

# Journal of Aboriginal Health

## Journal de la santé autochtone

December 2009, Vol. 4, Issue 2

décembre 2009, vol. 4, numéro 2

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# JAH JSA

Journal of Aboriginal Health Journal de la santé autochtone

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National Aboriginal Health Organization

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ISSN 1710-0712

PUBLICATIONS MAIL AGREEMENT NO. 40043978  
RETURN UNDELIVERABLE ITEMS TO NAHO  
220 LAURIER AVE., SUITE 1200  
OTTAWA, ON K1P 5Z9

# Building Foundations in Aboriginal Women's Health Research

Women have always played a central role in Aboriginal health. Since the beginning of time women have brought children into the world, cared for their families and were healers. In my own culture at the time of creation the Sky Woman brought medicines and food with her from the spirit world. It was the clan mother of the Bear Clan who was taught everything the Haudenosaunee needed to know about curing and healing. That is why I am so proud of this edition of the *Journal of Aboriginal Health* (JAH); women's voices need to be heard in health research. Madeleine Dion Stout in 2001 argued for an Indigenous research approach that engaged Aboriginal women to address gaps and weaknesses in Aboriginal women's health research. This edition is a step in that journey.

In this issue of the JAH, qualitative methodologies help bring life to the stories of women in their words and experience. First Nations, Inuit and Métis women's lives and health are stressed by demands of child-rearing, education, poverty, and cultural responsibility. Aboriginal health statistics do not provide a complete picture of the story of First Nations, Inuit and Métis women. The holistic approach to research design in this collection includes a literature review, interviews, stories of research team members, case study conversations with teenagers, and community stories. These papers are a major contribution to women's health research, recording the stories of Aboriginal teenagers and women from many parts of Canada. It's a first step in creating a broader dialogue around health and wellness issues. These stories, through the experiences of women, open our eyes and provide a greater understanding of women's health status and trends.

In their paper, "Beginning with Our Voices: How the Experimental Stories of First Nations Women Contribute to a National Research Project", Acoose, Blunderfield, Dell and Desjarlais share poignant moments of insight and reflection that changed their research process. For example, the stories of the three First Nations women researchers illustrate how their personal healing journeys contributed to the design and outcome of the research. The women describe how putting their experiences on paper affected the research and helped them in their healing. This methodology helped the team identify gaps and issues not addressed in previous studies.

In their paper, "Body-related Experiences of Two Young Rural Aboriginal Women," Fleming and Kowalski look at the body self-image of young Cree women from

Saskatchewan. Using a case study approach they address gaps in current health research which excludes young Cree women living off-reserve. Interestingly, the research points out that these young women's body-related emotional experiences may not be as negative as previous research indicates.

In "Culturally Competent Care for Aboriginal Women," Birch, Ruttan, Muth, and Baydala explore the experiences of Aboriginal women within western health care systems. The lack of culturally-competent care for birthing emerges as a clear need to be examined. Women's cultures place utmost importance on the value of the family, childcare practices and birthing. Birthing is seen as a part of life rather than an illness requiring hospitalization. Policies which require Aboriginal women to give birth in hospitals have had a negative impact on birthing traditions and identity. In the paper, it was found that First Nations, Inuit and Métis women giving birth in hospitals have experienced cultural insensitivity, lack of respect and feelings of isolation and anxiety. The study found the need for more research to shed light on knowledge deficits, best practices, health care delivery experiences, and needs of First Nations, Inuit and Métis women. The paper provides practical recommendations for the development and provision of culturally-competent health care.

In "Health Research, Entitlements and Health Services for First Nations and Métis Women in Manitoba and Saskatchewan," Haworth-Brockman, Bent and Havelock explore the historical developments leading to current legal entitlements to health services available to First Nations and Métis women. In this paper, terminology and background information regarding the complexity of health, health care

services and entitlements are clarified. Interviews of health care service providers were used to examine women's access to health care services provincially, uncovering inequity in access to health services, as well as jurisdictional and policy issues, and need for further research.

Lastly, in "the Responsibilities of Women: Confronting Environmental Contamination in the Traditional Territories of Asubpeechoseewagong Netun Anishinabek (Grassy Narrows) and Wabauskang First Nations," Simpson, DaSilva, Riffel, and Sellars examine mercury contamination in two First Nations communities between the 1960s and 1970s and how women were central in confronting environmental contamination. It is inspiring to see the resilience of women in keeping their traditional values and ways of life alive in the face of illness, death, flooding, pollution, and relocation. This paper provides insight into the strength of women who have and continue to struggle and live with the effects of environmental contamination on a daily basis.

This issue of the JAH clearly demonstrates the power of First Nations, Inuit and Métis women's voices on critical health issues. Through participatory research methods substantive insight is gained regarding women's real world experiences and problems. By researching through the lens of First Nations, Inuit and Métis women, a greater understanding of their health status and ways to improve health outcomes are realized. Seeing their words in writing

clearly demonstrates the power of the written word and the lived experience.

In my culture, we are taught that a women's body is the first environment. What more positive image do we need? We know from our midwives that traditional knowledge can help inform policy, delivery and care, and that this research contributes to the long-term vision for enhanced First Nations, Inuit and Métis health. It is my dream that this body of evidence makes its way into the policy and planning of health care institutions to improve access and care for First Nations, Inuit and Métis women. Aboriginal women's research clearly paves a path for the future. As mothers we clearly understand the value of traditional values, cultures, and ways in raising resilient and healthy children.

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# Bâtir les fondations de la recherche sur la santé des femmes autochtones

Les femmes ont toujours joué un rôle central dans la santé chez les Autochtones. Depuis le commencement des temps, les femmes ont mis les enfants au monde, ont pris soin de leurs familles et ont été des guérisseuses. Dans ma propre culture, lors de la création, la Femme du Ciel a apporté avec elle des produits médicinaux et des aliments, lorsqu'elle est venue du monde des esprits. C'était la mère de clan du clan de l'Ours qui avait appris tout ce que les Haudenosaunees avaient besoin de savoir pour soigner et guérir. C'est pourquoi je suis si fière de cette édition du Journal de la santé autochtone (JSA); les voix des femmes doivent être entendues dans la recherche sur la santé. En 2001, Madeleine Dion Stout a milité pour une approche indigène de la recherche qui engage les femmes autochtones à aborder les lacunes et les faiblesses existant dans la recherche sur leur santé. Cette édition est un pas dans cette direction.

Dans ce numéro du JSA, des méthodologies qualitatives aident à donner vie aux histoires des femmes, dans leurs propres mots et expériences. Les femmes des Premières nations, inuites et métisses voient leur vie et leur santé totalement accaparées par l'obligation d'élever les enfants, l'éducation, la pauvreté et la responsabilité culturelle. Les statistiques sur la santé chez les Autochtones ne reflètent pas complètement l'histoire des femmes des Premières nations, inuites et métisses. L'approche holistique en matière de conception de la recherche, dans cette collection, inclut une revue de la documentation, des entrevues, des récits de membres d'équipes de recherche, des conversations avec des adolescents sur des études de cas et des histoires communautaires. Ces documents marquent une contribution majeure à la recherche sur la santé des femmes, en enregistrant les histoires d'adolescents et de femmes autochtones d'un peu partout au Canada. C'est une première étape dans l'établissement d'un dialogue plus général sur les questions de santé et de bien-être. À travers les expériences des femmes, ces histoires nous ouvrent les yeux et nous font mieux comprendre l'état et les tendances de leur santé.

Dans leur communication, « *Beginning with Our Voices: How the Experimental Stories of First Nations Women Contribute to a National Research Project* » Acoose, Blunderfield, Dell et Desjarlais partagent les moments poignants d'introspection et de réflexion qui leur ont fait modifier leur processus de recherche. Par exemple, les histoires des trois chercheuses des Premières nations illustrent comment leur parcours vers leur propre guérison a influencé la conception et les résultats de leur recherche.

Elles décrivent comment le fait de mettre leurs expériences sur papier a influé sur leur recherche et les a aidées au cours de leur rétablissement. Cette méthodologie a aidé l'équipe à identifier les lacunes et les problèmes non abordés dans les études précédentes.

Dans leur communication, « *Body-related Experiences of Two Young Rural Aboriginal Women* », Fleming et Kowalski regardent la propre représentation corporelle de jeunes femmes cree de la Saskatchewan. En utilisant une approche d'étude de cas, elles se penchent sur les lacunes dans la recherche actuelle sur la santé, laquelle exclut les jeunes femmes cree qui vivent hors réserve. Chose intéressante, la recherche suggère que les expériences émotives de ces jeunes femmes, relativement à leur corps, pourraient ne pas être aussi négatives que le laissait entendre la recherche antérieure.

Dans « *Culturally Competent Care for Aboriginal Women* », Birch, Ruttan, Muth, et Baydala explorent les expériences des femmes autochtones dans les systèmes de santé occidentaux. L'absence de soins culturellement compétents lors des accouchements ressort comme une lacune flagrante qu'il faut corriger. La culture des femmes autochtones accorde la plus grande importance à la famille, aux pratiques de soins aux enfants et d'accouchement. L'accouchement est considéré comme un événement normal de la vie et non pas comme un état qui nécessite une hospitalisation. Les politiques imposant aux femmes autochtones d'accoucher dans un hôpital ont eu un impact négatif sur leurs traditions et leur identité. Le document montre que les femmes des Premières nations, inuites et métisses, qui ont accouché dans

un hôpital, ont été confrontées à une insensibilité culturelle, un manque de respect et ont ressenti des sensations d'isolement et d'anxiété. Il souligne la nécessité de faire plus de recherche pour faire ressortir le manque de connaissances, les meilleures pratiques, les expériences en matière de prestation de soins de santé ainsi que les besoins des femmes des Premières nations, inuites et métisses. Enfin, il fait des recommandations pratiques sur la mise au point et la prestation de soins de santé culturellement compétents.

Dans « *Health Research, Entitlements and Health Services for First Nations and Métis Women in Manitoba and Saskatchewan* », Haworth-Brockman, Bent et Havelock se penchent sur les développements historiques qui ont mené au droit actuel d'accès des femmes Premières nations et métisses des aux services de santé disponibles. Dans ce document, la terminologie et l'information contextuelle sur la complexité de la santé, les services de santé et les droits d'accès sont clarifiés. Des entrevues avec des fournisseurs de services de santé ont permis d'examiner l'accès des femmes aux services de santé, au niveau provincial, de découvrir les inégalités d'accès ainsi que les problèmes de juridiction et de politiques et le besoin de plus de recherche.

Pour finir, dans « *the Responsibilities of Women: Confronting Environmental Contamination in the Traditional Territories of Asubpeesewagong Neturn Anishinabek (Grassy Narrows) and Wabauskang First Nations* », Simpson, DaSilva, Riffel et Sellars se penchent sur la contamination par le mercure subie par deux communautés des Premières nations, dans les années 1960 et 1970 et ils examinent comment les femmes se sont trouvées au centre de la résistance à cette contamination environnementale. Cela inspire de voir la résilience dont les femmes ont fait preuve en conservant leurs valeurs et leur mode de vie traditionnels, face à la maladie, à la mort, aux inondations, à la pollution, et à la réinstallation. Ce document donne un aperçu de la force des femmes qui ont lutté et continuent de lutter et de vivre, au jour le jour, avec les effets de cette contamination environnementale.

Ce numéro du JSA montre clairement le pouvoir de la voix des femmes Premières nations, inuites et métisses sur les questions de santé les plus cruciales. Par des méthodes de recherche actives, on obtient un aperçu significatif des expériences du monde réel et des problèmes auxquels les femmes sont confrontées. À travers les femmes des Premières nations, inuites et métisses, on obtient une meilleure compréhension de leur état de santé et on trouve des manières de l'améliorer. Le lire sur papier, démontre clairement la puissance du mot écrit et de l'expérience vécue.

Dans ma culture, nous apprenons que le corps d'une femme représente l'environnement originel. De quelle image plus positive avons-nous besoin? Nous savons, par nos sages-femmes, que le savoir traditionnel peut aider à informer les politiques, la prestation et les soins et que cette recherche contribue à la vision à long terme d'une santé améliorée chez les Premières nations, les Inuits et les Métis. Je rêve de voir cet ensemble de preuves faire son chemin jusque dans les politiques et la planification des institutions sanitaires, afin d'améliorer l'accès et les soins pour des femmes Premières nations, inuites et métisses. Il est clair que la recherche par les femmes autochtones trace une voie pour l'avenir. En tant que mères, nous comprenons parfaitement l'importance des valeurs, des cultures et des façons traditionnelles pour élever des enfants résilients et en bonne santé.

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# The Responsibilities of Women: Confronting Environmental Contamination in the Traditional Territories of Asubpeechoseewagong Netum Anishinabek (Grassy Narrows) and Wabauskang First Nation

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## ABSTRACT

**From the early 1960s to the late 1970s, Reed Paper dumped more than 50 000 pounds of mercury into the English-Wabigoon River system. At the time, Anishinabek people, whose territory encompasses the river system, were dependent upon the river for food and water. Fish from the river system were a staple in the diet of community members, and fishing was an important cultural and economic activity. People got their drinking water from the river and hunted and trapped animals that were also dependent on the same resources. Many community members suffered from severe mercury poisoning, and all communities dependent upon the English-Wabigoon river system continue to deal with the social, cultural and health impacts of living in a contaminated ecosystem. In 2003, a group of women from the communities of Asubpeechoseewagong Netum Anishinabek (Grassy Narrows) and Wabauskang First Nation, located in North-Western Ontario began to study the impacts of environmental contaminants on their traditional territories using both Anishinabek knowledge and western science. They were concerned about the impact of environmental contaminants on the health and well-being of women and their children. From 2001 to 2005, the two communities completed a large traditional foods testing program and held two Anishinabek Knowledge workshops to discuss the impact of contamination on their communities. The purpose of this paper is to share the women's, Elders' and Anishinabek Knowledge Holders perspectives on how contamination continues to impact their communities.**

## KEYWORDS

**Environmental contamination, traditional foods, Indigenous Knowledge**

## Traditional Foodways, the Backbone of Community Health

**T**raditional food systems or foodways have been the foundation of community health for Indigenous Peoples in the Americas since time immemorial. In negotiating treaties with settler governments, Anishinabek people intended to protect these systems in order to ensure the health and well-being of future generations and the continuity of their way of life. The forces of colonialism, including deforestation, hydro-electric development and environmental contamination, have undermined and destroyed aspects of traditional food systems. Attacks on traditional food systems are direct attacks on Anishinabek culture, as it is through these traditional food systems that Indigenous Peoples foster their relations with the natural world, their relationships with other Indigenous nations, their economies, their spiritual practices, and the social systems that maintain the emotional well-being of families and communities.

The economy was fostered through respectful and reciprocal relations with the Gifts of Creation, practiced not for the purpose of getting rich, but to continue promoting a good life for the generations to come. The backbone of the Anishinabek economic lifeway was the careful harvesting of traditional foods, and the ceremonial practices of redistributing the wealth of the harvest amongst community members, particularly to the Elders and to families without hunters. Complex international trading relationships with other Indigenous nations were nurtured in part through the trade of traditional foods, which, in turn, maintained political relationships between these nations.

Traditional foodways provided the foundation for traditional Anishinabek governance. Clans tied groups of people from the same clan to an animal nation. Seasonal ceremonies, that frequently included feasts, maintained an essential connection and symbiotic relationship between the people and the natural world. Food was considered good medicine, a gift from Creation, given to sustain *mino bimaadiziwin*, the “good life” or “the continuous rebirth of life.” Feasting, both as a way of redistributing wealth and of offering thanksgiving, was (and remains) an important part of the ritualized spiritual life of Anishinabek people.

In contemporary times, many Indigenous Peoples see the restoration of their freedom and the recognition of their identity as Indigenous nations as the only way forward. They claim a future in which all people are able to decolonize themselves and revitalize traditional relationships is one in

which they are able to once again fulfill their responsibilities to Creation. Revitalizing Indigenous food systems is part of that larger goal, that requires Elders and Knowledge Holders to actively pass their knowledge down to their youth. It requires the protection of Indigenous territories from contamination and environmental destruction. It requires that Indigenous People disconnect themselves from western diets and begin to once again live active and healthy lives, sustained by their traditional foods (Waziyatawin, 2005).

## Anishinabe-kwewag and Traditional Foodways

To maintain sustainable traditional food sources, all members of Anishinabek communities had - and continue to have - responsibilities. As mothers, grandmothers, aunts, sisters, and daughters, Anishinabe-kwewag (Ojibway women) have important responsibilities to do with the land and with matters concerning the nation. Their relationship to water is part of those responsibilities.

Water is a purifier, cleansing our bodies and protecting us from disease. Water is the lifeblood that protects unborn children and nurtures them until they are ready to pass through the doorway into this world. Similarly, water is the lifeblood of ecosystems, purifying the land through rains and natural flooding, and it is the responsibility of women to protect that water, to ensure that it is clean and safe to drink.

