

## **Balancing Culture, Ethics, and Methods in Qualitative Health Research with Aboriginal Peoples**

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***Abstract:** Including Aboriginal women in qualitative health research expands our understanding of factors that contribute to their health and well-being. As part of the larger WHEALTH study, we gathered qualitative health data on midlife Aboriginal women living both on and off reserves. Despite careful planning and a commitment to methodological congruence and purposiveness we encountered a number of challenges that raised ethical questions. We present how we addressed these issues as we attempted to produce ethical, culturally sensitive, and sound research in a timely fashion. This article provides important considerations for other researchers and funding bodies while illustrating the benefits of working with Aboriginal women as an under researched population.*

***Keywords:** Aboriginal, women, qualitative health research, women's health, qualitative methodology, ethics*

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## Introduction

The health of Aboriginal peoples in Canada is well documented as being significantly poorer than that of other Canadians (MacMillan, MacMillan, Offord & Dingle, 1996; Tookenay, 1996; Royal Commission on Aboriginal Peoples, 1996; Health Canada, 2003; Tjepkema, 2002). These important epidemiological works measure health status by quantifiable indicators such as mortality rate, causes of death, and incidence and prevalence of some conditions (e.g., diabetes and cervical cancer). However, they do little to increase our understanding of underlying factors such as social context or social determinants of health. For instance, epidemiological research documents that three-quarters of all Canadian Aboriginal women have been victims of family violence at least once in their lives (Stout & Kipling, 2002) but stop short of asking why this is so. In a day-to-day context, an individual's ability to modify behaviour and achieve a healthy lifestyle is affected by a complex mix of many factors, including some that are outside the individual's control (Sunday & Eyles, 2001). Research that examines "root causes of health and illness...and the capacity of people to negotiate health sectors from which they are marginalized" is essential (Browne & Smye, 2002, p. 38).

Including Aboriginal perspectives about the underlying factors that affect their health, such as social context (e.g., racism, cultural, and socio-economic differences), is important (Ellerby, McKenzie, McKay, Gariépy, & Kaufert, 2000; O'Neil, Reading, & Leader, 1998) but often overlooked (Young, 2003). The unique health needs of Aboriginal women have been under-researched and subsumed in the population as a whole (Young). Urban Aboriginal women in particular have been "invisible and inaudible within conventional consultation frameworks" (Status of Women Canada, 2000, p.10). Including Aboriginal women in qualitative health

research to expand our understanding of factors that contribute to health is crucial if we are to effectively change health outcomes. Yet, inclusion of marginalized groups in women's health research is often challenging for a number of reasons (Berg, 1999), presenting potential barriers to both the participant and the research team (Harris & Roberts, 2003).

We have recently completed a project that describes midlife Aboriginal women's views of health, aimed at documenting factors that contribute to poor health outcomes for Aboriginal women and adding to our understanding of the mechanism through which this occurs. Despite careful planning and a commitment to methodological congruence and purposiveness (Morse & Richards, 2002) in the implementation of our research proposal, we encountered a number of challenges that affected the research methods and sometimes presented ethical dilemmas to the research team. By identifying and meeting these challenges we obtained rich data that capture Aboriginal women's views of some of the contributing factors underlying the statistics about their relatively poor health status. A series of articles that presents the results of this work is planned for publication. Our purpose in this article is to present the methodological and ethical challenges that arose in our research with Aboriginal women. Following Harris and Roberts (2003), we believe that acknowledgement and presentation of challenges encountered in the qualitative research process, and the means by which they were met, provide important information for other researchers and funding bodies.

## **Background**

### *The WHEALTH Project*

The Alberta Midlife Women's Health Study (WHEALTH) is a multistage multiphase project designed to describe health as experienced by women aged 40 to 65 years living in the province of Alberta, Canada. With the intent of representing a wide range of midlife Albertan women in this research, previous phases of the project included the perspectives of urban women, rural women, women who immigrated to Canada as adults, and women with disabilities (Meadows, Thurston & Berenson, 2001; Meadows, Thurston & Lackner, 2001; Meadows, Thurston & Melton, 2001). In the most recent phase of the WHEALTH Study, we planned to include Aboriginal women as participants, both those who lived on reserves and those who did not.

