

Globethics Repository



Culturally safe epidemiology

This page was generated automatically upon download from the Globethics Repository. More information on Globethics see <https://www.globethics.net>. Data and content policy of Globethics Repository see <https://repository.globethics.net/pages/policy>.

Item Type	Article
Authors	Cameron, Mary;Anderson, Neil;Mcdowell, Ian;Ledogar, Robert J
Publisher	Native Counselling Services of Alberta
Rights	With permission of the license/copyright holder
Download date	2026-09-18 16:17:09
Link to Item	http://hdl.handle.net/20.500.12424/176377

CULTURALLY SAFE EPIDEMIOLOGY: OXYMORON OR SCIENTIFIC IMPERATIVE¹

Mary Cameron
Neil Andersson
Ian McDowell
Robert J Ledogar

ABSTRACT

Since the early 20th Century, epidemiological research has brought benefits and burdens to Aboriginal communities in Canada. Many First Nations, Métis, and Inuit continue to view Western research with distrust; quantitative methods are perceived as especially inconsistent with indigenous ways of knowing. There is increasing recognition, however, that rigorous epidemiological research can produce evidence that draws attention and resources to pressing health issues in Aboriginal communities. We present a framework for culturally safe epidemiology, from the identification of research priorities, through fieldwork and analysis, to communication and use of evidence. Modern epidemiology and indigenous knowledge are not inherently discordant; many public health opportunities arise at this interface and good science must begin here too.

Keywords: cultural safety, research methods, indigenous knowledge, validity, intercultural epidemiology

INTRODUCTION

Epidemiologists and other Western scientists have studied health issues of Aboriginal communities in Canada for over a century. Sometimes well-intentioned and sometimes not, this research has brought both benefit and

1. Acknowledgements: We thank the Anisnabe Kekendazone Network Environments for Aboriginal Health Research, the Inuit Community Action Research Team and the communities participating in the Rebuilding from Resilience and Aboriginal Community Resilience to AIDS projects. This article is the product of work funded under the CIHR operating grant 84489: Rebuilding from Resilience — research framework for a randomized controlled trial of community-led interventions to prevent domestic violence in Aboriginal communities.

burden to First Nations, Métis, and Inuit communities; many continue to view research with distrust and suspicion.

To restore confidence in and local ownership of the research process, some scholars have explored alternative approaches that can be more culturally appropriate, including cultural sensitivity frameworks and participatory methods. These call for researchers to increase their cultural awareness and to integrate community perspectives into the research process. These approaches, however, generally fail to call into question certain implicit assumptions about the superiority of the Western scientific paradigm.

Discussion around the adaptation of research methods to the cultural context of those being studied is prominent in the realm of qualitative research, but less so in quantitative research, which is therefore often perceived as unreceptive to alternative epistemologies. As a result, quantitative research, including epidemiology, has benefited little from the development of culturally appropriate methodologies. Still, there is recognition that rigorous quantitative research can draw attention and resources to address pressing health issues in Aboriginal communities. Moreover, rigorous quantitative research addresses many of the questions communities pose about the health of their people.

Beginning with a brief overview of earlier approaches to Aboriginal health research and the emergence of concerns for cultural safety, this paper outlines a framework for culturally safe epidemiological research, raising discussion of points where indigenous and scientific knowledge may intersect or diverge.

EARLIER APPROACHES TO RESEARCH IN ABORIGINAL COMMUNITIES

Health services and health research in Aboriginal communities in Canada have changed substantially over the last several decades. In the early 20th century, when the Canadian government began systematically collecting statistical data on indigenous mortality and morbidity, there were marked health disparities between Aboriginal peoples and the general population in Canada. At that time, efforts to resolve health disparities were minimal, as the federal and provincial governments disagreed over who was legally responsible for the health of indigenous peoples (Young, 1988). The responsibility for Aboriginal health was not clearly addressed in the treaties, the Indian Act, or the British North America Act, leaving action on the part of

government to provide indigenous health services without a clear legal basis (Young, 1988).

After 1944, when the Indian Health Services became a part of the new Department of National Health and Welfare, the Canadian government began playing a much larger role in the health of Aboriginal peoples. This increased expenditures for health services as well as scientific surveys and other health research (MacInnes, 1946).

The increase in Aboriginal health research, encouraged by the government after the Second World War, Young argues, was not altogether altruistic in intent. He claims that government action against the epidemics raging through indigenous communities in the early 20th century was largely to protect neighbouring white communities (Young, 1984). That the provision of health services and research was seen by the government as an integral component of the policy to assimilate Canada's indigenous population is evident from the report of an Indian Agent in 1921: "nothing has a more civilizing effect upon them [Aboriginal peoples] than a display of the white man's skill in healing" (Canada, 1913, cited in Young, 1984). Young (1984) described early intervention to improve indigenous health as "benevolent paternalism."

Not surprisingly, much of the early research on Aboriginal health was led by non-Aboriginal academics or government agents; community input or participation was limited to providing information. This coincided with a lack of indigenous skills in epidemiological and other scientific methods. Several scholars have criticized the underlying paternalistic and colonizing attitudes, which permeated research relations at the time (Bartlett et al., 2007; Browne et al., 2005; Castellano, 2004; Cochran et al., 2008; Mohammed, 2006).

Over time, epidemiological research has made some positive contributions towards improving the health of Canada's indigenous peoples. For example, epidemiological research was crucial in detecting and drawing attention to the soaring rates of infectious disease, such as tuberculosis, among Canada's Aboriginal population in the early 20th century; this recognition brought about extensive government intervention and substantial declines in infectious disease (Hackett, 2005; Wilson and Young, 2008).

The impact of epidemiological and other scientific research, however, has not always been positive. The Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans describes a sensitive balance between harm and benefit in research with Aboriginal communities:

[T]here are historical reasons why Indigenous or Aboriginal Peoples may legitimately feel apprehensive about the activities of researchers. In many cases, research has been conducted in respectful ways and has contributed to the well-being of Aboriginal communities. In others, Aboriginal Peoples have not been treated with a high degree of respect by researchers. Inaccurate or insensitive research has caused stigmatization. On occasion, the cultural property and human remains of Indigenous Peoples have been expropriated by researchers for permanent exhibition or storage in institutes, or offered for sale.

Researchers have sometimes treated groups merely as sources of data, and have occasionally endangered dissident Indigenous Peoples by unwittingly acting as information-gatherers for repressive regimes. Such conduct has harmed the participant communities and spoiled future research opportunities. (The Inter-agency Advisory Panel on Research Ethics, 2009)

Much epidemiological research concerning First Nations, Métis, and Inuit remains firmly embedded in a rigid Western scientific paradigm, categorizing these populations collectively as a “high risk” group. This reinforces negative stereotypes and discrimination, often framing Aboriginal communities as “sick, disorganized and dependent” (Browne et al., 2005; O’Neil et al., 1998).