Mothering children gives Anishinabe-kwewag the responsibility of carefully monitoring the food they feed their families to keep them healthy. Women engaged in food preparation are in a unique position to evaluate the quality of their traditional foods, and, based on their experience with uncontaminated and healthy foods from the past, aunts and grandmothers assist in assessing this quality. Women also often care for the elderly, which allows them to be close to their Elders, and they are also involved in the health care of those who are sick. Womens' responsibilities make them clearly aware of the impact of environmental contamination on their food systems and therefore on the health and well-being of their family members.

The women of Asubpeechoseewagong Netum Anishinabek (Grassy Narrows) and Wabauskang First Nation take their responsibilities very seriously. For years, the women have noticed a decrease in the health and well-being of their families, particularly of their children. In addition to the ‘usual’ increase in diabetes and cancers amongst the older members of their families, they have witnessed an increase in neurological disorders,

miscarriages, birth defects, and life threatening childhood diseases. Women, Elders and traditional Knowledge Holders believe that these illnesses are a result of the environmental contamination that is wreaking havoc on their traditional food sources.

### **Mercury Contamination at Asubeechoseewagong Netum Anishinabek and Wabauskang First Nation**

The communities of Asubeechoseewagong Netum Anishinabek and Wabauskang have been coping with the destructive impacts of unsanctioned industrialized development on their territory for several decades. It began in Grassy Narrows in the 1950s when Ontario Hydro flooded a large tract of their territory for hydroelectric development. Rice beds were destroyed and community members were left to deal with the danger and destruction of fluctuating water levels, while Ontario Hydro shipped “cheap and clean” hydro electricity to the south.

In the 1960s, Indian Affairs relocated the community, causing another devastating upheaval for many people who had already been diminished by the impact of residential schools and, through the use of colonial legislation designed to undermine their culture, their rights, and sovereignty, the refusal of state governments to recognize the Anishinabek treaty rights.

But it was an event spanning from the early 1960s to the late 1970s that devastated these strong and resilient communities. During this period Reed Paper severely contaminated the English-Wabigoon River system in dumping more than 50 000 pounds of mercury into it. (LaDuke, 1999). Anishinabek people, who relied on the water from the river for drinking and fishing, were not told about the mercury until several years later. For over a decade they continued to drink the contaminated water and to eat the contaminated fish.

Fish from the river system were a staple in the diet of community members. As well, commercial fishing and guiding sport fishers provided the community with its main source of jobs, and when the federal and provincial governments of Canada finally acknowledged the contamination and made commercial fishing illegal, the employment rate plummeted from 90 per cent to 10 per cent (Brophy, 2005). Fishing represented a substantial component of the local economy, and when the fish were no longer edible, people lost their sustenance, their economic and food security, and their way of life became threatened.

Asubeechoseewagong Netum Anishinabek eventually received compensation for the contamination in the 1980s,

but their Elders and Anishinabek Knowledge Holders have continued to report that the mercury contamination is still in the river system and that it still has significant negative impacts on the fish, aquatic animals, water and wildlife, and still contributes to illness in the community. This perspective contrasts sharply with what the Anishinabek people were told at the time. Scientists and government officials assured community members that the system would be completely clean of mercury in 30 years.

The community of Wabauskang was never compensated for the mercury contamination, nor have they been tested for mercury poisoning, and community members continue to suffer from health impacts that they attribute to the contamination. Community members (who spoke little English and lived in relative isolation) did not know that they had been exposed to large amounts of mercury until the late 1980s. The people living at Quibell, which is located directly downstream from the mill, were drinking river water and eating fish throughout the 1970s, unaware of the contamination. Again, the impacts of contamination were severe and devastating for the families involved. Several babies who were being bottled fed with milk made from the river water died, and several others, including babies that were being breastfed, were permanently damaged by the contamination.

Betty Riffel, who was a child at the time, living with her family along the river at Quibell, remembers this horrific and traumatic experience very well. Her younger brother Donny was one of the babies that died. Sick from birth, he lived only nine months and had repeated and violent seizures until he died, as did all the other babies at the time. Medical officials told her parents that he had “an incurable disease.” Betty believes the death of these babies, along with the deaths and disabilities of community members, are consistent with severe mercury poisoning. Neither industry nor the federal or provincial government has attempted to make amends for this blatant injustice. After her baby brother died, Betty went for a long walk in the bush, during which she made a promise to herself and to him to do something about this horrible injustice. Her work on this project is part of that promise.

### **Confronting Contamination**

In 2001, two women from Grassy Narrows, Judy DaSilva and Roberta Keesic, with the support of the Elders and the youth, launched a three-pronged approach to address the continued attack on their land and their community. Contamination from the mercury spills, in the way the Elders had talked about it, had removed people from the

land. There was no point in fishing if you could not eat the fish. Deforestation on many trap lines had reduced the number of commercial trappers the territory could support. In response, the women held (and continue to hold) a women's gathering in which they developed an action plan for the future to protect our first mother, the Earth.

One of the outcomes of these gatherings is the A'ndawenjigwe Survival Project, a cultural immersion project using traditional methods, designed to teach youth basic survival and traditional skills. A second outcome of the gathering was the erection of a physical blockade on a logging road to stop the logging in the forest, and to raise public awareness of the impacts of corporate deforestation of Indigenous territories.

Many of the women in Grassy Narrows and Wabauskang know that when the environment is sick, the people will also become sick. They believe that the environment has been severely ill since the mercury contamination in the 1960s, and they believe that this combined with the rapid deforestation of their traditional lands (and the applications of pesticides in industrial reforestation programs) is the root cause of many of the diseases and illnesses experienced by their family members. They also know that because they have no "scientific proof" to back up the cause and effect relationship that seems so obvious to them, their concerns have been largely ignored by state governments.

For their third initiative, Judy and Roberta joined forces with Betty Riffel of Wabauskang First Nation, assembling a team to investigate the impacts of environmental contamination on their communities. From 2001 to 2005, a research team consisting of Judy DaSilva, Betty Riffel, Anishinabek academic Leanne Simpson, and non-Native scientist Patricia Sellers, using western science and Indigenous knowledge, completed three studies investigating the impact of environmental contamination on the two communities.

The research team was committed to doing things differently in our project. The two communities who lived through the contamination were the decision makers, while the scientists and academics involved in the project acted as advisors. Our largest and most comprehensive study, which came in 2004–2005, had three components:

1. The Anishinabek Knowledge component documented the impacts of contamination from the perspective of the Elders and community Knowledge Holders.
2. The traditional foods component monitored fish, wildlife and plants for heavy metals, dioxins, furans, and organochlorine contaminants.

3. The sediment and crayfish component tested sediments and crayfish for mercury in several lakes, most of which had not been tested before despite the known history of pollution.
4. The rest of this paper will focus primarily on the Anishinabek Knowledge component and the contaminants study.

### **An Anishinabek Research Process**

Research in Indigenous communities must abide by the intellectual traditions and research protocols of the people themselves and must approach the subject matter in a manner that colonizes neither the participants nor their knowledge. The methodology for this project was developed and carried out with the Indigenous Knowledge holders of Asubpeechoseewagong Netum Anishinabek and Wabauskang First Nation.

The research originated in the community and the community remained in control of the project from start to finish. Our project was rooted in Anishinabek Knowledge, and Elders were consulted in the customary way throughout the project, particularly when important decisions were being made regarding the research.

Beyond this commitment to Anishinabek Knowledge and process, the project also required a commitment to an indigenous and decolonizing approach. Indigenous or decolonizing methodologies contain a wide variety of evolving methods and strategies predicated on privileging indigenous voices, approaches, ontology, epistemology, and methodology (Rigney 1999, Smith 1999, Ladner 2000, Simpson 2004). This approach is necessary in Indigenous Knowledge research because this knowledge is part of a large, comprehensive (and poorly understood from a western perspective) system of knowledge, every bit as complex as western science. Elders in this type of knowledge system are considered to be experts, and their expertise is respected. The protocols embodied in this approach extend to western scientists who interface with the research process, the Knowledge Holders and the Elders on community-driven projects such as this.

Along with the Elders, Judy and Betty wanted to ensure that Anishinabek Knowledge regarding the contamination was being passed down to the youth. They also wanted to generate scientific data about contamination levels in their traditional foods. Because governments do not value Indigenous Knowledge, they thought it was important to gain scientific evidence in order to advance their political goals. Because community members do not trust studies done by those from outside the community, they also thought that it was important that they did the scientific studies themselves.

## **Indigenous Knowledge and Elders Shape Western Science**

The western scientific component of the project was necessarily shaped by the expressed concerns of the community and the Indigenous Knowledge embodied within it. The design of the sampling strategy for the traditional foods and sediment components began with visits to the communities and ended when enough had been learned from the Indigenous Knowledge Holders to design a strategy consistent with the directive from the Elders. In our study, the scientist listened to what people said about pollution, the land, and where they fish and do not fish. They asked questions and learned many things about the water (levels, currents, colour, seasonal changes) and about the animals, birds and fish that use the waters. Because Indigenous Knowledge Holders directly influenced the sampling strategy, it looked different from what it might have looked like had it been guided by western science alone. It was challenging for the scientist to take this approach in the design without compromising the integrity of the research.

Presenting results is a standard part of the scientific process and this component, too, required a design that deviated from standard methods. The community was the first to have access to the results and to see and hear the results in PowerPoint presentations made by the scientist. In these presentations, care was taken to minimize the use of complex scientific graphs and text and to maximize the use of photographs, maps, simple graphics, and plain language discussion. Presentation of the scientific results to the wider scientific community was made only after approval of it by the Elders. This approach to western science is different from standard practices, as it must be, if it is going to work for Indigenous People rather than against them.

## **Protecting Indigenous Knowledge**

As well as utilizing Anishinabek Knowledge throughout all aspects of the project, we also hosted a two-day workshop for Elders and youth to discuss the impact of contamination on the community. The Indigenous Knowledge research team, led by Judy, Betty and Leanne was inclusive of Anishinabek and Indigenous traditions, Anishinabek environmental philosophy and Anishinabek knowledge, and research protocols. Our community recorders had considerable experience with Anishinabek Knowledge and the traditions and protocols of their communities, and were also fluent speakers of Anishinabek language. The workshop proceeded in Anishinaabemowin (Ojibway language).

School children attended the workshop as observers, and it was broadcast over Grassy Narrows' community radio station.

The research proceeded as follows: Researchers introduced themselves and the project to the Elders and Knowledge Holders. The project's goals and objectives were explained in the Anishinabek language as was other pertinent information related to informed consent. In this research an ethical procedure for informed consent relied on respect for the traditions and customs of the research participants. Informed consent was obtained in accordance with Anishinabek research protocols. We did not use a written information/consent form because such forms are often viewed with suspicion and distrust, to the extent that many traditional people will not participate in the research because they view reliance on written documentation as indicative that the researcher and the project are unreliable and untrustworthy.

Informed consent was obtained orally according to community cultural traditions. The Elders and traditional land users were then invited to speak in whatever manner they chose as most appropriate. This process continued until the research participants informed the research team that they were finished. The research team thanked the participants and the meeting was closed using cultural protocols.

In order to fulfill the requirements of one of our funders, we were required to prepare a written report documenting the information that the Elders shared in the workshop. This was outlined in our funding agreement, which also stated that our funder would be able to distribute the report, transcribed interviews, recordings, and any other primary data as they saw fit. The Elders and members of the research team were concerned about this requirement, since Indigenous Knowledge is so often misused, taken out of context and made accessible without the permission of the Knowledge Holders. (Any report submitted to our government funders could be accessed by anyone through the Freedom of Information Act).

For the Elders, it was important that the knowledge was shared in an inherently culturally-appropriate way, and, coming from an oral culture, this meant that the youth were present to hear the knowledge in its original form. The Elders had little use for the written report and they believed, as did the members of the research team, that this knowledge belonged to the Knowledge Holders and to the community. As Knowledge Keepers, the Elders took their responsibilities for the protection of Indigenous Knowledge very seriously. Some of the Elders had shared knowledge

with outsiders before, and that knowledge had been used in inappropriate ways, which made them especially concerned with how funders might use the knowledge. They believed that, as the keepers of their community's knowledge, they were the owners of the knowledge and they had the right to decide how their knowledge would be shared and if it would be distributed.

The research team believed that the Elders and the community owned their knowledge. Although, after lengthy negotiations with the funders we were unable to get them to agree with our position, we were successful in changing the contribution agreement to be slightly more respectful of our rights. By modifying our methodology, we were able to meet both the needs of our funders and the needs of the Elders.

The workshop proceeded in an oral fashion, in Anishinaabemowin. The community recorders we hired were language speakers who recorded only information related specifically to the written objectives of the project. That information, which was in aggregate form (without the names of the Elders), was used to write the final report for our funders. Names of individuals participating in the Indigenous Knowledge Workshop were not recorded, comments recorded were not attributed to individual participants, and the "data" will be presented in aggregate form for reporting purposes. The information gathered at the workshop formed the basis for the funders' report.

## The Elders Speak

Few studies in the academic literature document the impact of environmental contamination on Indigenous communities from the perspectives of Indigenous Knowledge Holders (MacDonald et al., 1997, Simpson, 2001). However, reading more broadly, it is possible to find Indigenous perspectives on traditional foodways, health and wellness, environmental contamination, and decolonization. During the two-day workshop, Elders from Grassy Narrows and Wabauskang spoke about contamination in the same broad and holistic manner as the Anishinabek and Haudenosaunee Elders interviewed in the socio-cultural component of the EAGLE Project (Simpson, 2001).

The Elders emphasized the importance of traditional foods, as did other Indigenous experts in MacDonald et al. (1997), *Voices of the Bay*, in LaDuke's (2005) essay, "Food as Medicine: The Recovery of Traditional Foods to Heal the People," and in Cajete's "Indigenous Foods, Indigenous Health." Elders' perspectives on health and healing in the time prior to colonization echoed those found by Fox and Long (1996) in their study with Indigenous People in central Canada. Finally, the Elders' thoughts on colonialism

and traditional food systems resonate with Waziyatawin's essay, "Decolonizing Indigenous Diets" in *For Indigenous Eyes Only: A Decolonization Handbook*.

According to the Elders, life was good before the flooding, relocation, contamination, and deforestation. The plants and animals were healthy and in abundance, and the water was pure and cleansed the body of toxins. The people were healthy and well. Families spent large blocks of time out on the land, harvesting their traditional foods and medicines, drinking the water, and nurturing family relationships. The community was stable and many people worked in the commercial fishing economy as fishers and as guides. Diets were high in protein and low in fat. People were physically active, and had strong emotional bonds to extended families and community. There were far fewer diseases afflicting community members, which the Elders attribute to their healthy lifestyle. Although life was hard work, it had meaning for the people and Elders told many stories of good times.

With the contamination of the English-Wabigoon river system many things changed drastically over a short period of time. At first, no one knew what was happening around them – people suddenly got ill, for no apparent reason. When the commercial fishery was closed, families lost their livelihoods along with the fish that was a staple in their diet. People were no longer out on the waterways fishing with family members and friends. As people could no longer fish, aspects of their culture, language and way of life were affected.

In particular regions in the territory, aspects of the language associated with fishing and with being out on the water were used less. Store bought foods, which were expensive, highly processed and low in nutritional value replaced nutrient-rich traditional foods. The dramatic loss of the traditional economy and the ability for families to be self-sufficient sent the community into poverty and economic despair, which strained family relationships. Water was no longer safe to drink in the territory. Younger community members were lost, seeing little value in their own culture and few opportunities for the future.

The Elders believe that mercury contamination continues to cause severe health issues for the Anishinabek people living in the English-Wabigoon River system, and that these health issues are felt through the generations. They believe that the fish, animals, birds, and plants are sick, and that when the land is sick, the people are also sick. They believe that the relationships between these sicknesses must be fully addressed before the community can move forward and begin to rebuild.

Elders reported seeing a dramatic increase in cancers, diabetes, neurological disorders, miscarriages, and birth defects, both in the generation that lived through the mercury contamination and in the subsequent generations following it. From a social perspective, the Elders reported an increase in violence in the community, along with drug and alcohol abuse, and family breakdown.

The Elders also pointed out that mercury is not the only source of contamination within their territory. They are also concerned about the use of pesticides in the territory, done without permission from the forest industry, as well as other pollutants released by the pulp and paper industry, and contaminants transported to their community through the air.

The Elders believe that the impact assessment of contamination on health and well-being must be approached from a context that recognizes all the other “contaminants” with which the community must deal. Assessing the contaminant levels of a few chemicals is only one aspect of a much larger and more complex picture. The Elders take a long-term and holistic approach to assessing contamination, encouraging us to think about the impacts on the plants and animals and on the next seven generations of people. They believe that their waterways are contaminated with a “chemical soup” resultant from unmitigated industrial development and that as a result the whole ecosystem is sick. Viewing the ecosystem as an interconnected and interdependent system of which we are a part and taking a long-term holistic approach urges us to be both cautious and precautious about decisions we make today in regards to the environment. For the Elders, there are no “safe” levels of contamination.

The Elders strongly suggest that returning to a diet that includes traditional foods cooked in a traditional way would increase the health and well-being of our communities. The Elders regard traditional food as an integral part of a culturally grounded way of life given to them by the Creator. Traditional foods are part of their culture. Being out on the land, harvesting food properly and taking care of the food system as a whole requires people to live their culture. Traditional foods are seen as “good medicine,” high in nutrients and vitamins and inexpensive. Revitalizing traditional Anishinabek foodways is an important part of decolonizing. The Elders believe this, even while they are concerned about the impact of mercury and other contaminants on their traditional foods.

