



## BACKGROUND

Poor pain assessment and management in children remains a major problem in health care settings regardless of culture or place of residence. However, untreated pain may be even more profound and result in poorer outcomes among Aboriginal children given high rates of ill health and resource inequities in their communities. We know that infants, children, and youth who have repeated painful procedures react differently to subsequent pain (Grunau, Weinberg, & Whitfield, 2004; Rennick, Johnston, Dougherty, Platt, & Ritchie, 2002). These repeated unmanaged events can lead to learning disabilities, anxiety disorders, heightened pain reactivity, chronic pain, and altered health-related care activities later in life (Baulch, 2010; Blount, Piira, Cohen, & Cheng, 2006; Grunau, Weinberg, & Whitfield, 2004; Slifer et al., 2009; Young, 2005). Aboriginal children are known to have a higher prevalence of chronic, disease-related, and dental pain, and are more likely than non-Aboriginal children to experience pain and not be treated for it (Leake, Jozzy, & Uswak, 2008; Maudlin, Cameron, Jeanotte, Solomon, & Jarvis, 2004; Rhee, 2000). In addition to causing unnecessary suffering, these conditions may place First Nations children at a higher risk of impaired development.

Certain pain issues may be related to culturally based expectations of how children perceive and express their physical pain; currently, we are not certain about how children effectively convey their pain to non-Aboriginal health professionals in order for them to accurately assess it. In this paper, we will briefly review some of the historical issues that may help us to better understand how pain is considered from a cultural perspective, and then discuss what is known about pain assessment and management in Aboriginal children. The term “Aboriginal” is used to define multiple groups that encompass many different subgroups. The Constitution Act (1982) defines Aboriginal as an inclusive term referring to First Nations, Inuit, and Métis. These are three unique groups with distinct histories, languages, cultural practices, and spiritual beliefs. Aboriginal people refer to themselves according to their particular tribal affiliation (Mi’kmaq, Cree, Innu, Ojibwa) or by First Nations, Inuit, or Métis. In this paper, we use the term Aboriginal to represent people who identify themselves as part of one of these groups in general, and specifically where a particular group has been acknowledged.

Nationally, one-third fewer Aboriginal children seek physician-care than non-Aboriginal children (Canadian UNICEF Committee, 2009), and pain may be a common reason why they do eventually seek care. There may be several reasons for this health-seeking behaviour. It has been suggested that Aboriginal children express their pain differently than non-Aboriginal children. Prior research has revealed that some health professionals do not empathize with the pain of people from different ethnicities in the same manner as they do for those of their own culture (Rennick, Johnston, Dougherty, Platt, & Ritchie, 2002). Given this information and that little is known about how Aboriginal children express and convey their pain, this issue should be explored in more depth.

## WHY SHOULD WE PAY ATTENTION TO MANAGING PAIN IN CHILDREN?

Research conducted in animals and humans has shown that there are negative short- and long-term effects from untreated pain in infants and children (Cohen, 2008; Harvey, & Morton, 2007; Pillai Riddell, Horton, Hillgrove, & Craig, 2008; Slifer et al., 2009; Young, 2005). Immediate or short-term effects include hypoxemia and altered metabolic stress responses (Grunau, Weinberg, & Whitfield, 2004; Young, 2005). Children who experience repeated untreated painful procedures may develop alternate brain communication pathways that may be permanent and could explain altered stress responses and behaviour (Grunau, Weinberg, & Whitfield, 2004; Rennick, Johnston, Dougherty, Platt, & Ritchie, 2002; Young, 2005)..

Repeated procedural distress may put the child at risk for behavioural or psychological disturbances inside or outside of the medical context (Slifer et al., 2009). Some long-term effects include altered pain responses, increased anxiety, heightened medical fears, higher risk for attention deficit disorder, higher risk for posttraumatic stress disorder, and avoidance of health care (Blount, Piira, Cohen, & Cheng, 2006; Rennick, Johnston, Dougherty, Platt, & Ritchie, 2002; Young, 2005). Untreated pain can also lead to the development of chronic and neuropathic pain (Baulch, 2010). Given the short- and long-term impact of untreated pain, we need to understand how children with the highest rates of painful conditions are expressing their pain so that we can deal with it.



## PAIN EXPRESSION

Health care providers have an ethical responsibility to understand children's pain expressions and administer appropriate pain relief. However, if health care staff are unfamiliar with the cultural characteristics that define children's pain experiences, inaccurate and harmful responses may occur (Fenwick, & Stevens, 2004). Pain assessment depends on effective communication and interpretation of the pain expression and experience, yet there is little to no research on pain expression and management in Aboriginal children.