“Cultural essentialist” is Narayan’s term for depictions of heterogeneous people as homogeneous and unvarying; in fact the communities’ values, interests, ways of life, and moral and political commitments are internally plural and divergent (Narayan, 1998). The cultural essentialist view attributes complex health behaviours to summary “factors” such as ethnicity, minimizing the heterogeneity of such a category (Lynam and Young, 2000). According to Dyck and Kearns (1995, p. 139), “recognition of the fluidity of culture and ethnicity, and the social construction of ‘race’ as a category of difference challenges the continued use of such concepts as explanatory and static variables,” which can perpetuate stereotypical depictions of “lifestyle” and culture-blaming in the analysis. Cultural essentialist perspectives in research also tend to mislead health program and policymakers to focus on interventions at the level of cultural practices while disregarding the role of political processes in the perpetuation of unequal access to health services and other resources (Dyck and Kearns, 1995).

Stratifying results by ethnicity or culture can help to demonstrate some health disparities between Aboriginal communities and the general population in Canada. Analysis of this type has helped to draw attention and resources to the field of indigenous health (King et al., 2009).

Even from a traditional quantitative research perspective, the stratification of heterogeneous groups can pose a dilemma with respect to sample size and statistical power. It is tempting, therefore, to abandon quantitative methods for a more anthropological approach that focuses on the peculiarities of small groups, providing important insights into human functioning.

There is increasing recognition that exclusionary research, in which outside “experts” conduct research *on* a community while excluding those whom the research is intended to benefit, fail to account for cultural contexts and epistemological differences and are therefore ethically flawed and unacceptable to Aboriginal communities. They are also unlikely to improve understanding of the health issues facing Aboriginal peoples in Canada. Some scholars reject the “epistemic authority of Western scientists” (Kuokkanen, 2000; Mohammed, 2006; Smith, 1999), calling for culturally appropriate “decolonizing” research methodologies recognize an “urgent need for the perspective of Indigenous peoples to be adopted and valorized in the research process” (Bartlett et al., 2007).

SOME CONTEMPORARY APPROACHES

Recognition that research across cultures may cause more harm than good has inspired much scholarly discussion on the development of more appropriate theoretical and methodological approaches. “Cultural sensitivity” formed a transition phase in the evolution of approaches to research on Aboriginal peoples. Rogler defined culturally sensitive research as the “interweaving of cultural components and cultural awareness into all phases of the research process” (Rogler, 1989). The cultural sensitivity approach largely calls for visiting researchers to increase their knowledge of the host culture’s beliefs and practices (NAHO, 2008). While this is important, the National Aboriginal Health Organization (NAHO) of Canada recently emphasized that sensitivity is only the “first step towards learning about oneself within the context of one’s interaction or relationship with people of a different culture” (NAHO, 2008).

Some scholars are dissatisfied with the cultural sensitivity approach. Polaschek (1998), for example, argues that cultural sensitivity requires consideration of the “other” culture without challenging researchers to reflect upon how their own culture, social position, or biases may be influencing the research. For Polaschek, cultural sensitivity is superficial in its analysis because it does not require the researcher to acknowledge the social or polit-

ical positioning of a cultural group within a society or the power imbalances that may exist between the researcher and the researched.

Visiting researchers may unintentionally reinforce a power differential between themselves and the community by assuming an authoritative “expert” status in the researcher-researched relationship. This inevitably reduces the researchers’ receptivity to local input and potentially increases cultural risk by hindering community control over the research agenda. Wilson and Neville (2009) suggest that researchers can mitigate cultural risk by possessing a sense of humility; listening and observing before speaking; being willing to recognize the expertise of those being researched; and willing to include the community’s protocols, aspirations, and needs into the research design.

Cultural safety is a more recent alternative to the cultural sensitivity framework. Rooted in postcolonial theory, cultural safety analyzes power imbalances, institutional discrimination, colonization, and colonial relationships in the context of health services, policy, and research (NAHO, 2008). Culturally safe practice involves recognizing the power differentials underlying intercultural interactions and the historical origins of health disparities, including the ways in which colonialism continues to influence the lives and opportunities of marginalized groups.

Cultural safety theory originated among the Maori in New Zealand, expanding to include indigenous groups worldwide as well as immigrants and other ethnic minority groups. Until recently, the incorporation of cultural safety had largely been limited to nursing as a means to improve the quality of care in intercultural contexts (Brascoupé and Waters, 2009; Dyck and Kearns, 1995; Kirkham, 2006; Nursing Council of New Zealand, 2005).

Proponents of a cultural safety approach to nursing believe that health professionals who hold cultural prejudices and other assumptions may place the health of their patients at risk and seriously impair the quality of care (Kirkham, 2006; Nursing Council of New Zealand, 2005; Papps and Ramsden, 1996). Culturally safe care, therefore, requires the nurse to reflect upon his or her own cultural identity and recognize how it might influence his or her nursing practice (Papps and Ramsden, 1996). Cultural safety recognizes that actions and interactions may affirm (culturally safe) or diminish, demean, or disempower (culturally unsafe) the cultural identity and well-being of an individual (Nursing Council of New Zealand, 2005). Thus, in nursing practice, it is the recipient of care who judges whether it is culturally safe (Kirkham, 2006).

The culturally safe nursing movement has influenced other health practitioners working across different cultures, such as policy makers and researchers, to adopt a cultural safety approach. The following section will focus on the application of cultural safety theory to health research.

CULTURALLY SAFE RESEARCH

Cultural safety extends beyond cultural sensitivity to examine the role of age or generation; gender; sexual orientation; occupation and socioeconomic status; ethnic origin or migrant experience; religious or spiritual belief; and disability (Nursing Council of New Zealand, 2005). Thus, cultural safety in research recognizes that health status cannot be simply attributed to a cultural identity; a complex network of intersecting factors influences health. For example, identifying “Aboriginality” as an independent risk factor in an Inuk’s HIV positive status provides little real information. Cultural safety encourages us to consider the multiple underlying factors that may increase Inuit HIV infection, such as gender, gender violence, power gradients in a market economy, and other inequities.

This broader view of causality is in line with the recent shift away from linear models towards a systems approach in which health determinants are viewed as interacting systems. Moving away from the “black box” associated with attributing disease to a single risk factor, McDowell (2008) saw epidemiological analysis as needing to uncover interacting causal layers that contain separate pathways, including both harmful and protective mechanisms.

The concern for cultural safety attempts to dispel cultural stereotypes and discrimination. It shifts away from cultural essentialist approaches that incorrectly portray Canada’s indigenous peoples as homogenous, when this population is made up of some 600 recognized First Nations, scores of Métis, and dozens of Inuit groups coming from quite distinct historical, cultural, and geographic situations.