It is strongly felt amongst the Elders that there has been no justice with regard to the mercury contamination issue. They believe that governments have not lived up to

either their responsibilities or the promises they made to the community after the contamination was discovered and during the negotiation of the compensation agreement. The Elders believe that the people and the natural environment are still suffering from the impacts of this contamination and that unless the situation is cleaned up, we will pass on these problems to future generations.

The Elders also see colonialism and the occupation of our land as “contamination” that continues to impact both our lands and our people, including the denial of treaty relationships/rights with the Crown, the destruction of our traditional territories by deforestation, the impact of residential schools, and the institution of state policies designed to undermine our sovereignty, assimilate our children and carry out cultural genocide, all pollute our relationships with our sacred ecology.

Environmental contamination is just one facet of the colonial grip the government continues to have on our people. It is a symptom of a much larger problem in our relationship with the occupying nation, and of how it deals with the natural world. It is a symptom of disrespect, domination, control, aggression, and injustice.

## **Western Science and Anishinabek Knowledge**

In this study, western science was used within a larger Anishinabek framework, and we tried to respect both systems distinct traditions, ways of questioning, ways of generating new knowledge and understanding. We also recognized that western society recognizes western scientific knowledge over Indigenous Knowledge, creating a tremendous power imbalance that is reinforced by other colonial realities. We did not want to use western science to back up what the Elders were saying because we believe that their knowledge is valid in its own right. Instead, we used it to emphasize what is known by the Elders, using an approach and a language that would be understood by government officials and other scientists.

There is a broad feeling in Grassy Narrows and Wabauskang that justice has not been achieved in relation to the mercury contamination. Thirty years after the spill and 20 years after compensation, the community is still dealing with devastating environmental and health impacts, and the expression of these concerns are falling on deaf ears. Treaty #3 Tribal Council has demanded a public inquiry into the mercury contamination and how it was dealt with at the time. The Elders of Grassy Narrows and Wabauskang want the mercury “cleaned-up,” the deforestation to stop and the polluting of their lands and rivers by industry to stop.

Some people in Grassy have talked about raising funds for a permanent environment centre and program to monitor all of the environmental issues facing the community. Others continue to develop alliances with environmental and social justice groups in order to put pressure on the federal government to “do something.”

In January 2007, the Chief and Council, the Grassy Narrows Environmental Group, trappers, clan mothers, Elders and youth came together and declared a moratorium on industrial development on their traditional lands ([www.freegrassy.org](http://www.freegrassy.org)), because their “fundamental ability to traditionally harvest in order to feed and support our families, as we have for millennia, is being jeopardized” as a result of intensive clearcut logging of their traditional territory by Abitibi Consolidated and Weyerhaeuser. Through all of this, the women of Grassy Narrows and Wabauskang continue to live up to their responsibilities to the water, the land, their families and their communities, but their path has not been an easy one. They continue to struggle to protect their land and their foodways, and to protect their families from disease and illness as best they can under the very difficult circumstances described in this paper.

## ACKNOWLEDGEMENTS

The authors would first like to thank and acknowledge all of the Elders, Grandmothers, Grandfathers, and Anishinabek Knowledge Holders from Grassy Narrows and Wabauskang who participated in this project. Funding for this research was provided by the Health Canada’s Ontario Regional Contaminants Fund, the Commission for Environmental Cooperation’s North American Fund for Environmental Cooperation, Health Canada’s National First Nations Environmental Contaminants Fund, and in kind contributions from Grassy Narrows and Wabauskang First Nations.

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# Health Research, Entitlements and Health Services for First Nations and Métis Women in Manitoba and Saskatchewan

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## ABSTRACT

Since 1982, the term "Aboriginal" has been defined in the Canadian constitution as including Indian, Inuit and Métis peoples and has become part of the Canadian vocabulary. However, among the groups included in this term, there are significant differences in access to health care services based on treaty and historical entitlements and related government jurisdictions and policies. In spite of good intentions, research on Aboriginal women's health can fall short when it fails to recognize differences in entitlements and health services available under the term "Aboriginal." We explored the historical developments leading to current legal entitlements to health care services for First Nations and Métis women. We then interviewed service providers in Manitoba and Saskatchewan to investigate women's access to health, including barriers created by differing entitlements to services and lack of understanding about services. We discuss why the differences in health service entitlements must be taken into account for health research.

## KEYWORDS

Aboriginal women, women, First Nations, Métis, non-Status, access to care, entitlements, health jurisdictions, research methods, health research

“It almost seems like the general population doesn’t understand that there’s specific benefits for each of us and if you are First Nations you can access [certain programs and services] as long as you have that 10 digit number but First Nations women without Treaty Status, Métis women, and other women are distinctly different and if they do not have that 10 digit number they do have access to the same kinds of services and programs.”

– Service Provider

## INTRODUCTION

Since 1982, the term “Aboriginal” has been defined in the Canadian Constitution as the descendants of Canada’s original inhabitants, specifically Indian, Inuit and Métis peoples (Canada, 1982). The word “Aboriginal” is now part of the Canadian vocabulary. However convenient the term may be, Aboriginal groups have unique cultures with different languages and traditions and should not be thought of as homogeneous. There are particular implications in the realm of health care because terminology, identity, and legal status have direct bearing on who receives what health benefits. To ensure that differences in entitlements and access to services are taken into account, new health research must include a precise description of the women or men involved, which requires researchers to learn about and understand the history and current entitlements.

This project was developed in response to community women’s requests; to describe the differences in entitlements and jurisdictions for health services for Aboriginal women, to begin to understand how women are affected, and to explain why these differences should be taken into account in health research. The focus is on Métis and First Nations women (including women with and without Indian Status) in Manitoba and Saskatchewan.

### Who are the Women? Understanding the Labels and the History

#### *Indian and First Nations*

“Indian” was used to describe the original inhabitants of North America by European colonizers. “First Nations” is not a legally defined term but is a recent, more positive way to describe a particular band, people or residents of a reserve.

Treaties are signed agreements between First Nations and the British Crown (thus, the Government of Canada) in which the First Nations agreed to share the land and the Crown agreed to provide certain protections and rights to the First Nation(s) signing the Treaty and their descendants (Daugherty, 1983). Although it is not the case in all parts of Canada, the lands in what are now the provinces of

Manitoba and Saskatchewan are covered by treaties.

These treaties are critically important to current health services because of the federal government’s commitment, in signing, to provide health care. For example Treaty 6, which was signed in 1876 by the Cree Nation in relation to land in Saskatchewan and Alberta, includes a clause stating that a “medicine chest” will be kept in the house of each Indian Agent for the benefit of the Indian people. There was considerable debate in the following years about its meaning but the “medicine chest” clause was eventually interpreted to mean government provision of free medical care to Indian people (NAHO, n.d.). There are significant differences of opinion concerning the provision of this care. First Nations view federal health programs as a right based on a fiduciary responsibility, while the federal government views their provision of health services as voluntary, due to a policy commitment only.

The British North America Act (BNA Act) established the country of Canada in 1867. Section 91(24) of the Act states that legislative authority for “Indians, and Lands Reserved for the Indians” rests with the federal government (Canada, 1867). The BNA Act granted some of the responsibility for health care to the provinces while the federal government retained responsibility for certain aspects of health for all Canadians. This division of responsibilities created a complication for First Nations: since it was the British Crown that had signed the original treaties and the “medicine chest” clause, that responsibility now rests with the Canadian federal government, but the provincial governments have responsibility for health care provision to residents.

The Indian Act (1876 and 1958) defines the term “Indian” and spells out all the rights and entitlements of Status Indians. According to the Act, “Indian” means a person who pursuant to this Act is registered as an Indian or is entitled to be registered as an Indian.” Under the Indian Act, people with Status had rights to live on a reserve, vote for chief and council in bands, share in band money, and own and inherit property on a reserve. “Status” was handed down along the male line of the family (dismissing traditional matriarchies). The Act set the conditions under which an Indian person becomes enfranchised, that is,

acquires full Canadian citizenship (that is, loses their Status as an Indian). The Act is administered by Indian and Native Affairs Canada.

The term First Nations is used to describe Indian people whether or not they are registered with Status. Because of the extent of coverage of the lands by Treaty in Manitoba and Saskatchewan, and their connection to Indian Status, the terms “Treaty Status,” “Treaty Indian” or “Treaty” are frequently used to describe Indian people who have Status related to being covered by a Treaty.

Bill C-31, an Act to amend the Indian Act, was passed in 1985. The intention, in writing it, was to comply with the Canadian Charter of Rights and Freedoms (1982) and to correct the sex discrimination in the Indian Act that until then stripped a woman of her status if she married a non-Status man. According to Section 6 (1) of Bill C-31, the following groups are now entitled to Status registration:

1. People who already had Status before Bill C-31, including women who had acquired Status under the Indian Act when they married a Status man. (This can include Métis, Non-Status, Inuit or non-Aboriginal women).
2. People who had been removed from the Register because they or their mother had married a non-Status (or non-Indian) man.
3. People who had been removed from the Indian Register through “voluntary” enfranchisement.
4. People who had been removed from the Indian Register through other forms of involuntary enfranchisement (e.g. for joining a profession or receiving a university degree).
5. People whose parents were both entitled to registration under Bill C-31.
6. People who have one parent who can register under Section 6 (1) and one parent who is not entitled to register, are still entitled to register under Section 6 (2) of the Bill.

However, the children of people who register under Section 6 (2) have different rights and entitlements than do the children of people registered under Section 6 (1). This has been referred to as the second-generation cut-off (Figure 1) (Mother of Red Nations, 2005). As well, entitlements reinstated under Bill C-31 do not necessarily translate into band membership. Mother of Red Nations Women’s Council of Manitoba (2005, 2006) notes that women with Status who do not have band membership do not always receive their rights, privileges and services to which they

should be entitled. Since its introduction, Bill C-31 has been challenged repeatedly because instead of reducing discrimination against women, it has created a new class of people:

The Bill has created new divisions in Aboriginal communities and deepened some old ones - between Aboriginal people who have Status and those who do not, between people living on-Reserve and off, and between people who have band membership and those who do not (Mother of Red Nations, 2005).

### *Métis*

Métis are people of mixed Indian and European ancestry. On the prairies, the European ancestors were the first white settlers: English, Scottish, Irish, and French. Métis peoples have a distinct culture and in some areas a distinct language.

During the last several years, Métis organizations across Canada have been consulting with their members, legal experts and historians to develop a nationally accepted definition agreed to by the Métis people. In 2002, the Métis National Council (n.d.) comprised of Métis organizations from Ontario westward, defined a Métis person as “... a person who self-identifies as Métis, is of historic Métis Nation Ancestry, is distinct from other Aboriginal Peoples and is accepted by the Métis Nation.” This definition confines the use of “Métis” to descendants of the peoples from the historical settlements in the Prairies, Ontario and British Columbia, the “Historic Métis Nations Homeland,” but could enforce the argument that the government has historical obligations to Métis people (under this definition) and their descendants. Others might endorse a broader definition of Métis people based on self-identification and recognition by the Métis community. The national Congress of Aboriginal Peoples, which does not focus on a definition of Métis, works to represent the interests of Indian people who do not have Status, and Métis people, including people from British Columbia, Manitoba and other Eastern provinces (Congress of Aboriginal People, 2007).

Métis people were not signatories to treaties. Aside from a few limited grants or programs, the Métis people do not receive additional health services from the federal government. The Royal Commission on Aboriginal People noted that “...both Métis and non-Status Indians have been considered, for jurisdiction purposes, a part of the non-Aboriginal population by the federal and provincial governments” (Commission on Aboriginal Peoples, 1996). However, all groups representing Métis people have for many years stated

that, as one of the founding peoples of Canada, they should be receiving additional consideration in health care and other areas.

### **What the History Means in Terms of Entitlements to Health Services**

The Canada Health Act passed in 1985 outlines the provisions for federal, provincial, municipal, and territorial governments in the delivery of health care services, including cash disbursements for declared services (Government of Canada, 1985). These provisions include universal access to insured hospital care and primary health care provided by doctors and other health care professionals, although there is a variation by province, health region within provinces and geographic location. Health Canada (2006) reports that all Aboriginal people have access to these services, as does any other resident of Canada. However, Inuit and First Nations people who are registered as Status are entitled to additional federal health services. Until recently, the federal government did not acknowledge any additional responsibilities for Métis people's health other than those assumed for the general population of Canada.

As Boyer (2003) states, "Since 1982, Aboriginal and Treaty rights have been recognized and affirmed as constitutionally protected rights under section 35 of Canada's Constitution Act, 1982." She argues that from a legal standpoint, since non-Status Indian and Métis people are included as Aboriginal peoples, they should be entitled to all the health benefits to which their First Nations Status counterparts are entitled through the signed treaties (Boyer, 2003).

According to Boyer (2004a), despite the legal recognition and affirmation of both Aboriginal and treaty rights, the federal government of Canada still has not in good faith acknowledged what these rights mean in terms of health services to all Aboriginal peoples; from the federal point of view "the provision of health services to First Nations and Inuit Peoples is done as a matter of policy only and not because of any fiduciary obligation, or Aboriginal or Treaty right" (Boyer, 2004a). Boyer (2004b) further argues that within an international human rights context and the perspective of health as a basic human right, Canada does not meet its international and domestic obligations to provide Aboriginal people access to adequate health-related services. The implications are particularly unclear for Métis people because they have traditionally been left out of all health policy meetings until the recently held Blueprint on Aboriginal Health in which First Ministers and leaders of

national Aboriginal organizations, including Métis, met to discuss the pressing health issues for all Aboriginal Peoples (Canada, 2005).

As a result, service delivery between those administered by First Nations or Métis organizations and those still managed through the federal or provincial government may differ. Service delivery between bands or Métis organizations may also differ, due to differing political priorities or service needs. As noted, a woman with Status who registered under Bill C-31, for instance, may not have many connections to a band, or her home reserve may have a shortage of resources for such things as housing, education programs or health care. Mother of Red Nations (2006) notes that while women with Status are technically eligible for additional health care,

"Access to health services becomes more difficult when someone requires specialized care or medication and resides off First Nations territory. Many specialized services require an individual to live on reserve to get the service or care, or to receive the funding for access. In addition, many of the policies related to criteria or eligibility are further defined by individual band policies and procedures and therefore can be further discriminating about who has access to specialized services" (Mother of Red Nations, 2006).

For First Nations Peoples, the issues are also complicated by discussions, tensions and wrangling between the federal government and the provinces. Allec (2005) writes, "Ample documentation attests to the fact that the long standing conflict between the provincial and federal governments has negatively impacted First Nations Peoples and has resulted in the patchwork of fragmented services which exists today..."

Saskatchewan and Manitoba provincial governments provide full coverage or partial cost coverage for a wide range of health services: medical, hospital, surgical, x-ray and other diagnostic, physiotherapy, occupational therapy, chiropractic services, optometry, home care, long-term care, mental health, public health, services for persons with disabilities, addictions treatment, health information services, some dental services, some ambulance services, and prescription drug costs. Both provinces also provide some extra coverage for low-income families or individuals (Government of Saskatchewan, 2006; Government of Manitoba, 2006).

The federal Non-Insured Health Benefits (NIHB) administered by the First Nations and Inuit Health Branch of Health Canada is the key program available to

First Nations individuals with Status (and Inuit people), but it is not available to Métis people and non-Status First Nation people (Health Canada, 2006). NIHB provides additional coverage for:

1. Short-term crisis intervention.
2. Mental health counseling.
3. Certain medical supplies and equipment.
4. Drugs.
5. Dental care.
6. Vision care.
7. Medical transportation.

Even for people entitled to NIHB, the complexity of the program is a problem. The lists of services, health care, equipment and drugs change frequently as there are advances in medicine, new research, or even budget changes. The Assembly of First Nations (2005) has produced an in-depth report and a strategy for addressing concerns with NIHB to ensure First Nations people have access to health care services according to need, treaty and inherent rights to health.

Despite the wide range of funded services available, the costs for services not covered or not fully covered can pose significant difficulties for women. There is an assumption that employee benefits for private health insurance coverage are widely available and that “most” citizens have such benefits. Women report, however, that part time and low-paying jobs keep them from buying drugs or health care that they need (Savarese, 2003; Deiter & Otway, 2001).

## QUALITATIVE INTERVIEWS

To understand more about how jurisdictional differences and entitlements affect Métis and First Nations women (with and without Treaty Status) in Manitoba and Saskatchewan, we interviewed service providers, to share their understanding of the rules and regulations, and how they affect the women who are their clients.

Ten Métis and First Nations female health care workers were recruited in a non-random, snowball technique, either by telephone or email. Participating women were asked to provide their signed informed consent. The interviews were tape recorded and lasted between 45 and 90 minutes. The participants were asked nine semi-structured questions related to their experiences helping women looking for health care and their understanding of the women’s rights to services. The results were analyzed for relevant themes in relation to current services and traditional knowledge. If needed, a debriefing

period followed each interview to ensure recalling problematic events did not overly distress the participants.