### *Proposed Research Plan*

When the Aboriginal women's study was designed in 1998, methodological lessons from other researchers as well as insight from our previous work with other sensitive populations (e.g., ethnic minorities, women with disabilities) were considered and incorporated in the design (Meadows, 1999). For example, we established contact with a number of Aboriginal women and those working with them to act as cultural guides and to facilitate ongoing collaboration and consultation with women in the community. Heeding guidelines for entry into an Aboriginal community (Kowalsky, Verhoef, Thurston, & Rutherford, 1996), we budgeted extra time and resources to lay the groundwork for culturally appropriate work with Aboriginal women. Recruitment and training of Aboriginal women as research assistants was planned. In addition, we went to the Aboriginal Health Council of our local Health Region for suggestions and to make them aware of the project.

We proposed two stages of data collection. Recognizing that women familiar with an oral tradition background were likely to be more comfortable sharing stories than answering direct questions, we planned focus group interview for initial data collection, with in-depth individual interviews planned as the second phase. Focus group interview data would guide design of the loosely structured individual interview question guide. Using open-ended questions in both phases, we planned to encourage women to identify major life events, circumstances, or other issues they believed impacted their health, without restricting the topics. Typical of qualitative research, sampling, recruitment and data collection strategies would evolve in an iterative fashion as the study progressed.

Ethical considerations included review of the research by the Conjoint Health Research Ethics Board (CHREB) of the University of Calgary. Acting on suggestions from our Aboriginal Advisory Committee, permission was sought and received from CHREB to interview women using a study preamble and oral request for consent to participate if the woman preferred that to written consent. In addition, we sought and received permission from the ethics review board to use a simplified one-page version of informed consent. This form presented essential study information in an easy to read format that omitted some of the university's standard clauses regarding injury and liability. The standard verbatim clauses in the university's consent form are awkward and at times disconcerting, raising issues such as harm from the research and costs of subsequent treatment. These issues are traditionally intended to cover contingencies in clinical drug trials that often do not make sense in qualitative research (e.g., "In the event that you suffer injury as a result of participating in this research..." (see [www.ucalgary.ca/UofC/research/](http://www.ucalgary.ca/UofC/research/)

[html/ethics/chreb.html](http://html/ethics/chreb.html) for the full text). We have used a similar process when expedient in studies with other populations (e.g., foregoing signed consent in some immigrant populations, using plain language with developmentally disabled women) with ethical approval from our institute. The oral traditions of Aboriginal peoples and our Aboriginal committee guided us to make the informed consent process as unintrusive as possible.

We proceeded with the research believing we had addressed the major areas of concern likely to arise. In the process, we had reviewed the literature, carefully reflected on lessons learned in earlier stages of the WHEALTH project, incorporated the ongoing assistance of Aboriginal community members, and successfully acquired funding in an adjudicated competition. We felt well prepared to enter the field.

### **The Challenges**

In our attempts to implement the research as designed, we encountered a number of unexpected issues. In the process of meeting the challenges, we discovered that our original proposal had underestimated resource requirements in several key areas. In addition, at times we found particular circumstances that raised ethical questions where the values of the researcher in the academic setting seemed at odds with those of the individual participant and their communities. Conflict was created within us as researchers as we attempted to balance seemingly competing tensions - our desire to work ethically and in a culturally sensitive manner with midlife Aboriginal women as an under researched population, and our desire to produce excellent research in a timely fashion using sound methodology. We present four examples from our

study to illustrate the areas of challenge, including the sources of our tension, questions that were raised for us in this work, and the solutions with which we attempted to address the challenges.

### *Working with community researchers*

It was our intention to recruit and retain Aboriginal research assistants throughout data collection. However, we overestimated the research capacity within the Aboriginal community and underestimated the resources required to address this shortfall. Through key informants we recruited qualified Aboriginal women as research assistants and cultural guides. In our experience, women who were already qualified to work as research assistants had multiple skills that were in high demand. They were eager to work with us in the research, but that work was often in addition to already full schedules that involved them as Aboriginal representatives in many realms. We also recruited Aboriginal women who showed promise and interest in the work, but did not have research experience. To provide training, we brought together our full research team, including all research assistants and potential research assistants, for a full day training workshop. The research process, from conceptualization to dissemination, was discussed so that our research assistants got an idea of all of the elements that went into a study. Training was provided on recruitment, interviewing, ethics, and data management issues such as tape handling and confidentiality. As part of the process, we role played as interviewers and interviewees, then discussed the strengths and weaknesses of approaches. We also addressed the possibility that sensitive issues might arise as women shared their stories with us, and shared past experiences and ways of dealing with the information, as well as invited suggestions from our team members. We spent a second day reinforcing skills with the less experienced. We set up a feedback process designed to quickly transcribe tapes so that we could review them with the