An increasing number of researchers have referred to, if not used, the cultural safety lens to reflect on their own research practice (Browne et al., 2005; Dyck and Kearns, 1995; Kirkham et al., 2002; Lynam and Young, 2000; Wilson and Neville, 2009). Proponents of culturally safe research agree that researchers should reflect on their own cultural assumptions and analyze critically the impact their theoretical stance has on the knowledge they generate. This includes reexamining how we frame health and its determinants. Culturally safe researchers are cognizant of the historical relationship be-

tween research and Aboriginal communities and, throughout the research process, mindful that some indigenous communities may still associate research with a history of colonialism and suspicion.

The privileging of Western epistemologies and methods in research to the exclusion of other approaches may be ineffective in addressing the health issues facing Aboriginal communities. It can be damaging if researchers misinterpret findings and draw conclusions that portray those researched inaccurately (Wilson and Neville, 2009). To guard against this, concern for the target community's cultural safety should extend throughout the research process from the establishment of the research question to the dissemination of the findings (Wilson and Neville, 2009).

It is not the place of visiting researchers to judge what is culturally safe or unsafe; this can only be determined by the intended target or beneficiaries of the research. Wilson and Neville point out that in reality this is rarely the case and often it is the researcher who decides or determines whether the study has met the criteria for cultural safety (Wilson and Neville, 2009). To ensure the community has the opportunity to evaluate the cultural safety of the research, scholars of the cultural safety school agree that researchers must enable and encourage community involvement throughout the entire research process.

Recognition of the importance of community participation in research is not new. For many years, researchers and Aboriginal peoples alike have identified increased community participation as a crucial component to culturally appropriate research, as demonstrated by widespread advocacy for the OCAP (ownership, control, access and possession) principles (Schnarch, 2004) and the ever-increasing number of studies adopting a "community-based participatory research" (CBPR) framework. CBPR, which encompasses participatory action research (PAR) and other participatory approaches, is

a collaborative process that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change. (Minkler, 2004)

Proponents of these participatory approaches can overstate the advantages and conflate CBPR and PAR with culturally appropriate research. It is also possible to conduct culturally unsafe CBPR, using this as a front for research according to conventional exclusionary methods (Hagey, 1997). Consultation with a community leader or hiring a local research assistant may appear sufficient to satisfy the requirements of CBPR (Hagey, 1997).

Apart from the constraints of qualitative methods that currently dominate the practice of CBPR, the increasing use of a participatory lexicon in research with indigenous communities may, if not accompanied by changes in power relationships, further damage faith in the research process and reinforce suspicion toward outside researchers.

The cultural safety notion of community participation explicitly requires that local or indigenous knowledge, values, and epistemologies be valued equally alongside Western scientific epistemologies and methods and not simply “integrated” into a paradigm otherwise dominated by Western science (Dyck and Kearns, 1995). Thus, culturally safe research attempts to dismantle the conventional power structure between the researchers and the researched, where the former act as information-gatherers and the latter are treated merely as sources of data.

A PLACE FOR QUANTITATIVE METHODS

Qualitative research accommodates the belief that there are multiple realities rather than a single truth and that knowledge is constructed, not discovered (Sale et al., 2002). For this reason, qualitative methods are often perceived to be flexible, open to alternative ways of knowing, easily adaptable to cultural contexts, and encouraging of a high level of community control over the research process (Baum, 1995; Hines, 1993; Johnson and Onwuegbuzie, 2004; Kenny et al., 2004; Sale et al., 2002). Thus implemented, qualitative research may be culturally safe.

That almost all literature on cultural safety is qualitative in nature (Brascoupe and Waters, 2009) reflects the common belief, explicitly stated by Kenny et al. (2004, p. 12), that

Qualitative research methods that include individual and group interviews, focus groups and participant observation are often more compatible [than quantitative methods] with Aboriginal culture.

But not all questions related to health can be answered convincingly by qualitative research.

Quantitative research, including epidemiology, is often associated with positivism and methods that follow rigid and structured protocols, recognize a single truth or reality, and are conducted in a controlled manner by “objective researchers” to minimize undue influence or bias (Baum, 1995; Hines, 1993; Johnson and Onwuegbuzie, 2004; Kenny et al., 2004; Sale et al., 2002). Thus framed, epidemiology appears antithetical to cultural safety.

Kenny et al. (2004, p. 12) assert that although

Quantitative data help in the allocation of scarce resources ... the past has shown that research methods that focused solely on quantitative methodologies are not always conducive to 'the way things are done' in Aboriginal contexts.

Some authors question use of qualitative and quantitative methods in the same study. Sale believes that the increasingly popular “mixed methods” approach, combining incommensurate qualitative and quantitative methods, is a flawed effort to harmonize opposing philosophies concerning the nature of truth and reality. She argues that mixing research methods across paradigms fails to meet the standards of either approach. For her, attempts to introduce rigidity and objectivity to qualitative methods runs against the qualitative principle that knowledge is subjective and merely reflects the interpretive lens of the researcher. Meanwhile, accepting subjectivity into quantitative methods inevitably introduces bias, which epidemiologists so adamantly intend to minimize (Sale et al., 2002).

These dilemmas can arise when researchers adopt what McDowell and McLean termed a “hierarchical” approach to combining qualitative and quantitative methods in which one method is treated as primary and the other as adjunct, included to amplify the impression provided by the primary (McDowell and MacLean, 1998).

Not everyone sees the difference between qualitative and quantitative methods in such stark terms. Andersson and colleagues (1989) described a fundamentally epidemiological research process that consists of several moments, some requiring quantitative methods and others qualitative. They proposed that the qualitative-quantitative question is best approached by parsing the research process into moments, some of which are qualitative and some quantitative. This can be seen as “partnership” in which qualitative and quantitative methods are treated as equal but contrasting partners (McDowell and MacLean, 1998).

We believe that selection of study methods should be driven by the research question; drawing exclusively on qualitative or quantitative methods is inadequate to satisfy most research questions. Study of a single phenomenon using multiple methodological approaches requires clarity about when each method is in play; mixed method refers to the timing of high quality qualitative moments, followed by high quality quantitative moments. It is not a hybrid of qualitative and quantitative.

The challenge of culturally safe epidemiology adds complexity. Parallel to the quantitative–qualitative debate is the divide between indigenous and Western scientific knowledge, often believed to be associated with qualitative and quantitative characteristics, respectively. While some researchers believe indigenous and Western scientific knowledge are incompatible, Agrawal argues that the distinction may be somewhat artificial (Agrawal, 1995). Although there are

striking differences between philosophies and several forms of knowledge commonly viewed as either indigenous or Western ... we may also discover that elements separated by this artificial divide share substantial similarities. (Agrawal, 1995, p. 3).

That there are important distinctions between epistemological systems does not mean that there is no place for the use of Western scientific methods in indigenous protocols, or vice versa.

A first principle of intercultural health research is that the epistemological systems are rarely mutually exclusive in all aspects. If the different systems meet on a plane of mutual respect, including noninterference with sacred knowledge and acknowledgement of intellectual property, it is possible to establish an interface in which neither indigenous nor Western scientific protocols are compromised. This might be called *culturally safe space*, akin to what others have called *ethical space* (Poole, 1972). With a common goal to attain understanding and knowledge that is directly applicable to improving the health of the community, Western scientists can support indigenous communities with research methods and protocols that do not undermine cultural integrity.