In a recent comprehensive review of 28 studies that examined the experience, epidemiology, and management of pain among American, Alaskan, and Canadian Aboriginal people, only five studies included children and/or adolescents (Jimenez, Garrouette, Kundu, Morales, & Buchwald, 2011). In these studies, the resulting trend was clear and indicated that there were higher rates of dental pain (Leake, Jozzy, & Uswak, 2008), juvenile rheumatoid arthritis pain (Maudlin, Cameron, Jeanotte, Solomon, & Jarvis, 2004), headaches (Rhee, 2000), and musculoskeletal and chest pain (Buchwald, Beals, & Manson, 2000) in Aboriginal children and adolescents than in the general population. Buchwald, Beals, and Manson (2000) also reported higher rates of bodily pain in Aboriginal children with posttraumatic stress disorder. In one other Canadian study not specifically examining pain, Van der Woerd et al. (2005) reported that 765 (or 45 per cent) of 1,700 First Nations youth in one community said that pain issues kept them from participating in school, sports, and other extracurricular activities. In the little research conducted, it appears there is a higher incidence of pain in Aboriginal children that could potentially interfere with their achievement of optimal health and overall well-being. There is also some indication that Aboriginal people do not express physical pain in the manner that non-Aboriginal care providers are used to, and this may explain the under-assessment, under-treatment, and subsequent higher pain prevalence rates. Before tackling the issue of pain expression and measurement, we must understand some of the history of pain from a cultural perspective.

## UNDERSTANDING THE COMPLEXITY OF PAIN FROM A CULTURAL PERSPECTIVE

James David Audlin (Distant Eagle), who has compiled a collection of teachings of Native American Elders from across North America, explains that pain is not always perceived as a negative experience (Audlin, 2006). "All people in every culture rid themselves of pain with medicines [...] but traditional peoples believe that pain has a message for us, and that we are foolish not to listen to it" (p. 177); "in the most obvious level pain tells us that there is something wrong with our body, and the specific nature and location of the pain tells us what type of healing to seek" (p. 178). However, in cultures that value balance, pain may have a sacred dimension, and enduring it is deemed as necessary for personal growth and the development of wisdom. When considering pain and adversity, he states that traditional teachings convey that "pleasure and pain are simply something that passes through us as we follow the course of our lives" and that "there is no point in either complaining or seeking out adversity" because "no life is free of it" (p. 174); a "truly traditional person [...] accepts it when it comes, humbly and honorably" (p. 178). When considering these factors, it is understandable that someone who holds these beliefs in whole or in part may be less likely to express their pain or less likely to seek medical relief from it. This also explains why providers would describe this behaviour as stoic.

Emmett Peters, a Mi'kmaq Elder who ritually practices in Native Traditional norms says that "pain is something that cannot always be avoided so is something we must embrace" (personal communication, September 4, 2011). He believes pain to be "sacred when endured in traditional ceremony." Many First Nations use traditional practices that at times cause painful experiences, including practices such as Sweat Lodge Ceremonies, Fasting, and Sundances. It is believed that when one person endures pain, another person's pain is lessened or healed. Ceremonies such as these are seen as a sacrifice for those suffering from illness or hardships.

In addition, many Aboriginal people live in multigenerational households. It is not unusual for a grandmother to be the primary caregiver and to pass on her own beliefs about pain and health care practices (Smylie, 2001). Elders and grandparents of the current generation of youth were likely either directly or indirectly affected



by the residential school trauma. Negative memories of this institutionalization may create a distrust of other government-run institutions such as hospitals and clinics, resulting in avoidance until an illness is advanced (Smylie, 2001). In these severe cases, it is more likely that treatment will have to be sought in larger urban centers, where health professionals are even less familiar with cultural norms and misunderstandings are more likely to occur (Kurtz, Nyberg, Van Den Tillaart, & Mills, 2008).

Further, when Aboriginal people do seek treatment, the way health professionals approach them to determine if they are in pain and how to manage it is important. One of the cultural factors that may impact the relationship between health care providers and Aboriginal people is oral tradition and the concept of non-interference. In traditional Aboriginal culture, lessons are often imbedded in stories. Giving direct advice or orders is less common and potentially disrespectful (Leavitt, 1995). An Elder may instead tell a story about what other people have done, allowing the listener to decide independently what they might do in a similar situation. This is not consistent with the current medical model, where a patient is expected to approach an “expert” health care provider with a problem and leave with very specific instructions. This direct action of stating the “proper way” to care for a child in pain may be viewed as paternalistic or condescending. Even when treatment is sought, the way it is expressed and interpreted may be different.