interviewers. We also were in frequent contact by telephone and e-mail for immediate support and feedback. This investment of resources met with varying success. The quality and quantity of work some assistants produced was insufficient. Some assistants had difficulties recruiting; some used the interview guide as a survey questionnaire rather than a guide. Some of the assistants initially produced good data but were forced by life circumstances (e.g., illness) to withdraw early from the work. This often represented a loss in resources when the research assistant withdrew before adequate data were collected, particularly in remote locations, so that saturation of issues that might be locally specific was not possible.

Ironically, we had a similar experience in an earlier study in a rural setting when new community researchers were used. Interviewers in that study shied away from asking some questions on the guide that they saw as ‘too personal’ and tended to limit recruitment to their own circle of friends. For researchers, especially those responsible for managing a study, commitment to a practice of iterative data collection, transcription and feedback before further recruitment will ideally speak to this issue. However, the rationale for the apparently stalled process while data are checked needs to be communicated to novice team members in a way that maintains the community assistants’ enthusiasm for participation. Our experience has led us to a practice of clearly outlining our expected time commitment for our interviewers, and reaching mutual agreement to clearly and quickly communicate any changes in timelines (usually from the investigative team) and availability (usually from the interviewers).

After multiple attempts over a period of 18 months we had successfully conducted one series of focus group interviews with 10 urban Aboriginal women participants; these produced sound data



and allowed development of the individual question guide. We had also met with and sometimes interviewed several Elders and community health representatives. However, we had obtained less than ten individual interviews, the content of which lacked breadth and depth. We were faced with the following questions:

- Was it ethical to continue the work without Aboriginal research assistants?
- Would participation and/or information shared be different if gathered by non-Aboriginal researchers? What difference would it make if the Aboriginal research assistant were from a different nation than the interviewees?
- What was the most responsible use of resources - continued attempts to find and/or train Aboriginal research assistants? Or to collect data using a well-experienced, but Caucasian interviewer already part of the research team?

In another project, a case study of the Aboriginal Health Council (Quantz, 2001), participants had been asked if they preferred an Aboriginal interviewer and no one made this choice. When asked if they thought having an Aboriginal interviewer would make a difference in responses, the general theme was around trustworthiness and approach of the interviewer, regardless of their identity (unpublished data). Our decision, therefore, was to attempt to recruit women using the experienced non-Aboriginal interviewer.

Through the community contact the interviewer had on one reserve in Alberta, the research team was able to access appropriate stakeholders within the community that allowed the research to proceed (see “Accessing the community”). Using a series of steps to introduce the research (see “(Non)-participation”), we were successful in completing one group interview with five participants and thirteen individual in-depth interviews on this reserve in about three months.

*Accessing the community*

Our funding resources and timelines did not allow for consultation with entire communities; gaining entry to Aboriginal communities through key contacts with Aboriginal women both on and off reserves was planned based on success in previous research with other ethnic communities (Meadows, Thurston & Melton, 2001). However, as the timeline of the research extended, continuity of the relationships with our established contacts was threatened. People changed positions, relocated, or were otherwise unable to continue with the work. Using snowball sampling techniques (Kuzel, 1999) members of the research team persistently explored key contacts in multiple communities. As we approached recruiting through new avenues the following questions arose:

- Who best represents the interests of the individual or the community to be studied?
- What if recognizable community leaders (e.g., band councils) are neither representative of nor concerned about the population the researcher hopes to access?
- Is the consent and approval of the whole community required if the research is only with a specific population within that community?
- What if individuals wish to participate but the community does not endorse the research?