There are several theoretical and practical reasons why quantitative scientific research, including epidemiology, should be culturally safe. Some research questions posed by communities require quantitative methods. Recent questions posed by communities in CIET's community support program include "Is local industry increasing our risk of cancers?" or "How common are sexually transmitted infections in our community?" or "Is what we're doing to prevent domestic violence in our community working?"

These requests for research support all involve quantifying occurrence and exploring cause and effect through quantitative measures of association. As these processes were initiated by a request from the communities, this information can be pivotal in improving health and in efforts to attract attention to the needs and health priorities of the community.

The supposed absolute incompatibility between indigenous and Western knowledge may also be unfounded because it “seeks to separate and fix in time and space (separate as independent and fix as stationary and unchanging) knowledge systems that can never be so separated or fixed” (Agrawal, 1995, p. 3). There is no doubt that scientific knowledge is continuously advancing and evolving and there is little reason to assume that indigenous knowledge is any different. The belief that indigenous knowledge is fixed in time and space stems from an incomplete perspective on the ethnogenesis of indigenous peoples — the process by which indigenous groups have come to be understood by themselves and others as ethnically distinct (Roosens, 1989; Taylor, 1979).

Yancey and other scholars (Nagel, 1994; Roosens, 1989; Yancey et al., 1976) denounce the assumption that ethnicity is influenced and defined purely by a common heritage, tradition, or nationality that a group carries from one generation and place to another. These scholars alternatively propose that ethnic boundaries and features, including indigenous knowledge, can also be shaped, modified, and reconstructed by contemporary demographic, political, social, and economic processes and therefore cannot be considered fixed in time and place.

A FRAMEWORK FOR CULTURALLY SAFE EPIDEMIOLOGY

To understand the possibilities for conducting culturally safe epidemiology it helps to parse the research process, breaking it up into distinct methodological moments: framing the issue, ethical review, funding, study design, review of existing knowledge, questionnaire development, sampling and recruitment, data collection and management, data analysis, interpretation of results, communication and application of evidence. The following sections outline these moments, from identification of research priorities to the application of evidence, highlighting areas where scientific and indigenous interests may interface or diverge.

FRAMING THE ISSUE

Culturally safe research would usually begin with a request from a community or, where it is the outside agency that initiates the research, consultation with community members to understand how they frame the issue. Most published epidemiological research in Aboriginal communities has been initiated by an external academic institution or government agency with their

own research agendas and their own framing of the issue. Among other things, this often involves researchers entering the community to understand a “health problem among Aboriginal peoples.” This raises immediate issues of cultural safety *and* scientific validity.

Framing the issue in an essentialist way (“Aboriginal”) inappropriately generalizes First Nations, Métis, and Inuit. Culturally safe research responds to requests for research coming from and designed specifically for each particular group, be it a First Nation or group of First Nations, Métis, or Inuit, each with its unique experiences and priorities. This makes it much more likely that interventions based on the research findings will be meaningful and relevant to the community or communities that requested it. It also increases the scientific validity of the research, ensuring the results more accurately reflect the realities of the target population and diverse subpopulations.

Framing health issues as “problems” with “risk factors” can also reinforce unhelpful stereotypes of First Nations, Inuit, or Métis as a sick, troubled population that is dependent on external help. This does not resonate with communities working towards greater self-determination and control over their own affairs. A focus on resilience, defined as “the means by which people choose to use individual and community strengths to protect themselves against adverse outcomes and to build their future” (Andersson et al., 2008, p. 94), is more acceptable to research participants who may feel more comfortable completing a questionnaire that emphasizes their strengths rather than risks. A strengths-based approach may simultaneously increase the cultural safety of the research and decrease selection bias by improving response rates.

Framing the issue is a research moment preeminently suited to qualitative methods. That process of consultation should lack nothing in the thoroughness that can be achieved by the best managed qualitative research. Cognitive mapping, for example, allows community members to express their perspectives and frame their issue on their own terms by mapping out concepts and causal links contributing to the outcome of interest. At the planning stage, such an exercise enables research partners to identify priorities and objectives. We discuss fuzzy cognitive mapping in a later section.

ETHICAL REVIEW

Another consideration in culturally safe research is the evaluation of the study by a research ethics board (REB) cognizant of cultural safety. Academic research involving humans and all research funded by the Canadian Treasury (for example via the Canadian Institutes for Health Research) must receive

approval from a REB before the study can begin. Research ethics boards aim to protect the rights and welfare of the participants and focus primarily on free and informed consent, privacy and confidentiality, and a fair distribution of benefits and burdens.

Scientific validity is a critical factor in ethical review since research must first be scientifically sound before it can be considered ethically acceptable (Freedman, 1987). For instance, if the methods are unable to answer the research question, the results become meaningless and certainly provide no benefit to the participants or their community.

For research involving Aboriginal peoples, many REBs have added special considerations and guidelines to which researchers are expected to adhere (The Interagency Advisory Panel on Research Ethics, 2009). Increasingly, Aboriginal communities are forming their own review boards to approve the research proposal whether or not it is already approved by another board. This is analogous to the guidance given in the International Guidelines for Ethical Review of Epidemiological Studies developed by the Council for International Organizations of Medical Sciences, which recommends that studies sponsored in one country but conducted in another satisfy the ethical standards of the host community in addition to the standards of its sponsor (CIOMS, 2002).

Local review committees often examine factors that the committee of an academic institution may or may not consider. This includes the relevance of the research question to local priorities, the potential burden on community resources, the cultural appropriateness of the methodology, and other considerations of cultural safety.

Balancing conflicting demands from institutional review boards and local Aboriginal committees can be difficult. While a university REB may expect the methods and instruments to be finalized and submitted along with the ethics application, an Aboriginal process may require a greater degree of flexibility and openness to input from local stakeholders and adaptation to cultural context throughout the research process. It can be difficult to persuade a university ethics committee that the community will take an active part in developing a questionnaire, for example, when they are used to seeing a fully developed questionnaire prior to their approval to initiate contact with the community. This usually requires a separate conditional approval for design consultations.

Without harmonization between the institutional and Aboriginal ethics review processes, it can be a challenge to satisfy requirements of scien-

tific validity and cultural safety. Notwithstanding recent changes to the Tri-Council Policy Statement reflecting the widespread concern about inappropriate research in Aboriginal communities, there is often little recognition among REBs of the complexity involved in conducting research that is at once ethically sound, scientifically rigorous, and culturally safe (Flicker et al., 2007; Khanlou and Peter, 2005). The Tri-council guidelines are directed entirely at researchers “going in” to communities, rather than to researchers involved in their own communities.

