

<b>Article details: 2013-0086</b>	
Title	A qualitative investigation into aboriginal children and youth's expression of pain: What's the story?
Authors	Margot Latimer, Allen Finley, Sharon Rudderham, Stephanie Inglis, Julie Francis
<b>Reviewer 1</b>	<b>Michael Moffatt</b>
Institution	Winnipeg Regional Health Authority
General comments	<p>This is a report of a community-based participatory action research project with mainly qualitative methods, carried out in a large Mi'kmaq First Nations community in Nova Scotia. The subject is the elicitation of pain in children and youth, but the main messages are about cross-cultural communication and the historical relationship between western culture (as represented by the health care system) and this group of First Nations people. Readers who work professionally with First Nations people will likely find that the themes uncovered here resonate to many other parts of the country. It is also true that they could have used any other health-related symptom as a focus and likely obtained similar results. There is not a large body of serious research looking at cultural proficiency as it pertains to Canada's health care system and how it serves the 1.3 million Aboriginal people, and as such, the lessons learned here need to be widely disseminated among health professionals.</p> <p>The central thesis in this study is that pain is common among Aboriginal children and youth, that it is often undiagnosed or under-estimated. The results of the quantitative part of the study do suggest that pain is common and is frequently a reason for missing school. This would indeed be cause for concern, not just because of the suffering, or the educational implications, but also because pain is a critical symptom in the diagnostic process for so many illnesses. If we can't communicate with Aboriginal children well enough to elicit pain, then we may frequently delay diagnosis of significant illness.</p> <p>This reviewer is not an expert in qualitative methods, but the study appears to use standard ethnographic techniques. The sample is quite large for a qualitative study. They used purposive sampling methods to assemble focus groups of 76 students across all age spans and smaller numbers of health professionals, teachers and parents. They also conducted interviews with 5 Elders. They seem to have validated themes with community members and participants. There is no reason to doubt that the themes uncovered are an honest representation of the findings.</p> <p>From a clinician's point of view, the findings of most importance can be summarized as: pain is common in this population and may be a source of school absenteeism; stoicism is a prominent cultural characteristic; the Mi'kmaq language has no word for the noun pain; story-telling is an important way of describing symptoms (this takes time and time-is-money in western medicine); Mistrust of health care is common and often reinforced by the way we relate to Aboriginal children and families around pain (and other issues I suspect); numerical and pictorial pain scales are probably not valid in this population; Mistrust translated in to a perception of racial discrimination; Aboriginal children use a variety of non-medical strategies to cope with pain. The authors might want to ensure that the manuscript brings these themes out directly if it is to be published in a clinical journal.</p> <p>In terms of areas for improvement, the tables and quotes in boxes are quite numerous. The quotes do illustrate the themes, but I wonder if some editing could reduce either the number of boxes or the number of quotes?  There seems to be a small inconsistencies between the Abstract and the methods section. The abstract does not reflect the fact that the Elders underwent individual interviews (I think that is my understanding from the methods).  The text, though quite readable, occasionally seems to miss or misuse a word here or there. Without providing an exhaustive list, a few examples are: p13 25 children....with "high pain" - awkward;p11first line "Clinicians said Aboriginal children were shy, are... - changes tense. A careful editing for grammatical construction would be worthwhile.</p> <p>The authors wisely do not suggest solutions. Despite the many very interesting observations they have made, it is not clear how this all fits together and how much of the cultural approach to pain is inherent in their culture versus a response to colonial history. Some of the strategies may be quite appropriate in the circumstances. A wholesale change to more liberal use of western pain treatments might end up with significant complications. Evidence (Fischer B et al. Pain Physician 2012;15:ES191-203) shows that Canadian Aboriginal people are over-represented in the area of opioid abuse. Aboriginal people also suffer from significant</p>