We were successful in recruiting participants in a series of steps that provided opportunities for the community to become familiar with our research team. These included working with reserve health committees, attending health fairs and visiting the reserves on multiple occasions; depending on the circumstances we provided refreshments and/or contributed a door prize to the event. Having gained a level of community acceptance, we then planned several field trips as opportunities for casual encounters to introduce the research to women and to offer appointments to potential participants. In this way we were successful in recruiting over 50 midlife Aboriginal

women who lived on three reserves and in two urban locations for either group or in-depth individual interviews.

*(Non)-participation*

Previous research demonstrated that gaining entry into an Aboriginal community passes through four theoretical stages: stopping, waiting, transition, and entry (Kowalsky et al., 1996).

“Stopping” and “waiting” are closely related, and represent time for community assessment of the research; “transition” and “entry” are demonstrable by events that indicate increasing levels of trust in the researcher and acceptance of the research (Kowalsky et al.). Procession through the stages may be neither linear nor unidirectional, and can take place at the community or individual level (Kowalsky et al.). We found our research illustrated these stages at both the level of the Aboriginal community and the individual participants.

A composite example of the stages at the community level would be: the research team presents the research to a community but after weeks of waiting has little response (stopping & waiting); the researcher follows up and is invited to speak again, this time to the health council and is given information about upcoming events (waiting); the researcher requests and receives permission to present the research at an event such as a health fair or support group meeting (transition); and finally, the researcher is successful in gaining a group interview with the support group (entry).

When we eventually gained access to community members we found women themselves followed a process of gradual acceptance of the research. For instance, when hearing about the

study, dozens of women showed interest in being contacted for participation in the research. Yet this initial enthusiasm sometimes resulted in fully scheduled interview days where few, if any, interviewees kept the appointment. Despite our acknowledgement of the stages of entry, a number of questions arose for the research team around this issue:

- Were women demonstrating passive non-consent or did barriers (e.g., lack of transportation or childcare) prevent participation?
- Would additional recruitment attempts and/or provision of an honorarium be viewed as coercion or encouragement?
- How did using a key contact and/or honoraria influence the representativeness of our sample and data collected?
- Did women not participate because they lacked understanding or belief in the value of their own contribution?
- What influence did past research experiences, cultural differences and/or colonialist social structures have on participation?

Various approaches were employed to resolve these questions. By increasing flexibility and addressing potential barriers we hoped to actively but ethically encourage women's participation. Appointment setting processes that we believe contributed to success in eventually gaining interviews are summarized in Table 1. We found that spending multiple consecutive days in the community significantly increased participation. Although our initial days in any community yielded few interviews, on our last days some women would approach us and ask to participate in the research having heard about the study from other interviewees.

**Table 1: Encouraging participation**

Women who provided contact information were followed up by telephone after a lag time of a couple of weeks to allow time to think about participation.

- On follow up, we arranged a mutually agreed upon interview time with the woman, scheduled at a familiar community location (e.g., an interview room at the tribal health unit). Although the offer was consistently made, few Aboriginal women were interested in being interviewed in their homes.
- Setting appointment times worked best when we were actually in the community. Appointments set from the research team's urban setting even a day or two prior to interview produced multiple bookings, but few actual interviews. However, when the researcher could say, "I'm here on your reserve today until Thursday," more appointments were made and kept.
- Reminder phone calls prior to the interview appointment were already our practice. When women missed appointments we phoned with a friendly invitation to set a new time. Although this was always well received and usually resulted in a new appointment time, again only some women would keep the appointment. Missing a second appointment time was assumed non-consent, and not followed up. However, if the woman initiated contact, we would gladly set another interview time.
- For some women, time away from paid employment was an issue. We responded with flexibility. Scheduling for interviews and information sessions included evenings to accommodate those who worked in the daytime. Women who worked at the same workplace would sometimes arrange a convenient group interview (e.g., just after work).
- Providing refreshments at group meetings or interviews was always well received, and set a friendly tone to open the discussion.
- Through various health care professionals in the community (e.g., community health representatives) we learned that transportation, parking and childcare costs could be barriers for some women. We provided an honorarium of \$20.00 per interviewee to help cover these costs and to thank women for their participation. We mentioned the honorarium to potential participants in case women were hesitant because of these costs, but embarrassed to mention them.
- Interviewers were prepared to productively spend potentially long periods of time waiting, bringing related work that could be conducted if the scheduled interviewee did not attend.