The interviews used indigenous methodologies wherever possible. Reliance on the spoken response is in keeping with oral traditions, for instance, which is why we include direct quotes from the women who took part in this study. As well, the main researcher for this part of the project situated herself within the study as is common when using and integrating an indigenous methodological narrative approach in research (Smith, 1999). The study follows both standard and Aboriginal ethical procedural guidelines and received ethics approval from Prairie Women’s Health Centre of Excellence.

All the women interviewed were involved either directly as front line workers or indirectly as managers helping First Nations, Métis or other Aboriginal women access health services and programs. All the women interviewed stated that they either experienced themselves or witnessed problems related to getting health services and programs as a result of entitlement and jurisdictional issues. They all knew women who had difficulty accessing health programs and services, no matter if they lived on-reserve, rural off-reserve, off-reserve but near-reserve, or in urban areas.

## RESULTS

The interviews revealed three important points:

1. There are several significant barriers to health care affecting all Aboriginal women: transportation, language, age, health, lack of empowerment, lack of education, and a history of abuse and discrimination.
2. For First Nations women with Status, a lack of awareness of what their entitlements are, and what programs and services are available to them as part of their entitlements, keeps women from getting the care and service they need.
3. For Métis and non-Status women, the most significant point is the women’s complete lack of entitlements beyond what is provided by the provinces.

Providers spoke of the confusion among women about the services and programs to which they are entitled, lack of general information, and the need to dispense with the artificial lines of jurisdiction for families and neighbours.

Recent cutbacks to the benefits covered by the NIHB program have restricted access to proper medical treatment for some women; final approval comes from NIHB.

Sometimes there is confusion concerning the paperwork

required for approval to receive benefits. For example, as one woman stated,

A couple of years ago there was a medication that was quite costly, and the client could not afford it, and they wanted the client to write a letter, but they denied it. It was a prescription for dementia. They wanted the client to write a letter explaining why it was needed. We wrote the letter back, asking how a client with dementia could be expected to write a letter.

It would seem that this type of written confirmation should have been prepared by a doctor. Another woman explained,

We had a client denied a walker, she got a prescription, had taken it to wherever, and it was not covered. So [she] came, and we wrote the letter, and they wrote the letter back stating that [she was] not covered unless [she was] oxygen dependent, overly obese, so we purchased a wheeled walker, and lent it to [her].

Bill C-31, as noted, provides for the reinstatement of persons who lost their Status through the Indian Act. There are many cases of women who have different Status from their children, or in some cases, from their husbands. The women reported that when complaints are voiced to federal officials they are told that the band gets money for Bill C-31 individuals and so complaints should be addressed to band leaders. When the complaints are taken to the band officials, the officials deny that funds are received in this manner.

On the other hand, non-Status and Métis women have no entitlements. Many people do not have private or employment-related health insurance to cover the extra costs of dental and eye care, extra prescriptions not covered in the drug formularies or ambulance transport. "If you are Métis and you don't have money how are you going to access medicine?" one provider asked.

Some providers work around these limitations, providing care and help to anyone who lives on a reserve. One woman stated,

It doesn't matter if they are Métis, Status or non-Status. For Non-Status peoples we do our best here at the clinic to get their equipment or whatever they need provided that they stay on the reserve. But once they leave the reserve ... I guess that is when the province or whoever takes over.

The same woman commented on how it is more difficult to give non-Status people access to needed drugs.

We are not able to access drugs for them. Basically if they are non-Status they are on their own. We had a little fund here at the clinic where people who cannot purchase the drugs on their own, we help them out [with] that.

Provincial welfare systems can make these issues more complex. One provider gave the following example,

I had a person come up to me who lives in the community, but I think that she's Métis, and I don't know if it would make a difference or not that she's on provincial welfare, because if you're on provincial welfare, and live in the community, that is who gives you your welfare whether you're Treaty or not. I understand that the mother had a child that was medi-vaccated to [place], so the Mom obviously went with the child because the child was under age. Three days into whatever was wrong with this child, the Mom was still in [place], and I don't know how this system works, but income security got a hold of her, and they were going to start deducting from her welfare check because she was in [place], and they were going to pay [where she was staying], and reduce the amount of her monthly check because she was in [place].

There is a sense that the real needs of the women are not taken into account.

One woman stated:

We try to phone people to state our concerns but we get the blind eye you could say from government people because basically the decision making is done through there... [but] it affects the grassroots people. Not really thinking that it is expensive to live up North, not to mention your medical expenses, when you are being flown out of Winnipeg. Or you could be flown to Thompson and then Winnipeg.... You don't have to pay for the air transportation to get you to the nearest care facility, but you have to pay for all those [other] ambulances. It's a burden.

Another service provider said,

I think that maybe sometimes there may be some covert exclusion, stemming from a lack of understanding about some of the issues or ability to empower Aboriginal people as well as other cultures.

The on-reserve and near-reserve health care providers, however, had no problems defining and discussing the difficulties associated with access to programs and services. They spoke of difficulties in transportation, language, inadequate or insufficient numbers and kinds of programs offered, lack of awareness of what programs and services are available, lack of awareness of what funding resources are available (i.e., what will be covered by their First Nation or other funding sources), discrimination towards addicts and women of the street, and tedious FNIHB and provincial policies related to access to medications, services and programs.

Given the geography of Saskatchewan and Manitoba, community isolation and the vast distances that must be traveled, transportation for medical purposes is a prime issue for all Aboriginal women. Participants spoke of how the mode of transport is determined by Status. A Métis woman commented,

We all go to the same health centre but another example would be if I had an appointment in Winnipeg, made by the doctors here. If I had to go I would get a warrant from the nursing station and I would go on the bus. If my daughter, who is Status, went to the nursing station with me, she would fly to Winnipeg, so that's a big thing we see. My brother had an angioplasty done and the next day they wanted to send him home on the bus, and he couldn't even walk. That's through Northern Transportation, so that is government policy. It's mainly because he wasn't Treaty at the time, but now he's Treaty, so now he gets to fly. In Winnipeg, if you had to go to Toronto if you were Status you would fly, but if you're not you'd have to take the bus.

As one interviewee stated on the topic of access, "...if a Métis person is medi-vacc'd out of the community and if you're not on welfare you are basically on your own." Non-Status and Métis women who do not have additional private benefits have to provide their own means to cover the costs, compounding the stress caused by their health issue.

## DISCUSSION AND CONCLUSIONS

There is no shortage of documentation about the poor health status of Aboriginal people in Canada, including women (Dion Stout et al., 2001). However, despite the many materials written and the promises of programs and funds, the situation persists. Some recent attention has been given by policy makers and politicians to improve access to care, and by implication reduce the inequities.

Understanding the current situation takes some time, since entitlements to health care services are complicated by over 400 years of colonial rule and more than 150 years of legislation and policy. We have seen that there have historically been differences in entitlements to health care services for Métis and First Nations people.

Women are affected differently than men because provisions under the Indian Act made Indian women more likely than men to be enfranchised through marriage. Indian Status reinstated under Bill C-31 provides some women with renewed entitlements, but not all women have been treated equitably. Métis residents, as noted, are entitled to only those health care services available to all provincial residents. Settlement patterns, family ties and geography have contributed to having some people receiving health care on one side of a road (or lake) and others not.

The term Aboriginal is an accepted term and is in our Canadian Constitution, but it clearly has limited value when discussing health care services and access to care. For policy makers and providers directly involved in health and Aboriginal issues negotiations and discussions, the differences in health entitlements among Aboriginal people are central. But in many documents and discussions about Aboriginal health, the ambiguity about who is being discussed remains, or the population included varies substantially. To ensure that differences in entitlements and access to services are taken into account, new health research must include a precise description of the Aboriginal women involved, which requires researchers to learn and understand the history and current entitlements.

### Health Research that Includes Health Entitlements

While the poor health status of First Nations women has been documented, there is less data available for Métis women. As well, there has been only limited research done on the factors that influence women's health or positive health practices (see Bennett, 2005 for example).

Recently, Aboriginal organizations are taking a lead in guiding new research that is culturally appropriate. New

protocols and ethics standards have been developed for doing research appropriately with, for and by Aboriginal women (Saskatoon Aboriginal Women's Committee, 2004; Canadian Institutes for Health Research, 2005).

Any research or new study examining determinants of health, healthy living, health care access, outcomes, wait times, or service provision must be very clear about the population to be studied or involved in the study and what legislated entitlements they have. Researchers must bear in mind that even members of the same family may be technically entitled to different health care. As well, in many communities in Manitoba and Saskatchewan (Cross Lake and The Pas, for example) where reserve and non-reserve lands are adjacent, the residents live their lives on one side and the other, but cannot necessarily seek or receive the same health care services. Researchers must also become familiar with the study community's history and how women of the community can or cannot make use of the project, program or service examined. A research study of health care access requires this historical and entitlement account to set the context fully.

Research based on existing administrative, survey, population, and other data sets is limited by how populations were included. For example, Statistics Canada uses several methods for identifying Aboriginal ancestry; most often using a broad definition, allowing survey and census respondents to self-identify as having Aboriginal ancestry. Some First Nations reserves, however, refused to take part in some national surveys, and in other cases survey design did not include residents of the northern territories, most of whom are Aboriginal. Manitoba Health, in contrast, collects health utilization data about all Manitobans and data can be retrieved about those persons who voluntarily declare their First Nations status to Manitoba Health. The Manitoba Vital Statistics registry of deaths, however, includes as "First Nations" all those, and only those, whose place of residence at the time of their death was a First Nations reserve, thus excluding all Aboriginal Manitobans who live off reserve and making no distinction about Métis or Status (Donner et al., 2006). Smylie and Anderson (2006) summarize the numerous limitations in the existing data sets. The authors also note that the population health measures were by and large set by non-Aboriginal people and do not yet include health measures that reflect Aboriginal health concepts. The authors state "...data coverage and quality, data jurisdiction and utility, data governance and relevance, and infrastructure and human resource capacity" are challenges to any measure of Aboriginal health in the existing health measurement systems. That is, using or interpreting these data without

the context of health entitlements can lead to erroneous understandings of the health of a population.

Lost in the confusion of words and regulations are the women themselves. As we have seen, Aboriginal women and the people who wish to assist are equally entangled in the words and regulations. Although they are directly affected, the women may not have the time to sort it out or adequately gain thorough explanations of the complex details of evolving policies and regulations. But women do recognize the inconsistencies in the treatment of First Nations with Status, those who do not have Status, and Métis people. Further research on the specific differences and how access to services particularly affects women's health would provide greater insight into priorities for addressing the problems created by jurisdictional differences - but it would not diminish the urgency of the current recommendations from the women in this study for improving health and access to health care.

The providers interviewed for this report see access to services as linked with a number of factors affecting their lives and the lives of the women they work with, and state that these factors must be taken into consideration and addressed. They also emphasize that work must be done to ensure a more sensible and equitable way to provide health services to all Aboriginal people.

## ACKNOWLEDGEMENTS

This paper is adapted from a larger policy and research report. The authors thank members of the research steering committee who provided guidance throughout the project. Funding for the project was provided through Health Canada's Women's Health Contribution Program to Prairie Women's Health Centre of Excellence. The views expressed in this paper do not necessarily represent official policy of Health Canada. This is PWHCE project # 149. The full report will be available at [www.pwhce.ca](http://www.pwhce.ca).

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# Culturally Competent Care for Aboriginal Women:

## A Case for Culturally Competent Care for Aboriginal Women Giving Birth in Hospital Settings

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### ABSTRACT

Increasing numbers of Aboriginal women are using urban hospital settings to give birth. Culturally competent care, including an understanding of cultural, emotional, historical, and spiritual aspects of Aboriginal Peoples' experience and beliefs about health and healthcare, is important to the provision of quality care. While there is a body of literature on culturally competent care, no models specific to Aboriginal women giving birth in hospital settings exist. This article explores Aboriginal peoples' historical experience with western health care systems, worldviews and perspectives on health and healing, and beliefs regarding childbirth. Some of the existing models of culturally competent care that emphasize provision of care in a manner that shows awareness of both patients' cultural backgrounds as well as health care providers' personal and professional culture are summarized. Recommendations for the development of cultural competency are presented.

Acquisition of knowledge, self-awareness and development of skills are all necessary to ensure quality care. It is essential that - at both systemic and individual levels - processes are in place to promote culturally competent healthcare practices. Recommendations include: partnering with Aboriginal physicians, nurses, midwives and their representative organizations; conducting community-based research to determine labour and delivery needs; identifying and describing Aboriginal values and beliefs related to childbirth and its place in the family and community; and following Aboriginal women's birth experiences in hospital settings with the overarching goal of informing institutional practices.

### KEYWORDS

Aboriginal women, culturally competent care, hospital birth, obstetrics

Giving birth is a major life event for Aboriginal<sup>1</sup> women and their families. The experience can be positively or negatively affected by the care received, (Callister, 2004; Carlton, Callister & Stoneman, 2005; Matthews & Callister, 2004; Ottani, 2002), which can affect subsequent interactions with health care providers (Carlton et al., 2005). Culturally competent care, pre-natally, during the birthing experience, and post-natally, is critical to the provision of quality care (Callister, 2001; Edgecombe, 1996; Foster, 2006; Martin-Misener & Black, 1996; Matthews & Callister, 2004; Ottani, 2002; Smith, Varcoe & Edwards, 2005). Social, political and cultural changes that Aboriginal women in Canada have faced have negatively affected their education and cultural identity and traditional values, as well as their health (Adelson, 2005; Carroll & Benoit, 2001; Dion-Stout, Kipling & Stout, 2001). Culturally competent care is more likely to be successful than culture-blind care in addressing population health disparities, including gestational diabetes, high birth weights and higher post-natal death, including Sudden Infant Death Syndrome (SIDS) (Adelson, 2005; Smylie, 2001b). Given the history of negative experiences with mainstream health care institutions and the impact these factors have had on health outcomes of Aboriginal women, providing culturally competent care is particularly important for Aboriginal women who are giving birth in Canadian hospitals.

### **Aboriginal includes First Nations, Inuit, and Métis Peoples of Canada.**

Over the past 30 to 40 years, increasing numbers of Aboriginal women have given birth in large urban hospital settings. For many communities, this change began in the 1970s when the Canadian government established an evacuation policy for women living in remote northern communities (Hiebert, 2001; Inuit Tapiriit Kanatami, 2004; Kaufert, Koolage, Kaufert, & O'Neil, 1984; Smith, 2003; Smith et al., 2005). To give birth in urban facilities, women are often required to leave their families and communities, usually for several weeks at a time (Couchie & Sanderson, 2007). With the closing of many small, rural hospitals, women from reserve communities also give birth in large urban hospitals. In addition, half of all Aboriginal people in Canada now live in urban centres, adding another dimension to the picture of Aboriginal birthing. A needs assessment conducted by the National Aboriginal Health Organization (NAHO) (2006) found that 93 per cent (27 of 29) of the First Nations and Inuit women who completed the assessment questionnaire gave birth in a hospital setting. Efforts are being made to renew Aboriginal midwifery and

birthing in homes or community-based facilities. In the meantime, the majority of Aboriginal women, currently give birth in hospital settings (NAHO, 2006). While there is a rich body of literature on the general topic of cultural competence, little has been written about applying this concept to healthcare professionals working with Aboriginal women giving birth in Canadian hospital settings. The purpose of this article is to summarize the issues involved and to illustrate the need for increasing culturally competent care with Aboriginal women giving birth in hospital settings.

### **Models of culturally competent care**

The concept of culturally competent care dates back to the mid-twentieth century and was used by increasing numbers of nurses and other health professionals throughout the 1980s (Leininger, 1988). Several nursing scholars have formulated models and frameworks of culturally competent care to guide practice and research (e.g., Campinha-Bacote, 2002; Davidhizar & Giger, 2001; Leininger, 1988; Purnell, 2002; Schim, Doorenboos, Benkert, & Miller, 2007; Spector, 2002; Suh, 2004). The development of these models was influenced not only by the needs of historically marginalized communities but by the increasing variety of immigrant ethnic communities in health service populations in Western countries. In Canada, an increasingly vocal indigenous critique of health care practices and the colonial practices endemic in western-based health systems contributed to the development of culturally competent care practices (Dion-Stout et al., 2001). The literature on models of culturally competent care is extensive and ongoing (Shen, 2004).

Leininger's (1988, 2002) culture care model, an early approach to culturally competent care, is also known as "the sunrise model." With the aim of facilitating, enabling or maintaining well-being through transcultural care decisions and actions, it promotes nursing care that matches the worldview and experience of the patient through a process of cultural assessment (Shen, 2004). In another model, Spector (2002) integrates concern for what she refers to as heritage consistency (the degree to which people's lifestyles reflect their traditional culture), HEALTH traditions (the balance of all facets of a person, physically, mentally and spiritually, within a context that includes a person's family, culture, work, community, history, and environment), and a range of cultural phenomena. Spector draws on Davidhizar and Giger's (2001) six cultural phenomena that vary among cultural groups and affect health care: environmental control, biological variations, social organization, communication, space and time orientation. In another model, Campinha-

Bacote (2002) emphasizes that gaining cultural competence must be understood as an ongoing process consciously carried out to provide effective care to patients, while keeping in mind the variations that occur within ethnic groups. Campinha-Bacote suggests this process includes: developing cultural awareness, cultural knowledge, cultural assessment skills while engaging in cultural encounters, and having what she refers to as cultural desire or personal motivation to engage - with humility - in cultural learning.