## WHAT IS KNOWN ABOUT PAIN EXPRESSION

In research with Aboriginal people, low pain expression is often reported. For example, Elliott, Johnson, Elliott, and Day (1999) showed that Ojibwe patients only reported pain if severe, and Kramer, Harker, and Wong (2002) indicated that Aboriginal study participants used vague descriptions such as “ache” to express severe pain symptoms. Similarly, Fenwick (2006) noted that some health professionals assessed Australian Aboriginal people’s pain response as “stoic.” However, she includes a caution: simply because Indigenous people fail to express their pain vocally, labelling them as stoic could be a culturally unsafe practice and result in under-treatment, as their silence does not necessarily indicate a lack of pain. Finley, Kristjánsdóttir, and Forgeron (2009) caution against stereotyping pain expression by culture. They provide a comprehensive literary discussion

of influences of pain assessment in children from different cultures and discuss stoicism or “kreng jai” (translated as “awe heart”) in Thai children. Kreng jai is a Thai social warning against causing distress to others, specifically those who are senior or elders (McCarty et al., 1999). In other research conducted among Thai children, stereotypical behaviours such as being stoic or unmoved by needles were also reported (Forgeron, Finley, & Arnaout, 2006). In informal discussions with members from one First Nations community, words such as stoic, suppressed, and muted were used to describe how children respond to pain (Latimer et al., 2011). Another clinical nurse specialist who works in an Inuit community noted that the response of children in severe pain is often muted with little facial or verbal cues and perceived as stoic (A. Steenbeek, personal communication, April 15, 2011). In this example, the nurse described the child as having a severe dog bite and the mother encouraging her child to think of himself as a warrior in response to the pain.

According to Honeyman and Jacobs (1996), Indigenous people suppress pain behaviours and are reluctant to discuss their pain experience with others. It has been suggested that this is the result of the oppression and suppression experienced by Aboriginal people since colonization (Fenwick, 2006). Fenwick noted that expressing pain may be viewed by Indigenous people as a human weakness, resulting in a tendency to not want to draw attention to their pain experience. This may explain, in part, the under-assessment and under-treatment of Aboriginal people’s pain by non-Aboriginal health providers (Drwecki, Moore, Ward, & Prkachin, 2011).

## INTERPRETING PAIN WHEN IT IS REPORTED

Although it is well documented that accurate and timely pain assessment leads to better pain management, evidence indicates that there are racial differences in pain assessment (Drwecki, Moore, Ward, & Prkachin, 2011) and pain treatment (Mills, Shofer, Boulis, Holena, & Abbuhl, 2010). Studies show that health clinicians may react differently to pain reported by patients from different ethnic backgrounds (Anderson et al., 2000). Higher rates of pain under-treatment in Aboriginal populations may be related to not knowing how to ask an Aboriginal child about their pain experience or how they conceptualize or convey pain; or, it may be related to the existence of a valid and reliable



way for health providers to assess all Aboriginal children's pain. For example, current pain assessment measures quantify intensity of pain [i.e., the Visual Analogue Scale (VAS) and the Numerical Rating Scale (NRS)]; pain may not be considered so one-dimensionally in Aboriginal culture. In fact, Aboriginal people think about pain within a broad context of well-being and as a function of mind, body, and spirit (Strickland, 1999). In one Australian study, the use of the VAS was reportedly discontinued with a group of Aboriginal people, possibly because the scale did not correspond with their understanding of pain (Padianathan, 2000).

Various instruments have been developed to capture children's pain intensity. Two of these instruments include the Wong-Baker Faces Pain Scale (WBFPS) (Wong, & Baker, 1988) and the Faces Pain Scale-Revised (FPS-R) (Bieri, Reeve, Champion, Addicoat, & Ziegler, 1990). Some clinicians and researchers have adapted the images of non-white, Anglo-Saxon faces in these rating scales to be more representative of others who are non-white. One group of Canadian clinical researchers led by nurse Dr. Jacqueline Ellis developed and validated the Northern Pain Scale (NorthPS) (Ellis et al., 2011) by adapting the WBFPS scale using Inuit language and culture. The WBFPS faces were redrawn to reflect an Inuk person's expression and their style of dress and then translated into Inuktitut. In Ellis' study, Inuktitut participants from an Eastern Canadian community compared the NorthPS with the NRS and WBFPS. While the younger children preferred the WBFPS, participants over 40 years of age chose the NorthPS. Ellis et al. accounted for this finding by indicating that the Inuit people have well-developed spatial abilities that would be more in tune with the "northern images" providing a more visually rich experience; this was thought to be more relevant when compared to the linearity of the numerical rating scale. This discussion is important to consider when understanding how Aboriginal children in general express their pain. The NorthPS is one of the first culturally and linguistically adapted options for the assessment of pain intensity for Inuktitut-speaking children and adults. The images, however, are specific to northern Aboriginal groups for language and dress.