*Working with sensitive data*

Although the Aboriginal population has been identified as having significant health problems and social concerns, we were unsure what information participants would feel comfortable sharing with our interviewers. In our research proposal we had not addressed the research team's ability to deal with sensitive and/or disturbing data, nor to our knowledge has it been adequately addressed in the health research literature, although those issues were raised during the ethical review process. Through the research process, we encountered various perspectives. Not surprisingly each individual had her own perspective and experience of what constitutes sensitive issues for them as individuals and as members of Aboriginal communities. Some Aboriginal research assistants working with us disclosed their discomfort and reluctance to broach potentially sensitive topics such as residential schools; one suggested she would prefer to end the interview if the topic arose, even if the interviewee raised it herself. For others this was not seen as an issue. Some community contacts suggested the opposite view: that our interviewers needed to be able to listen and respond appropriately if interviewees raised these issues as factors that influenced health and well-being.

The issues of what constitutes topics that are sensitive for researchers and those who share their experiences with us are not limited to Aboriginal populations. In talking with women about the determinants of their health issues related to gender, violence, death, discrimination and economics are potentially raised. Researchers need to be reflexive as the realities of fieldwork unfold. In all interviews the participants were free to end the interview at any point in time. We also ensured that our interviewers and our transcriptionist understood that they too could initiate closure, or terminate transcription if the subject matter became uncomfortable for them. We

were aware that sensitive issues were discussed in interviews, and provided opportunities for debriefing with all research team members.

Beyond the level of the individual, some community members and interviewees questioned the researchers closely about the dissemination of research results. They were concerned that release of community level information would taint community reputation and increase stigma against Aboriginal peoples. The following questions were raised:

- How did the interviewer's connection with the community influence data collection? Were participants more or less likely to share sensitive information with an interviewer from the community or one viewed as external to the community?
- How well were interviewers prepared to listen and respond to issues that women might raise in the context of health (e.g., fracture due to domestic violence, history of substance abuse and/or sexual abuse and/or suicide)?
- Given the open-ended nature of the interviews, and assuming the interviewee herself raised a sensitive issue, personal or community, what were the appropriate boundaries for gathering data in the interview?
- What resources did interviewees and/or the researchers themselves have for debriefing, if necessary, after the interview?

Throughout the tenure of the study interviewers regularly debriefed with other members of the research team after data collection. Ethical considerations (e.g., setting boundaries in the interview) and decisions (e.g., ways to present pertinent information while maintaining community anonymity) were discussed by the research team until consensus of comfort was obtained. Before focus group interviews began, ground rules were established and agreed on by all participants. At times during focus group interviews women disclosed information about several sensitive issues and painful experiences. As a group participants (including members of the study team who were present) provided non-judgmental support, allowing women to share

their stories and bearing witness to those experiences. One group of women formed their own support group as a consequence of their participation in the research. Team members routinely debriefed after the interviews on an on-going basis, providing an opportunity for them to consider appropriate strategies for future interviews.

The researcher who conducted most of the interviews had a social work background, extensive interviewing experience, and felt and demonstrated confidence in her ability to conduct potentially sensitive interviews. Once women were comfortable in the interview situation, many did indeed disclose highly sensitive information about themselves, their families and their communities. It was not uncommon for women to be moved to tears when explaining their difficulties achieving certain aspects of health. For example, a woman might speak of her addictions recovery, explaining the substance abuse masked unresolved grief at the multiple deaths among her children. Sometimes women discussed information that was sensitive at the community level. For example, women might speak about aspects of band council politics that affected their abilities to get jobs, or present their opinions of the competence of the (native) police officer as a reason why they would not report domestic violence. Thus, the interviewer had to be comfortable and competent dealing with this level of revelation, while maintaining the research purpose of the interview and not adopting other roles, such as counselor or judge of community standards.

The copy of the consent form retained by the interviewees included researcher contact information should women wish to contact the research team after the interview. Post interview, the researchers received a few phone calls or emails from interviewees who wanted to add more



information to the interview or to thank the interviewer for additional information the research team had provided. All members of the research team, including external contract employees such as transcriptionists, were required to sign confidentiality agreements, and regular reminders of the importance of confidentiality in this research were distributed.