These models have in common a focus on healthcare delivery in which the provision of care shows awareness of both the client's cultural background and one's own personal and professional culture. Culturally competent care is more than simply a matter of cultural sensitivity or awareness, culturally competent care is actions that change policy and procedure (Brach & Fraserirector, 2000).

Models for culturally competent care were initially developed to address appropriate care for immigrant populations. Studies specific to Aboriginal women giving birth in hospital settings are limited. Available literature suggests serious concerns about the lack of both cultural sensitivity and respect by non-Aboriginal people (Baker & Daigle, 2000; Browne, 1995). The term, culturally competent care, is, therefore, a generic term that was not designed for Aboriginal women. Because no hospital-based models exist specifically for Aboriginal women giving birth in hospital settings, research in this area is necessary to respond effectively to the health care needs of this population.

### **Implications from recent research**

In considering the importance of culturally competent care, health care providers must be able to understand the vulnerability people feel and the potential loss of dignity they experience upon admission to hospital (Matthews & Callister, 2004). Respect, dignity, choice and empowerment, some of the characteristics that comprise quality care, decrease the influence of learned helplessness, increase autonomy and enhance health care outcomes (Waller, 2002). These factors are even more important when delivering healthcare to patients from diverse and marginalized cultures (Matthews & Callister, 2004; O'Brien, Anslow, Begay, Pereira, & Sullivan, 2002). Beliefs, practices and perceptions regarding pregnancy, birth and post-natal care vary worldwide. Particularly meaningful is an understanding of who should attend the birth, the gender of the physician, the role of the nurse as information provider or simply as comforter, the experience of pain, and of the degree of technology involved (Callister, Khalaf, Semenic, Kartchner, & Vehvilainen-Julkunen, 2003; Carlton et al.,

2005; Raines & Morgan, 2000). The post-partum period is often particularly sensitive and includes culturally-based differences regarding who is the primary focus of attention following birth, whether the mother and baby should be kept cool or warm, issues related to sleeping, breast feeding, the need for rest, the meaning and role of visitors, appropriate food, the need for prayer, and when to leave the hospital (Banks, 2003; Cioffi, 2004; Kim-Godwin, 2003; Raines & Morgan, 2000).

For Aboriginal women in North America, particularly salient issues include aspects of the holistic world view of Native American culture (Lowe & Struthers, 2001). Seven dimensions identified by Lowe and Struthers as useful in the development of nursing practices with Aboriginal people include spirituality, respect, trust, caring, traditions, connection, and holism. Spirituality, in the Aboriginal context, is the most important of the dimensions discussed, and yet is probably the least understood by health care providers. Traditionally, the relationship with the child is understood to begin before birth. Preparations for a good birth and a healthy baby include avoiding stress, listening to teachings of older women, remaining physically active, connecting with the child, and caring for oneself in a spiritually healthy way (L. Bill, personal communication, May 15, 1990; Long & Curry, 1998; Paulette, 1990, 1999; Sokoloski, 1995). In the context of health care and especially of birthing, cultural competence for Aboriginal women means that the whole person(s), both mother and baby, must be considered not only physically, but also spiritually, emotionally, culturally, and historically (Foster, 2006).

A recent study examining women's birthing experiences found that while the quality of the childbirth experience is enhanced by a sense of empowerment gained through the patient's involvement in decisions and interventions, the respect received from health care providers is even more important (Matthews & Callister, 2004). Respect must be understood in Aboriginal terms and applied to all interactions (Browne, 1995; Ellerby, 2001; Foster, 2006). Browne (1995) studied the meaning of respect in the context of interactions between Cree-Ojibway patients and health care providers. Respect was seen as a reciprocal process that acknowledges in word and action the equality of individuals and communities; respect was communicated through behaviours such as active listening, making genuine efforts to understand the patient's perspective, providing clear explanations and through demonstrations of personal integrity. In later work in Northern British Columbia, Browne, Fiske and Thomas (2000) confirmed this

concern for respect and found that First Nations women's experiences were enhanced when practitioners allowed for active engagement in health care decisions, projected genuine caring and affirmed respect for personal and cultural identity.

In their study involving interactions with health care providers and Indigenous women in Ontario, Manitoba and the North central United States, Dodgson and Struthers (2005) found three areas of concern: the experience of historical trauma as a continuing lived marginalization; the demands of biculturalism as marginalization; and the difficulties involved in interacting in complex health care systems. Concerns raised included experiencing a lack of understanding of Aboriginal decision-making processes, experiencing disrespectful treatment and hesitating in informing health care providers of sensitive details. Trust and the lack of it was a major issue and, in the case of some younger women living in urban settings, lack of trust meant they avoided health care services altogether (Dodgson & Struthers, 2005).

Mi'kmaq hospital patients in Eastern Canada also reported dilemmas related to bicultural issues stated as differences between "our ways, their ways" (Baker & Daigle, 2000). Current research being conducted with Mi'kmaq women by Whitty-Rogers (2006) will provide further insight. A common source of conflict is the definition of a family member – and who is considered to be one – that comes up when large numbers of hospital visitors present as family members. What made a difference in women's hospital experiences was respect and personalized care, treatment as equals of and as equals to non-Aboriginal patients and importantly, acceptance of often large numbers of visitors (Baker & Daigle, 2000; Sokoloski, 1995).

Other concerns involved discomfort with the degree of technological interference experienced; for example, induction and fetal monitoring, as well as choice regarding birthing positions and gender of physicians (Sokoloski, 1995). Concerns related to the proper care, rather than disposal of the placenta have been noted (Paulette, 1999). Avoiding conflict over the assumptions of hospital staff regarding the proper roles of mother and grandmother in postnatal care is important. For example, physicians and nurses may not realize that for some families the grandmother holds the baby first. Beliefs regarding appropriate weight gain during pregnancy and weight loss while breast-feeding may also be quite different from those held by medical staff and judgmental attitudes must be avoided (Vallianatos et al., 2006).

Effective communication is essential to culturally competent care. In order for Aboriginal people to be fully involved in their own care, services must be available in Aboriginal languages (Smylie, 2001b). Foster (2006) notes that, "cultural and language differences can lead to miscommunication, misdiagnoses and inappropriate treatments" (p. 28). Understanding non-verbal communication is also important (Ottani, 2002). For example, norms for eye contact or the absence of it, tone of voice, and degree and forms of participation in discussion and decision-making vary across cultures, and are often misinterpreted (Davidhizar & Bechtel, 1998; Ellerby, 2001). As noted by Ellerby (2001), avoiding eye contact and speaking softly, both signs of respect in Aboriginal cultures, are often misperceived by western professionals as avoidance. To communicate effectively, it is important for health care providers to allow for the time, pacing and acknowledgement of nonverbal communication that may be needed for the patients to express their questions comfortably (Dobbelsteyn, 2006).

Dissatisfaction with service provision was found in mothers who perceived a lack of support, control and communication throughout their birthing experiences (Fowler, as cited in Matthews & Callister, 2004). Taylor and Dower's (1997) study also found dissatisfaction with services due to lack of cultural sensitivity by health care providers. Loneliness, misunderstandings of cultural or spiritual beliefs, and fear are also cited as maternity experiences for Indigenous women worldwide (Watson, Hodson, Johnson, & Kemp, 2001). Cultural needs not being met may result in women avoiding utilization of a health care system during pregnancy until critically necessary, followed by early leave taking (Browne et al., 2000; Kaufert et al., 1984; Petten, 2002; Rankin & Kappy, 1993). Browne (2005) describes how popular societal discourses, which marginalize Aboriginal Peoples, influence the perceptions and attitudes of nursing staff. Aboriginal women are often represented in medical discourses both as having easy births and as being high risk, in each case differentiating them from the mainstream population. These stereotypes must be examined as such.

The need for culturally competent care for Aboriginal women to develop an understanding of Aboriginal Peoples' worldviews on health and western healthcare, it is necessary to consider the following issues: (a) respect for health, healthcare and childbirth beliefs and practices (Davidhizar & Bechtel, 1998; Milligan, 1984a); (b) diversity of perspectives within and between Aboriginal communities; and (c) potential for conflict in cross-cultural interactions.

Healthcare providers must also develop greater awareness of their own assumptions regarding health, illness and appropriate care (Dobbelsteyn, 2006; Edgecombe, 1996; Foster, 2006; Kulig et al., as cited in Leipert & Reutter, 1998; Lowe & Struthers, 2001; Mattson, as cited in Callister, 2001; Spector, 2004).

Spector (2004) points out that “to understand health and illness beliefs and practices, it is necessary to see each person in his or her own unique sociocultural world” (p. xiv). Many Aboriginal people tend to view health holistically, as the balanced interaction of the whole person including physical, mental, spiritual and emotional aspects (L. Bill, personal communication, May 15, 1990; Dobbelsteyn, 2006; Mussell, Nicholl & Adler, as cited in Health Canada, 2001; Paulette, 1999; Waldram, Herring & Young, 2006). In this context, health does not stop at the individual; it includes the relational aspects of life in community. Good or poor health occurs within the experience of family and community health and relationships.

Prior to colonization, Aboriginal people relied on their own beliefs, knowledge systems, practices and practitioners for health and healing. Results of a NAHO telephone survey with First Nations Peoples across Canada suggest that these traditional practices still exist. In this survey, 51 per cent of respondents had relied on traditional Aboriginal healers or medicine over the past 12 months, 72 per cent of the respondents agreed with the statement, “I trust the effects of traditional medicines or healing practices,” and 68 per cent indicated they “would use traditional medicines or healing practices more often if they were available through [the] local health centre” (NAHO, 2004, p. 99). Acknowledging and showing respect for traditional beliefs, practices and healers would enhance the cultural competency of current health care systems (Chen, 1999). Canadian examples exist in which health care institutions have successfully integrated both traditional and western medical philosophies (Smylie, 2001b). While keeping in mind that not all Aboriginal patients have the same history or the same preferences, Smylie describes “the use of traditional medicines, including the burning of sage, cedar, sweetgrass or tobacco in the hospital setting” (p. 8). By supporting cultural practices and healing, conditions of safety, respect and prayer are created.

A traditional Indigenous understanding of health is developed from a collective standpoint (Mussell et al., as cited in Health Canada, 2001) where “one’s position and relationships in society and one’s surroundings determine the state of one’s health” (Eby, 1996, p. 64). Culturally competent care during childbirth is important not only because it is a major life event, but also, more importantly,

because childbirth practices are rooted in culture (Ottani, 2002). Where and how one is born has an important impact on who one is and who one may become (Paulette, 1999). Health care providers who understand and show respect for cultural beliefs and practices are much better equipped to understand the cultural meanings of life events, including birth (Browne, 1995; Davidhizar & Bechtel, 1998). From an Aboriginal point of view, childbirth is a significant but normal event; it is a matter of wellness, not illness, and should not be unduly interfered with (Sokoloski, 1995). Many Aboriginal women have their own knowledge systems, traditional competencies, preferences and methods for prenatal care and birthing (Long & Curry, 1998; Paulette, 1999). Pregnancy involves taking care of oneself and the baby by eating the right foods, being active, avoiding stress and focusing on the developing relationship with the baby rather than on external issues (L. Bill, personal communication, May 15, 1990). Postnatal care occurs as a part of everyday life and involves the extended family; mothers and their newborns are cared for by older women and family members (Kaufert et al., 1984; Milligan, 1984a; Sokoloski, 1995; Vallianatos et al., 2006).

Hospitalization for the purpose of giving birth is a foreign and often isolating event for many Aboriginal women. For example, the shift from family and community control of the childbirth experience to hospital births in far away urban centres, without family members present, has had far reaching implications for the Inuit community (Douglas, 2006). Chamberlain and Barclay (2000) explored the psychosocial outcomes of Inuit women who were required to leave their communities to give birth. The most frequently cited stressor among these women was enforced separation from family, culture and community. Mothers reported being bored, homesick and lonely in unfamiliar surroundings, and concerned for the well-being of other children left behind; they wished family members were there to participate in the birth.

It is paramount that health care providers understand and appreciate the importance that family and community play in the lives of Aboriginal Peoples. The Society of Obstetrics and Gynecology Canada (SOGC) policy document points out that “the concept of family is culturally specific.” For example, in Aboriginal culture, “aunts, uncles, grandparents, cousins, and older siblings may play a role comparable in significance to the western European ‘parent’” (Smylie, 2001b, p. 7). The role of mothers and grandmothers as essential to maintaining the cultural nature of birthing, and pre- and post-natal care cannot be overemphasized.

A diversity of perspectives exist within and between Aboriginal communities. Creating environments where traditional practices are accepted is important, but it is also important to acknowledge that Aboriginal Peoples and their beliefs, experiences and values are not homogeneous (Callister, 2001; Ellerby, 2001; Foster, 2006; Seideman, Haase, Primeaux, & Burns, 1992). "Aboriginal Peoples in Canada embody approximately 50 culturally diverse groups, the roots of which are found in distinct languages and land bases" (Smylie, 2000b, p. 5). Further, members of any one Aboriginal community vary in the degrees to which they identify with indigenous or western belief systems. To develop a truer perspective of patients and their families, individual life experiences and the meaning of those life experiences within variable cultural settings must be understood (Callister, 2001; Smith et al., 2005). Care must be taken to avoid stereotypes and to evaluate individual beliefs and practices regardless of cultural background (Davidhizar & Bechtel, 1998; Ottani, 2002).

The potential for conflict in cross cultural interactions must be acknowledged. Spector (2004) warns that "extreme events . . . can occur when two antithetical cultural belief systems collide within the overall environment of the health care delivery system" (p. 4). Jones and Spector (as cited in Callister, 2001) remark that health care involves three perspectives: the culture of the health care provider, the culture of the woman and her family, and the culture of the health care delivery system. Assumptions from within any single standpoint may result in cultural blindness (Callister, 2001), which may then lead to potential conflict when interacting with persons who hold other perspectives. Tensions are inevitable when individuals come together in a specific health care situation lacking understanding of others' points of view. Conflicts can arise from different cultural views on health care (Callister, 2001; Milligan, 1984a); strongly held expectations regarding what constitutes appropriate birthing practices and a good birth can heighten this dilemma. These differences can result in the patient feeling isolated, disrespected and disempowered (Paulette, 1999; Smylie, 2001b).

Holistic views on health - in which one works towards balance to maintain or achieve health, and an illness is often thought to represent an imbalance in one or more areas - are common among many Aboriginal Peoples (Eby, 1996; O'Brien, et al., 2002; Stevenson, as cited in Health Canada, 2001). Wellness requires a commitment to work towards correcting imbalance through spiritual, mental, physical and emotional processes. The western view on health is individualistic and emphasizes a mind/body

dualism. In addition, western health care systems and service providers have traditionally seen the health care provider as the expert and decision maker. Ellerby (2001) reminds us that "socio-political power relationships are epitomized and maintained through cultural dominance of Western medical practitioners" (p. 7). This situation often exacerbates the power dynamic with people whose voices have already been marginalized (Eby, 1996). In addition to developing a greater understanding one's own beliefs and practices on health, as well as a greater understanding of Aboriginal beliefs and practices, exploring the larger social and political influences on different health models and practices is key to becoming truly culturally competent (Eby, 1996; Foster, 2006; O'Brien et al., 2002).

## RECOMMENDATIONS

The provision of culturally competent care for Aboriginal people must include an understanding of the history and impact of colonization (Adelson, 2005; Browne, Smye & Varcoe, 2005; Polashek Wood & Schwass, as cited in Smith et al., 2005; Smylie, 2000a). As Smith et al. (2005) stress, "health status and experiences like pregnancy and parenting must be seen within a broad understanding of the impact of colonization on Aboriginal people" (p. 55). This includes sending children away from parents and communities as experienced in residential schooling and the placement of many children in non-Aboriginal foster or adoptive homes in a phenomena referred to as "the sixties scoop." Moreover, it is important to understand the various terms used to refer to Aboriginal people and the legal and cultural implications associated with such terminology. Understanding the difference between status and non-status, treaty and non-treaty would enhance the development of culturally competent practices and reduce stereotypes (Smylie, 2001b).

Only 56 per cent of respondents of the NAHO (2004) poll agreed that "Aboriginal peoples are treated, as well as non-Aboriginal people in the health care system" (p. 129). In fact, 15 per cent of respondents reported unfair or inappropriate treatment "by a health care provider because they are Aboriginal" (p. 16). Understanding the roots of respondents' views is important. Much can be learned from situations where there has been a lack of cultural sensitivity or appropriateness; these cases should be highlighted and discussed with an eye to effecting change (Kaufert et al., 1984).