FUNDING

The conditions under which research is funded constitute an important factor in the balance of cultural safety and scientific validity. Decisions by scientific bodies that fund large grants are mostly based on the credibility of the key researcher, the importance of the research question, and whether the proposed methods are adequate to answer the research question. Funders of epidemiological research expect that researchers will follow the scientific protocol outlined in the original funding proposal, so concerns about cultural safety have to be handled up front, at the protocol stage.

To recognize the unique circumstances of research with Aboriginal communities, the Canadian Institutes for Health Research (CIHR) recently released its *Guidelines for Health Research Involving Aboriginal People*, recommending a participatory approach to Aboriginal health research (CIHR, 2007). To enable researchers to meet these guidelines, CIHR funding policies will need to allow for the additional resource requirements that often accompany research protocols designed to be both culturally safe and scientifically sound. A number of researchers have cited a discrepancy between the time and financial resources required to conduct research in a culturally safe way and the amount of funding that is made available for such projects (Anderson et al., 2003; Castellano, 2004; Greenhill and Dix, 2008; Shreffler, 1999).

Although research grants often include funds to hire local research assistants or data collectors on a temporary or part-time basis, there is rarely enough to permit full-time participation, which may lead the community to feel disempowered and lose interest. Fortunately, there is some indication that the situation is improving as CIHR has begun investing in the research process through development grants that help to fund partnership building and research planning. The work of CIET in Canada illustrates how a series of projects supported by different funding envelopes can be aligned to the advantage of communities (Andersson and Ledogar, 2008).

Still, much progress is to be made before researchers and communities have the resources needed to maintain cultural safety throughout the research process.

Another consideration is the additional pressure that culturally safe research may place on the resources of the community. The equal distribution of power that is central to culturally safe research brings both opportunity and cost to the community as well as the researchers (Brascoupé and Waters, 2009). Greater control over the research process means greater responsibility, which can be burdensome to the community. This has to be offset by the advantages to the community, which are usually more tangible with community-initiated research than with externally initiated research.

In the past, researchers have used this as an excuse to carry on without local input (Hagey, 1997). Instead, this should prompt researchers to consider whether extra resources can be secured, if activities should be postponed until the community is ready, or if the study is appropriate or even needed at all.

STUDY DESIGN

The nature of the research question posed by the community should set the research design. This is a sufficient basis to question the idea that culturally safe research must apply qualitative methods or even that qualitative research is inherently culturally safe. Suppose, for example, that a community is concerned about the impact of their efforts to reduce domestic violence. If the interest is how the programs can affect the lives of individual survivors of domestic violence, a qualitative design using unstructured interviews is an obvious choice. If the interest is to demonstrate to government and other decision that the programs reduced the occurrence of domestic violence, and that they require more funding, a robust quantitative design would be in order.

Among quantitative designs, randomized controlled trials (RCTs) are considered to produce the highest quality of evidence in the hierarchy of research designs (Concato et al., 2000). Ill-suited to the investigation of environmental health concerns, RCTs are especially useful in demonstrating the effectiveness of interventions to attract resources (Johnson, 1997). But the rigorous scientific study protocol in this design requires special consideration for issues of cultural safety. A systematic review of research in Aboriginal communities in Australia found very few studies had a randomized controlled trial design (Morris, 1999). The author of the review suggests as possible explanations a lack of local expertise, inadequate resources

and infrastructure, and insufficient sample sizes in rural and remote communities.

The article by Andersson and colleagues in this issue describes a randomized community controlled trial on domestic violence that is led by 12 Aboriginal women's shelters across Canada (Andersson et al., 2010). The trial evaluates locally developed interventions to reduce domestic violence in Aboriginal communities. In order to influence decision makers and to obtain the resources they need, communities recognized that hard quantitative evidence was required to demonstrate that the programs were effective and deserved financial support. Drawing random numbers from a hat, directors of women's shelters allocated themselves to two waves of intervention, the second wave serving as controls for the intervention in the first wave. This example illustrates how RCTs can be run by Aboriginal communities, investigating an issue they consider to be a high priority, in full cultural safety.

REVIEW OF EXISTING KNOWLEDGE

Most high quality research entails a literature review of published material on the subject of interest. It seems reasonable to question the cultural safety of a review that is limited to Western scientific knowledge. Most reviews of published work are by definition limited to Western scientific knowledge, when a great deal of valuable knowledge exists at the community level.

Just as one might follow a rigorous protocol to review scientific literature, a review of indigenous knowledge requires a rigorous protocol. One promising method is cognitive mapping. This is a graphical representation of expert knowledge on the relationships between elements of a system or issue, comprised of concept nodes and causal links, which can be weighted according to relative importance (Khan and Quaddus, 2004). Thus weighted, introducing a "fuzzy" aspect, fuzzy cognitive maps (FCM) can be a useful representation of otherwise unstructured knowledge about causalities (Khan and Quaddus, 2004).

Fuzzy cognitive mapping is commonly applied as a group decision support tool to better understand the complexity of factors contributing to a particular outcome or decision. FCMs have helped to assess clinical decision-making tasks, such as medical diagnosis, in hospitals and other health care settings where the "experts" are physicians and other health professionals (Papageorgiou et al., 2009; Stylios et al., 2008).

In culturally safe epidemiological research, FCM may be an effective tool to review local knowledge and beliefs around a community health issue. For

example, Giles and colleagues (2007) applied FCM to understand the epidemiology of diabetes in a Mohawk community, contrasting the local belief system around diabetes to that of Western science. This expert knowledge, based on an intimate understanding of the local realities, can go on to inform various stages of the research process, including the formulation of hypotheses, questionnaire development, and even data analysis.

QUESTIONNAIRE DEVELOPMENT

The development of a research questionnaire is often informed by previous research; the benefits include prior validation and comparability implicit in standards-based instruments. The resulting questionnaire may account for health determinants associated with the outcome of interest in previous epidemiological studies.

Often, however, participating communities have hypotheses of their own that have not been considered, let alone measured and tested. Members of the study population likely face the realities of the issue under investigation on a daily basis and, as a result, have a well-informed understanding of the associated and potentially contributing factors and contexts. Few researchers, however, consult with community members during questionnaire development.

When consultation does occur, participation is often limited to a local ethical review committee that assesses the final draft of the questionnaire to ensure it is culturally appropriate and ethically sound. By this time, however, the researchers have already finalized the objective and much of the content of the questionnaire and it may be too late for the researchers to address the more fundamental concerns of the community. If the community is engaged and working alongside the researchers from the onset, the objectives and development of the questionnaire can be both culturally safe and scientifically sound.

Parsing the questionnaire development into several steps allows community participation in setting the research question or the conceptual framework of the enquiry; with this in hand, existing standard questions can be applied for many of the community-led categories. Further consultation followed by translation and back-translation helps to verify the relevance of the standard question.