	<p>social and spiritual pain which has been shown to aggravate physical pain. Finally, I would not assume that better management of pain would lead to better school attendance. It might, and would be great if it does, but that needs to be studied carefully.</p> <p>The authors might want to say more about the limitations of the study, and specifically that it is an exploratory foray into the issue of cross-cultural understanding of pain and that further research is needed. Furthermore, it involves only one community. I strongly suspect that findings would be similar elsewhere, but the research has not been done.</p>
<p><b>Author response</b></p>	<p>1. Please include completed COREQ checklist (a reporting guideline for qualitative papers.) This is available at <a href="http://www.equator-network.org/">http://www.equator-network.org/</a>. R. COREQ completed and attached. R. Completed and attached.</p> <p>2. The paper is around 4200 words, excluding boxes and tables. This is more than 1000 words longer than we typically allow in a qualitative paper. As mentioned below, your Interpretation section is probably the best place to make some substantial cuts. Another place would be the methods section. Please be more concise here. R. All sections have been revised and reduced.</p> <p>3. Please avoid editorializing, particularly in the Interpretation. For example: "The messages are consistent but little is being done to change the outcomes." should be removed [Third paragraph of Interpretation. R. These comments have been deleted]</p> <p>4. Please avoid claims of precedence. One such claim is made in the Interpretation section ("This study was the first of its kind in an attempt to understand..."). R. Comments deleted.</p> <p>5. In the Interpretation section, you note: "Some of the Elder's sessions were not audiotaped and themes were captured in field notes after the sessions that may have meant some of the content was missed" – In the methods section, it is implied that none of these sessions were audiotaped. Please clarify. R. This has been clarified on line 22, page 5</p> <p>Title</p> <p>6. The title should be in CMAJ Open style (e.g. Expression of pain in Aboriginal children and youth in New Brunswick: a qualitative study). R. The title has been changed.</p> <p>7. The title could specifically mention the Mikmaq community. R. The community would prefer to be acknowledged as an Atlantic Canadian Mi'kmaq community.</p> <p>Abstract</p> <p>8. The abstract should be included at the beginning of the paper. [It is currently only in the abstract box in ScholarOne.] R. It is now included at the beginning of the paper.</p> <p>9. Please structure the abstract into 4 main sections:</p> <ul style="list-style-type: none"> <li>• Background: Provide the context for the study. Explain the problem or issue (the reason you decided to conduct your study) in the first sentence. State the objective of your study (the question you set out to answer) in the second sentence.</li> <li>• Methods: Include 4 elements: setting, patients, study type or design, and key measurements or outcomes.</li> <li>• Results: Provide data for the key measurements. Describe the data in absolute and relative terms, if applicable. Give confidence intervals for differences where appropriate, or other measures of statistical significance.</li> <li>• Interpretation: Begin with a sentence that answers your research question (What did the study show?). The second sentence should be a brief statement about implications for practice or research (What do the findings mean?). Avoid speculation and generalization.</li> </ul> <p>R. The Abstract has been completely revised to reflect the requested changes see page 2.</p> <p>Introduction</p> <p>10. This section should inform the reader of the topic being studied and provide the context for the research question. The objective of the study should be clearly stated. The section should be no more than two paragraphs.</p> <p>R. The section has been revised to be more concise including the context, objective and is now 2 paragraphs (pages 3-4).</p> <p>Methods</p> <p>11. Thank you for providing additional details on Aboriginals in Canada. Please move this to the Introduction section. R. This has been moved to line 16, page 3.</p> <p>12. The rationale for study methods should be significantly shortened and/or moved to the Interpretation section. R. The rationale for method has been shortened and remains in the methods section line 1, page 6.</p> <p>13. In the Setting and Sample subsection, you note that the study was conducted 500 kms away from the regions tertiary pediatric centre. Please provide a clearer idea as to where the community is located. R. The statement now includes reference to Atlantic Canada, see line 20, page 4.</p> <p>14. Thank you for clarifying that 6 of the 13 HCPs were Aboriginal. Please consider defining which quotes came from Aboriginal physicians, nurses and psychologists are Aboriginal. R.</p>

Since the sample size of health professionals is so small and no one group is larger than 5, we are hesitant to identify specific comments by discipline and Aboriginal status.

15. [Reviewer 1]: The sampling was not clear, for example, statements such as 'sample using a purposive method (by school grade and adult group)' need more explanation. It was not clear exactly who was interviewed singularly or in focus groups/conversation groups. It would help to list the composition of each focus group, the number of single interviews (5?) and how this related to the total group of 114. R. This has now been further clarified on line 4, page 5.

16. [Reviewer 1]: Mention was made that the themes were 'confirmed with participants' – how did this process happen? R. This is now clarified on lines 10-13 page 6.

#### Interpretation

17. The Interpretation section needs to be reorganized to improve flow. Please use of the following subheads (required for CMAJ Open) may be helpful here: Main findings; explanation and comparison with other studies; limitations; and conclusions and implications for practice and future research. This section is currently over 1800 words. Please consolidate using the headings above. R. The section has been extensively revised to improve flow and the headings have been used.

18. [Reviewer 2]: The authors might want to say more about the limitations of the study, and specifically that it is an exploratory foray into the issue of cross-cultural understanding of pain and that further research is needed. Furthermore, it involves only one community. I strongly suspect that findings would be similar elsewhere, but the research has not been done.

R. The limitations have been revised to include these two points. Page 15.

#### References

19. Please use numbers in square brackets for your references (e.g., [1]). R. This has been done.

20. Reference required for "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." [End of first paragraph of Interpretation.] R. This has been revised. See line 13, page 10.

21. Reference required for: "This feeling of not being listened to was also a main theme reported in the Health Council of Canada's Empathy, Dignity, Respect: Creating Cultural Safety for Aboriginal People's 2012 initiative." [Third paragraph of Interpretation.]

R. Reference provided see line 17, page 11.

#### Tables and Figures

22. [Reviewer 2]: The tables and quotes in boxes are quite numerous. The quotes do illustrate the themes, but I wonder if some editing could reduce either the number of boxes or the number of quotes? R. These tables have been edited. It is difficult to know which quotes to cut-the remaining quotes seem to substantiate the themes.

23. Please rename Tables 1 and 3 as Boxes. R. Done

24. [Reviewer 1]: Box 2 needs more work as there are a number of themes and at times the information is contradictory. For example, the box juxtaposes statements saying that Mi'kmaq people cannot express pain through words alongside actual descriptions of pain in words. Perhaps it would be best to divide the statements into two boxes or put in sub-theme headings. R. Box 2 is now identified as Box 4 and it has been revised using this suggestion and now includes 3 subheadings.

25. Thank you for distinguishing between parents and elders. Box 4 still uses the abbreviation CA. Please revise. R. This is done.

26. Box 5 should be renamed to more clearly indicate that it includes health care professionals' comments on how Aboriginal patients respond when asked about pain. R. Done

27. Please renumber tables and boxes. R. Done

Note also that we will need: R. We are preparing these documents to send.

- an author contributors' statement (see our submission checklist for details: [http://www.cmajopen.ca/site/authors/submission\\_checklist.xhtml](http://www.cmajopen.ca/site/authors/submission_checklist.xhtml))

- all authors listed on the title page, with up to 2 degrees each and affiliations

- signed copyright and ICMJE forms from each author

- signed permission to acknowledge (A) each person mentioned in the acknowledgement section (B) and anyone who is named and provided a personal communication