There is ample support in the literature for the benefits of developing cultural competency in health care providers (Callister, 2001, 2005; Davidhizar & Bechtel, 1998; Martin-

Misener & Black, 1996; O'Brien et al., 2002; Ottani, 2002; Smith et al., 2005; Spector, 2004; Taylor & Dower, 1997; Watson et al., 2001). This is particularly important, considering the historical experiences of Aboriginal people in Canada with health care systems, health care providers and differential health care legislation. Cultural competency can be enhanced through acquiring knowledge, examining attitudes, engaging in new experiences, changing behaviour, and developing appropriate skills. A variety of methods are available to do this. Learning through open experiences with patients is probably one of the most important. Another method, described by Edgecombe (1996), is the use of value orientation profiles, which provide information on how individuals or groups rank-order the values in their society. This tool could be utilized in learning both about healthcare practitioners' own values and about other culturally-based value systems in order to recognize potential areas of misunderstanding. Similarly, completion of a cultural assessment model, as Leininger advocates, can give health care providers insight into their own beliefs and practices related to health and illness, as well as those of their patients (Mattson, as cited in Callister, 2001).

Providing cross-cultural education to healthcare providers is another means of moving forward (Baker, Findlay, Isbister, & Peekeekoot, 1987; Foster, 2006; Petten, 2002; Rankin & Kappy, 1993). Reading literary works that address cultural beliefs, practices, and issues at staff meetings (Callister, 2001), participating in cultural events, and attending workshops would enhance the education of health care providers (Ellerby, 2001; Smylie, 2001b). Following up initial educational activities with mentoring could precipitate learning through role modeling while providing opportunities to discuss experiences, and reinforcing good practice.

However, while increasing cultural sensitivity is necessary, it is insufficient if it does not lead to behaviour change; staff must be supported systemically at all levels in using knowledge gained to change practice. Particular systemic interventions may include using cultural brokers, partnering with traditional healers, developing culturally appropriate teaching practices and materials, initiating and maintaining training programs for all staff, and recruiting professionals who have relevant background and experience in policy development (Callister, 2005; Brach & Fraserirector, 2000).

Partnering with Aboriginal health care providers (Hart-Wasekesikaw, 1999) including the Aboriginal Nurses Association of Canada (ANAC), the National Indian and Inuit Community Health Representatives Organization

(NIICHRO), the Indigenous Physicians Association of Canada (IPAC), the Native Mental Health Association of Canada (NMHAC), the Institute of Aboriginal Peoples' Health (IAPH), and the National Aboriginal Health Organization (NAHO) can provide valuable connections for learning about ways of implementing cultural approaches to healthcare and, also, about common areas of sensitivity (Smylie, 2001b). Engaging in two-way knowledge translation and capacity building activities with these and other organizations is important (Smylie et al., 2004).

The need for more research in this area is evident (Whitty-Rogers, 2006). In their review, Brach and Fraserirector (2000) indicate more research on the beneficial impact of culturally competent techniques on outcomes, including the reduction of health inequity, is needed to determine if the practice of culturally competent care actually makes a difference in the experience of patients. Another recommendation is to conduct culturally appropriate community-based research to discover knowledge deficits, determine best practices and explore the healthcare delivery experience and needs of Aboriginal women (Kuptana, 1996; Petten, 2002; Smylie et al., 2004). Narrative inquiry and other qualitative methods are appropriate for exploring Aboriginal women's birth experiences in hospital settings and can be instrumental in informing institutional practices (Callister, 2004; Matthews & Callister, 2004; Watson et al., 2001). As well, further research to determine whether changes in staff and organizational attitudes and behaviours have indeed occurred will be necessary following the implementation of culturally competent practice policies (Brach & Fraserirector, 2000).

## CONCLUSION

As the literature reveals, a key component in the provision of quality health care practices is the development of cultural competency. Culturally competent care includes honouring the birthing practices respected by each culture (Matthews & Callister, 2004). Health care providers must be willing to "integrate traditional practices or approaches to health care when the client needs or wants them" (Dobbelsteyn, 2006, p. 34). However, care must be taken to acknowledge the diversity that exists amongst Aboriginal Peoples in order to avoid engaging in further stereotyping. Incorporating a reflective and learner-based approach in health care delivery would greatly assist health care providers in achieving culturally competent practices. Recognition of the influence on any one health care provider of the biomedical "provider

culture” (Spector, 2002, 2004) with its own normalized beliefs and assumptions regarding appropriate health choices is also essential.

Although models for culturally competent care exist, research outcomes on culturally competent practices for Aboriginal women giving birth in hospital settings in Canada are sparse. Additional research on the needs of Aboriginal women delivering babies in hospital settings is vital not only to informing health care policies and practices, but to address gaps and barriers that prevent access or effective access to the health care system. Culturally competent care is important; developing and using cultural sensitivity and relevant practice skills is critical to good care, as is institutional responsiveness to this issue. Moreover, understanding the historical and sociopolitical dynamics involved is an essential component of respect and may influence not only current encounters but women’s willingness to engage in health services during both the pre- and postnatal periods. Forming partnerships with Aboriginal communities and professionals to develop policy and conduct research on these issues is important; doing so may assist in addressing the power imbalances between Aboriginal peoples and those working in the health care system. While awareness of the issues discussed in this article is increasing among health professionals, it continues to be critically necessary to develop a dialogue resulting in policy change and the application of strategies and practices that will promote an increased level of culturally competent care for Aboriginal women in hospital labour and delivery wards.

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## END NOTES

1. For the purposes of this study, women's health is defined as mental and emotional health, physical health, and social well-being. When health is defined as mental, physical and social well-being, and not merely the absence of disease and infirmity, cultural and social practices become critical contributing factors to health (Arctic Council, 2004).
2. Obstetric evacuation is a mandatory practice in most Nunavut communities, except for Iqaluit where there is a hospital, and Rankin Inlet, where a low-risk delivery birthing centre is located.
3. Inuktitut word meaning "people of Nunavut."
4. Inuit is the Inuktitut word for "people." Inuk is the singular form meaning "person."

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# Beginning with Our Voices: How the Experiential Stories of First Nations Women Contribute to a National Research Project

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## ABSTRACT

The purpose of this paper is to review how the experiential stories of First Nations women contribute to a national research project. The project focuses on how women's healing is impacted by their views about themselves as - and the stigma associated with being - a drug user, involved in crime and an Aboriginal woman.

Our project began with three First Nations women on our research team documenting the role of stigma and self-identity in their personal healing journeys from problematically using drugs and being in conflict with the law. In this paper we discuss how key components of feminist research practices, Aboriginal methodology and community-based research helped us position the women's experiential stories in authoritative, recognized and celebrated ways in our study. We illustrate how the women's stories uniquely contributed to the creation of our interview questions and the research project in general. We also discuss how the women personally benefited from writing about and sharing their experiences. Key benefits include the women discovering the impact of the written word, promotion of their healing, personal recognition of their ability to offer hope to women in need, increased self-esteem, and increased appreciation of the importance of sharing their lived experiences with others. Our method of research differs from a conventional western scientific approach to understanding, and as such made important contributions to both the project itself and the women who shared their experiential stories.

## KEYWORDS

Stigma, healing, identity, drug use, criminalization, community-based research, Aboriginal methodology, feminist research practices

“With every stroke on the keyboard there are years of pain being washed away  
and there is a joy that is overwhelming. Lost and desolate no more.  
Elated and heavenly are the feelings that pump through my veins straight  
from my heart into yours. My heart feels so good from having shared with you my life.  
Freedom is my friend.”

(Acoose, unpublished manuscript)

## INTRODUCTION

The idea for this project came out of a phone conversation between representatives from the National Native Addictions Partnership Foundation (NNAPF), the Canadian Centre on Substance Abuse (CCSA) and Colleen Anne Dell, the eventual Principal Investigator on the project—who was at the time from Carleton University. All participants agreed during our conversation that stigma has a destructive impact on the recovery of women in treatment for problematic drug use, in particular on their self-identities, and that little is known about how to effectively address this. We also acknowledged that many women in drug treatment share the experience of having been in conflict with the law.

We drafted a research grant application in response to our discussion. We sought additional partners to contribute their expertise, including an Aboriginal Elder, Aboriginal treatment providers, First Nations women who have been in drug treatment, treatment centre directors, academic researchers, and community agencies working with criminalized Aboriginal women. We also engaged three expert mentors to provide advice to our team in specialized areas, including traditional Aboriginal healing, drug treatment and rehabilitation. In June 2005, our team was awarded a three-year research grant from the Canadian Institutes of Health Research, Institute of Aboriginal Peoples' Health, to examine the role of stigma, identity and criminalization in First Nations women's healing from problematic drug use.

The problematic use of drugs among First Nations women is a serious health concern in Canada. According to the 2002-2003 First Nations Regional Longitudinal Health Survey, although the documented rate of illicit drug use in the past year is low (7.3 per cent) among First Nations (9.3 per cent for men, 5.3 per cent for women), it is still more than double the rate of the general Canadian population (3.0%) (First Nations Centre, 2005, p. 116). Aboriginal women also make up a disproportionate percentage of Canada's injection drug use (IDU) population, and IDU is a key mode of transmission for the human

immunodeficiency virus (HIV) (Barlow, 2003; Craib et al., 2003). Between 1998 and 2003, 66.9 per cent of all HIV-positive tests among Aboriginal women were attributable to IDU (Public Health Agency of Canada, 2004). Aboriginal women, including First Nations, are also over-represented in Canada's criminal justice system, including incarceration at the federal and provincial levels (Balfour & Comack, 2006; Canadian Human Rights Commission, 2003; Dell, 2001). In 2006, Aboriginal women made up 31 per cent of the federal prison population (Correctional Service Canada, 2006, p. 12), while Aboriginal Peoples represented approximately 3.3 per cent of Canada's total population (Statistics Canada, 2003). To further illustrate, between April 1, 1999 and March 31, 2004, over 2,700 Aboriginal females and about 900 non-Aboriginal females (a ratio of 3:1) were involved in Saskatchewan's correctional services (Johnson, 2005, p. 8), yet Aboriginal women made up only about 11 per cent of the province's population (Saskatchewan Women's Secretariat, 1999, p. 12).

Little is understood either about how women's healing from drug use is impacted by their views about themselves as drug users, involved in crime and Aboriginal women, or about the stigma associated with these identities. Our research team is currently conducting interviews with First Nations women in treatment at a sample of nine National Native Alcohol and Drug Abuse (NNADAP) programs in Canada. NNADAP centres are the main source of substance abuse treatment for Aboriginal Peoples in Canada. The goal of our study is to contribute to the drug treatment field original knowledge that will help improve the burden of ill health faced by First Nations women.

The purpose of this paper is to review how the experiential stories of First Nations women contribute to our research project. The project began with three First Nations women on our research team documenting the role of stigma and self-identity in their personal healing journeys from problematically using drugs and being in conflict with the law. In the first part of this paper, we discuss how key components of feminist research practices, Aboriginal methodology and community-based research helped us position the women's experiential stories in authoritative, recognized and celebrated ways in our study. We illustrate

how their stories uniquely contributed to the creation of our interview questions and research project in general. We then discuss how the women personally benefited from writing about and sharing their experiences. Our method of research differs from a conventional western scientific approach to understanding, and as such made important contributions to both the project itself and the women who shared their experiential stories.

### **Incorporating Our Voices Through Feminist, Aboriginal and Community-Based Research Approaches**

Our research grant application centred on our team's commitment to doing research "by, for and with" women in drug treatment rather than "on" them (Fitzgerald, 2004; Kirby & McKenna, 1989). For us, this translated into designing our research to respect the rights, beliefs and values of everyone involved, including community members and academics participating on our research team and the research participants. Our team came to its understanding of respect over time and with the guidance of two Aboriginal Elders. We put our team's understanding of respect into practice in the project primarily by integrating it into the experiential stories of three First Nations women who had previous drug use problems and who had been in conflict with the law. It is important to acknowledge that we did not directly involve women currently in drug treatment because of their potentially vulnerable positions. Our inclusion of First Nations women's experiential voices challenges the claim that western scientific method is the only way to produce knowledge (Gatenby & Humphries, 2000). Contrary to our own methodology, that of western science does not typically accept people's everyday experiences as valid "knowledge" (Tickner, 2005). Neither does it generally promote working in collaboration with the holders of such knowledge (Smith, 1999). Our inclusion of women's voices also disrupts the long-standing power inequalities between the researcher and the "researched" that are characteristic of western science (Shope, 2006; Deutsch, 2004; Hunter, 2002).

To put our understanding of doing research "by, for and with" into action, that is, in incorporating the lived experiences of First Nations women into our project, we drew on principles of feminist research practices (Pederson, 2002; Kirby & McKenna, 1999), Aboriginal methodology (Schnarch, 2004; Gilchrist, 1997) and community-based research (Stoecker, 2003; Institute of Medicine, 1998). We chose these three methodologies because they coincide with our team's commitment to respecting the rights, beliefs and

values of everyone involved in the research process. The three approaches are also in accordance with one of the goals of our research, which is to provide a successful model of collaborative research.

Drawing on key components of feminist research practices (i.e., to privilege women's experiences), Aboriginal methodology (i.e., to serve Aboriginal interests) and community-based research (i.e., to produce knowledge with marginalized community members), it was decided that three First Nations women on our research team would document their experiences with stigma and self-identity in their personal healing journeys from problematically using drugs and being in conflict with the law. Sharon Leslie Acoose, Valerie Desjarlais and Jane Smith (pseudonym) each have a unique and elaborate history; two have been in and out of treatment and jail for many years and have both been sober for more than 17 years, and one has a primary concern of mental health and a secondary one of problematic substance use. A biography for two of the women is included at the end of this article. The objective was for Sharon, Valerie and Jane to reflect on their personal healing journeys in areas we identified as central in our research grant, including problematic drug use, mothering, stigma, treatment, identity as an Aboriginal woman, being in conflict with the law, as well as any additional areas they identified.

At the start of our project, Sharon, Valerie and Jane each shared her story in approximately 5,000 words. Anticipating multiple uses for the stories, it was decided that writing would be the most appropriate means to record them. Members of our team reviewed the women's written account of their experiences for descriptions, themes and patterns among them (Greaves et al., 2006; Carney et al., 1997). The women's stories, in conjunction with the academic literature, assisted our team in creating our interview questions and generally strengthened our project. The three methodologies that supported the documentation of the women's experiences and their incorporation into our project are briefly introduced below. We discuss how each helped us position the experiential voices of First Nations women in our study in authoritative, recognized and celebrated ways.

### **Feminist research**

Central to feminist approaches to research is the improvement of women's lives (Fonow & Cook, 2005; Harding & Norberg, 2005). Such approaches accept as "truth" that women occupy a marginalized position in society, and that social structures seek to maintain a power

imbalance through patriarchy, misogyny and gendered and racialized practices (de Laine, 2000). Foundational to feminist research is that understanding women's oppression requires privileging their experiences. This is contrary to traditional approaches to social science (Cook & Fonow, 1986). Focusing on women as a general category, however, does not address existing power imbalances or recognize women's varied experiential knowledge (Shope, 2006). Privileging the experiences of First Nations women is particularly important in this project given the oppressive history of colonization of Aboriginal Peoples in Canada. That said, it is also important to acknowledge that First Nations women who are criminalized and who problematically use drugs are not a homogeneous group; they differ in countless ways, ranging from drug of choice to ethnic background and cultural experiences.

Our project's commitment to privileging First Nations women's experiences is illustrated in our approach to the development of our interview questions. As discussed, our project began with three First Nations women on our research team documenting their personal healing journeys from problematic drug use and criminalization. Each reflected on the important role of self-identity and the impact of stigma on her own healing. The women's experiential stories were reviewed alongside the empirical and theoretical academic literature. The experiential stories advanced our team's understanding of First Nations women's healing in several key areas, including the significance and meaning of community, the central role of hope in an individual's healing from problematic drug use, and the importance of physical and mental health in the healing journey.

### **Aboriginal methodology**

Aboriginal research has been described as more a method than an area of study (McNaughton & Rock, 2003). Central to the method is directing research to serve Aboriginal interests, which is referred to by some as Aboriginal self-determination in research (Schnarch, 2004). This is important because the history of research with Aboriginal Peoples is fraught with disrespect and the appropriation of power, which is reflective of the history of colonization of Aboriginal Peoples in Canada (Smylie, 2004; Dua, 1999).

Aboriginal methodology maintains that Aboriginal interests should be central to the research study. Some Aboriginal communities follow ethical and moral protocols to ensure research is helpful and not in any way harmful. (Fisher & Ball, 2003; Castellano, 2004). A well-known Aboriginal research protocol in Canada is the OCAP

(ownership, control, access, possession) principles, which are rooted in the work of the 1997 National Steering Committee of the First Nations and Inuit Regional Longitudinal Health Survey. The OCAP principles suggest that avoiding the abuse and mistreatment of First Nations communities under study requires the administration of an inclusive protocol that indicates the collective ownership of group information, First Nations control over research and information, First Nations management of access to their data, and physical possession of data by First Nations (Schnarch, 2004).

In our team's attempt to serve Aboriginal interests with our project, we used the OCAP principles as a beginning point to discuss varied and often contentious aspects of our research. In addition to the OCAP principles, we relied on ethical protocols from treatment centres involved in the study, guidelines from the National Native Addictions Partnership Foundation and an Elder's teaching on Aboriginal philosophy and clanship. The women's experiential stories and discussions about their documentation have also provided ethical and moral guidance to our study.