SAMPLING AND RECRUITMENT

Conventional Western scientific wisdom posits that a large, randomly selected sample will ordinarily be representative for purposes of an epidemio-

logical study. In many Aboriginal communities, particularly in rural or remote regions, immediate logistical problems arise with this sampling strategy. The situation is still more complicated where “cultural access” is a major issue. People who are easy to reach, who are more likely to respond, and who are open to scientific research are seldom those most affected. Some members of a population are often hard to reach by conventional random sampling methods. In many cases, this hidden population is of utmost importance in understanding the health issue.

In the case of the randomized controlled cluster trial on domestic violence (Andersson et al., 2010), for example, it will be important to include hard-to-reach members of the community such as the disabled, temporary migrants, or violent offenders. One reason is that reaching this “hidden” population may be crucial to understanding the causes and effects of domestic violence in the community. Another reason is that the inclusion of hard-to-reach populations in the study is important to capture the diversity of the community, achieving a more truly representative sample.

Undersampling of some subgroups means a representative sample may not always be achieved. The rationale for random sampling can be difficult to explain to a community, Aboriginal or otherwise. Scientifically rigorous, culturally safe researchers may need to draw on alternative methods — for example, universal coverage — to increase the size and representativeness of a sample and appreciate local expertise in the composition and distribution of the population to improve the scientific validity and cultural safety of the sampling and recruitment process.

DATA COLLECTION AND MANAGEMENT

With household surveys and interviews, the greatest interaction between the researchers and the participants occurs during data collection and management, rendering this step in the research process especially prone to threats to both internal validity and cultural safety. For example, an interviewer may unknowingly bias a participant’s answer by influencing how the question is posed or clarified. Similarly, during data entry, the recording of unclear responses may be subject to the researcher’s interpretation. Conventional research follows a standardized protocol to capture the participants’ responses accurately without exerting influence or bias. Yet this protocol must also respect individual differences in comprehension, and respect community preferences.

One approach to achieving this balance is to train community-based researchers (CBRs), who have insight into the local culture. This has ad-

vantages and disadvantages. Community members conducting research in their own community may feel more invested in the success of the research, and therefore be highly committed to following local protocols. However, CBRs may find it difficult to remain impartial in their own community and unknowingly introduce bias into the research process. In addition, when researching sensitive issues, such as domestic violence, the presence of local interviewers may reduce disclosure. CIET works around this by exchanging CBRs between communities, allowing participants to be interviewed by someone like themselves, but from a distant if similar community.

A participatory approach is not appropriate for all stages of research. Certain steps must be closed to participatory input or opinion. In data entry, for example, the researcher must enter the data according to a rigid protocol developed with prior consultation, including double data entry and validation of key strokes, without interpretation.

DATA ANALYSIS

Data analysis is one of the most important and most challenging steps in conducting scientifically rigorous, culturally safe research. Conventional statistical methods may not be appropriate or relevant in the community setting. One reason is that conventional (frequentist) statistics do not formally integrate existing indigenous or local knowledge into statistical analysis, which communities may perceive to be exclusionary and culturally unsafe. The conventional approach that combines analysis and inference — rejecting a null hypothesis through significance testing — is not intuitive, participatory, or mindful of knowledge beyond the variables being tested.

Bayesian approaches formally incorporate pre-existing evidence and beliefs as a prior distribution of probabilities; this offers a useful strategy to bridge local and scientific knowledge formally into statistical analysis. Several efforts are under way to translate fuzzy cognitive maps into Bayesian belief networks, using local knowledge and weighting of concepts to generate locally informed prior distributions that researchers can integrate formally into data analysis. This would allow the analysis to be conditioned, in a very real sense of the term, by indigenous knowledge.

Even where this is not possible, it is almost always possible to separate the analysis, seen as the mechanical if skilled “crunching” of data into summary parameters, and interpretation, the giving of meaning to these summaries. This fits with a Bayesian approach to analysis — separate steps for analysis and interpretation — even if it does not apply Bayesian statistics.

INTERPRETATION OF RESULTS

When communities seek the expertise of epidemiologists, they often want to answer a question of causality. Yet determining the cause of health outcomes is difficult and in most cases impossible. Although detecting associations among variables is central to the science of epidemiology, there are no fixed criteria to determine whether an association is causal; even the “gold standard” randomized controlled trial can be insufficient. Epidemiologists have long recognized that no single set of criteria demonstrates causality, but most agree on a minimum set of measures that increase confidence in an association hypothesized to be causal. These include minimizing the possibility that the association is due to chance, confounding, or biases — considerations of analysis more than of interpretation.

Culturally safe epidemiology implies a mature analysis where these issues have received due attention. From that point on, usually interacting with the supporting epidemiologist, communities and other stakeholders should be involved in the interpretation of research findings to inform locally relevant decision making. One advantage is that emerging recommendations are more likely to reflect the community’s true needs, and what is feasible in the setting.

COMMUNICATION AND APPLICATION OF EVIDENCE

Without community control over research, data and results may be misused, resulting in culturally unsafe communication and application of evidence, which may perpetuate the concern that research continually portrays communities in a negative light. Few community members and advocates would agree that research ends with academic conferences and publications in scientific journals. While they may see the merit in communicating the results to press for new programs or resources, a common concern is that negative results will stigmatize the community. It is not uncommon that First Nations, Inuit, and Métis prefer to restrict the application of evidence to within their own communities.

CIET has called this stage of the research SEPA (socializing evidence for participatory action), a communication and planning process that enables the integration of different voices from the community into planning to support an increasingly informed engagement and mobilization around priority issues in the community (<http://www.ciet.org/en/documents/methods/200781612224.asp>). SEPA differs from social marketing, social advocacy, and social mobilization. Certain social marketing tools may be used at the

dissemination stage of SEPA, but they are not inherently part of the process. Some elements of social mobilization are present in SEPA — dialogue and action at the level of government, public services, and communities, and between these spheres — but this mobilization seeks to avoid the pitfalls of social manipulation. It is a way of raising collective awareness and interest around the issues and the evidence, contributing to an increasingly informed, self-sustained environment for participatory action and change.

The key to culturally safe communication and use of evidence lies in the design. No protocol for the communication of evidence can be defined *a priori* as culturally safe. Communities should have the opportunity to participate in the interpretation and discussion of the research products and, based on that, establish how the results should be communicated and integrated into decision making.

CONCLUSION

We argue that modern epidemiology should play a role in addressing health issues facing Aboriginal communities and should be included in the movement towards culturally safe research. We maintain that scientific and indigenous knowledge are not mutually exclusive and that epidemiological research in Aboriginal communities can and should be both culturally safe and scientifically sound. A modern study's scientific validity can often depend on indigenous knowledge. We propose that rigour and methodological discipline are essential to cultural safety. While cultural safety literature is typically preoccupied with the epistemological biases and methods of nonindigenous researchers, indigenous researchers could find the same concerns relevant in their adaptation of Western scientific methods to their own priority concerns. It is at the interface in which neither indigenous nor Western scientific protocols are compromised that a culturally safe space can be achieved.