The pain scales discussed have been used reliably in studies with Inuit children (Ellis et al., 2011), Thai children in Bangkok (Neuman et al., 2005), and African-American children in the United States (Luffy, & Grove,

2003). As well, the FPS-R was also understood by Arab children in a study in Amman, Jordan (Finley, Forgeron, & Arnaout, 2008). Although Neuman et al. reported that African-American children used significantly fewer verbal responses to pain, similar to what some consider is the Aboriginal child's pain expression, and compared to European-American children, the Faces Pain Scale was still deemed reliable (Neuman et al., 2005). This has not been documented in Aboriginal children. While these scales reportedly reliably measure pain intensity, it might be helpful to consider the child's pain experience and conceptualization of pain more broadly. We may want to explore the issue more holistically and from the child's cultural socialization of the pain experience—what has become the norm or what is acceptable to endure.

## PAIN EXPERIENCE

According to the 2007/2008 Canadian Community Health Survey, 1 in 10 Canadians ages 12–44 years (1.5 million people) experience chronic pain; the incidence is highest among low income and Aboriginal households (Ramage-Morin, & Gilmour, 2011). In addition, Meana, Cho, and DesMeueles (2004) explored women's health issues and found that the highest rates of chronic pain across Canada were noted in Aboriginal women less than 65 years old. Both of these studies linked chronic pain with limitation on daily activities, functional outcomes, and work. Interestingly, lower rates of immunizations—routine procedures known to cause pain—have been reported in Canadian Aboriginal children. Lemstra et al. (2007), for example, found the measles, mumps, and rubella (MMR) immunization rate to be 43 per cent among Aboriginal children compared to 90 per cent among non-Aboriginal children. There are higher incidences of pain-related illnesses in Aboriginal youth mentioned above (e.g., headaches, juvenile rheumatoid arthritis, dental and musculoskeletal pain). Vaccines are used to prevent advanced illnesses such as human papilloma virus and thus cervical cancer. Given all of the above, we must deepen our knowledge of the expression and interpretation of pain among Aboriginal children since this may be a barrier to health-seeking behaviour.

## WHAT ARE THE NEXT STEPS?

In clinical practice, especially with an initial consultation, parents are relied upon to assist a health care provider in understanding a child's pain and the way that



they express it to determine what is normal and what is not. It has been observed that women in Aboriginal communities make the majority of health care decisions for themselves and their families (Kurtz, Nyberg, Van Den Tillaart, & Mills, 2008). Establishing effective communication with Aboriginal women is therefore as important as communicating with their children. Understanding how decisions are made regarding health-seeking behaviour within the family would be an important first step in understanding who to interact with and how to gather health information. Furthermore, understanding how pain is conceptualized and the expectations regarding management would be equally important to identify from a cultural perspective. Traditional medicine and health practices may include discussing emotional pain when assessing physical pain (Smylie, 2001). Therefore, it may be appropriate for health care providers to ask “what does this (pain) mean to you?” rather than “how bad is it?” Then, the health care provider should ask “how have you managed it in the past?” or “what is your expectation of how it could be managed?”

It has been shown that children in Aboriginal communities suffer unnecessarily from pain more frequently than non-Aboriginal children. Factors that contribute to this are complicated and may include reduced health status related to historical events, cultural influences, social determinants of health, and interactions with health professionals, all of which result in ineffective assessment and treatment of pain. We are concerned that this likely creates a cycle of untreated pain and distrust, and that children are suffering unnecessarily as a result. We believe it could be helpful to find new ways to understand children's pain that may not be based on what non-Aboriginal health providers are used to (i.e., pain scales measuring intensity). Rather, we should explore new culture-based approaches to communicating in general, both verbal and non-verbal, and through family members.

Next steps should include researching ways to learn about the family's conceptualization and decision-making process when it comes to pain tolerance and treatment, the child's learned pain expression, and the health provider's interpretation of that pain. Once we have a better understanding of these areas, it would be essential to again partner with community members to spread evidence-based culturally appropriate pain knowledge. The goal would be to reduce the incidence of pain experiences for Aboriginal children and increase their life-long wellness. This paper

provides a forum for discussion and discovery of what is known and what needs to be known about pain expression, interpretation, and management for Aboriginal children. It may be helpful to guide those with an interest in exploring this issue further.

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