Sharon, Valerie and Jane raised fundamental issues about recording their lived experiences, including how the stories will be used in the future, how they will be compensated for sharing the stories and how to support the emotional well-being of the writers in the documentation of their lived experiences. They also suggested that the stories be shared with the research participants to offer them hope and guidance in their healing. Consequently, we put two of the women's stories in a booklet that we distributed upon completion of interviews at treatment centres. Again, adhering to a purely western approach to understanding, which relies on secondary sources in the form of published academic literature, would neither have provided our team with depth of understanding nor instilled compassion as did the women's stories. It is simply not possible to serve Aboriginal interests with our research without the experiential voices of First Nations women.

### **Community-based research**

Community-based research is generally defined as "a collaborative approach to research that equitably involves, for example, community members, organizational representatives and researchers in all aspects of the research process" (Israel, 1998, p. 177). The focus on community participation is rooted in constructionist and critical theorist evaluations of "the socially created nature of scientific knowledge" (Israel, 1998, p. 177). It can be argued that

those in marginalized social positions have traditionally been excluded from the production of knowledge. Community-based research focuses on shared participation throughout the research process and works with the strengths and resources of community members to increase the quality of the research (Fletcher, 2003).

The contributions of Sharon, Valerie and Jane's experiential stories to the construction of our interview questions illustrate our team's commitment to producing knowledge with marginalized community members. A second and possibly more insightful illustration is the knowledge gained by our team from the women's experiential stories about the importance of hope in an individual's healing from problematic drug use. Not only was this critical in the construction of our interview guide, it was also perceived as providing our research participants with a tangible "message of hope", the applicability of which we verified with all members of our research team. Messages of hope are not found in academic literature.

Turning the idea of a "message of hope" into action, we decided to offer the interviewees a tangible gesture of hope in the form of a gift of an oyster/pearl. The inspirational story of the oyster is described by Nabigon (2006): The strongest example I can find in Nature comes from Sister Water, the cradle of Mother Earth's womb. In her depth can be found the teachings of the oyster totem. Here the oyster's precious jewel, a pearl that starts out as a grain of sand, is nothing more than an irritant that has entered the barnacle or oyster at some point and cannot be removed. That oyster has lodged in its folds something that is very painful to its habitat-being. The sand cannot be removed and now the oyster must contend with it, using its natural abilities to deal with the situation. Unlike humans who pretend "it" will go away, the clam pulls from its inner qualities a working solution. The clam totem's teaching resembles our own feeble attempts to make peace with our emotions. It didn't ask for the lesson, but it was forced to take a negative aspect of life and work with its principles. In this instance Nature teaches the oyster to tap into its intrinsic abilities to protect itself from corrosion. The oyster now heaves up its own mucus in multiple layers until it polishes smooth the intrusive entity—the grain of sand. Time then becomes the key. The outcome is a jewel that is admired by all. (pp. 52-53)

Upon completion of an interview, we provide the interviewee with a natural oyster that has a pearl in it. While the oyster is being opened, the researcher shares the story of the pearl as Nabigon describes it.

The experiential stories of three First Nations women on our research team meaningfully informed our research in

multiple ways. The majority of these important contributions could not be gained through a strictly western scientific approach to research that relies primarily on academic sources and generally neglects the everyday lived experiences of individuals, in particular those who are marginalized and typically not a part of the production of knowledge. We share the perception that drawing on key components of feminist research practices, Aboriginal methodology and community-based research has helped us position the experiential knowledge of First Nations women in our study. In conjunction with a western scientific approach, the women's voices led our team to an enhanced understanding in key areas of our study and a strengthened research project.

### **The Benefits of Sharing Our Stories**

For this paper, Sharon, Valerie and Jane each reflected in writing on what it has meant to them to share their healing journeys with the project. In approximately 1,000 words, each woman wrote freely about her experiences and thoughts. The women wrote separately because of the personal nature of their reflections and because they could potentially influence each other's assessments. They answered two questions, one about what it has meant to be asked to share their story, and another about any benefits or drawbacks to them personally from sharing their story. Their reflections were reviewed for descriptions, themes and patterns among them. Five dominant themes were identified, discussed and verified among the authors.

None of the women wrote about negative consequences from sharing their stories, with the exception of describing the difficulty of doing so, as discussed below. The five main themes identified in their reflections are: discovering the impact of the written word, promotion of their healing, recognition of their ability to offer hope to women in need, an increase in their self-esteem, and increased appreciation of the importance of sharing their lived experiences with others. Each benefit is presented in the women's own powerful and candid words.

### **The impact of writing about our experiences**

Sharon, Valerie and Jane each relayed how writing about their personal experiences affected them differently than speaking about them. The tangibility of their words was equated with confirmation of their healing. They also thought that writing their stories gave them a sense of permanency. The women relayed that it was in some ways more difficult to write about their experiences, although the words they used were identical. The written word was identified as having potential to leave a powerful and lasting impression on the reader as well as the writer.

Sharon: Sharing my story always gives me a new faith in myself, as I am able to look at what I wrote. Sometimes I never cease to amaze myself because I feel so silly for what I put me through. Trust me, there are days when I can jump on the pity train and my ass rides for a long time. But when I read what I wrote... then I become revived once again.

Valerie: I verbally shared my story so many times in the past 20 years, but never actually sat down to write it. I asked myself 'How do I write this?'... As I wrote my story, I realized it was similar yet different than verbally telling my story. Well, words are words that come out of your mouth and people can misinterpret what you're saying, and some even forget the message you're leaving. Whereas, with writing, you can leave a message of hope and can provide courage to someone who is really searching to understand one's life. Someone may be reading my story 50 years from now, when I have passed this physical life and moved to the spiritual realm.

### **Sharing our experiences is a part of our healing journeys**

Each of the women communicated how sharing her story with the project was an important part of her own healing journey. Once again, they acknowledged that while it is difficult to reflect on their pasts, it is important for them to do so to progress in their healing.

Jane: Putting my experiences on paper was extremely difficult yet exhilarating... I must continue to vocalize the challenges I have faced and those that are ongoing. That is how I survive; by sharing and loving, contributing to my community and thereby growing.

Sharon: Sharing my story is what I do. It is where my continued healing journey brings me new appreciation for other women who are in need... The ghosts of the past surface at different times when I am sharing and the memories are painful. But at the end of the day I know that I will be okay because it is all part of my continuous healing journey... Writing this is self-discovery of my inner Medicine Wheel that I carry in my heart, mind, body, and soul.

### **Our stories offer hope to women in need**

The idea of offering hope to the participants in our study through the gift of an oyster/pearl was discussed

as an illustration of First Nations women's experiential voices contributing to the project. Hope was relayed in Sharon, Valerie and Jane's motivation for sharing their life experiences. Their collective desire is to provide hope to women in need, with whom they have experiences in common.

Sharon: It meant that sharing my life without alcohol/drugs might benefit the lives of others that are new in recovery and need to hear the possibilities. When I was out on the street or in prison or in treatment there was never anyone there for me. When I am asked to do something today that may save a soul, I have no hesitation. It is important to be able to reach out and touch the heart of a woman that has no idea how to love and to show her the way. It is important to give her hope for a renewal of life that she thought would never be and to give her peace of mind... Through sharing my life, perhaps one day another woman will benefit... I hope it will give one woman one small chance at full recovery.

Valerie: I realize people will make use of the only resources that they have within reach and if its alcohol and drugs, then that's the only resource they have. This is one of the main reasons I agreed to write my story. I hope this written document can become a resource for inspiration and hope rather than turning to addictions.

### **Documenting our lived experiences increases our self-esteem**

The women spoke of an increased sense of self-esteem and a general feeling of well-being as a result of sharing their experiential stories with the project and with the women who will participate in interviews. It has been documented in the literature that this benefit occurs when individuals tell their stories in their own voices and perspectives. (Ristock & Pennell, 1996; Stanley & Wise, 1991). Once again, the women noted that the necessity of reflecting on their experiences didn't make it easy.

Jane: Although frightening at times, I am committed to breaking the stigma... An improved self-identity has emerged and I am learning more about myself as I continue on my lifelong healing journey. With the love and support of my family, friends and community I am stronger... Through my experiences in this project with my story I now feel more worthy of holding my Spirit name.

Sharon: Whenever I am asked to write or speak to my recovery as an addict it is an honour that I bestow to be very high and it makes me feel good about being alive. It always means so many good things when you are asked to share, it makes you feel worthy and important to another human being... Being asked to write this important piece of work is just another stepping-stone in my path. It has brought me great joy to be able to do it... I am very fortunate to be able to break the silence so that other First Nations women will know it is okay to reach out. So yeah, being asked to write this has been a revelation and a means to an end. It is self-discovery... [For] me being asked to do something like this is a tiny miracle that makes me feel like a million bucks.

### **Appreciation of the importance of sharing what we have learned**

Sharon, Valerie and Jane each wrote at length about the importance of sharing with others what they have learned in life. Writing their stories for the project provided them with this opportunity. They saw sharing what they have learned as markedly different from sharing hope. The latter is about encouraging and inspiring individuals to take up the challenge to heal, whereas the former is more about the mechanics of "how to" heal.

Sharon: So you ask what it has meant to me to share? Well, it is amazing. And, if there is more that I can do to put a smile on some First Nations woman's face by her benefiting from my story then all this would have been worth it. This is fierce... I want so much to make a difference in another First Nations woman's life. I mean, I know that I cannot save the world, but maybe I can help save one small piece.

Valerie: The first initial thought I had for writing this story was, "They are going to use our stories just like a 'guinea pig,' don't they ever quit trying to study Indian people and see what makes them tick." But then I realized writing my story also provided me with the opportunity to continue to carry the message to those whom are still struggling with substance abuse and provides them with an opportunity to really look at what keeps them a prisoner in their own world.

## **CONCLUSION**

This paper has focused on how including First Nations women's experiential voices in an otherwise standard western scientific approach to research has benefited both the research project and the women who shared their stories. We drew upon components of feminist research practices, Aboriginal methodology and community-based research to design our study to be "by, for and with" our research participants rather than "on" them. For us, this means that our research respects the rights, beliefs and values of everyone involved in it. This paper has discussed and provided examples of how we have honoured our commitment to this form of research by incorporating into our project First Nations women's experiential stories about stigma and self-identity in their personal healing journeys from problematically using drugs and being in conflict with the law.

### **Biographies of Sharon and Valerie**

Sharon Leslie Acoose is from Sakimay First Nation in Eastern Saskatchewan and is of Saulteaux decent. A recovering addict with 17 years of sobriety, she has spent many years in and out of both prison and treatment. She is presently an Assistant Professor with the School of Indian Social Work at the First Nations University of Canada, Saskatoon Campus. She is also enrolled in the PhD program in the College of Medicine, Department of Community Health and Epidemiology at the University of Saskatchewan. Her passion, her love and her life is to work with other Indian women who have mirrored her life.

Valerie Desjarlais is a Saulteaux woman who resides at the Kawacatoose First Nation in Saskatchewan. She is a graduate of the University of Regina with a Bachelor of Human Justice degree. She has specialized training in therapy, domestic violence and chemical dependency. Along with her formal education credentials, Valerie has personal life experiences of violence, addictions, incarceration and loss. She shares these experiences in blunt and humorous ways. She enjoys challenges in her life, and as frustrating it sometimes gets, she continues to pray and to rely on the Creator to help her with her everyday tasks.

## **ACKNOWLEDGEMENTS**

We would like to acknowledge the tireless and outstanding work of all members of our research team in getting the project to the point where we could write this paper. Our

team members are: Sharon Acoose, Marie Anderson, Eli Beardy, Debbie Blunderfield, Kathleen Cayer, Whisper Chase, Sharon Clarke, Colleen Anne Dell, Valerie Desjarlais, Catherine Fillmore, Sheila Grantham, Jennifer Kilty, Tara Lyons, Margaret Marin, Joyce Paul, Jane Smith (pseudonym), Kendra Tagoona, Edith Reiger, and Ellen Smith. Our expert mentors are Carol Hopkins, Gary Roberts and Richard Garlick.

This work was supported by Canadian Institutes of Health Research (CIHR) grant FRN: 74289.

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# Body-related experiences of two young rural Aboriginal women

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## ABSTRACT

There has been a gradual increase in health research that explores the body-related experiences of young Aboriginal women living in urban and reserve settings. However, the voices of rural Canadian Aboriginal women not living on reserves, appear to be absent from this literature. The purpose of this study, therefore, is to better understand the body-related experiences of young Aboriginal women living in rural Canadian communities. Case study was utilized as the strategy of inquiry in which each of two young women (both 15 years of age) represented a case. One-on-one interviews were used to explore the young women's experiences. Four themes emerged: (1) fitting in, (2) rural uniqueness, (3) role models, and (4) body talk. The primary contribution of this study is that it sheds light on the unique body-related experiences of two young women, each living in a rural community where she is the only teenaged Aboriginal woman. Despite some similarities, the young women related very different stories of their experiences in their respective communities.

This research also highlights some of the ethical challenges of ensuring that the stories of the young women are adequately represented, while their confidentiality is respected.

## KEYWORDS

Young Aboriginal women, health, rural, body-related experiences, Canada

## INTRODUCTION

Since 1990, there has been a steady increase in obesity research among Aboriginal Peoples (e.g., Gruber & Ponton, 1995; Hanley et al., 2000). While there is a concentrated focus on the "obesity epidemic," Marchessault (1999) argued that there is much less focus on body image concepts and the concerns that some Aboriginal youth have about their weight. Although researchers have highlighted the link between body image concerns and health among the general population (Harter, 1999; Leary, 1995), the voices of Aboriginal women are rare in this literature. Even rarer in body literature (i.e., research focused on body image) are the voices of rural Canadian Aboriginal women.

In the United States, large scale surveys (e.g., Cummins, Ireland, Resnick, & Blum, 1999; Neumark-Sztainer, Story, Resnick, & Blum, 1997; Story, French, Resnick, & Blum, 1995; Story et al., 1994) have included objective measures of

American Indian adolescents' body image, and such studies highlight an overwhelming sense of body dissatisfaction among their participants. However, few researchers have explored Canadian Aboriginal Peoples' body-related experiences. Studies that include Canadian Aboriginal participants have typically utilized quantitative methods (e.g., Gittelsohn et al., 1996; Marchessault, 2004), and have usually included individuals living on reserves (e.g., Gittelsohn et al., 1996). Overall, and similar to previous American research, Canadian studies suggest that young Aboriginal women are dissatisfied with their bodies. While such quantitative research has been helpful in drawing attention to concerns that Aboriginal women may have with their bodies, Marchessault (1999) argues that these studies suggest nothing new but that qualitative research about Aboriginal Peoples' experiences with their bodies are just "newly studied."

Our previous research (i.e., Fleming et al., 2006) was one of the first Canadian studies to focus exclusively on Canadian Aboriginal women's body-related experiences. Four young women participated in this study and one of the primary contributions of the research is its suggestion that Aboriginal women's body-related emotional experiences might be more positive than previous research has indicated. We attributed our findings partially to our case study approach in which we used voice-centered methods (i.e., focus group, one-on-one interviews) that supported the young women in describing their complex body-related experiences.

While our research has highlighted the experiences of urban Aboriginal women, the voices of rural Aboriginal women are still absent from body literature. The young women involved in our previous research suggested that concerns with their bodies impact their overall health. It is important to explore rural Aboriginal women's body experiences, because as the Ministerial Advisory Council on Rural Health (2000) stated, the health of people living in rural and Aboriginal communities is poorer than that of urban dwellers. In light of the current gaps in the body literature, the purpose of this research is to better understand the body-related experiences of young Aboriginal women living in rural Canadian communities.

### **Significance of the Study: Addressing Recommendations**

In a detailed report on rural, remote and northern women's health, Sutherns, McPhedran and Haworth-Brockman (2003) recommend several future research priorities; our research addresses three of these recommendations. First, this research sheds light on the health of rural women in Canada. Sutherns et al. argue that the health of rural women in Canada is typically overlooked by researchers. Our research has produced one of the first studies that provides a sole focus on rural Canadian women's body-related experiences. Second, this research sheds light on the health of a specific rural population. Working with young Aboriginal women addresses a current gap in the body literature. Third, our research adheres to Sutherns et al.'s suggestion to use more "interactive methods" to better understand women's experiences. The one-on-one interviews used in this study serve as a starting point for a broad exploration of rural Aboriginal women's experiences.

## **METHODS**

Case study was the qualitative method of inquiry used in this study. As suggested by Stake (1995), case study supports the complexity and distinctiveness of a case. He explains that people are often cases of interest and that researchers are interested in them not only for their uniqueness, but also for their commonality. Reinharz (1992) argues that the power of a case study comes from its capacity to clearly convey the dimensions of individual life or social phenomena. This is a collective case study in which two young Aboriginal women helped to provide insight into the body-related experiences of young Aboriginal women living in rural Canadian communities.

## **PARTICIPANTS**

The two participants who took part in this study self-identified as Aboriginal women, and were both 15-years-old at the time of their interviews. After we obtained ethical approval from our university's Behavioural Research Ethics Board, we recruited participants through a known sponsor.