The challenge, of course, is to develop research methods and protocols that locate these culturally safe spaces. In a recent literature review on cultural safety and its applicability to the Canadian context, Brascoupe and Waters concluded that “the practicalities of cultural safety as an outcome rather than a concept have yet to be realized” (Brascoupe and Waters, 2009, p. 27). Indeed, the literature on cultural safety has focused mainly on theory rather than practical applications. Qualitative and quantitative researchers alike must now collaborate with communities to jointly develop scientifically and culturally safe methods and protocols. This may be more chal-

lenging for quantitative researchers, but it is achievable. We have outlined some of the challenges and opportunities for culturally safe research protocols while identifying areas in need of further investigation.

After the rocky historical relationship between Aboriginal communities and scientific research, application of cultural safety theory to research can help to restore trust and to increase the stake that Aboriginal communities have in their own research. The principles of culturally safe research may also be relevant to other populations that feel demeaned, disempowered, or misunderstood through research. For example, the methodology of research on health issues facing immigrants, youth, or sex trade workers is rarely informed by contributions from the “target” community.

REFERENCES

- Agrawal, A. (1995). Indigenous and scientific knowledge: Some critical comments. *Development and Change*, 26(3), 413-439.
- Anderson, J., Perry, J.A., Blue, C., Browne, A., Henderson, A., Khan, K.B., et al. (2003). “Rewriting” cultural safety within the postcolonial and postnational feminist project: Toward new epistemologies of healing. *Advances in Nursing Science*, 26(3), 196-214.
- Andersson, N., Martinez, E., Cerrato, E., Morales, E. and Ledogar, R.J. (1989). The use of community-based data in health planning in Mexico and Central America. *Health Policy and Planning*, 4(3), 197-206.
- Andersson, N., Shea, B., Archibald, C., Wong, T., Barlow, K., and Sioui, G. (2008). Building on the resilience of aboriginal people in risk reduction initiatives targeting sexually transmitted infections and blood borne viruses. *Pimatisiwin: Journal of Aboriginal and Indigenous Community Health*, 6(2), 89-110.
- Andersson, N. and Ledogar, R.J. (2008). The CIET Aboriginal youth resilience studies: 14 years of capacity building and methods development in Canada. *Pimatisiwin: Journal of Aboriginal and Indigenous Community Health*, 6(2), 65-88.
- Andersson, N., Sioui, G., Shea, B., Harper, A., McGuire, P., et al. (2010) Rebuilding from resilience: Research framework for a randomized controlled trial of community-led interventions to prevent domestic violence in Aboriginal communities. *Pimatisiwin: Journal of Aboriginal and Indigenous Community Health*, 8(2), 95-124.
- Bartlett, J.G., Iwasaki, Y., Gottlieb, B., Hall, D., and Mannell, R. (2007). Framework for aboriginal-guided decolonizing research involving Métis and First Nations

- persons with diabetes. *Social Science & Medicine*, 65(11), 2371–2382.
- Baum, F. (1995). Researching public health: Behind the qualitative-quantitative methodological debate. *Social Science & Medicine*, 40(4), 459–468.
- Brascoupé, S. and Waters, C. (2009). Cultural safety: Exploring the applicability of the concept of cultural safety to aboriginal health and community wellness. *Journal of Aboriginal Health*, 5(2), 6–41.
- Browne, A.J., Smye, V.L., and Varcoe, C. (2005). The relevance of postcolonial theoretical perspectives to research in aboriginal health. *Canadian Journal of Nursing Research*, 37(4), 16–37.
- Canada. (1913). Sessional papers. 27, p. 130.
- Castellano, M.B. (2004). Ethics of aboriginal research. *Journal of Aboriginal Health*, (January), 99.
- Canadian Institutes for Health Research (CIHR). (2007). *CIHR Guidelines for Health Research Involving Aboriginal People*. Ottawa, ON. Retrieved from: www.cihr-irsc.gc.ca/e/documents/ethics_aboriginal_guidelines_e.pdf
- Council for International Organizations of Medical Sciences (CIOMS). (2002). *International Ethical Guidelines for Biomedical Research Involving Human Subjects*. Geneva. Retrieved from: http://www.cioms.ch/frame_guidelines_nov_2002.htm
- Cochran, P.A.L., Marshall, C.A., Garcia-Downing, C., Kendall, E., Cook, D., McCubbin, L., et al. (2008). Indigenous ways of knowing: Implications for participatory research and community. *American Journal of Public Health*, 98(1), 22.
- Concato, J., Shah, N., and Horwitz, R.I. (2000). Randomized, controlled trials, observational studies, and the hierarchy of research designs. *The New England Journal of Medicine*, 342(25), 1887.
- Dyck, I. and Kearns, R. (1995). Transforming the relations of research: Towards culturally safe geographies of health and healing. *Health and Place*, 1(3), 137–147.
- Flicker, S., Travers, R., Guta, A., McDonald, S., and Meagher, A. (2007). Ethical dilemmas in community-based participatory research: Recommendations for institutional review boards. *Journal of Urban Health*, 84(4), 478–493.
- Freedman, B. (1987). Scientific value and validity as ethical requirements for research: A proposed explication. *IRB: Ethics and Human Research*, 9(6), 7–10.
- Giles, B.G., Findlay, C.S., Haas, G., LaFrance, B., Laughing, W., and Pembleton, S. (2007). Integrating conventional science and aboriginal perspectives on diabetes using fuzzy cognitive maps. *Social Science & Medicine*, 64(3), 562–576.

- Greenhill, J. and Dix, K. (2008). Respecting culture: Research with rural aboriginal community. In: P. Liamputtong, ed., *Doing Cross-cultural Research: Ethical and Methodological Perspectives*. Attadale, AU: Springer, pp. 49–60.
- Hackett, P. (2005). From past to present: Understanding first nations health patterns in an historical context. *Canadian Journal of Public Health*, 96, 17–21.
- Hagey, R.S. (1997). Guest editorial: The use and abuse of participatory action research. *Chronic Diseases in Canada*, 18(1), 1–4.
- Hines, A.M. (1993). Linking qualitative and quantitative methods in cross-cultural survey research: Techniques from cognitive science. *American Journal of Community Psychology*, 21(6), 729–746.
- Johnson, K.C. (1997). Randomized controlled trials as authoritative knowledge: Keeping an ally from becoming a threat to North American midwifery practice. In: R.E. Davis-Floyd and C.F. Sargent, eds., *Childbirth and Authoritative Knowledge: Cross-cultural Perspectives*. Berkeley and Los Angeles: University of California Press, pp. 350–365.
- Johnson, R.B. and Onwuegbuzie, A.J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher*, 33(7), 14.
- Kenny, C., Faries, E., Fiske, J.A., and Voyageur, C. (2004). *A Holistic Framework for Aboriginal Policy Research*. Ottawa: Status of Women Canada.
- Khan, M.S. and Quaddus, M. (2004). Group decision support using fuzzy cognitive maps for causal reasoning. *Group Decision and Negotiation*, 13(5), 463–480.
- Khanlou, N. and Peter, E. (2005). Participatory action research: Considerations for ethical review. *Social Science & Medicine*, 60(10), 2333–2340.
- King, M., Smith, A., and Gracey, M. (2009). Indigenous health part 2: The underlying causes of the health gap. *The Lancet*, 374(9683), 76–85.
- Kirkham, S.R. (2006). Cultural safety in Aotearoa, New Zealand. *Contemporary Nurse: A Journal for the Australian Nursing Profession*, 22(2), 333–334.
- Kirkham, S.R., Smye, V., Tang, S., Anderson, J., Blue, C., Browne, A., et al. (2002). Rethinking cultural safety while waiting to do fieldwork: Methodological implications for nursing research. *Research in Nursing & Health*, 25(3), 222–232.
- Kuokkanen, R. (2000). Towards an “Indigenous paradigm” from a Sami perspective. *Canadian Journal of Native Studies*, 10(2), 411–436.
- Lynam, M.J. and Young, R.A. (2000). Towards the creation of a culturally safe research environment. *Health*, 4(1), 5.

