminology to explain what's wrong with them.

CA8: It's hard for us to communicate.

CA9: They don't listen to us. They are racist

CA10: They may be listening but they are not hearing

CA11: He didn't even touch her back or try to visualize the pain. Wouldn't listen to her.

CA12: I broke a hand not too long ago, but it doesn't hurt there, it hurts up here. I don't know if there's a relation. But sometimes, you can't explain the pain, you can't.

CA13: If somebody tells you how to make a pie and gives you bits and pieces you have to put it together yourself. I mean, you say, oh okay I see where that pie came from. So you have to give all these different symptoms. You have to.

Notes: Quotes are verbatim from individual interviews and conversation sessions.

CA: Community Adult could be a parent and/or Elder participant

Box 3:

Community members and youth on health care discrimination.

CA2: My daughter had this thing and she was trying to explain to me, and most of the time she was just sitting there quiet. She'll tell me if she's sore, but she was just holding it in. Then she said 'I want to see a doctor mom' and it took four or five hours before we saw the doctor and we finally went in they stitched it up. And there was like 50 people that came through and were gone two hours later and they kept passing us.

CA1: Sometimes you have to scream or make a huge deal in order to be seen.

CA2: So I went to the register person and I said if you don't see my daughter now, I'm going to call the cops, I'm sorry but I'm going to f***ing threaten you. She looked at me and said what? I said I'm going to threaten you. I said look at my daughter's finger. I took the bandage off and they seen the gash. And she said oh my God, and I said yeah! I told you that first time. They took her in right away.

CA5: they don't listen, after seeing doctor 5 times finally took us for an x-ray"

Y2: At the hospital it took me 8 hours just to check my collarbone. A lot of people kept going in even though I got there before them.

Notes: Quotes are verbatim from individual interviews and conversation sessions.

CA: Community Adult; Y: Youth

Box 4:

Health Clinician and Community participant remarks on pain scale.

HCP1: I do ask people to rate their pain but then again I take it with a grain of salt what they give me back.

HCP2: I don't use any valid way. I think the 1-10 scale is ridiculous.

HCP3: I don't think there is any way to objectify. It's a subjective interpretation. The scale might work if you are in the middle of treating someone you know it was a 5, now it's a 6. I might buy into that but to just walk in and say my pain is a 9/10 that means nothing to me.

HCP4: I see tons of people who say their pain is 9/10 and they are carrying on their activities.

CA2: Frig I don't really tell them that it's a 10, because I don't know how to compare it to if someone else is more hurt than me? I usually say uh, it's a five?

CA5: Because that's what they ask me what does it feel like from 1-10 and isn't it what everyone's opinion on what it is from 1-10?

CA7: Yeah I usually say 8 or 9 usually. It doesn't really make sense.

Notes: Quotes are verbatim from individual interviews and conversation sessions.

HCP: health care professional; CA: Community Adult.

Box 5:

Aboriginal patient when they are asked about their pain.

HCP: They kind of turn away. Like for children anyways there is a kind of shyness. They don't want anyone to be near them.

HCP: I find they look more to their family member to discuss it.

HCP: They defer, not just kids I find.

HCP: If there is someone else in the room they always defer. Young adults who can clearly tell you how they are feeling just go mute. And won't answer your questions.

HCP: I do find native kids a little more stoic, they won't tell you anything.

HCP: I still think you have to look for the crying, grimacing, holding a part.

HCP: It's like they look to ask permission too. Before they say anything to you.

HCP: I don't know if it is a respect thing or what it is

HCP: Some come right out and blurb whatever, then others don't want to say

HCP: I'm always amazed how many kids you see with an adult who is not their parent

HCP: I'm amazed by the number of kids we see who come in on their own, with no one with them

HCP: Compared to nonnative kids I find it's a lot tougher to get a history of any sort from a child here.

HCP: I bust out my Mi'kmaq and talk to them. I even try and say now listen kid we are going to talk. And you ask the parents to ask the child to talk. And it's almost like the parents don't want that. They want to do it.

Notes: Quotes are verbatim from individual interviews and conversation sessions.

HCP: Health care professional

Box 6:

Pain Self-Management Strategies

Y: "It's all in your mind. Pain is always in your mind. You can get rid of it like nothing. You just think pain is not really there you just think about something else and forget about the pain eventually. The pain will just disappear"

Y: ..this is what my grandma used to do. Like lets say you felt a sharp pain on your thumb…she will pinch you somewhere else and she will make you think about that pain instead. And then usually the pain in your hand will usually disappear

Y: Whenever I get a needle my dad will squeeze my hand

Y: Sometimes when I feel pain what my mom does to us. She makes us sage ourselves every couple hours and stuff and usually the pain will go away faster

Y: My brother smudges his room every day. He said it gets away all the spirits… all that stuff. But he said it like gets rid of all emotional pain he is feeling or anything, so he does that every night. Whenever I am hurt he will come in my room and smudge me before I go to bed.

Notes: Quotes are verbatim from individual interviews and conversation sessions.

Y: Youth

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