The known sponsor, identified through our social network because of her strong ties with young women in rural prairie communities, was approached with a short list of selection criteria for the participants. The intent was to interview two to four self-identified Aboriginal women between the ages of 14 and 18 who live in rural Canadian communities. The strength of case study research comes from the depth of the information obtained from each individual rather than from the breadth of individuals involved; Creswell (1998) asserts that case studies involving multiple individuals typically involve a maximum of four cases. Because research suggests that adolescents are particularly vulnerable to body image disturbances, our goal was also to work with adolescent women (Levine & Smolack, 2002). For identification of a rural community, we adhered to Statistics Canada's (2003) definition of rural and remote communities that are removed from the services and resources of urban areas and have populations of less than 10,000 people. Finally, we chose to include young women who self-identified as Aboriginal, since this term encompasses individuals who identify as legal or status Indian, non-status Indian, Inuit, and Métis (National Aboriginal Health Organization, 2007).

The young women who participated in this study self-identified as Aboriginal and, similar to the women who participated in Lawrence's (1999) research, use the terms Aboriginal and Native interchangeably. Although it

was not in our initial criteria, the two young women in this study were the only teenaged Aboriginal women living in their respective communities at the time of the interviews. To protect their identities, both young women chose pseudonyms (Andrea, Dana) that have been used to report the findings from this research.

Prior to participating in this study, Andrea had lived in her rural community of approximately 400 people for less than a year, and reported that approximately 10 other young women her age live in her community. Andrea explained that she lives in a “foster home” and that she had recently moved from her home in a nearby rural community that had more Aboriginal people. She also explained that she was planning to “move back home” after she finished the current school year. When asked to describe her physical appearance she said, “I am really short...and I am darker than most of them [other women her age], actually all of them.”

Dana, on the other hand, grew up in a community of about 800 people that includes about 20 other young women her age, and in at school that has “a lot of different kinds of people.” Despite being the only Aboriginal woman her age, and one of the few young women with dark hair and skin, she explained that her relatively small community is quite multicultural. As well, she noted that some nearby communities have larger populations of Aboriginal Peoples. When asked to describe her physical appearance she said, “I am kind of tall... and it’s not like I am a perfectionist and look at my body all the time and think its perfect, but it’s okay. I don’t go on extreme diets or anything and try to be super skinny, but I accept it.”

## Data Collection

After obtaining informed consent from both participants and their respective parent/guardian I, the first author, engaged in a one-on-one semi-structured interview with each participant. Because I am first author and the facilitator of the participant interviews, I offer a brief description of my personal background so that readers may better understand my research perspective. I am a young, privileged, white woman who grew up in a middle-class neighbourhood in Eastern Canada. Although my family is small, it is quite ethnically diverse and includes Aboriginal Peoples. When I first began researching women’s body-related experiences, I was surprised to find so few Canadian research studies that include Aboriginal women. Through experiences I have had within my family, I have learned to recognize and respect the diversity of all women, and my experiences motivate and guide me through my research journey.

Individual interviews were used because they allow researchers to enter into a participant’s perspective, with the assumption that it is meaningful (Patton, 2002). Stake (1995) says that interviews are important for case studies because the topic being investigated will be seen differently by everyone; thus, interviews are one of the best ways to better understand multiple realities. Each interview was conducted at a convenient time and location for the participants; in this case during school hours in private rooms at the participants’ respective schools. Questions that explored the participants’ body-related experiences were asked (e.g., How do you feel about your body? When do you feel most comfortable with your body?), and the semi-structured nature of the interview provided participants with opportunities to share experiences that may not have been specifically solicited by the researcher. Each interview took approximately 90 minutes, and was audio-recorded and transcribed verbatim by the researchers.

## Data Analysis

Consistent with thematic analysis, Stake’s (1995) guidelines for case study data analysis were utilized, beginning with a general review of typed transcripts. Participants signed transcript release forms that stated they would have an opportunity to review their interview transcripts and final reports and to add, alter, or delete information from the documents. Neither participant made changes, affirming that the transcripts and final report accurately reflect their experiences. We (i.e., both researchers) adhered to Stake’s suggestion to use direct interpretation and categorical aggregation to search transcripts for meaning. We looked through the transcripts for single instances of meaning (i.e., direct interpretation) and then searched for issue-relevant meanings by looking for a collection of instances (i.e., categorical aggregation). The meaning units derived were then grouped together to form themes (Stake, 1995). The words of the participants are used to support each theme, all four of which are presented in the following section.

## RESULTS

The purpose of this study is to better understand the body-related experiences of two young Aboriginal women living in rural Canadian communities. While both young women indicated their general sense of satisfaction and acceptance of their bodies, it is important to provide further detail of their experiences to ensure that their stories are adequately represented. The four themes that emerged from the interviews are: (1) fitting in, (2) rural uniqueness, (3) role models, and (4) body talk.

### Fitting in

Both participants have dark hair and dark skin, and each participant described her thoughts about whether she “fits in” or “blends in” with the other, predominately white, people in her community. Despite some similarities, the young women’s experiences of fitting into their communities are quite different. Andrea explained that “there is hardly no Aboriginal people around here...and there’s not really anything traditional here that we would do. We just do everything like they [non-Aboriginal people] would do, not us.” As well, she said that she has lived in her community for less than a year and “most of the people around here I don’t know, and it scares me because they always look at me and I really don’t know them.”

Andrea’s belief that she looks different than others in her community shed light on the difficulty she feels in fitting in. Andrea said that she does not like to wear shorts or skirts, and in highlighting the reasons for this explained, “most of my friends they don’t have tans, and they always say that I have a natural tan ...and they always wonder why I am really, really dark.” She said that her friends know she is “Native” but, she laughingly explained, that they still “see who can be the darkest.” In further addressing the issue of feeling scrutinized by others, she said that she would likely feel more comfortable living in a town with more Aboriginal people because then she would “blend in.”

Dana, who has lived in her community for her whole life, presented a story highlighting her perceived acceptance in that community. She said, “Sometimes I wonder if I will fit in or not but... I’ve grown up with these kids since I was really young.” Dana often used terms such as “we” and “us” to describe her experiences, and it became apparent in the interviews that there is a strong sense of belonging in her class. She explained that almost everyone in her class grew up together and that, “it’s not like our class is trying to impress anybody. It’s just like acceptance, we just like accept everybody for who they are.” In providing a deeper explanation for why she perceives that her classmates exhibit such acceptance she explained, “cause there are a really a lot of different shapes of girls in our class. Like a really big difference.” The acceptance and sense of belonging described by Dana is attributed to her belief that she “fits in” to the community.

### Rural uniqueness

The young women also shed light on how rural community characteristics influence their body-related experiences. Andrea said that it probably would not matter if she lived in a city or in her rural community, and how she feels about

herself would “probably be the same.” Although she did not envision herself feeling differently about her body if living in a city, she thought she would feel more comfortable if living on a reserve. She said, “if you went to a reserve, it would probably be all Native kids.” Thus, she anticipates that her experience might be different if she could “blend in” with other people who also have dark skin.

Somewhat contrary to Andrea’s experience, Dana anticipated that her experiences would likely be very different living in a city. She perceives that young women present themselves differently in urban and rural communities and that how young women feel about their bodies depends on where they live. She said, “well, I notice that girls in the city do dress different than people here... the new brands and stuff, but the people on the farm [her community] will just get something local.” She also noted that cities have more “cliques and stuff,” and that young women in cities “are probably like, ‘oh I have to dress like this person.’” She suggested that there is probably more pressure in cities to look a certain way, “because it [the city] is more accessible in terms of the clothes and stuff like that, and the latest thing.” She said that her small class is comprised of people who all look different, in terms of styles and overall appearance. She even joked that “if we went to the city, we’d be weirdos.” To Dana, her friends in her rural community are far more accepting than individuals in cities.

### Role models

Both participants described how the role models in their lives impact the way they - and other young women - feel about their bodies. Although one might initially think of role models as individuals living in the same communities (e.g., parents, siblings), both participants explained that young women often view individuals in the media as role models. Andrea remarked that young Aboriginal women’s experiences with their bodies are probably influenced by magazines. She explained that young Aboriginal women may have negative experiences with their bodies because the “beautiful” women depicted in magazines “never look Native,” and that they never have dark hair and dark skin. Thus, Andrea appeared to have a very clear notion of what Native women look like. Building on this belief she said, “You don’t see very much African American women in magazines, it’s all on white girls, and there is no Native kids, I never see none.” She further explained that many young women do not feel good about their bodies because “they don’t have the greatest role models.” Andrea explained how she is lucky because she has “a whole bunch of different role

models,” including her guardians, siblings, and friends who are both Aboriginal and non-Aboriginal.

Andrea’s sentiments are echoed by Dana who said that young women need good role models in their lives. She noted that women’s body-related experiences are often influenced by “a comment said to them by a teacher or an acquaintance, or by their parents or their siblings.” Dana also said that celebrities often serve as role models for young women: “the family and the media has a lot to do with it [body-related experiences]. Like the one girl is in love with all of the celebrities and stuff.” Dana illustrated this with a portrait of a girl in her class who is constantly “reading about Paris Hilton.” While Dana acknowledges the powerful role of media, she does not think that media images impact negatively on Aboriginal women.

### Body talk

Both young women explained that, despite their general feelings of satisfaction towards their bodies, it is important to put more focus on talking about the body. Andrea said that if people spent more time talking about the body or worked together to implement programs, “it [programs] would probably help you to see your body and how you think about your body.” She continued that it might help young women if their teachers talk more about their body-related experiences. She said, “You see your teachers everyday at school and if they talk to you about body image, you get to know more about that and what it can do to you.”

Dana also emphasized the importance of engaging in body talk. She said, “In health class we don’t really learn about it [body-related experiences] very much...but now with the media, and the way people look, I think it really is a big deal. I think they [teachers] should teach it. Focus on it more than what they do.” In her health class, “we don’t go in great detail about it [body-related experiences].” Dana also mentioned that she and her friends did not talk much about the body. She said, “we never really talk about that [body]”. She continued, “personally I don’t think it is [a problem], but I think it is a big problem for like young girls, everyone.” That is, while she feels okay about her body, she recognizes the social value of being encouraged to engage in conversations about the body.

## DISCUSSION

This research highlights the unique stories of two young women as well as shedding light on some of the ethical challenges of trying to ensure the participants’ stories are adequately represented, while their identities are kept confidential.

### Two Unique Stories

Consistent with our previous research with young Aboriginal women living in urban centres (i.e., Fleming et al., 2006), the two young women who participated in this study described a general sense of satisfaction and acceptance of their bodies, a finding that is somewhat inconsistent with previous quantitative research (e.g., Gittelsohn et al., 1996; Marchessault, 2004) that explored body shape perceptions of Canadian Aboriginal women. However, quantitative research has not provided Aboriginal women an opportunity to share their experiences. As suggested by Sutherns et al. (2003), we moved beyond the participants’ reports of satisfaction and provided a forum in which they could describe the complexity of their body-related experiences. As the young women described how their body-related experiences are often influenced by the context of the situation (e.g., comments made by their role models), general reports of “body satisfaction” appeared to oversimplify their experiences.

While both young women described a general level of satisfaction with their bodies, their stories suggest many complexities, some of which emerged when the young women spoke about “fitting in” to their communities. Despite both having dark hair and dark skin, the extent to which they think about “fitting in” differs. Their stories suggest that “fitting in” or “blending in” to their communities is based primarily on one’s appearance. Lawrence (2004) explained that “Nativeness” often depends on how one is defined by others and in white society it is largely dependent on how one looks. For Andrea, it seemed that her “Nativeness” meant that she did not “fit in” to her community. Her experiences echo those of a previous research participant who said, “the belonging...how we can never be like white people” (Fleming et al., 2006, p. 526). Dana, in contrast, does not perceive that her looks separate her from her community. We speculate that the length of time each young woman has spent in her community has influenced the extent to which she feels she belongs or “fits in.”

Andrea and Dana’s stories also suggest a uniqueness among rural communities that influences their body-related experiences. Such findings are consistent with the general health literature that suggests that the geographical and sociocultural characteristics of rural communities influence women’s health (Sutherns et al., 2003). Other factors (e.g., ethnicity, class, gender) also add to the diversity of women’s experiences (Collins, 1986; Olesen, 2000). While it is important to highlight diversity, we believe that it is also important to highlight the common themes that often link

women's experiences. The young women in this study, for example, share the common characteristic of being the only teenaged Aboriginal woman in their communities. As available researchers interested in working with young Canadian Aboriginal women in similar rural situations is sparse, the stories of these two young women help to shed light on this overlooked population.

Also highlighted by these stories is the importance of role models in young women's lives, including the power attributed to media. One participant expressed her concerns that depictions in the media are mostly of white women and never of Aboriginal women. The concerns expressed by this participant are consistent with the views of Blood (2005) who explains that our media dominated culture perpetuates the notion that a woman's body is her best attribute and that she should be able to present the idealized norm of white, thin, toned and flawless. Consequently, a woman's body is in the control of strong powers that impose constraints and obligations. Blood further argues that young women who perceive themselves to fail at achieving "normal" visual standards inevitably experience feelings of inadequacy with respect to their bodies. The potential harm in the messages that young Aboriginal women get from the media underscores the importance of the participants' suggestion that other young women be engaged in body talk so they can learn to deconstruct the media messages.

### **Ethical Challenges**

As well as highlighting the body-related experiences of two young Aboriginal women living in rural communities, this research also sheds light on some of the ethical challenges we encountered engaging in research in rural communities. We highlight these challenges not because we have solutions, but because others might benefit from hearing our story. As our study is unique in that we worked with two young Aboriginal women who are the only teenaged Aboriginal women living in their respective communities, the remainder of this paper will focus on the challenges we faced ensuring participant confidentiality.

Throughout this research we found ourselves examining our many responsibilities as university-based, non-Aboriginal researchers trying to engage in respectful/ethical research. Because of the far-reaching impact of colonization on research institutions, Aboriginal Peoples have asked for new standards of ethics that "speak to the multiple responsibilities of researchers and institutions" (Battiste, 2002, p.34). As a result, various Aboriginal scholars (e.g., Battiste, 2002; Battiste & Henderson, 2000; Bishop, 2005; Harrison, 2001; Smith, 1999, 2005), as well as various

organizations and committees (Canadian Institutes of Health Research Ethics Office, 2005; First Nations Centre, 2007; Royal Commission on Aboriginal Peoples [RCAP], 1996), have developed ethical guidelines for individuals engaging in research with Aboriginal Peoples. Because concepts of respect or ethics have been previously defined by western sensibilities, the above-mentioned researchers, organizations and committees have drawn upon the expertise of many Aboriginal Peoples in the development of their guidelines (Smith, 2005). While all researchers must adhere to ethical guidelines, as previously mentioned, our focus is on guidelines specific to participant confidentiality.

For Aboriginal Peoples, consent is often about credibility and trust, which, because of its dynamic nature, must be constantly negotiated (Smith, 1999). Smith (1999) explained how the process of consent is not simply an ethical procedure in which the participants tick a box; rather it is a process of negotiation in which researchers must continually engage. Although the participants and their respective parent/guardian signed consent forms prior to their interviews, I (the first author and interviewer) also conversed with the young women about consent before, throughout and after their interviews. The participants and I negotiated the manner in which we could ensure their anonymity, and the precise manner in which their personal stories would be shared with the academic community.

Although the process of consent was negotiated, the small rural communities in which the interviews were conducted presented many challenges with respect to the process of confidentiality. Both participants chose their schools as the interview location, and upon arrival at each school I was greeted by many welcoming school members. Along with friendliness, most individuals (particularly the teachers) showed considerable curiosity about why I was there, making it difficult to hide that I was there to speak with the only Aboriginal woman in each school. Nevertheless, the young women requested that the interviews take place at their respective schools and it was important to respect their requests.

It was also important to negotiate with the participants about the manner in which their stories would be shared. The participants and I agreed that their names and the names of their communities would not appear in any publications or presentations that derived from the interviews. This posed a new challenge, as most guidelines for research with Aboriginal Peoples (e.g., Smith, 2005) state that researchers must ensure that communities are benefiting from the research. How could we ensure that the community benefits from the research while being unable

to present the community with any final documents because such sharing would jeopardize the confidentiality of the participants? Recognizing their unique situations, the young women agreed to participate in this study because they want their stories to be heard by other health researchers. Guidelines (e.g., Battiste, 2002) state that Aboriginal Peoples should have control of their own knowledge; respecting participants request for confidentiality is an expression of that respect for control over their own knowledge.

## CONCLUSION

The two stories presented here highlight the need for future researchers to engage more young Aboriginal women living in rural communities in conversations about body-related experiences. The voices of young Aboriginal women, and of young rural Aboriginal women in particular, are noticeably absent from the body literature. The diverse stories of the two participants in this research underscore a need for future researchers to explore the commonality and uniqueness of these stories. Given how many young Aboriginal women live in rural Canadian communities, many more stories need to be heard. Young women are the experts of their experiences and we must not continue to overlook the power of their voices.

## ACKNOWLEDGEMENTS

This research was funded by the Canadian Institutes of Health Research (CIHR). The first author is a CIHR Strategic Training Fellow in the Public Health and the Agricultural Rural Ecosystem (PHARE) Training Program and research is funded by the CIHR Strategic Training Program and Partner Institutes.

We thank the two young women for sharing their stories and making this research possible.

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