- MacInnes, T.R.L. (1946). History of Indian administration in Canada. *The Canadian Journal of Economics and Political Science*, 12(3), 387–394.
- McDowell, I. (2008). From risk factors to explanation in public health. *Journal of Public Health*, 30(3), 219.
- McDowell, I. and MacLean, L. (1998). Blending qualitative and quantitative study methods in health services research. *Health Informatics Journal*, 4(1), 15.
- Minkler, M. (2004). Ethical challenges for the “outside” researcher in community-based participatory research. *Health Education & Behavior*, 31(6), 684.
- Mohammed, S.A. (2006). Moving beyond the “exotic”: Applying postcolonial theory in health research. *Advances in Nursing Science*, 29(2), 98–109.
- Morris, P.S. (1999). Randomised controlled trials addressing Australian-Aboriginal health needs: A systematic review of the literature. *Journal of Paediatrics and Child Health*, 35(2), 130–135.
- Nagel, J. (1994). Constructing ethnicity: Creating and recreating ethnic identity and culture. *Social Problems*, 41(1), 152–176.
- National Aboriginal Health Organization (NAHO). (2008). *Cultural Competency and Safety: A Guide for Health Care Administrators, Providers and Educators*. Ottawa: National Aboriginal Health Organization.
- Narayan, U. (1998). Essence of culture and a sense of history: A feminist critique of cultural essentialism. *Hypatia*, 3(2), 86–106.
- Nursing Council of New Zealand. (2005). Guidelines for cultural safety: The treaty of Waitangi and Maori health in nursing education and practice. Wellington, NZ: Nursing Council of New Zealand.
- O’Neil, J.D., Reading, J.R., and Leader, A. (1998). Changing the relations of surveillance: The development of a discourse of resistance in aboriginal epidemiology. *Human Organization*, 57(2), 230–237.
- Papageorgiou, E.I., Papandrianos, N., Karagianni, G., Kyriazopoulos, G., and Sfyras, D. (2009). Fuzzy cognitive map based approach for assessing pulmonary infections. In: *Lecture Notes in Computer Science*. Berlin: Springer, pp. 109–118).
- Papps, E. and Ramsden, I. (1996). Cultural safety in nursing: The New Zealand experience. *International Journal for Quality in Health Care*, 8(5), 491–497.
- Polaschek, N.R. (1998). Cultural safety: A new concept in nursing people of different ethnicities. *Journal of Advanced Nursing*, 27(3), 452.
- Poole, R. (1972). *Towards Deep Subjectivity*. New York: Harper & Row.

- Rogler, L.H. (1989). The meaning of culturally sensitive research in mental health. *American Journal of Psychiatry*, 146(3), 296–303.
- Roosens, E. (1989). *Creating Ethnicity: The Process of Ethnogenesis*. Newbury Park, CA: SAGE publications.
- Sale, J.E.M., Lohfeld, L.H., and Brazil, K. (2002). Revisiting the quantitative-qualitative debate: Implications for mixed-methods research. *Quality and Quantity*, 36(1), 43–53.
- Schnarch, B. (2004). Ownership, control, access, and possession (OCAP) or self-determination applied to research. *Journal of Aboriginal Health*, (January), 81.
- Shreffler, M.J. (1999). Culturally sensitive research methods of surveying rural/frontier residents. *Western Journal of Nursing Research*, 21(3), 426.
- Smith, L.T. (1999). *Decolonizing Methodologies: Research and Indigenous Peoples*. London: Zed Books.
- Stylios, C.D., Georgopoulos, V.C., Malandraki, G.A., and Chouliara, S. (2008). Fuzzy cognitive map architectures for medical decision support systems. *Applied Soft Computing Journal*, 8(3), 1243–1251.
- Taylor, R.L. (1979). Black ethnicity and the persistence of ethnogenesis. *The American Journal of Sociology*, 84(6), 1401–1423.
- The Interagency Advisory Panel on Research Ethics. (2009). *Tri-council Policy Statement: Ethical Conduct for Research Involving Humans*. 2010, from <http://www.pre.ethics.gc.ca/eng/policy-politique/tcps-epct/section6-chapitre6/>
- Wilson, D. and Neville, S. (2009). Culturally safe research with vulnerable populations. *Contemporary Nurse*, 33(1), 69–79.
- Wilson, K. and Young, T.K. (2008). An overview of aboriginal health research in the social sciences: Current trends and future directions. *International Journal of Circumpolar Health*, 67, 2–3.
- Yancey, W.L., Ericksen, E.P., and Juliani, R.N. (1976). Emergent ethnicity: A review and reformulation. *American Sociological Review*, 41(3), 391–403.
- Young, T.K. (1988). *Health Care and Cultural Change: The Indian Experience in the Central Subarctic*. Toronto: University of Toronto Press.
- (1984). Indian health services in Canada: A socio-historical perspective. *Social Science & Medicine*, 18(3), 257–264.

Mary Cameron is a Master of Science candidate at the University of Ottawa's Department of Epidemiology and Community Medicine.

Dr Neil Andersson is the executive director of CIET and adjunct professor in the Faculty of Medicine at the University of Ottawa. He has three decades of experience designing, implementing and managing evidence-based health planning initiatives. A medical epidemiologist, for the last 15 years he has supported training of researchers in more than 200 Canadian First Nations, Métis and Inuit communities. www.ciet.org

Robert J. Ledogar, D Theol, MCP, is Associate Executive Director of CIET Canada.

Ian McDowell, Ph.D., is a professor in the Department of Epidemiology and Community Medicine at the University of Ottawa. He is Director of Curriculum Integration for the Faculty of Medicine where he coordinates the undergraduate medical curriculum component on Society, the Individual, and Medicine. He also teaches courses in the M.Sc. program in Epidemiology.