### **Discussion**

The Tri-Council Policy Statement of Ethical Conduct for Research Involving Humans describes good practice guidelines for working with Aboriginal peoples and recommends that researchers include groups that have been disadvantaged (e.g., women) (Tri-Council, 2003). In addition, a number of authors have recently presented guidelines for involving Aboriginal peoples in health care initiatives such as programs or interventions, patient care guidelines, and research (O'Neil et al., 1998; Piquemal, 2000; Macaulay et al., 1998; Potvin et al., 2003; Smylie, 2001; Ellerby et al., 2000; Downie & Cottrell, 2000), while recognizing the need to adapt guidelines to fit the research project (Macaulay et al.). Since these works were published after our proposal was written, we discuss the principles pertinent to our project in light of our own experiences. A list of considerations for research implementation is presented in Table 2.

#### *Aboriginal peoples included in research process*

Research guidelines consistently recommend inclusion of Aboriginal peoples at various stages of the research project (O'Neil et al., 1998; Piquemal, 2000; Tri-Council, 2003) with some presenting guidelines specific to participant observation (Piquemal, 2000; Piquemal, 2001) and participatory research (Macaulay et al., 1998; Macaulay et al., 1999; Potvin et al., 2003; WHO, 1984). As inclusion of Aboriginal peoples is valued as a vital part of the research process, we

**Table 2: Considerations**

- Ethical review of the research is multi-faceted and not limited to the researchers' institution. Rather, it is an ongoing process involving the institution, the community and individuals.
- The issue of adequate community consultation needs further attention and discussion, as whom and what represents the community is not clear-cut. Simple notions of representation may disadvantage sub-populations.
- In research proposals, consider including strategies for preliminary recruitment of communities until a targeted number of communities are found where mutually agreeable research goals can be reached.
- Partnership roles, data ownership and publication could be included in discussion and agreements of research goals.
- Research budgets need to include sufficient funding to allow ethical research according to guidelines (i.e., community consultation, skilled staff with Aboriginal representation, reporting back to the community, provision of honoraria).
- Timelines must reflect the need for community consultation, recruitment and/or training of researcher(s) within the community, and multi-stage processes of consent.
- Among the research team, regularly discuss challenges, propose solutions, and address barriers to participation (e.g., provision of honoraria, flexible interview scheduling through drop-in appointments).
- Participants' potential needs for debriefing should be considered and procedures outlined in the research agreement with communities. Initial steps (e.g., contact information for follow-up post interview) should be included on consent forms. Regular debriefing among research team members working with sensitive or disturbing data concerning individuals and populations is recommended.
- Review work of researchers who have outlined procedures for working well with Aboriginal peoples. Document and publish methodology issues so that other researchers and funding institutions can access and reference accurate information about these issues.

attempted to include Aboriginal participation at multiple stages, as members of the research team, and as community consultants. However, the difficulties we experienced in finding and retaining consistent participation suggests the community's capacity to respond to research must

be thoroughly considered in the project's design. One potential solution is including strategies for community recruitment in research proposals and reflecting this in timelines and budgets. For example, researchers would preliminarily work with numerous communities until they found a targeted number where mutually agreeable research goals could be reached. Community preferences for Aboriginal representation and/or roles in the research, criteria for these positions, contingency plans for replacement of vacated positions, and data ownership and publication could all be discovered, discussed and agreed upon at this stage. Mutual commitment to timelines and contribution of resources should also be reached, and clear conduits for communication established. Reference to groundwork laid by other researchers would be beneficial; for guidelines in working well with Aboriginal people on research including stages of entry, the definition of partnership roles, data ownership and codes of ethics see Kowalsky et al. (1996), Macaulay et al. (1998), Potvin et al. (2003), O'Neil et al. (1998), Downie & Cottrell (2000), and WHO guidelines (1984).

### *Community representation*

Approval of the research at the community level is certainly recommended, may be required (Tri-Council, 2003; Piquemal, 2000) and should be considered an ongoing process that is confirmed at various stages of the research (Piquemal, 2000). O'Neil et al. have suggested researchers have sometimes chosen inappropriate representatives or avoided choosing to reduce community-based controls over the research (O'Neil, p.234). Yet, what and who represent the community is not clear-cut (WHO, 1984). Whether or not it is legitimate to interview individuals as individuals, without community consultation may require specific institutional

ethics review board review (Tri-Council, 2003). However, the decision of the review board may not reflect the opinions of the community (Piquemal, 2000).

