

The ethics of research involving Canada's Aboriginal populations

The recent publication of 2 epidemiologic studies examining Aboriginal populations^{1,2} raises ethical concerns. Neither study describes any consultations with First Nations or Métis community members in the formulation of the research questions, development of the research protocols, interpretation of the data or dissemination of the results. This apparent lack of consultation is particularly problematic given that both studies could have policy implications that would affect First Nations and Métis individuals and communities. A related ethical and methodologic concern is raised by the use of "Aboriginality" as a risk factor in the multivariate analyses of both studies.

As a health research scientist trained in the Western academic disciplines of medicine and public health and as a Métis woman, I respect the efforts of these authors to produce much-needed information on the health of First Nations and Métis peoples. However, I have come to understand that it is only through an approach of mutual understanding, respect and partnership that academic research will be able to contribute to improving the health outcomes in First Nations, Métis and Inuit communities.³⁻⁸

"Aboriginality" is a social construct with little grounding in the day-to-day realities of the heterogeneous groups to which it refers. Tremendous cultural, historical, socioeconomic and political diversity exists between and within these groups. What is shared is the experience of colonization and the resultant legacy of poverty and social stressors. Use of this pan-ethnic term as one of several "risk" variables, while perhaps necessary to achieve adequate study power, devalues the unique experiences of First Nations, Métis and Inuit communities and perpetuates colonial processes of marginalizing or "pathologizing" Aboriginal peoples.

Methodologically, the use of the "Aboriginal" variable in the study by

Tonelli and associates¹ is problematic. Cox regression analysis assumes that the effects of different variables on survival are constant over time and are additive, but I am not sure that these assumptions are met with respect to the "Aboriginality" factor. Rather, there may be an interaction or multiplicative effect between "Aboriginality" and socioeconomic status, for example. In the study by Wenman and colleagues² there are methodologic problems with the way in which ethnicity was determined. In addition, multiple-ethnicity responses, such as Caucasian and First Nations, were excluded, and the study was underpowered because the sample of First Nations and Métis women was insufficient.

The editorial by Alan Cass⁹ does not address the ethical issues raised by the apparent lack of Aboriginal consultation or the ethical problems relating to the use of the pan-ethnic "Aboriginal" category as a risk factor for disease.

If "Aboriginality" is the factor that these scientists are interested in understanding, I suggest that they start by building relationships with one or more First Nations, Métis or Inuit communities. They may be pleasantly surprised by how quickly this approach will provide new insights and perspectives regarding Aboriginal health and medicine more generally.

Janet Smylie

Director, Indigenous Peoples Health
Research Centre
Associate Professor
Department of Community Health and
Epidemiology
University of Saskatchewan
Saskatoon, Sask.

References

1. Tonelli M, Hemmelgarn B, Manns B, Pylpchuk G, Bohm C, Yeates K, et al. Death and renal transplantation among Aboriginal people undergoing dialysis. *CMAJ* 2004;171(6):577-82.
2. Wenman WM, Joffres MR, Tataryn IV, Edmonton Perinatal Infections Group. A prospective cohort study of pregnancy risk factors and birth outcomes in Aboriginal women. *CMAJ* 2004;171(6):585-9.
3. *KSDPP code of research ethics*. Kahnawake Territory, Mohawk Nation (QC): Kahnawake Schools Diabetes Prevention Project; [date unknown]. Available: www.ksdpp.org/code.html (accessed 2004 Nov 17).
4. Royal Commission on Aboriginal Peoples. Appendix E: Ethical guidelines for research. In: *Report of the Royal Commission on Aboriginal Peoples*. Vol 5. Renewal: a twenty-year commitment. Ottawa: The Commission; 1996, updated 2004 Apr 23. Available: www.ainc-inac.gc.ca/ch/rcap/sg/sgmm_e.html (accessed 2004 Nov 17).
5. Inuit Tapirisat of Canada. *Negotiating research relationships: a guide for communities*. Ottawa: Nunavut Research Institute, Inuit Tapirisat of Canada; 1998.
6. Masuzumi B, Quirk S. Dene tracking. *A participatory research process for Dene/Metis communities: exploring community-based research concerns for Aboriginal northerners*. Yellowknife: Dene Nation; 1993.
7. Tri-council policy statement. *Ethical conduct for research involving humans*. Ottawa: Natural Sciences and Engineering Council of Canada, Medical Research Council of Canada, Social Sciences and Humanities Research Council of Canada; 1998. Available: www.ncehr-cnerh.org/english/code_2/ (accessed 2004 Nov 17).
8. United Nations Working Group on Indigenous Populations. 1994/45 draft United Nations declaration on the rights of indigenous peoples. Geneva: United Nations; 1994. E/CN.4/Sub.2/1994/56.
9. Cass A. Health outcomes in Aboriginal populations [editorial]. *CMAJ* 2004;171(6):597-8.

DOI:10.1503/cmaj.1041676

[Dr. Tonelli and 3 coauthors respond:]

We appreciate this opportunity to describe the involvement of Aboriginal communities in the interpretation and dissemination of our research findings.¹ We fully agree that relationships with Aboriginal communities are essential for conducting relevant and helpful investigations of the health of