Our experiences illustrate a number of challenges presented by these recommendations.

Determination of who represents the community and who may legitimately authorize or stonewall the research is fraught with difficulties. We present a number of questions for consideration:

- To aid ethics review board decision-making, a researcher may wish to gauge community responsiveness. What boundaries govern the researcher in community consultation prior to institutional ethical review?
- The term ‘community’ cannot be used to obscure multiple identities and the problems inherent in politics. Aboriginal peoples living on one reserve may have been born to one nation but now live on a different nation’s reserve; and, the individual may or may not have treaty status. By what community are they represented or what community do they represent?
- Lack of representation for women or the perception that their views are overlooked in recognized leadership structures such as band councils is not uncommon (O’Neil et al. 1998; Status of Women Canada, 2000; Sayers & MacDonald, 2001).
- What ethics govern the researcher when subgroups within the population are not represented in decision-making bodies?
- By what processes is it legitimate to increase their representation or inclusion in research?
- For Aboriginal people living off reserves defining community and representatives of the community is even more difficult.
- Is community approval still required, for example, with urban Aboriginal women, or with Métis or non-treaty status Aboriginal peoples? If so, what and who represents the participant’s community?

Pat answers to these questions are neither possible nor desirable. However, debate with the purpose of creating guidelines for researchers committed to ethical methodology in research with Aboriginal people is paramount.

*Resources*

Culturally sensitive methodology that involves researchers moving through the stages of acceptance within any given community, working with communities as partners, and adapting to community ethical standards requires substantial resources of both time and money. When researchers are presented with the ethical duty to include under-represented groups (Tri-Council, 2003) yet encounter barriers such as maintaining academic and funding agency deadlines that are difficult (Status of Women Canada, 2000) or sometimes impossible (O'Neil et al., 1998), it can and does result in researcher attrition (Potvin et al., 2003). Researchers and funding institutions must recognize and accommodate the need for sensible processes and sufficient resources to work with Aboriginal peoples. For example, institutional policy requiring signatures for receipt of honoraria compromises participant confidentiality. Discussion of acceptable honoraria is also required. In our research we were prepared to purchase traditional offerings of tobacco, but our Aboriginal assistant advised that the women preferred cash because they needed it more. Food, honoraria, gifts, and coverage for expenses such as childcare and transportation must be recognized as allowable and reasonable budget expenses. Finally, researchers would benefit by the availability of references to published work of other researchers who have frankly documented methodology issues such as resource requirements, expected timelines, and field procedures (e.g., interviewing strategies) that have met with more or less success. For our team these experiences reminded us of the importance of reflexivity in research that provides and schedules on-going opportunities to share experiences and incorporates insight from those in the community with whom we are doing research, creating a culture of shared knowledge to benefit future research and the communities who contribute to it.

### Summary

Overcoming barriers to inclusion of marginalized groups such as Aboriginal women in qualitative health research is challenging. Acknowledging tensions that arise when researchers attempt to balance culture, ethics and methods, and documentation of the means by which the challenges were met, provides important information to other researchers. We presented examples to illustrate areas of challenge, the sources of tension, questions that were raised for us in this work, and the solutions with which we attempted to address them.

To strengthen and maintain relations with Aboriginal communities we have now established dialogue with multiple stakeholders within the community, so that research relationships do not depend on any one individual. We also intend to maintain our visibility and credibility as a research team by presenting our results to participants and sometimes to the community at large (e.g., poster presentations at health fairs). We continue to invite Aboriginal women's input as collaborators on proposed research within their communities, as well as developing ways to incorporate participants' views about the research process (e.g., effective recruiting strategies, dissemination of results) within our methodology.

Although this article presents forthright discussion about the challenges of methodologically and ethically sound research with Aboriginal peoples, we present it because we wish to encourage other researchers. Surmounting the barriers resulted in rich in-depth data about health from more than 50 Aboriginal women. The quality and quantity of this data provides the basis for a series of papers that illustrate the complex web woven between the social determinants of health and

quantifiable health outcomes, such as rates of domestic violence, in a population whose voices are seldom heard. Challenges in doing qualitative health research with marginalized groups can be met. Continuing to find and share successful ways of practicing qualitative health research is essential if we are to effectively change health outcomes.

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